The Senate

Select Committee on Autism

Services, support and life outcomes for autistic Australians

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Committee web page: www.aph.gov.au/senate_eec
PO Box 6100 E-mail: eec.sen@aph.gov.au
Parliament House Ph: 02 6277 3521
Canberra ACT 2600 Fax: 02 6277 5706

Executive Summary

The evidence provided over the course of this inquiry provides a compelling case for change. Autistic Australians[1] and their families are often discriminated against and have difficulty accessing the services and supports that they need. Maintaining the status quo is simply not an option.

At the centre of the committee's proposed reform pathway is a National Autism Strategy. This strategy would coordinate efforts to improve life outcomes for autistic people and have clear and measurable goals by which progress could be tracked.

The committee envisages that the national strategy would be complemented by a series of action plans and roadmaps for specific areas—such as health and mental health, advocacy, employment, research, and the service delivery workforce.

The committee thanks all the individuals and organisations that participated in the inquiry and believes that a better future for autistic Australians and their families is achievable with greater understanding and the right policy settings.

Life outcomes for autistic Australians are unacceptably poor. This comes at an enormous personal, social and economic cost.

The headline statistics are stark. Autistic people have a life expectancy more than 20 years shorter than the general population, with more than twice the mortality rate. Autistic people experience high rates of co-occurring mental health conditions and are more likely to attempt or commit suicide than other groups. Seventy-five per cent of autistic people do not complete more than a Year 12 education, while the unemployment rate for autistic people is almost eight times that of people without disability. Autistic people also appear to be overrepresented in the justice system and at higher risk of homelessness than the general population.

Inclusion of autistic people in the community is also poor, with many experiencing loneliness, isolation, exclusion and discrimination. Significant numbers of autistic people report having no friends other than family or paid staff. Likewise, many families say they feel unwelcome at community events, or unable to leave the house due to negative public reactions to their child's autism.

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[1] The committee is aware that there are people in the autistic community who prefer 'identity first language', people who prefer 'people first language', and people who use the terms interchangeably. The committee respects that language is a highly personal choice and that each person will have a preferred way of communicating and self-describing. In the context of this inquiry, the committee has used identity first language in its report in order to ensure consistency with the terms of reference.

These are not simply statistics on a page. Behind each set of numbers are thousands of autistic children and adults who have been denied the opportunity to fulfil their potential and live healthy, safe and productive lives, as well as scores of families who have been pushed to breaking point.

Meaningful systemic changes would have an enormous impact, with instances of good practice demonstrating how this can be achieved.

During the course of the inquiry, the committee heard first-hand accounts of the devastating impact that inadequate or inappropriate support has on the lives of autistic people and their families.

However, the committee does not believe these problems are insurmountable. Significant inroads could be made by improving service integration and access, increasing understanding of autism in both community and professional settings, encouraging the development of autism-specific and autism-friendly services, and building workforce capacity and capability.

To this end, the committee is encouraged by accounts of appropriately tailored support and good practices that are occurring across a range of sectors. Such actions and initiatives have already made a difference to the lives of some inquiry participants and the autism community more broadly.

Too often, though, access to adequate support appears to be a matter of chance; relying heavily on the knowledge and skill of individual teachers, support workers, and health care professionals who have adjusted their practice to accommodate the needs of autistic students, clients and patients.

While good practice is not yet widespread, the committee is optimistic that a concerted and coordinated effort to address the underlying drivers of poor outcomes will be a catalyst for meaningful and long-lasting systemic change.

The drivers of poor outcomes for autistic people are complex and interrelated.

It is clear to the committee that there is no single cause of the poor outcomes experienced by autistic Australians. While the extent of symptoms and the presence of co-occurring conditions play a role, these can be made worse by external stressors such as poverty, unaccommodating environments, exclusion and discrimination. Among other factors, the committee heard that key drivers of poor outcomes for autistic Australians include:

- poor understanding of autism within the community and among service providers;
- workforce capacity constraints;
- delays in diagnosis and early intervention;
- a complex and poorly integrated service environment; and
- services that are not designed to meet the needs of autistic people.

Poor understanding of autism within the community and among service providers

Despite its prevalence—and the fact that autistic people make up the largest single disability group within the NDIS—autism appears to be poorly understood in Australia.

The committee heard that ignorance of autism within the community, as well as stereotypical views of autistic people, present significant barriers to the social and economic inclusion of autistic people and their families in Australia.

This lack of understanding also extends to providers who deliver services to support autistic people. Concerningly, this includes professionals such as general practitioners, paediatricians, psychiatrists, early childhood educators and school teachers—who are often the first point of contact for parents who are concerned about their child's development. Indeed, the committee received multiple accounts of health professionals who espoused outdated and harmful views about autism and/or refused to take parents' concerns seriously. However, this lack of knowledge does not only affect children. The committee persistently heard that autism is perceived as a childhood condition which results in inadequate support for autistic adults, including difficulties in obtaining a diagnosis later in life.

In addition, the committee heard that the low level of autism understanding in Australia provides a foothold for the spread of misinformation and leaves autistic individuals and their families susceptible to marketed interventions that can be expensive, ineffective and, in some cases, even harmful.

Workforce capacity constraints

As with the broader disability workforce, the inquiry identified a critical shortage of professionals with autism-specific skills, knowledge and understanding. This relates both to deficits in the skills of the existing workforce, as well as shortages of professionals in specific sectors—particularly diagnosis and early intervention—as well as some geographic locations. Together, these challenges contribute to longer service waiting lists, lower quality services and fewer choices for autistic people and their families.

Delays in early identification and family education and support services.

Evidence provided to the committee revealed unacceptably long wait times for autism diagnoses in Australia. Delays in diagnosis can mean children miss out on the opportunity to benefit from appropriate early intervention. This is particularly troubling given the importance of early supports to improving life outcomes for autistic children.

Cost, service availability, and workforce capacity all contribute to current delays in diagnosis. The committee is concerned that, in many cases, the ability to obtain a timely diagnosis appears to be reliant on living within close proximity to a metropolitan centre and/or having the financial means to access private diagnosis services. Cost can be a particular barrier for those seeking a diagnosis later in life as Medicare subsidies for autism diagnosis are not available after 12 years of age.

In addition, while it is unrealistic to expect all health care professionals to be experts in autism, evidence provided to this inquiry suggests that some lack even the most basic understanding of autism. The committee is disturbed by accounts of health care professionals who dismiss parents' concerns, perpetuate misinformation and harmful stereotypes, and promote a 'wait and see' approach to diagnosis.

Evidence also suggests there is a lack of consistency in approaches to diagnosis. The committee heard this is confusing for people seeking a diagnosis and results in diagnostic practices of varying quality. This variability persists despite the release of the *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorder in Australia* (the National Guidelines) in 2018.

In relation to early intervention, the inquiry found there is a lack of information about good practice intervention, a shortage of appropriately skilled professionals, as well as long waiting lists for early intervention services. As with diagnosis, the committee is concerned about the impact of socio-economic status and geographical location on the ability of families to access early intervention services.

Complex and poorly integrated service environment

It is clear that autistic people and their families find the current service environment complex and poorly integrated. According to multiple stakeholders, the shared responsibility for delivering funded services and supports—involving all Australian governments, the non-government sector, businesses and the wider community—creates a disjointed approach to policy and program delivery.

As a result, many autistic people and their families feel as though they are engaged in a constant battle to access services, with the outcome often dependent on their resources and capacity to sustain the fight. Also, while the National Disability Insurance Scheme (NDIS) is a critical source of support for many autistic people, engaging with the National Disability Insurance Agency (NDIA) is a significant source of stress. Indeed, the time and effort required to navigate the NDIS has been described as equivalent to a full-time job.

While service delivery within a federation presents challenges, the committee finds the current environment to be unnecessarily fragmented and difficult to navigate. Worryingly, the committee heard this is likely to have a disproportionate effect on already vulnerable cohorts, including:

- people from lower socio-economic backgrounds;
- First Nations people;
- people from culturally and linguistically diverse backgrounds;
- people in regional and remote locations;
- LGBTQIA people;
- people in the child protection and criminal justice systems; and
- people with multiple and complex needs.

Given the high reliance on informal supports for autistic people, the committee is also concerned that navigating the current service environment is placing an undue burden on families and carers.

Services are not designed to meet the needs of autistic people

Currently, there are currently few services designed for autistic people. Instead, the committee heard that autistic people are often forced to make do with generic services, or with services designed for people with other disabilities, neither of which account for the specific sensory and communication challenges facing autistic people.

While many adjustments can be implemented quite easily—for example, reduced sensory stimulation in waiting areas—the committee heard they are not often made. Indeed, the committee heard multiple accounts of service providers ignoring, refusing or ridiculing autistic people's requests for relatively minor adjustments to service environments or processes.

Generic disability strategies have proven ineffective at improving life outcomes for autistic people.

More than a decade after the introduction of the first National Disability Strategy, outcomes for autistic people have not improved.

While acknowledging that the design of the new *Australia's Disability Strategy 2021–2031* has involved consultation with the autistic community, the committee agrees with the widely expressed view that generic disability approaches will not deliver the change needed to improve outcomes for autistic people and their families.

A National Autism Strategy should form the centrepiece of efforts to improve outcomes for autistic Australians

The committee heard overwhelming stakeholder support for a National Autism Strategy that establishes a clear roadmap, with specific goals and targets, toward improving the lives of autistic people in Australia.

The committee is also encouraged by international experiences which show that national strategies, while not a panacea, do lead to improved outcomes. Importantly, they serve to establish a baseline against which progress can be measured and reported.

Accordingly, the committee supports the development of a National Autism Strategy to guide comprehensive and coordinated efforts to improve life outcomes for autistic people.

The National Autism Strategy should be person and family-centred, address whole-of-life needs for all autistic people, and include targeted actions to support vulnerable cohorts.

The committee heard that taking a holistic view of the needs of autistic people across their lifetime will help to ensure people remain at the centre of the National Autism Strategy. Likewise, a person-centred (rather than diagnosis-based) approach will mean that the needs of people who have not yet received a diagnosis are not overlooked.

In addition, given the importance of the broader family dynamic to the wellbeing of autistic individuals, the National Autism Strategy should focus on promoting family-centred approaches to the delivery of services and supports.

The committee is also aware that within the broad framework of a National Autism Strategy, targeted action will be needed to support cohorts that face additional challenges and compounding disadvantage.

The National Autism Strategy should be co-designed by the autism community

The inquiry found that the diversity of views within the autism community is linked, at least in part, to the breadth of the spectrum itself. The divergence in views was most apparent between autistic self-advocates and parents of autistic children with more complex presentations, who are heavily or completely reliant on parent or carer advocacy. However, tensions are also apparent within the autistic community itself, with stakeholders describing a lack of acceptance among some autistic advocates for views that do not accord with their own.

To this end, the committee views the National Autism Strategy as an opportunity to identify common ground and unify the broader autism community around a shared set of goals. Accordingly, the committee believes that an inclusive co-design process—drawing on the autistic community, as well as parents, carers, researchers, and policy makers—must underpin development of the strategy.

Accountability will be critical to delivering genuine change

The committee agrees with the view that strong accountability measures will be critical to the success of the National Autism Strategy. Without such measures, the National Autism Strategy risks becoming another aspirational yet ineffective plan for change. Therefore, the committee recommends that the National Autism Strategy adopt a range of accountability mechanisms, including:

- clear and measurable actions, targets, and milestones;
- an implementation plan with clearly defined responsibilities;
- ongoing monitoring and reporting requirements; and
- built in timelines for review and renewal of the strategy.

Key priorities for the National Autism Strategy should be guided by the recommendations of this inquiry

Given the breadth of issues addressed by the inquiry, the content of the National Autism Strategy, including any priority actions, should be guided by the full suite of recommendations contained in this report. While not an exhaustive list, some of the key priorities identified by the committee include:

- building understanding of autism within key professions and across the wider community;
- improving access to early diagnosis and intervention;
- improving service integration and coordination;
- improving education, employment and health services for autistic people;
- supporting parents and carers; and
- establishing a national autism research agenda.

Building understanding of autism within key professions and across the wider community

The need to increase autism understanding was raised repeatedly by stakeholders during the inquiry. The committee heard that ignorance of autism within the community, as well as misconceptions about autistic people, are significant barriers to the inclusion of autistic people and their families in the community, at school, as well as in workplaces. Accordingly, the committee sees value in a public education campaign to increase awareness and understanding of autism in the community.

Improving access to early diagnosis and intervention

While the committee acknowledges that autism diagnosis can be a complex process, it is not acceptable that people are waiting years for a diagnosis. The committee believes a maximum timeframe for diagnosis must be established nationally and reported on at least annually. The timeframe should be based on the best practice target of three months.

To improve access to timely diagnosis, the committee makes recommendations aimed at increasing the supply of health care professionals who can diagnose autism and improving the knowledge and skills of the existing workforce. As part of this approach, the committee recommends that action be taken to improve understanding of autism within key professions. The committee also recommends expanding the range of pathways to diagnosis and making changes to the Medicare Benefits Schedule to both encourage take up of the National Guideline and make diagnosis more affordable—particularly for people aged 13 and over who are currently ineligible for diagnosis-related Medicare subsidies.

In relation to early intervention, the committee believes there is a need to continue to build on existing research and to make information and evidence on good practice more widely available to the autistic community and service providers, as well as to government agencies, including the NDIA.

The committee also makes a number of recommendations aimed at more clearly identifying and coordinating post-diagnosis supports. This includes investigating options for a 'one-stop-shop' to help families navigate the pathway from diagnosis to appropriate support services.

Improving service integration and coordination

As a priority, the committee recommends that the National Autism Strategy identify actions to better integrate federal and state service systems. In particular, this should include development of a roadmap to integrate NDIS and mainstream services.

Additionally, the committee also makes recommendations aimed at improving NDIS service coordination. This includes building the capacity of NDIS staff, as well as ensuring that support coordination is available to all new NDIS participants, as well as participants with significantly underutilised plans and those from disadvantaged and vulnerable cohorts.

Improving education, employment and health services

Education

The reported experiences of autistic Australians and their families within the education system are deeply troubling. In relation to schools, the committee heard that autistic students and their families contend with gatekeeping practices, inadequate consultation, a lack of appropriate adjustments, high rates of bullying, and the use of restrictive practices in place of proper behavioural support strategies. While the committee also heard evidence of good practices in schools, this appears to be heavily dependent on the skills and experience of individual principals and teachers.

Of these, bullying stands out as a particular issue, with many anti-bullying strategies failing to understand and account for the social and communication challenges that make autistic students especially vulnerable to bullying. The committee believes urgent action is required to reduce bullying of autistic students in schools.

The committee heard diverse and sometimes conflicting views on the type of schools that are best able to meet autistic students' needs—from fully inclusive mainstream settings to autism-specific schools and home-schooling options. It is clear to the committee that one size does not fit all in education and that choice remains an important concept in school education. However, in order to make informed choices, parents and carers need more information about the options available to them and the support that is on offer.

While supporting choice in schooling, the committee also believes that all mainstream schools should work toward becoming inclusive schools, modelled on universal design principles. However, this comes at an additional financial cost that many mainstream schools simply aren't resourced to meet. In addition, most teachers and school leaders are already time-poor and overburdened.

To this end, the committee makes a number of recommendations aimed at improving training for teachers, school leaders and support staff in mainstream schools, including in the use of evidence-based adjustments to assist autistic students. However, the committee also recognises that training alone is not sufficient and that teachers will require additional specialist support if they are to meet the needs of autistic students.

Disappointingly, the committee also heard that the intersection between the NDIS and in-school supports for autistic students remains problematic, despite being a known issue for many years. The committee finds it difficult to attribute this lack of progress to anything other than an absence of genuine resolve to fix the problem. This must now be addressed as a matter of urgency.

Incredibly—given the poor education outcomes of autistic students—there also appears to be no concerted effort by governments to measure whether current funding for students with disability is making a difference to outcomes. While the committee acknowledges the difficulties involved in determining the impact of individual measures on education outcomes, the committee believes that work in this area is long overdue.

In relation to higher education, the committee heard that significant numbers of students do not disclose their diagnosis for fear of discrimination. However, this can mean students are left without support and are exhausted from trying to mask their autism. In turn, this can result in students withdrawing from their studies, as well as suffering potentially long-lasting mental health impacts.

Even when students do disclose their autism, it appears that very few adjustments are made to meet their needs. This may, in part, reflect a lack of pedagogical knowledge and skills among teaching staff, especially in relation to students with disability, including those with autism. As university teaching staff do not require teaching qualifications, the committee recommends that autism understanding should form part of ongoing professional development requirements for teaching staff. This should also apply to staff working in administration and student support roles.

The committee also believes there is a need to better support student transitions into higher education. As the committee learnt, only a very small percentage of autistic students receive adequate transition support. Peer mentoring programs have been identified as one very important source of support but they need to be used more widely.

Employment
Evidence presented to the inquiry highlighted the poor employment outcomes for autistic people in Australia. Among other factors, this largely reflects the failure of the Disability Employment Services (DES) system to support autistic people. The committee heard evidence that the DES system is hampered by a lack of autism expertise, an overreliance on traditional job-seeking mechanisms, and perverse incentives that reward DES providers for the speed of job placements rather than their appropriateness or sustainability. Evidence also suggests that DES providers are failing to provide in-placement support for autistic job-seekers, despite the DES system making provision for this.

Other factors that contribute to poor outcomes include the use of mainstream recruitment and induction processes that are largely inaccessible and ineffective for autistic people, as well as a lack of adjustments for autistic people within the workplace. In addition, while there are some successful autism-specific employment programs, they are predominantly ICT focused and are relatively limited in reach.

Accordingly, the committee recommends development of a National Autism Employment Framework to coordinate and drive measures to improve autistic employment outcomes. Priorities for the framework should include actions to:

- improve information for both autistic job seekers and employers;
- communicate the benefits of hiring autistic people;
- improve education and training for DES providers and employers;
- expand both ICT and non-ICT autism-specific employment programs; and

- identify ways to support self-employment, further establish governments as employers of choice, and incentivise private sector employment.

In addition, the committee supports calls for a more coordinated approach to education-to-work transition planning that begins well before the end of secondary school.

Health and mental health

As with other sectors, health services are not well prepared to meet the needs of autistic people. The committee heard evidence of poor autism understanding, diagnostic overshadowing, inappropriate treatment approaches, the use of restrictive practices, and a lack of autism-friendly health care environments. In addition, there appears to be a lack of data and evidence that could be used to help monitor and improve health outcomes for autistic people.

Diagnostic overshadowing is a particular concern for autistic people with co-occurring mental health conditions. The committee heard accounts of autistic people being turned away by both disability and health services because neither service felt equipped to deal with both autism and mental health issues.

Given the complexity of the health care system and the breadth of issues identified over the course of this inquiry, the committee recommends the development of a National Roadmap for Improving Health Services for Autistic People. Priorities for the roadmap should include, but not be limited to:

- promoting best practice models of care for autistic people;
- aligning Medicare Benefit Schedule items and associated funding with best practice models of care;
- ensuring the availability and appropriateness of tools and resources to support diagnosis of comorbidities (including mental health conditions) and the provision of reasonable adjustments for autistic people in health care settings;
- building better connections between health care service sectors, including mental health services, disability services and the NDIS;
- eliminating restrictive practices in health care settings; and
- improving autism education and training for health professionals.

The roadmap should also be accompanied by an associated National Autism Mental Health Plan aimed specifically at improving the treatment of autistic people with co-occurring mental health conditions.

Supporting parents and carers

Despite the wellbeing of parents and carers being critical to the success of autistic people, there is overwhelming evidence that support for parents and carers is currently inadequate. This includes a lack of respite care and other services that are family-centred and offer wraparound supports. There are also particular concerns in relation to the support available under the NDIS.

Accordingly, the committee believes that the National Autism Strategy should recognise vital role of families, parents and carers play in supporting autistic individuals. The committee also makes recommendations to address gaps in respite services and improve the transparency and consistency of supports provided under the NDIS.

A national autism research agenda

Evidence suggests that funding for autism research is disproportionately low compared to its prevalence and impact in the community. Given this—and in light of concerns about the sustainability of the NDIS—the committee believes governments should consider prioritising autism more highly within national research agendas. This could be done by creating autism specific funding streams within existing grants programs.

However, the committee also recognises there will always be constraints on the amount of funding available for research. As a result, the committee recommends the development of a National Autism Research Framework to guide autism research in Australia and maximise the impact of available funding. The national framework should establish research priorities and ensure an appropriate mix of basic and applied research, as well as longitudinal and cross-sectional studies.

To this end, the committee notes the significant work done by the Australian Autism Research Council to determine national priorities for autism research in Australia. This work, along with the recommendations in this report, should form the basis of the new autism research framework. Critically, the committee believes co-production of research with the autistic community must be adopted as a core principle of the framework.

In addition, the committee sees significant benefit in establishing a national autism register that would enable data linkage across states and between levels of government. More comprehensive data would improve autism understanding, contribute to the growing evidence base around effective interventions, and help identify and address deficiencies in existing services and supports.

The effectiveness of the National Disability Insurance Scheme for autistic Australians should be the focus of a separate inquiry

Lastly, it is apparent to the committee that the NDIS needs to substantially improve the provision of services and supports that autistic children and adults require. While recognising this is symptomatic of broader problems with the scheme, the committee heard that many NDIA staff and service providers seem to lack even the most basic understanding of autism and the kinds of supports autistic people need. This is particularly troubling given the high number of autistic participants in the NDIS.

However, resolving problems with the NDIS for autistic participants will require a more focused consideration of the issues than was achievable within the broad terms of reference for this inquiry. Accordingly, the committee recommends an inquiry be undertaken by the Joint Standing Committee on the National Disability Insurance Scheme to examine how the NDIS supports autistic participants.

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Recommendations

A National Autism Strategy

Recommendation 1

5.62 The committee recommends that the Australian Government develop a National Autism Strategy and accompanying implementation within 12 months to drive nationally-coordinated action to improve services and supports for autistic Australians. The National Autism Strategy should:

- **be both person- and family-centred;**
- **address whole-of-life needs for people across the breadth of the spectrum;**
- **align with other national strategies, including the National Disability Strategy; and**
- **be informed by the recommendations of this inquiry and the Disability Royal Commission.**

Recommendation 2

5.67 The committee recommends that development of a National Autism Strategy be driven by a national taskforce established under the auspices of the National Federation Reform Council. The taskforce should adopt a co-design approach drawing on the autistic community, as well as parents, carers, researchers, and policy makers. The definition of co-design, and the principles underpinning it, should be agreed at the start of the development process.

Recommendation 3

5.71 The committee recommends that the National Autism Strategy and accompanying implementation plan include an outcomes framework, as well as specific and measurable actions, targets and milestones. Where appropriate, the framework and measurable items should align with those in other national strategies.

Recommendation 4

5.72 The committee recommends that the taskforce monitor and report annually on the implementation of the National Autism Strategy.

Recommendation 5

5.73 The committee recommends that an independent review of the National Autism Strategy be undertaken three years after implementation begins, with

the findings to be publicly released and used to inform the next iteration of the strategy.

The adequacy of available services and supports

Recommendation 6

6.121 The committee recommends that the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) undertake an inquiry into the experiences of autistic participants in the NDIS with particular focus on:

- **the level of reasonable and necessary supports required by autistic participants across the course of their life;**
- **whether the NDIS is currently funding these reasonable and necessary supports;**
- **the implementation of the new Early Childhood Approach;**
- **whether adequate information and support is being provided to participants and prospective participants in a timely manner;**
- **how autism diagnosis is recognised by the NDIS;**
- **the ability and capacity of NDIS planners to make informed decisions regarding the reasonable and necessary supports to be funded by the NDIS;**
- **the level of under-utilisation in NDIS plans for autistic participants;**
- **ensuring there is sufficient service capacity to deliver funded supports; and**
- **how the NDIS interacts with other government funded support services—such as education, employment and health services—to provide coordinated and holistic care for autistic participants.**

Recommendation 7

6.128 The committee recommends that the National Autism Strategy identify actions to drive better integration between federal and state service systems, including a roadmap to better integrate NDIS and mainstream services. This roadmap should be consistent with the recommendations made by the Joint Standing Committee on the NDIS in relation to service integration and overlap with other systems.

Recommendation 8

6.129 The committee recommends that the National Disability Insurance Agency provide support coordination assistance as a default inclusion in plans for autistic NDIS participants who:

- **have complex or high care needs;**
- **are from other identified disadvantaged and vulnerable cohorts; and**
- **have significantly underutilised plans.**

6.130 One year of support coordination assistance should also be a default inclusion in plans for all new NDIS participants.

Recommendation 9

6.131 The committee recommends that the National Disability Insurance Agency continue to improve the capacity of its staff, including Local Area Coordinators, to provide better support to autistic people. This should include a focus on both understanding and meeting autistic participants' support coordination needs.

Recommendation 10

6.134 The committee recommends that a National Autism Strategy identify actions to increase community understanding of autism. This should include consideration of a public education campaign that portrays the diversity of the spectrum and helps improve inclusion across a range of settings, including schools, workplaces and in the general community. All materials should be tailored and accessible to First Nations and Culturally and Linguistically Diverse audiences.

Recommendation 11

6.138 The committee recommends that the National Autism Strategy identify actions to promote awareness of, and access to, quality, evidence-based information about autism for autistic people, their families, and professionals in autism-related sectors.

Recommendation 12

6.139 The committee recommends that the Australian Government develop guidelines on autism-friendly service design through the National Autism Strategy in order to help service providers tailor services and service environments to meet the needs of autistic individuals.

Recommendation 13

6.143 The committee recommends that a National Autism Workforce Plan be developed under the auspices of the National Autism Strategy to ensure the supply of a suitable and appropriate workforce to deliver services for autistic people. The National Autism Workforce Plan should identify actions, accompanied by clear and measurable outcomes, to:

- **improve data around current and future workforce gaps and shortages (as they relate to the needs of the autism community);**
- **attract, train and retain workers in identified areas of shortage (both geographic and sector/profession-specific);**

- **increase autism content in relevant undergraduate training courses;**
- **develop accredited autism-specific short courses (or promote existing accredited courses) for current workers; and**
- **embed autism as part of ongoing professional development requirements related to professional registration.**

6.144 Where appropriate, the National Autism Workforce Plan should align with existing workforce strategies, including the *NDIS National Workforce Plan: 2021–2025*.

Recommendation 14

6.145 The committee recommends that the Department of Home Affairs work with the Departments of Social Services, Health, and Education, Skills and Training, as well as the National Disability Insurance Agency, to ensure current skilled migration arrangements facilitate migration to fill identified autism workforce shortages.

Recommendation 15

6.151 The committee recommends that the National Autism Strategy include measures to allow for monitoring and reporting of the social inclusion of autistic people within the community.

Recommendation 16

6.152 The committee recommends that peer-to-peer networking and support projects continue to be funded as a priority under the Department of Social Security's Information, Linkages and Capacity Building program.

Recommendation 17

6.153 The committee recommends that online resources be developed by existing autism education and advocacy organisations—funded through the Department of Social Security's Information, Linkages and Capacity Building program—and made widely available to help community organisations understand how they can actively support and include autistic people.

Supports and services for specialised groups

Recommendation 18

7.79 The committee recommends that the National Autism Strategy include a focus on meeting the needs of all autistic people. This should include a particular focus on the provision of adequate and appropriate services for autistic adults, women and girls, as well as disadvantaged and vulnerable cohorts of autistic people such as:

- **people from lower socio-economic backgrounds;**
- **people in regional and remote locations;**
- **First Nations people;**
- **people from culturally and linguistically diverse backgrounds;**
- **gender diverse and non-heterosexual people; and**
- **people with complex needs.**

Recommendation 19

7.80 The committee recommends that the National Autism Strategy include specific actions to improve access to services in regional and remote areas. This should include options for remote service delivery (such as telehealth), as well as working with relevant medical colleges and professional bodies to increase the supply and retention of clinicians and allied health professionals available to work in regional and remote locations.

Recommendation 20

7.81 The committee recommends that the National Autism Strategy include specific actions to improve access to services for First Nations peoples. This should include building the capacity of Aboriginal Community Controlled Health Organisations to deliver autism services in First Nations communities, as well as trialling the use of alternative care models, such as those in place to support individuals with Foetal Alcohol Spectrum Disorders.

7.82 In addition, the taskforce established to develop the National Autism Strategy should include First Nations representation.

Recommendation 21

7.83 The committee recommends that, as a priority, all governments through the National Federation Reform Council review their approaches to coordinating service delivery for autistic people with complex needs and implement actions to ensure integrated and appropriate support for individuals and families with complex support needs, particularly during times of crisis.

Recommendation 22

7.89 The committee recommends that the National Autism Strategy recognise the vital role that families, parents and carers play in supporting autistic individuals.

Recommendation 23

7.90 The committee recommends that the National Disability Insurance Agency work with stakeholders and experts to:

- **clarify the operation of the 'ordinary role of parenting' principle, recognising the significant additional responsibilities borne by parents and carers of autistic individuals; and**
- **institute a family-centred approach to planning that extends beyond the Early Childhood Approach and is supported by training in family-centred approaches for National Disability Insurance Scheme Planners, Local Area Coordinators, and Support Coordinators.**

Recommendation 24

7.91 **The committee recommends that the National Disability Insurance Agency publish its guidance for planners regarding the role of caregivers and families to improve transparency and consistency of support provided.**

Recommendation 25

7.92 **The committee recommends that state and territory governments undertake a mapping of respite and support services for parents and work with government and non-government providers to address identified gaps in support.**

Research and data collection

Recommendation 26

8.43 **The committee recommends that a National Autism Research Framework be agreed under the auspices of the National Autism Strategy. This framework should be:**

- **based, as a starting point, on the research priorities agreed by the Australian Autism Research Council;**
- **informed by the recommendations in this report; and**
- **compatible with the National Disability Research Agenda being developed by the National Disability Research Partnership.**

Recommendation 27

8.44 **The committee recommends that the taskforce established to develop the National Autism Strategy investigate options for improving the collection of data about autistic people to better inform research, policy and practice in relation to improving life outcomes for autistic people. This should include:**

- **exploring the feasibility of establishing a National Autism Register;**
- **engaging with the Disability Advisory Council to ensure any proposed activities build on (or are compatible with) the results of the National Disability Data Asset pilots;**

- **engaging with the Disability Advisory Council to ensure that data needs in relation to autistic people are adequately represented in any future National Disability Data Asset; and**
- **identifying any gaps in data collection that will not be met by the National Disability Data Asset.**

Recommendation 28

8.45 The committee recommends that the Australian Government prioritise autism research as part of the National Disability Research Agenda and National Disability Data Asset, given that autism represents the most prevalent (and fastest growing) primary disability type in the NDIS. This should include the creation of separate autism-specific funding streams within existing research grant programs.

Advocacy

Recommendation 29

9.56 The committee recommends that the Commonwealth, state and territory governments re-commit to a national approach to disability advocacy. This should include:

- **reviewing the effectiveness of the National Disability Advocacy Framework, including the current status of its outputs and reform and policy directions; and**
- **updating the National Disability Advocacy Framework to include performance measures and reporting requirements for each of the outputs and reform and policy directions.**

Recommendation 30

9.57 The committee recommends that a National Autism Advocacy Plan be developed under the auspices of the National Autism Strategy. The National Autism Advocacy Plan should:

- **align with the National Disability Advocacy Framework; and**
- **identify actions to:**
  - **improve data collection and reporting on the utilisation and effectiveness of advocacy services for autistic people;**
  - **encourage the growth of autism-specific advocacy services, including autistic-led services;**
  - **increase the numbers of autistic people appointed to key positions in all organisations, including autism and disability-related organisations;**

- **ensure better understanding of, and advocacy for, the needs of autistic people with complex presentations; and**
- **bring together the diverse views and perspectives of the autistic community to improve advocacy for all autistic people.**

Recommendation 31

9.62 The committee recommends that the proposed National Autism Advocacy Plan reflects the need for differentiated advocacy services to support the range of presentations across the spectrum and the stage of life for those autistic people requiring advocacy.

Recommendation 32

9.66 The committee recommends that the Australian Government ensure that the National Disability Advocacy Program and other Commonwealth-funded disability advocacy programs fund at least one autism-specific advocacy service in each state and territory.

Recommendation 33

9.67 The committee recommends that state and territory governments commit to funding autism-specific advocacy services under their funded disability advocacy programs. Progress toward implementation could be monitored through the National Federation Reform Council.

Recommendation 34

9.68 The committee recommends that the Australian Government, through the Department of Social Services' Information Linkages and Capacity Building program, fund autism-specific advocacy groups to build the capacity of general disability advocacy organisations to support autistic people.

Recommendation 35

9.71 The committee recommends that the Australian Government, through the Department of Social Services' Information Linkages and Capacity Building program, fund autism-specific advocacy groups to build the self-advocacy and self-determination skills of autistic people (and their families), including through peer support programs.

Recommendation 36

9.72 The committee recommends that the Department of Education, Skills and Employment work with state and territory education authorities, the Australian Curriculum, Assessment and Reporting Authority, Education Services Australia and other relevant stakeholders to provide guidance and resources to help schools teach self-advocacy skills. While applicable to all

school children, there should be a particular focus on making this content accessible to students with autism.

Recommendation 37

9.73 **The committee recommends, as part of the inquiry into the National Disability Insurance Scheme proposed in Recommendation 6, that consideration be given to whether the National Disability Insurance Scheme could play a greater role in supporting the development of self-advocacy skills (as part of a participant's Capacity Building budget).**

Diagnosis

Recommendation 38

10.106 **The committee recommends that, as a matter of priority, the National Autism Strategy identify actions to improve access to autism diagnosis. This should include:**

- **establishing, and publicly reporting on progress against, an agreed target for a maximum waiting time for diagnosis that reflects best practice;**
- **improving information for families and adults about autism and the pathways to diagnosis;**
- **identifying opportunities to co-locate autism screening and assessment services within existing services, such as maternal health clinics, early childhood and child care services, and school education settings;**
- **a national rollout of the Olga Tennison Autism Research Centre’s training program for maternal and child health nurses to improve early identification of autism;**
- **identifying opportunities for collaboration between maternal health care nurses and early childhood educators to support identification of, and communication about, autism in early childhood and child care settings;**
- **promoting use of the ASDectect app by parents, health practitioners and educators**
- **developing diagnostic tools that are more sensitive to the heterogenic presentation of autism, particularly in women and girls;**
- **working with medical colleges and professional bodies to improve the supply of healthcare professionals with expertise in autism diagnosis;**
- **embedding autism within initial education courses for healthcare professionals and educators, including training in the heterogenic presentation of autism;**
- **promoting use of the Autism HealthPathways platform to aid clinical decision-making in relation to autism assessments; and**
- **identifying ways to improve access to diagnostic services for people in regional and remote areas, including telehealth options.**

Recommendation 39

10.107 The committee recommends that state and territory governments review their child health and development screening programs to identify opportunities to improve early identification of autism.

Recommendation 40

10.108 The committee recommends that the Australian Government task the Medicare Benefits Schedule (MBS) Review Advisory Committee with an immediate review of MBS items related to diagnosis of autism. The aim of the review should be to align current MBS items with the diagnostic process established in the *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorder in Australia*, as well as recommend new items required for the same purpose.

Recommendation 41

10.109 The committee recommends that the Department of Health prioritise implementation of the remaining recommendations of the Medicare Benefits Schedule Review Taskforce (the Taskforce) in relation to the diagnosis of autism, complex allied health assessments and multidisciplinary planning (as set out in the Taskforce's June 2020 *Report on Primary Care*).

Recommendation 42

10.110 The committee recommends the removal of the current age limit on Medicare Benefits Schedule items related to the diagnosis of autism.

Early intervention and support

Recommendation 43

11.60 The committee recommends that the Australian Government commit funding to quality research to continue addressing gaps in the evidence for early intervention approaches.

Recommendation 44

11.61 The committee recommends that the Australian Government investigate options to improve post-diagnosis support, including a one-stop shop for directing individuals to the most appropriate support services.

11.62 The one-stop shop should be accessible via a range of platforms, including more traditional mediums such as print and phone support services.

Recommendation 45

11.63 The committee recommends that all National Disability Insurance Scheme planners and educators associated with the new Early Childhood Approach undergo training in understanding autism and best evidence-based approaches to intervention.

Education

Recommendation 46

12.159 The committee supports implementation of the recommendations of the *2020 Review of the Disability Standards for Education 2005* and recommends that the Department of Education, Skills and Employment and state and territory education authorities:

- **work with the taskforce established to develop the National Autism Strategy to apply an 'autism lens' to the implementation of the Disability Standards for Education review recommendations; and**
- **include specific actions to ensure the Disability Standards for Education meet the needs of autistic students.**

Recommendation 47

12.160 The committee recommends that the Australian Government coordinate with all government and non-government education authorities to ensure that policies on bullying include specific measures to address bullying of autistic students, including the use of:

- **frameworks for positive behaviour interventions and support; and**
- **opportunities for supported social engagement.**

Recommendation 48

12.164 The committee recommends that the Education Ministers Meeting develop and implement a framework for regularly monitoring and publicly reporting on education outcomes for students with disability from 2023. This should include monitoring and reporting on outcomes for autistic students as a separate cohort and should be informed by consultation with the taskforce established to develop the National Autism Strategy.

Recommendation 49

12.174 The committee supports the 2019 recommendation of the National School Resourcing Board in relation to refining the costing model for the students with disability loading to inform the loading settings from 2023. Accordingly, the committee recommends that implementation of the new costing model be accompanied by stronger accountability measures requiring government and

non-government education authorities to demonstrate that schools are receiving adequate funds to meet the needs of students with disability—including autistic students.

Recommendation 50

12.175 **The committee recommends that, where state and territory education authorities use targeted programs to distribute funding for students with disability, eligibility for these programs be reviewed and adjusted to better meet the needs of autistic students.**

Recommendation 51

12.176 **The committee recommends that the Australian Government work with state and territory education authorities and relevant stakeholders to identify and implement measures to build the capacity of teachers, school leaders and parents to support the inclusion of autistic students in schools. This should include the provision of additional specialist support in schools.**

Recommendation 52

12.177 **The committee recommends that the Australian Institute of Teaching and School Leadership work with state and territory teacher regulatory authorities to:**

- **ensure all initial teacher education courses include at least two units on inclusive education, with a focus on the functional challenges experienced by autistic students, as well as evidence-based strategies for supporting autistic students in classrooms; and**
- **incorporate autism understanding into professional development requirements tied to teacher registration.**

Recommendation 53

12.178 **The committee recommends that the Australian Institute of Teaching and School Leadership work with relevant stakeholders create additional autism-related Illustrations of Practice—across all domains of teaching and for all career stages—to help teachers better support autistic students in classrooms and schools.**

Recommendation 54

12.179 **The committee recommends that the Department of Education, Skills and Employment works with state and territory governments and the non-government school sector to develop clear guidance on the schooling options available for autistic students so that parents and carers can make more informed choices. This should include information about the role of—and**

interaction between—mainstream, special schools, autism-specific schools and home-schooling options within the education ecosystem.

Recommendation 55

12.183 The committee recommends that the Australian Government coordinate the National Disability Insurance Agency, the Department of Education, Skills and Employment, and state and territory education authorities to:

- **resolve, as a matter of urgency, any outstanding issues in relationship to the intersection of school funding and the NDIS; and**
- **develop clear guidance in relation to the intersection of school funding and the NDIS, including in relation to the provision of NDIS supports within schools.**

Recommendation 56

12.190 The committee recommends that the Equity in Higher Education Panel include a specific focus on the needs of autistic students as part of its work to develop a Student Equity in Higher Education Roadmap. This should include consultation with the taskforce established to develop the National Autism Strategy, as well as a focus on:

- **increasing autism understanding among all teaching and administrative staff;**
- **creating autism-friendly information for current and prospective students;**
- **creating autism-friendly campus environments and services; and**
- **widespread adoption of autism inclusion and peer mentoring programs.**

Recommendation 57

12.192 The committee recommends that a Transition to Work Roadmap be developed under the auspices of the National Autism Strategy and as part of the National Autism Employment Framework proposed at Recommendation 58. This should provide a nationally agreed and coordinated approach to transition planning across school and higher education settings and should identify actions to:

- **improve students' social and employability skills;**
- **embed the use of evidence-based transition planning resources, such as Better OutcOmes and Successful Transitions for Autism (BOOST-A) and the *MyWAY Employability* web platform in schools and work preparation programs (including the NDIS School Leaver Employment Supports);**
- **improve the autism understanding of NDIS School Leaver Employment Supports providers;**
- **expand the reach of the Ticket to Work program; and**

- **establish stronger links between schools, universities and employers to facilitate autism-aware work experience opportunities.**

Employment

Recommendation 58

13.112 The committee recommends that a National Autism Employment Framework be agreed under the auspices of the National Autism Strategy. The framework should identify actions to:

- **promote the benefits of hiring autistic people to governments and business;**
- **further establish governments as employers of choice;**
- **incentivise private sector employment;**
- **encourage the expansion of both ICT and non-ICT autism-focused employment programs;**
- **support self-employment options for autistic people;**
- **improve information for autistic job seekers about available supports and DES providers with autism experience; and**
- **improve autism-related education, training and resources for DES providers and employers (building on existing resources where available).**

13.113 The framework should also be compatible with the ***Employ My Ability*** **strategy and should help inform the new Disability Employment Support (DES) Model being developed by the Department of Social Services for implementation in 2023.**

Recommendation 59

13.114 The committee recommends that the Department of Social Services ensure that all monitoring and evaluation activities related to the ***Employ My Ability*** **strategy and the new Disability Employment Support Model allow for disaggregation by disability type, including autism.**

Recommendation 60

13.115 The committee recommends that the Department of Social Services incorporate into the design of the new Disability Employment Support Model:

- **relevant elements of the National Autism Employment Framework; and**
- **lessons from autism-specific employment programs about what works in relation to achieving long-term employment outcomes for autistic people.**

Health and mental health

Recommendation 61

14.115 The committee recommends that the Department of Health work with the taskforce established to develop the National Autism Strategy to develop a National Roadmap for Improving Health Services for Autistic People, similar to the *National Roadmap for Improving Health Services for People with Intellectual Disability*. This roadmap should include, but not be limited to, actions that address:

- **best practice models of care for autistic people, including mental health care;**
- **the alignment of Medicare Benefit Schedule items with best practice models of care for autistic people;**
- **reasonable adjustments for autistic people in health care settings;**
- **the availability and appropriateness of tools and resources to support diagnosis of comorbidities (including mental health conditions) and the provision of reasonable adjustments for autistic people in health care settings;**
- **better connections between health care service sectors, including mental health services, disability services and the National Disability Insurance Scheme;**
- **the elimination of restrictive practices in health care settings; and**
- **improved autism education and training for health professionals.**

Recommendation 62

14.116 The committee recommends that the new National Roadmap for Improving Health Services for Autistic People include an associated National Autism Mental Health Plan aimed specifically at improving the treatment of autistic people with co-occurring mental health conditions. This Plan should also align with the National Mental Health and Suicide Plan.

Recommendation 63

14.117 The committee recommends the Australian Government work with state and territory governments and relevant stakeholders to encourage hospitals and public health care settings to adopt measures to improve the experience of autistic people in their care. This may include measures such as providing guidance about reasonable adjustments or employing autism liaison officers to facilitate health care services for autistic people.

Recommendation 64

14.118 The committee recommends that the health and wellbeing priority under the new National Autism Research Framework include a focus on:

- **routine analysis and reporting of population health data for autistic people, including health status, health service utilisation, health outcomes and mortality data;**
- **the risk factors, causes and presentation of comorbidities; and**
- **evaluation of health and mental health interventions for autistic people.**

Recommendation 65

14.122 The committee recommends that the Australian Government work with state and territory governments and relevant stakeholders to develop and widely promote clinical care pathways to help autistic people navigate the health care system, including mental health services.

Recommendation 66

14.123 The committee recommends that the Australian Government work with state and territory governments and relevant stakeholders to implement specialised care models targeted to meet the needs of autistic people, including mental health care needs. These models should offer tiered services and supports that are available to autistic people and their families throughout their health care journey, with a particular focus on mental health services and on preventing individuals and families from falling through the cracks between systems or reaching a crisis point.

Recommendation 67

14.124 The committee recommends that a national standard for information accessibility be developed under the auspices of the National Autism Strategy. This standard should align with existing accessibility standards but should also be tailored to meeting the needs of autistic people.

Housing

Recommendation 68

15.64 The committee recommends, as part of the inquiry into the National Disability Insurance Scheme proposed in Recommendation 6, that the effectiveness of funded supports to enable autistic people to live independently be reviewed. This should have particular reference to:

- **the high proportion of autistic adults living in their family home;**
- **the impact (and appropriateness) of the informal care burden on parents and carers; and**
- **the need for long-term accommodation planning to enable independent living following the death of a participant's parents or carers.**

Recommendation 69

15.66 The committee recommends that the National Disability Insurance Agency work with relevant stakeholders to review the Specialist Disability Accommodation Design Standard to ensure it accounts for the sensory issues experienced by autistic participants.

Recommendation 70

15.67 The committee recommends that the Australian Government work with state and territory governments and relevant stakeholders to develop housing strategies to encourage the construction of social housing that responds to the needs of autistic people in relation to housing design and type.

Recommendation 71

15.71 The committee recommends that the National Disability Insurance Agency work with state and territory governments and non-government housing providers to increase the supply of the 'robust' category of Specialist Disability Accommodation.

Recommendation 72

15.72 The committee recommends the National Disability Insurance Agency work with state and territory governments to clarify the intersection of responsibilities in relation to housing for people with complex support needs.

Justice

Recommendation 73

16.54 The committee recommends that, as part of the inquiry into the National Disability Insurance Scheme proposed in Recommendation 6, the Complex Support Needs Pathway be reviewed to ensure its focus is on preventing (rather than responding to) escalating behaviours that may result in interactions with the justice system.

Recommendation 74

16.55 The committee recommends that the Australian Government work with states and territory governments and relevant stakeholders to investigate options for diversionary programs, rather that custodial sentences, where appropriate.

Recommendation 75

16.60 The committee recommends embedding autism as part of initial education courses and ongoing professional development requirements for all

personnel involved in the justice system, including police, lawyers, and court staff.

Recommendation 76

16.61 The committee recommends that all jurisdictions encourage the adoption of community policing approaches in order to build understanding and trust between police and the autistic community.

Recommendation 77

16.62 The committee recommends that the Australian Government work with states and territory governments to promote a culture in the justice system where autistic people feel supported to disclose their diagnosis and where people with undiagnosed disabilities feel comfortable requesting an assessment.

Recommendation 78

16.65 The committee recommends that the Australian Government work with state and territory governments and relevant stakeholders to develop nationally consistent guidance on the type of adjustments that should be made available to autistic people in justice settings. This should include:

- **the provision of autism-friendly information resources;**
- **the involvement of disability advocates as standard practice in police interviews and during court proceedings; and**
- **adjustments to physical environments and police and court interview processes.**

Recommendation 79

16.68 The committee recommends that, as part of the inquiry into the National Disability Insurance Scheme proposed in Recommendation 6, the effectiveness of the National Disability Insurance Agency's response to previous recommendations of the Joint Standing Committee on the NDIS be assessed in relation to support for autistic people within the justice system.

Recommendation 80

16.72 The committee recommends that the National Disability Insurance Agency publish:

- **the findings of its review into the Complex Support Needs Pathway; and**
- **the Maintaining Critical Supports Framework, including its policy on provider of last resort arrangements.**

Recommendation 81

16.73 The committee recommends that, as part of the inquiry into the National Disability Insurance Scheme proposed in Recommendation 6, the effectiveness of the Justice Liaison Officer program be assessed in relation to supporting the transition of autistic people from detention settings into the community.

Chapter 1
Introduction

1.1 On 27 November 2019, the Senate resolved to establish a Select Committee on Autism to inquire into and report on the services, support and life outcomes for autistic people in Australia and the associated need for a National Autism Strategy, with particular reference to:

(a) current approaches and barriers to consistent, timely and best practice autism diagnosis;
(b) the prevalence of autism in Australia;
(c) misdiagnosis and under representation of females in autism data, and gender bias in autism assessment and support services;
(d) international best practice with regards to diagnosis, support services and education, effectiveness, cost and required intensity;
(e) the demand for and adequacy of Commonwealth, state and local government services to meet the needs of autistic people at all life stages;
(f) the interaction between services provided by the Commonwealth, state and local governments, including:
    (i) health and mental health,
    (ii) education,
    (iii) employment,
    (iv) justice, and
    (v) housing;
(g) the social and economic cost of failing to provide adequate and appropriate services, including to support key life stage transitions of autistic people;
(h) the adequacy and efficacy of the National Disability Insurance Scheme (NDIS) for autistic people, including:
    (i) autism understanding within the NDIS,
    (ii) the utility of the Early Childhood Early Intervention Pathway for autistic children,
    (iii) the ability of the NDIS to support autistic people with complex needs, including those transitioning from prison settings, and
    (iv) the adequacy and appropriateness of supports to empower autistic people to participate in the NDIS planning process, and exercise self-determination through choice and control over their support services;
(i) the development of a National Autism Strategy and its interaction with the next phase of the National Disability Strategy;
(j) the adequacy of funding for research into autism;
(k) the social inclusion and participation of autistic people within the economy and community;

(l) the capacity and sustainability of advocacy, self-advocacy and self-determination supports for autistic people, including mechanisms to self-represent to government as enshrined in the United Nations Convention on the Rights of Persons with Disabilities;

(m) any bill that relates to matters within the scope of this inquiry that is referred to this committee; and

(n) any other related matters.[1]

1.2 The committee was to report on or before the first sitting day of October 2021.

1.3 Following a resolution of the committee on 2 February 2021, and in accordance with the motion agreed by the Senate on 23 March 2020,[2] the reporting date for the inquiry was extended to the last sitting day of March 2022.

Conduct of the inquiry

1.4 The committee advertised the inquiry on its website and wrote to relevant stakeholders inviting them to make submissions by 14 April 2020. The committee subsequently extended the deadline for submissions to 25 June 2020. Submissions continued to be accepted after this date. The committee received 168 submissions, as well as additional information and answers to questions on notice, which are listed at Appendix 1.

1.5 The committee held nine public hearings:

- Canberra – 27 July 2020;
- Sydney – 28 July 2020;
- Adelaide – 16 November 2020;
- Melbourne – 11 February 2021;
- Melbourne – 12 February 2021;
- Brisbane – 3 March 2021;
- Sydney – 15 April 2021;
- Launceston – 28 April 2021; and
- Hobart – 29 April 2021.

1.6 A list of witnesses who appeared at these hearings is available at Appendix 2.

1.7 The committee also conducted site visits to Springbank Secondary College on 16 November 2020 (Adelaide, South Australia), WithYouWithMe on 26 November 2020 (Sydney, New South Wales), and the Olga Tennison Autism Research Centre on 14 April 2021 (Melbourne, Victoria).

1.8 Links to public submissions, Hansard transcripts of evidence and other information published by the committee for this inquiry are available on the committee's website.

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[1] *Journals of the Senate*, No. 30, 27 November 2019, pp. 944–946.

[2] *Journals of the Senate*, No. 47, 23 March 2020, p. 1545.

Acknowledgements and references

1.9 The committee thanks those individuals and organisations who contributed to this inquiry by providing submissions and giving evidence at public hearings.

1.10 The committee regrets that travel restrictions related to the COVID-19 pandemic prevented the committee from meeting with as many people and organisations throughout Australia as it would have liked. The committee also recognises that videoconferencing is a poor substitute for learning about people's experiences face-to-face.

1.11 References in this report to the Hansard transcripts for the public hearings are to the proof Hansard. Page numbers may vary between proof and official Hansard transcripts.

Structure of the report

1.12 This report comprises 16 chapters, including this introductory chapter, with the remaining chapters set out as follows:

- Chapter 2 provides a background on autism, the way it is diagnosed, its prevalence in Australia and the diversity of the spectrum.
- Chapter 3 summarises information on life outcomes for autistic people.
- Chapter 4 outlines the economic and social costs of failing to support autistic people.
- Chapter 5 evaluates whether a National Autism Strategy should be developed.
- Chapter 6 examines the adequacy of available services and supports for autistic Australians.
- Chapter 7 looks at services and supports for specific groups of autistic people, including adults, females, disadvantaged and vulnerable cohorts, and families and carers.
- Chapter 8 explores the current state of research and data collection.
- Chapter 9 considers if current advocacy services are adequate.
- Chapter 10 examines diagnostic services and current challenges to obtaining a consistent, timely and best-practice diagnosis.
- Chapter 11 evaluates early intervention approaches and post-diagnosis support.
- Chapter 12 considers ways to improve the education experiences and outcomes for autistic people.
- Chapter 13 investigates employment outcomes for autistic people and how they might be improved.
- Chapter 14 considers the interface for autistic people with health and mental health systems.
- Chapter 15 looks at housing and accommodation services for autistic people.

- Chapter 16 explores the over-representation of autistic people in the criminal justice system.

Language used in the report

Identifying language

1.13 The committee recognises that people use many terms when talking about autism. The committee is aware that there are people in the autistic community who prefer 'identity first language', people who prefer 'people first language', and people who use the terms interchangeably.

1.14 People first language seeks to put the person before their disability and avoid the disability becoming the primary, defining characteristic of an individual. For example, 'person with autism'. Identity first language reflects the belief that being autistic is a core part of a person's identity which cannot, and should not, be treated as separate. For example, 'autistic person'.[3]

1.15 The committee recognises there is no consensus as to which language should be used, and that each member of the autistic community will have their own opinion on terminology. The committee also understands that each person will have a preferred way of communicating and self-describing. The committee respects that language is an individual and highly personal choice.

1.16 In the context of this inquiry, the committee has used identity first language in its report in order to ensure consistency with the terms of reference.

Functioning labels

1.17 The committee acknowledges that language around needs and functioning is another area where there are differing views within the autistic and autism communities.

1.18 The committee acknowledges that functioning labels (for example, 'low functioning' or 'high functioning') may be used by clinicians, educators, parents, or autistic people. However, it notes that such labels are not official diagnostic terms, and generally tend to be used as qualifiers when people are trying to describe a particular kind of profile on the autism spectrum.[4]

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[3] Amaze, *Talking about autism: guidelines for respectful and accurate reporting on autism and autistic people*, www.amaze.org.au/wp-content/uploads/2019/06/Talking-about-autism-a-media-resource_web.pdf (accessed 1 July 2020); Simon M Bury, Rachel Jellett, Jennifer R Spoor, and Darren Hedley, '"It Defines Who I Am" or "It's Something I Have": What Language Do [Autistic] Australian Adults [on the Autism Spectrum] Prefer?', Journal of Autism and Developmental Disorders, PMID: 32112234, 2020.

[4] Autism Awareness Australia, *Why we should stop using the term "high functioning autism"*, https://autismawareness.webflow.io/aupdate/why-we-should-stop-using-the-term-high-functioning-autism (accessed 9 February 2022).

1.19 Functioning labels may also be counterproductive as they can ignore the strengths and capabilities of someone labelled low functioning or fail to recognise the challenges faced by someone labelled high functioning.[5]

1.20 For this reason, the committee has chosen to use the terms lower or higher/complex support needs throughout the report, unless the terms low functioning or high functioning have been used in source material.

Communities

1.21 Lastly, the terms 'autistic community' and 'autism community' are used throughout the report and are distinct in meaning. Autistic community is used by the committee to refer solely to autistic people, while the term autism community refers to the broader community of autistic people, their families and carers, as well as autism organisations and others with a connection to autism.

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[5] Amaze, *Talking about autism : guidelines for respectful and accurate reporting on autism and autistic people*, www.amaze.org.au/wp-content/uploads/2019/06/Talking-about-autism-a-media-resource_web.pdf (accessed 1 July 2020).

Chapter 2
Background

2.1 This chapter provides an overview of autism spectrum disorder, the diagnostic process, the prevalence of autism in Australia, and the diversity of the autism spectrum.

What is autism spectrum disorder?

2.2 Autism spectrum disorder (autism) is a lifelong neurodevelopmental condition that affects how people communicate, interact, and make sense of the world. Autistic people experience difficulties with communication and social interaction, sensitivity to sensory inputs, and restricted or repetitive interests and behaviours (see Box 2.1).[1] In some cases, the difficulties experienced by autistic people may also lead to behavioural challenges.[2]

2.3 There is no known cause of autism. Current evidence suggests that autism results from changes to the development and growth of the brain, which may be caused by a combination of genetic, developmental and environmental factors. Genetic factors appear to be particularly significant. For example, family members of an autistic person tend to have higher rates of autistic traits, the concordance rate of autism in twins is higher in identical twins than in fraternal twins, and families with one autistic child are more likely to have another autistic child when compared to the general population.[3]

2.4 Despite the myths that surround the condition, autism is not the result of bad parenting or vaccination. Neither is it a childhood condition, one that affects boys only, or something that can be 'cured'.[4]

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[1] ND Australia, *Neurodevelopment conditions: autism*, www.ndaustralia.com/conditions, (accessed 21 June 2021)

[2] Autism Awareness Australia, *Understanding autism*, www.autismawareness.com.au/could-it-be-autism/understanding-autism/ (accessed 21 June 2021).

[3] Amaze, *About autism*, www.amaze.org.au/understand-autism/about-autism/ (accessed 1 July 2020); Autism Awareness Australia, *Causes of autism*, www.autismawareness.com.au/could-it-be-autism/causes-of-autism/ (accessed 1 July 2020).

[4] Autistica, Autism myths and causes, www.autistica.org.uk/what-is-autism/autism-myths-and-causes (accessed 22 June 2021); Autism Awareness Australia, *Myths*, www.autismawareness.com.au/could-it-be-autism/myths/ (accessed 22 June 2021). The biggest myth surrounding autism is that it is caused by vaccines. Numerous large-scale, high-quality studies involving hundreds of thousands of people have consistently shown that vaccines do not cause autism.

2.5 While behavioural characteristics of autism are often present very early in life—in some cases from birth—they may not become obvious to other people until the school years, or sometimes even later.[5]

Box 2.1 Characteristics of autism spectrum disorder

Difficulties with social-emotional reciprocity

- For example, being unable to maintain normal 'back and forth' conversations, having little or no interest in sharing interests and emotions, or displaying little or no interest in social interactions.

Difficulties with non-verbal communication

- For example, abnormal eye contact, difficulties understanding and using gestures, body language and facial expressions.

Difficulties developing and maintaining relationships appropriate to age and development

- For example, a child may have difficulties with imaginative play and making friends.

Stereotyped or repetitive speech, movements, or use of objects

- For example, lining up toys, flapping hands, toe walking, or echolalia (repeating words and phrases).

Inflexible adherence to routines, patterns or behaviour, and becoming distressed at changes

- For example, eating the same foods, travelling the same route to a location.

Sensory hyper- or hypo-reactivity

- For example, to sounds, textures, smells, touch or pain.

Restricted or fixated interests

- For example, only playing with certain toys, or discussing certain topics.

Source: Autism Awareness Australia, Understanding autism, www.autismawareness.com.au/could-it-be-autism/understanding-autism/ *(accessed 21 June 2021).*

How is autism diagnosed?

2.6 There is no definitive test for autism. Diagnosis is made on the basis of developmental assessments and behavioural observations.[6]

2.7 Since 2013, autism has been diagnosed using the American Psychiatric Association's *Diagnostic and statistical manual of mental disorders* (5th edition)—

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[5] Royal Australasian College of Physicians, *Submission 29*, p. 3; Cheryl Dissanayake, 'The trouble with autism: delays in early identification and diagnosis', *InPsych*, vol. 34, Issue 3, June 2012.

[6] Department of Social Services, Department of Health, Department of Education, Skills and Employment, *Submission 53*, p. 4.

commonly referred to as the DSM-5. The DSM-5 introduced a single diagnosis of 'autism spectrum disorder'. This replaced the former sub-categories of 'autistic disorder', 'Asperger syndrome', 'childhood disintegrative disorder' and 'pervasive developmental disorder – not otherwise specified'.[7]

2.8 The DSM-5 defines how many autistic characteristics must be present in order to confirm a diagnosis of autism. To be diagnosed, a person must have difficulties with 'social communication' and 'restricted, repetitive and/or sensory behaviours or interests'. Signs must also have been present from early childhood, even if they were not recognised at the time.[8] (see Appendix 3.A)

2.9 The DSM-5 also requires assessors to specify the severity of symptoms as Level 1, 2 or 3. Each level relates to the amount of support needed for daily function. Examples of symptom severity at each level include:

- Level 1 – requires support
  - social communication deficits cause noticeable impairments, difficulty initiating social interactions and clear examples of atypical or unsuccessful responses to social overtures, possible decreased interest in social interactions; and
  - inflexible behaviour interferes with functioning in one of more contexts, difficulty switching between activities, organisation and planning problems hamper independence.
- Level 2 – requires substantial support
  - marked deficits in verbal and non-verbal social communication skills and evident social impairment (even with support in place), reduced or abnormal responses to social overtures; and
  - inflexible behaviour, difficulty coping with change, or other restricted/repetitive behaviours are noticeable to casual observers and interfere with functioning in a variety of contexts, distress and/or difficulty changing focus or action.
- Level 3 – requires very substantial support
  - severe deficits in verbal and non-verbal social communication cause severe impairments in functioning, very limited initiation of social interactions and minimal response to social overtures; and

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[7] Raising Children: the Australian parenting website, *DSM-5: autism spectrum disorder diagnosis*, www.raisingchildren.net.au/autism/learning-about-autism/assessment-diagnosis/dsm-5-asd-diagnosis (accessed 22 February 2022).

[8] *Diagnostic and statistical manual of mental disorders*, 5th edition, American Psychiatric Association, Washington, DC, 2013, pp. 50–51.

- inflexible behaviour, extreme difficulty coping with change, or other restricted/repetitive behaviours interfere markedly with functioning in all spheres, great distress/difficulty changing focus or action.[9]

Prevalence of autism in Australia

2.10 Stakeholders spoke of a lack of accurate, comprehensive data on the prevalence of autism in Australia.[10] This was attributed in part to problems with data collection,[11] including the lack of a register to monitor autism diagnoses,[12] as well as general challenges in determining the true prevalence of autism given increasing awareness of autism, improved diagnosis of autism, and changes in diagnostic criteria.[13]

2.11 The most recent figures from Australian Bureau of Statistics (ABS) show that in 2018 there were 205 200 autistic individuals in Australia—a 25.1 per cent increase since 2015.[14] However, a number of submitters questioned the accuracy of the figures,[15] with most suggesting they underestimated the true prevalence of autism in Australia.[16] As an example, one submission cited a study that put the actual prevalence of autism in Australia at between 2.4 and 4.4 per cent of the population, or between 600 000 and 1 million people.[17]

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[9] *Diagnostic and statistical manual of mental disorders*, 5th edition, American Psychiatric Association, Washington, DC, 2013, p. 52.

[10] Australian Medical Association (AMA), *Submission 40*, p. 2; Cooperative Research Centre for Living with Autism (Autism CRC), *Submission 46*, p. 10.

[11] See, for example, Queensland Law Society, *Submission 124*, p. 23; Autism Awareness Australia, *Submission 47*, p. 4; Commissioner for Children and Young People South Australia, *Submission 88*, p. 6; Commissioner for Children and Young People Western Australia, *Submission 42*, Attachment 1, p. 4.

[12] See, for example, CliniKids, *Submission 15*, [p. 4]; Monash University, *Submission 94*, p. 7; ND Australia, *Submission 97*, [p. 7]; BioAutism, *Submission 93*, p. 14.

[13] See, for example, Autism CRC, *Submission 46*, p. 10; Assistance Dogs Australia, *Submission 43*, p. 3, PEERS Australia, *Submission 108,* Attachment 1, [p. 22]; Mr David Staples, *Submission 143*, [p. 6]; Mr Cameron Boyd, *Submission 157*, [pp. 6-7].

[14] Australian Bureau of Statistics (ABS), *Survey of Disability, Ageing and Carers, Australia: Summary of Findings 2018: Autism in Australia*, 29 November 2020, www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features102018?opendocument&tabname=Summary&prodno=4430.0&issue=2018&num=&view= (accessed 21 July 2020).

[15] See, for example, Department of Developmental Disability Neuropsychiatry, University of New South Wales (UNSW 3DN), *Submission 95*, p. 4.; Autism Advisory and Support Service, *Submission 21*, p. 3; Reframing Autism, *Submission 24*, [p. 4]; Name withheld, *Submission 9*, p. 4

[16] See, for example, UNSW 3DN, *Submission 95*, p. 4; Australian Autism Alliance, *Submission 52*, p. 8; St Vincent's Health Australia, *Submission 72*, p. 3; ND Australia, *Submission 97*, p. 7, AMA, *Submission 40,* p. 2.

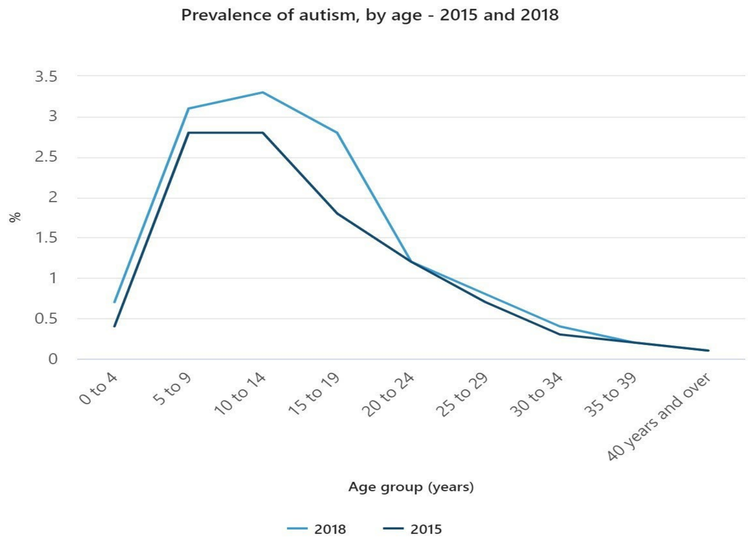
[17] Scope-University of Melbourne Partnership, *Submission 83*, p. 6.

2.12 The most commonly cited alternative to the ABS figures was a prevalence rate of 1 in 70 people, calculated in 2018 by Autism Spectrum Australia using prevalence data in comparable countries, such as the United States of America and Canada, as well as local Australian data.[18] Based on the current Australian population, this would equate to approximately 367 200 Australians who would meet the diagnostic criteria for autism,[19] meaning it is likely the ABS figures underestimate the prevalence of autism in Australia by over 160 000.

Prevalence by age

2.13 ABS data indicates much higher prevalence rates of autism among children and early teens compared to any other age group (see Figure 2.1).

Figure 2.1 Prevalence of autism by age – 2015 and 2018



Source: Australian Bureau of Statistics, Disability, Ageing and Carers, Australia: Summary of Findings 2018.

2.14 The most commonly cited reasons for the drop in prevalence were changes to the diagnostic criteria over time,[20] inadequate record keeping and a lack of

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[18] Autism Spectrum Australia, *Autism prevalence rate up by an estimated 40% to 1 in 70 people*, 11 July 2018, www.autismspectrum.org.au/news/autism-prevalence-rate-up-by-an-estimated-40-to-1-in-70-people-11-07-2018, (accessed 21 July 2020). See also, AMA, *Submission 40*, p. 2; Assistance Dogs Australia, *Submission 43*, p. 3; JFA Purple Orange, *Submission 84*, p. 7.

[19] ABS, *National, state and territory population*, 16 September 2021, www.abs.gov.au/statistics/people/population/national-state-and-territory-population/mar-2021, (accessed 16 October 2021). This figure was calculated using a total population figure of 25 704 340 and a prevalence rate of 1 in 70 people.

[20] Monash University, *Submission 94*, p. 7; Commissioner for Children and Young People Western Australia, *Submission 42*, Attachment 1, p. 4; Assistance Dogs Australia, *Submission 43*, pp. 3–4. This theory is also suggested in ABS, *Survey of Disability, Ageing and Carers, Australia: Summary of Findings 2018: Key statistics*, www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#key-statistics.

research, as well as the under-diagnosis of autistic adults.[21] The under-diagnosis of adults was thought to be primarily a function of the cost of diagnosis.[22] Other suggested barriers to diagnosis included a lack of information about autism and fears about the impact of a diagnosis, including experiencing stigma and discrimination.[23]

2.15 The ABS also theorised that another factor in the decline may be the way its survey was conducted, with a surveyor speaking to the first available adult in a household to determine if there was an autistic person living there. The ABS suggested that while parents may be willing to reveal their children's diagnoses, those children may be less likely to reveal they are autistic once they have moved out of home.[24]

2.16 Other theories about the drop in prevalence included people 'losing' their diagnosis over time—although it was noted that the reasons for this needed to be explored further, with Monash University stating that such research would need to include 'whether treatment has been effective or whether children have been unnecessarily diagnosed with autism'.[25]

Prevalence by gender

2.17 The ABS data from 2018 indicated that males were 3.5 times more likely than females to be diagnosed with autism.[26] While this gap had narrowed since 2015, when males were 4.1 times more likely to be diagnosed with autism,[27] a number

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[21] Autism Aspergers Advocacy Australia (A4), *Submission 54*, p. 3; Commissioner for Children and Young People Western Australia, *Submission 42*, Attachment 1, p. 4; Mr Cameron Boyd, *Submission 157*, pp. 6–7, Scope-University of Melbourne Partnership, *Submission 83*, p. 24.

[22] See, for example, Reframing Autism, *Submission 24*, p. 4, Autism Queensland, *Submission 129*, p. 2.

[23] Spectrum Labor, *Submission 1*, [p. 4]; Australian Autism Alliance, *Submission 52.2*, p. 8.

[24] ABS, *Survey of Disability, Ageing and Carers, Australia: Summary of Findings 2018: Key statistics*, https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#key-statistics.

[25] Monash University, *Submission 94*, p. 8. Recent research by Monash University suggested that between the ages of 10 and 16, one in four children had 'lost' their parent-reported autism diagnosis.

[26] ABS, *Survey of Disability, Ageing and Carers, Australia: Summary of Findings 2018: Autism in Australia*, 29 November 2020, www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features102018?opendocument&tabname=Summary&prodno=4430.0&issue=2018&num=&view= (accessed 21 July 2020).

[27] ABS, *Survey of Disability, Ageing and Carers, Australia: Summary of Findings 2015: Autism in Australia*, 29 April 2016, www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-first-results/latest-release (accessed 21 July 2020).

of stakeholders argued the figures may still not reflect the true male to female ratio of autism and that females are still underrepresented in the statistics.[28]

2.18 The most commonly cited reasons for higher prevalence in males were that autistic females may present differently to males and are better able to mask social differences,[29] and that there is a gender bias in current diagnostic tools.[30]

2.19 Clinical knowledge was also thought to contribute to the gender gap by delaying diagnosis of females with autism,[31] as well as under diagnosing females with co-occurring intellectual disability.[32]

Gender diversity and sexual orientation

2.20 It was also noted that the female presentation of autism may also be present in atypical and gender diverse males who can experience challenges in diagnosis.[33]

2.21 There is growing evidence of an increased prevalence of gender variance in autistic people compared to the general population.[34] Additionally, autistic people are also more likely than the general population to experience gender incongruence.[35]

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[28] See, for example, Autism CRC, *Submission 46*, p. 11; Yellow Ladybugs, *Submission 49*, p. 1; La Trobe University – Olga Tennison Autism Research Centre (OTARC), *Submission 55*, pp. 8–9, The Sycamore School, *Submission 118*, p. 6.

[29] Australian Psychological Society, *Submission 110*, p. 8; CliniKids, *Submission 15*, [p. 5]; Autism CRC, *Submission 46*, p. 11; OTARC, *Submission 55*, p. 9, Yellow Ladybugs, *Submission 49*, p. 7.

[30] See, for example, Spectrum Labor, *Submission 1*, [p. 6]; PEERS Australia, *Submission 108 (Attachment 01), [p. 38]*, Australian Psychological Society, *Submission 110*, p. 8; CliniKids, *Submission 15*, [p. 5]; Autism CRC, *Submission 46*, p. 11; Yellow Ladybugs, *Submission 49*, p. 1; Australian Autism Alliance, *Submission 52*, p. 18.

[31] OTARC, *Submission 55*, pp. 8 and 9. OTARC found the ratio of autistic females to males decreased from 1:15 at 12 months of age to 1:3.2 by 24 months. In children without intellectual disability the prevalence of autistic females to males is much lower (1:10) than when there is intellectual disability (1:1.5). See also, Queensland Law Society, *Submission 124*, p. 3. This submission referred to a 2016 Scottish study which also found a decreasing ratio of autistic females to males over time. In very young children, the ratio was 1:5.5. In children and adolescents the ratio was 1:2.3. In adulthood, the ratio dropped to 1:1.8.

[32] OTARC, *Submission 55*, p. 8.

[33] Coalition of Autistic Women, *Submission 125*, [p. 7]; Speech Pathology Australia, *Submission 87*, p. 10.

[34] See, for example, Autism CRC, *Submission 46*, p. 11; Australian Autism Alliance, *Submission 52*, p. 18; Spectrum Labor, *Submission 1*, [p. 10]. See also, Laura Pecora, Grace Hancock, Merrilyn Hooley, David Demmer, Tony Attwood, Gary Mesibov and Mark Stokes, 'Gender identity, sexual orientation and adverse sexual experiences in autistic females', *Molecular Autism*, vol. 11, no. 57, 2020, https://doi.org/10.1186/s13229-020-00363-0, p. 2.

[35] See, for example, Australian Psychological Society, *Submission 110*, p. 8; Speech Pathology Australia, *Submission 87*, p. 11.

2.22 Non-heterosexual orientation is also more common among autistic people than in the general population, with greater variability in sexual orientation among females.[36]

Prevalence in specific cohorts

2.23 Given the lack of general data on the prevalence of autism in Australia, the data on prevalence in specific cohorts, such as Aboriginal and Torres Strait Islander peoples and those from culturally and linguistically diverse (CALD) backgrounds, is also deficient.[37]

Aboriginal and Torres Strait Islander peoples

2.24 Little is known about the prevalence of autism in Aboriginal and Torres Strait Islander peoples. However, given the high prevalence of disability in Indigenous Australians,[38] stakeholders suggested that the autism is likely to be undiagnosed in Aboriginal and Torres Strait Islander peoples for a number of reasons, including:

- barriers to accessing diagnostic services;
- misdiagnosis with schizophrenia or Foetal Alcohol Spectrum Disorder;
- hearing loss and otitis media (which can delay or mask an autism diagnosis);
- shame and stigmatisation around disability; and
- cultural and language barriers.[39]

Culturally and linguistically diverse communities

2.25 As with prevalence in Aboriginal and Torres Strait Islander peoples, there is an absence of data on the prevalence of autism in people from CALD backgrounds in Australia.[40] It was suggested that autism may be under-diagnosed in CALD individuals due to a lack of knowledge about autism, language barriers, and/or cultural traits—such as very fixed social rules or different expectations about looking people in the eye—that may mask symptoms.[41]

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[36] Laura Pecora, Grace Hancock, Merrilyn Hooley, David Demmer, Tony Attwood, Gary Mesibov and Mark Stokes, 'Gender identity, sexual orientation and adverse sexual experiences in autistic females', *Molecular Autism*, vol. 11, 57, 2020, https://doi.org/10.1186/s13229-020-00363-0, p. 2.

[37] See, for example, National Aboriginal Community Controlled Health Organisation, *Submission 104*, [p. 3]; Queensland Family and Child Commission, *Submission 36*, p. 5; Ethnic Disability Advocacy Centre, *Submission 75*, p. 4; The Autistic Realm Australia, *Submission 86*, p. 9.

[38] Northern Territory Office of the Public Guardian, *Submission 20*, [p. 9].

[39] National Aboriginal Community Controlled Health Organisation, *Submission 104*, [pp. 3 and 5]; Queensland Family and Child Commission, *Submission 36*, p. 5.

[40] Ethnic Disability Advocacy Centre (EDAC), *Submission 75*, p. 4.

[41] EDAC, *Submission 75*, p. 4; Name withheld, *Submission 2*, pp. 6 and 7; BioAutism Ltd, *Submission 93*, p. 4

Diversity of the autism spectrum

2.26 When describing the diversity of autistic people, numerous stakeholders referenced the well-known quote by Dr Stephen Shore—'if you've met one person with autism, you've met one person with autism'.[42]

2.27 This reflects the nature of autism as a 'spectrum' condition. The term spectrum is used to emphasise that autism presents differently in each individual and may also change over time. As explained by the Cooperative Research Centre for Living with Autism (Autism CRC):

> Every person on the autism spectrum is unique. The developmental challenges and their presentation can vary widely in the nature and severity between individuals, and in the same individuals over time.[43]

2.28 Some stakeholders also stressed that the spectrum is not a linear scale of autism severity. Rather, it is better described as a 'constellation' of traits (Figure 2.2).[44] As one witness explained:

> …it's a spectrum. But at the moment people are looking at it as a linear line, like 'he's low functioning, he's high functioning'. Autism isn't a linear spectrum. Autism is a colour palette spectrum. It's a soundboard spectrum, where every single person on the spectrum fits into a different part.[45]

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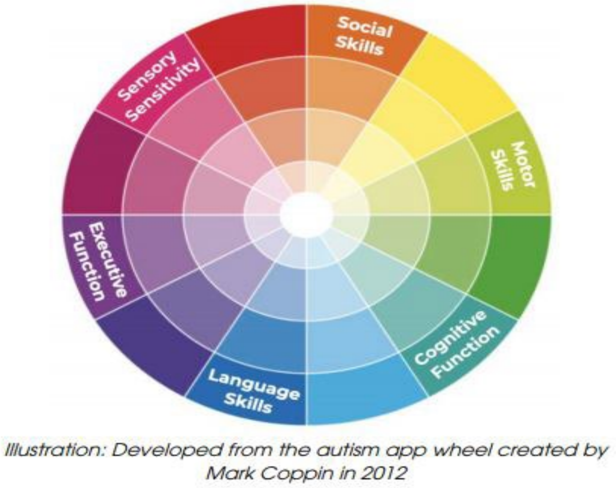
[42] Lime Connect, *Leading Perspectives on Disability: a Q&A with Dr Stephen Shore*, www.limeconnect.com/opportunities_news/detail/leading-perspectives-on-disability-a-qa-with-dr-stephen-shore (accessed 22 June 2021). See, for example, Mr Phillip Morris, *Submission 25*, p. 4; Ms Jenny Karavolos, Chief Executive Officer, Autism SA, *Proof Committee Hansard*, 16 November 2020, p. 9.

[43] Autism CRC, *Submission 46*, p. 3.

[44] Amaze, *Talking about autism: guidelines for respectful and accurate reporting on autism and autistic people*, www.amaze.org.au/wp-content/uploads/2019/06/Talking-about-autism-a-media-resource_web.pdf, p. 5; Autism Spectrum Australia, *What is autism*, www.autismspectrum.org.au/about-autism/what-is-autism (accessed 22 June 2021).

[45] Ms Chloe Hayden, Amaze, *Official Committee Hansard*, 11 February 2021, p. 14.

Figure 2.2 Autism spectrum traits



Source: Amaze, Talking about autism: guidelines for respectful and accurate reporting on autism and autistic people, p. 5.

Co-occurring conditions

2.29 The diversity of autism presentation is also impacted by the high number of co-occurring physical and psychiatric conditions experienced by autistic people.[46] According to the Raising Children website, nearly 75 per cent of autistic children have a co-occurring condition.[47] Chief Clinical Adviser and Founder of ND Australia, Professor Adam Guastella, explained to the committee that it was not surprising that comorbidities were high across neurodevelopmental disorders:

> …a child who starts to show difficulties or divergence in one domain of functioning, whether it's social, motor language or cognitive development, will start to show delays or divergence in other areas of development.[48]

2.30 Commonly co-occurring conditions include intellectual disability and developmental delays, language delay, motor difficulties, epilepsy, sleep problems, anxiety, depression, attention deficit hyperactivity disorder (ADHD), unusual eating behaviours, and gastrointestinal symptoms.[49] ND Australia provided the following estimation of the rate of certain comorbidities:

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[46] UNSW 3DN, *Submission 95*, p. 6.

[47] Raising Children: the Australian parenting website, *Conditions that can occur with autism*, www.raisingchildren.net.au/autism/learning-about-autism/about-autism/conditions-that-occur-with-asd (accessed 10 December 2021).

[48] Professor Adam Guastella, Chief Clinical Adviser and Founder, ND Australia, *Proof Committee Hansard*, 15 April 2021, p. 1.

[49] Raising Children: the Australian parenting website, *Conditions that can occur with autism*, www.raisingchildren.net.au/autism/learning-about-autism/about-autism/conditions-that-occur-with-asd (accessed 23 June 20121).

- 30–40 per cent of autistic children have an intellectual disability or developmental delays;
- 60–70 per cent of autistic people have ADHD;
- 40–60 per cent of autistic children have anxiety;
- 20–30 per cent of autistic people have epilepsy;
- 4–5 per cent of autistic children have Tourette syndrome and another 9–12 per cent have tics of some kind;
- 30 per cent of children with Cerebral Palsy are also autistic; and
- up to 40 per cent of people with Down Syndrome are also autistic.[50]

2.31 These co-diagnoses 'profoundly affect' how a person with autism functions.[51]

Variation and complexity of needs

2.32 Autism has been described as 'among the most complex, prevalent and heritable of all neurodevelopmental conditions'.[52] Its complexity is reflected in the broad diagnostic 'umbrella' of Autism Spectrum Disorder, which a submitter noted 'covers people in very different "worlds", with vastly diverse experiences and conflicting worldviews regarding autism'.[53]

2.33 Accordingly, there is significant variation in the presentation of autism and the complexity of autistic people's support needs.[54] For example, while some autistic people are able to live completely independently,[55] most experience difficulties negotiating everyday living and a 'significant proportion' have multiple and complex needs that necessitate intensive intervention and long-term support.[56] As described by the Royal Australasian College of Physicians:

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[50] ND Australia, *Submission 97*, [p. 2].

[51] Autism Awareness Australia, *Understanding autism*, www.autismawareness.com.au/could-it-be-autism/understanding-autism/ (accessed 23 June 2021).

[52] Autism CRC, *Submission 46*, p. 10.

[53] Name withheld, *Submission 31*, p. 3.

[54] Synergies Economic Consulting, *Cost-Benefit Analysis of Providing Early Intervention to Children with Autism*, August 2013, p. 4. This report defines three categories of impairment:

- children with severe intellectual impairment, who are likely to be non-verbal and suffer from significant behavioural issues and anxieties;
- children with mild to moderate intellectual impairment, who are likely to experience difficulties with language and communication, particularly in social settings; and
- children with High Functioning Autism, who do not suffer from intellectual disabilities but can experience difficulties in other areas that can adversely impact long-term outcomes in key areas.

[55] Autism Awareness Australia, *Understanding autism*, www.autismawareness.com.au/could-it-be-autism/understanding-autism/ (accessed 23 June 2021).

[56] St Vincent's Health Australia, *Submission 72*, p. 1.

> A child at one end of the spectrum may only need minimal supports to reach their potential while another child, with the same condition, may have complex problems that require lifelong care.[57]

2.34 This variation was also reflected in personal experiences conveyed to the committee by stakeholders in the inquiry, with some having achieved personal and professional success with minimal or no government support,[58] while others struggled to manage the routine activities of daily living.[59]

2.35 The committee notes that the breadth of the spectrum appears to be the source of some tension in the autism community, particularly between autistic adult self-advocates and parents of autistic children with more 'severe' autism and cognitive and functional impairments. More than one participant suggested that alternative classifications or sub-classifications may be needed to help improve understanding of the differences and challenges across the autism spectrum.[60]

Complex needs

2.36 Within the autism spectrum, those diagnosed as Level 2 or Level 3, and/or those with significant co-occurring conditions, are likely to have more substantial and complex support needs. Individuals with more complex needs may be non-verbal and experience significant behavioural issues and anxieties. They are also likely to need assistance with self-care activities, such as showering, dressing, toileting and food preparation. They may also require full-time supervision.[61]

2.37 While the committee heard there is no clear definition of 'complex needs' (particularly in relation to the National Disability Insurance Scheme [NDIS]),[62] stakeholders indicated that those with complex needs can include individuals presenting with more 'severe' autism, intellectual disability, mental health conditions, behaviours of concern and language disorders.[63]

2.38 However, others noted that complex needs can also arise from the intersection of autism with 'contextual stressors', such as poverty, unaccommodating environments, drug and alcohol dependence, unsafe home environments,

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[57] Royal Australasian College of Physicians, *Submission 29*, p. 5.

[58] See, for example, Mr David Staples, *Submission 143*, [p. 16]; Mr Cameron Boyd, Submission 157, [pp. 3–5]. It should be noted that this does not mean these individuals do not face challenges that require support. Rather, the necessary supports have been provided largely through personal resources and informal support networks, with minimal government support.

[59] See, for example, Name withheld, *Submission 31*, p. 1; Name withheld, *Submission 60*, [p. 2]; Name withheld, *Submission 111*, [p. 4].

[60] See, for example, Name withheld, *Submission 31*, p. 1; Name withheld, *Submission 2*, p. 2.

[61] Synergies Economic Consulting, *Cost-Benefit Analysis of Providing Early Intervention to Children with Autism*, August 2013, p. 22.

[62] See, for example, AEIOU Foundation, *Submission 50*, [p. 2].

[63] See, for example, Irabina Autism Services, *Submission 130*, p. 3; Name withheld, *Submission 31*, p. 2

and/or contact with the criminal justice system.[64] Late diagnosis can also lead to autistic people presenting with 'preventable conditions that can be severe and complex in nature'.[65]

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[64] UNSW 3DN, *Submission 95*, p. 6; Victorian Department of Health and Human Services, *Submission 100*, Attachment 1 (State of Victoria, *Victorian Autism Plan*), p. 6; St Vincent's Health Australia, *Submission 72*, pp. 5–6.

[65] National Disability Insurance Agency, *Submission 56*, p. 10.

Chapter 3
Life outcomes for autistic people

3.1 This chapter provides information on life outcomes for autistic people across a number of domains, including health, education, employment, housing, justice and social inclusion.

Overview

3.2 Numerous stakeholders submitted that autistic people experience worse life outcomes than other disability cohorts and vulnerable population groups.[1] Key statistics highlighted for the committee included:

- autistic people have a life expectancy 20–36 years shorter than the general population, with over two times the mortality rate;
- 75 per cent of autistic people do not complete education beyond year 12;
- the unemployment rate for autistic people is almost eight times the rate of people without disability;
- 50–70 per cent of autistic people experience co-existing mental health conditions; and
- 51 per cent of autistic people and their families feel socially isolated and 39 per cent feel unable to leave the house due to concerns about negative behaviours.[2]

3.3 The reasons for these results are multifaceted and interwoven. As noted by some stakeholders, life outcomes for autistic people are influenced not only by the presence and magnitude of autism symptoms but also by co-occurring physical and psychiatric conditions, as well as socio-cultural factors and other stressors, such as poverty, unaccommodating environments, exclusion and discrimination.[3]

3.4 Poor outcomes for autistic people are also cumulative. For example, a number of stakeholders reflected that poor educational experiences and high rates of school disengagement reduce post-school opportunities for further education, employment, and independent living. In turn, this can increase social exclusion

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[1] See, for example, Australian Autism Alliance, *Submission 52*, p. 8; Commissioner for Children and Young People Western Australia, *Submission 42*, p. 4; Cooperative Research Centre for Living with Autism (Autism CRC), *Submission 46*, p. 3; Department of Developmental Disability Neuropsychiatry, University of New South Wales (UNSW 3DN) *Submission 95*, p. 2.

[2] Mr Benjamin Biro, Community Member, Australian Autism Alliance, *Proof Committee Hansard*, 12 February 2021, p. 2.

[3] See, for example, UNSW 3DN, *Submission 95*, p. 6; PEERS Australia, *Submission 108*, p. 3; Scope-University of Melbourne Partnership, *Submission 83*, p. 8; Name withheld, *Submission 119*, p. 9

and lead to, or exacerbate, feelings of poor self-worth and/or mental health conditions.[4]

3.5 Overall, it appears that life outcomes are poorer for autistic people with concurrent medical conditions or disabilities, such as intellectual disability.[5] There is also some evidence that outcomes may be worse for autistic people from disadvantaged groups such as those from low-socioeconomic backgrounds, those with low English proficiency, and those living in regional and remote Australia.[6]

Health outcomes

3.6 It appears there are relatively few large-scale studies about health outcomes for autistic people. Some of the available studies acknowledge that further research is needed,[7] while others highlight obstacles to conducting large-scale research, such as an inability to establish sufficient sample sizes and/or trace participants for an adequate period of time.[8] Accordingly, the summary below relies heavily on a few key Australian and international studies—as do a number of submissions made to the inquiry.[9]

Life expectancy

3.7 The available evidence indicates that life expectancy for autistic people is significantly lower than for the general population. For example, a report by the United Kingdom (UK) autism research charity, Autistica, found that autistic people die an average of 16 years earlier than the general population, while autistic people with concurrent intellectual disability die more than 30 years earlier.[10] Similarly, a recent University of New South Wales (UNSW)

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[4] See, for example, Speech Pathology Australia, *Submission 87*, p. 15; Children and Young People with Disability Australia, *Submission 109*, p. 4; Reframing Autism, *Submission 24*, [p. 10].

[5] Hwang, Y.I., Srasuebkul, P., Foley, K., Arnold, S. and Trollor, J.N. (2019) 'Mortality and cause of death of Australians on the autism spectrum' *Autism Research*, vol. 12 no. 5, doi:10.1002/aur.2086, p. 1.

[6] Australian Autism Alliance, *Submission 52*, p. 11.

[7] Dr James Cusack, Simon Shaw, Jon Spiers and Rebecca Sterry, *Personal tragedies, public crisis*, Autistica, 2016, p. 6.; Hwang, Y.I., Srasuebkul, P., Foley, K., Arnold, S. and Trollor, J.N. (2019) 'Mortality and cause of death of Australians on the autism spectrum' *Autism Research*, vol. 12 no. 5, doi:10.1002/aur.2086, p. 1.

[8] Svend Erik Mouridsen, Henrik Brønnum-Hansen, Bente Rich, and Torben Isager, 'Mortality and causes of death in autism spectrum disorders: an update', *Autism: the international journal of research and practice*, vol. 12 no. 4, https://doi.org/10.1177/1362361308091653, p. 411.

[9] See, for example, Australian Autism Alliance, *Submission 52*, p. 19; Royal Australian and New Zealand College of Psychiatrists, *Submission 17*, p. 3; Mr Cameron Boyd, *Submission 157*, p. 14; Name withheld, *Submission 126*, p. 21.

[10] Dr James Cusack, Simon Shaw, Jon Spiers and Rebecca Sterry, *Personal tragedies, public crisis*, Autistica, 2016, p. 3.

study found that the overall mortality rate for autistic people was approximately twice that of the general population.[11]

3.8 Although the reasons for lower life expectancy are not fully understood,[12] much of the evidence indicates that co-occurring medical conditions and concurrent intellectual disability, rather than autism itself, are the cause of lower life expectancy for autistic people.[13]

3.9 Diagnosis and treatment of physical illnesses can also be delayed or made more difficult by the presence of concurrent intellectual disability, difficulty with communication and social interaction, a need for stability and routine, and the insensitivity to pain and cold experienced by some autistic people.[14]

3.10 In addition, it is likely that high rates of social exclusion and unemployment among autistic people also contribute to poorer health outcomes and lower life expectancy.[15]

3.11 While all autistic people face an increased risk of premature mortality, the risk appears greatest for those with a concurrent intellectual disability. This aligns with the findings of the UNSW study which concluded that the high mortality rate for autistic people was driven primarily by concurrent intellectual

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[11] University of New South Wales Newsroom, *Death rates in people on the autism spectrum twice those of the general population: new research*, 26 February 2019, www.newsroom.unsw.edu.au/news/health/death-rates-people-autism-spectrum-twice-those-general-population-new-research (accessed 30 November 2020).

[12] Dr James Cusack, Simon Shaw, Jon Spiers and Rebecca Sterry, *Personal tragedies, public crisis*, Autistica 2016, p. 6.

[13] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., and Bolte, S. (2016) 'Premature mortality in autism spectrum disorder', *The British Journal of Psychiatry*, vol. 208, doi: 10.1192/bjp.bp.114.160192, p. 232.

[14] Svend Erik Mouridsen, Henrik Brønnum-Hansen, Bente Rich, and Torben Isager, 'Mortality and causes of death in autism spectrum disorders: an update', *Autism: the international journal of research and practice*, vol. 12 no. 4, https://doi.org/10.1177/1362361308091653, p. 412.

[15] Australian Institute of Health and Welfare, *Social determinants of health*, 23 July 2020, www.aihw.gov.au/reports/australias-health/social-determinants-of-health (accessed 28 February 2022). The AIHW snapshot discusses a number of social determinants of health that impact on health outcomes and life expectancy, including social support and exclusion, employment and work, socioeconomic position, and housing and homelessness. The AIHW states that, 'according to the World Health Organisation, social inequalities and disadvantage are the main reason for avoidable and unfair differences in health outcomes and life expectancy across groups in society'.

disability.[16] For autistic people without concurrent intellectual disability, the mortality rate appears to be similar to that of the general population.[17]

3.12 However, other studies found an increased risk of death even for autistic people with low levels of intellectual disability. For example, while concluding that intellectual disability was the most influential factor in relation to mortality and autism, a Californian study found that individuals with no, or very low, levels of intellectual disability still had a higher standardised mortality rate than the general population.[18]

Leading causes of mortality

3.13 While cancer and circulatory diseases were the most common causes of death in the general population, the NSW study found that for people on the autism spectrum, injury and poisoning (including accidents and self-harm) and nervous system and sense disorders (e.g. epilepsy) were the leading causes of death.[19]

3.14 There findings are consistent with a 2016 Swedish study, which found that the most common cause of death for autistic people with a concurrent intellectual disability was epilepsy, while autistic people without concurrent intellectual disability were found to be at much higher risk of suicide. However, this study also noted that increased mortality of autistic people was 'not limited to certain causes of death, such as diseases of nervous system, but was elevated for all analysed categories' and argued that autism 'accounts for substantial health loss across the lifespan'.[20]

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[16] University of New South Wales Newsroom, *Death rates in people on the autism spectrum twice those of the general population: new research*, 26 February 2019, www.newsroom.unsw.edu.au/news/health/death-rates-people-autism-spectrum-twice-those-general-population-new-research (accessed 30 November 2020).

[17] Hwang, Y.I., Srasuebkul, P., Foley, K., Arnold, S. and Trollor, J.N. (2019) 'Mortality and cause of death of Australians on the autism spectrum' *Autism Research*, vol. 12 no. 5, doi:10.1002/aur.2086, p. 6.

[18] Spectrum Labor, *Submission 1*, Appendix 3 (Synergies Economic Consulting, Economic Costs of Autism Spectrum Disorder, April 2007), p. 53.

[19] University of New South Wales Newsroom, *Death rates in people on the autism spectrum twice those of the general population: new research*, 26 February 2019, www.newsroom.unsw.edu.au/news/health/death-rates-people-autism-spectrum-twice-those-general-population-new-research (accessed 30 November 2020).

[20] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., and Bolte, S. (2016) 'Premature mortality in autism spectrum disorder', *The British Journal of Psychiatry*, vol. 208, doi: 10.1192/bjp.bp.114.160192, pp. 235-236.

Epilepsy

3.15 While epilepsy affects one per cent of the general population, it is thought to affect 20–40 per cent of autistic people[21] and is more common in autistic people with severe intellectual disability or other neurological conditions.[22] For example, the risk of epilepsy in autistic children with concurrent intellectual disability is 20 per cent (versus 8 per cent for autistic children without concurrent intellectual disability). For those with severe intellectual disability, the risk can be as high as 40 per cent.[23]

3.16 Epilepsy in autistic people can also present differently from epilepsy in the general population—often appearing in adolescence and potentially being more resistant to treatment. Of all autistic people with a concurrent intellectual disability and epilepsy, half do not live to see their 40th birthday.[24]

Suicide and mental health

3.17 Autistic people are more likely to attempt or die by suicide than other groups.[25] For example, while autism affects only one percent of the population in the UK, up to 11 per cent of people who die by suicide in the UK may be autistic.[26] In one recent Australian study of autistic people without intellectual disability, 66 per cent reported suicidal ideation and 35 per cent reported suicide plans or attempts—about five times higher than the general population.[27]

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[21] Autistica, *Autism and epilepsy a guide to managing epilepsy in autism*, www.autistica.org.uk/downloads/files/Epilepsy-autism-E-LEAFLET.pdf (accessed 8 December 2020).

[22] Raising Children website, *Conditions that can occur with autism spectrum disorder*, 20 June 2018, www.raisingchildren.net.au/autism/learning-about-autism/about-autism/conditions-that-occur-with-asd#seizures-and-epilepsy-nav-title (accessed 8 December 2020).

[23] Dr Roberto Tuchman and Angela Barker, *Epilepsy and autism*, The National Autistic Society, 14 June 2017, https://www.autism.org.uk/advice-and-guidance/professional-practice/epilepsy-autism (accessed 14 February 2022).

[24] Autistica, *Autistica Action Briefing: Epilepsies*, April 2019, www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Epilepsies.pdf (accessed 9 December 2020).

[25] Autistica, *Autistica Action Briefing: Suicide Prevention*, March 2019, www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Suicide-Prevention.pdf (accessed 9 December 2020).

[26] Autistica, *Autistica Action Briefing: Suicide Prevention*, March 2019, www.autistica.org.uk/downloads/files/Autistica-Action-Briefing-Suicide-Prevention.pdf (accessed 9 December 2020).

[27] Hwang, Y.I., Srasuebkul, P., Foley, K., Arnold, S. and Trollor, J.N. (2019) 'Mortality and cause of death of Australians on the autism spectrum' *Autism Research*, vol. 12 no. 5, doi:10.1002/aur.2086, p. 2. The rate of suicide ideation for the general population aged 16-85 at any time was 13.3 per cent in 2007. Slade T., Johnston A., Teesson M., Whiteford, H., Burgess P., Pirkis J., Saw S. (2009) *The mental health of Australians 2. Report on the 2007 National Survey of Mental Health and Wellbeing*, Department of Health and Ageing, Canberra.

3.18 This may reflect the high rate of co-occurring psychiatric conditions among autistic people,[28] with between 69–79 per cent of autistic people experiencing at least one mental health condition during their life.[29] It has also been suggested that autistic people may also lack 'protective factors', such as social networks, coping mechanisms, and overall life satisfaction, which could decrease the risk of suicide.[30]

3.19 The committee heard that depression, anxiety disorders and/or obsessive-compulsive disorder are the most common mental health conditions experienced by autistic people,[31] with anxiety and depressive disorders particularly common among autistic females and males at higher risk of suicide.[32] Autistic mothers are also at a higher risk of experiencing pre- and post-natal depression than non-autistic mothers.[33]

3.20 Stakeholders also observed that autistic people who identify as LGBTQIA are also more likely to experience mental health issues than the heteronormative population.[34] It was suggested that the issues experienced by this group were magnified by the intersection of autism, mental health, gender and sexual identity.[35]

3.21 However, participants also stressed that mental health problems are not inevitable for autistic people and instead can be the result of, or made worse by,

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[28] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., and Bolte, S. (2016) 'Premature mortality in autism spectrum disorder', *The British Journal of Psychiatry*, 208, doi: 10.1192/bjp.bp.114.160192, p. 232.

[29] Queensland Nurses and Midwives' Union, *Submission 69*, p. 3.

[30] Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., and Bolte, S. (2016) 'Premature mortality in autism spectrum disorder', *The British Journal of Psychiatry*, 208, doi: 10.1192/bjp.bp.114.160192, p. 237.

[31] See, for example, Australian Association of Social Workers, *Submission 96*, p. 6; Autism Queensland, *Submission 129,* p. 12; NSW Government, *Submission 65,* p. 7; UNSW 3DN, *Submission 95* p. 6.

[32] See, for example, Australian Psychological Society, *Submission 110*, p. 8; Autism Queensland, *Submission 129,* p. 12; Cameron Boyd, *Submission 157,* [p. 8]; Royal Australian and New Zealand College of Psychiatrists, *Submission 17,* p. 1.

[33] Australian Autism Alliance, *Submission 52*, p. 21. Forty per cent of autistic women experience pre-natal depression and 60 per cent experience post-natal depression (compared with 12 per cent generally).

[34] See, for example, Australian Psychological Society, *Submission 110*, p.8; I CAN Network, *Submission 107*, p. 10.

[35] Australian Psychological Society, *Submission 110*, p.8.

discrimination and isolation.[36] As an example, some submitters pointed to the mental health impacts of using masking behaviours in order to 'blend in'.[37]

Education outcomes

School education

3.22 The most recent Australian Bureau of Statistics (ABS) data shows that, in 2018, the proportion of autistic students whose highest level of educational attainment was Year 10 or below was more than double that of those without disability. The proportion was similar for those whose highest attainment was Year 11 or 12 (Table 3.1).

Table 3.1 Highest level of education attainment by disability status (per cent)

	No disability	All disability	Autism spectrum disorders
Year 10 or below	15.4	34.9	32.4
Year 11 or 12	21.7	14.7	43.2
Advanced diploma, diploma or certificate III/IV	28.1	29.4	17.9
Bachelor degree or higher	31.2	16.1	8.1

Source: Source: Australian Bureau of Statistics, Disability, Ageing and Carers, Australia: Summary of Findings (2018)

3.23 Poor school completion rates were attributed largely to educational restrictions, a lack of support and negative school experiences.[38] Autistic students also experience higher rates of bullying, isolation and academic underachievement.[39]

3.24 In relation to educational restrictions, the ABS reported that, in 2018, 92.3 per cent of autistic students had some form of educational restriction. Of these, a small number were unable to attend school because of their

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[36] Coalition of Autistic Women, *Submission 125*, p. 10.

[37] See, for example, Yellow Ladybugs, *Submission 49*, p. 4; Name withheld, *Submission 2*, p. 2. See also, Nancy Volkers, 'Invisible Girls', *The ASHA Leader*, Vol. 23, no. 4, April 2018, https://doi.org/10.1044/leader.FTR1.23042018.48.

[38] See, for example, Children and Young People with Disability Australia; *Submission 109*, p. 4, The Sycamore School, *Submission 118*, p. 9; Coalition of Autistic Women, *Submission 12*, p. 18.

[39] See, for example, Commissioner for Children and Young People Western Australia, *Submission 42*, p. 5; Name withheld, *Submission 120*, p. 5; Coalition of Autistic Women, *Submission 12*, p. 18; Autism Queensland, *Submission 129*, pp. 11-12.

disability. Of the young autistic people attending school, two in five attended a special school (or a special class in a mainstream school) and 77.7 per cent experienced difficulties at their place of learning. The main problems reported were:

- fitting in socially (59.8 per cent);
- learning difficulties (55.3 per cent); and
- communication difficulties (51.5 per cent).[40]

Post-school education

3.25 As with school education, the ABS found that, in 2018, autistic people were less likely to complete post-school education than people without disability. They were also less likely to complete post-school education than people with disability (Table 3.1).

3.26 In addition, the committee heard that autistic school leavers who pursue post-school education are more likely to pursue vocational education than university studies and are also more likely to enrol in higher education on a part-time basis.[41] Of those autistic individuals who do commence tertiary education, it is suggested that up to 25 per cent withdraw from their course before completion.[42]

3.27 Stakeholders identified a number of factors that may contribute to poor tertiary education completion rate. For example, the Olga Tennison Autism Research Centre (OTARC) at La Trobe University identified the following issues thought to affect students' progress:

- social-communication difficulties;
- structure, routine and sensory sensitivities;
- mental health, especially anxiety and depression;
- planning and organising;
- fine motor skill difficulties; and
- disability and academic support.[43]

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[40] Australian Bureau of Statistics (ABS), *Disability, Ageing and Carers, Australia: Summary of Findings*, www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/2018#autism-in-australia (accessed 5 July 2021).

[41] Australian Autism Alliance, *Submission 52*, p. 28.

[42] Mentoring Autism Community of Practice, *Submission 73*, [p. 1]. See also Autism Queensland, *Submission 129*, p. 21. An Autism Queensland survey found that, of the 69 adolescents that had started tertiary education, around 29 per cent did not complete their study.

[43] La Trobe University – Olga Tennison Autism Research Centre (OTARC), *Submission 55*, p. 12. See also, Mentoring Autism Community of Practice, *Submission 73*, [pp. 1–2]. This submission also identified challenges with general transition, navigating the built environment, and adjusting to different teaching formats.

Employment outcomes

3.28 Numerous submissions highlighted the poor employment outcomes for autistic people in Australia.[44] Stakeholder estimates of the number of unemployed autistic people ranged from around 46 000[45] to 80 000.[46] It was also estimated that around 45 per cent of autistic people are living near, or in, poverty as a result of being unemployed.[47]

3.29 According to the ABS, in 2018, the labour force participation for autistic people aged 15–64 years was 38 per cent (compared to 53.4 per cent of people with disability and 84.1 per cent of people without disability). The unemployment rate for autistic people was 34.1 per cent—more than three times the rate for people with disability (10.3 per cent) and almost eight times the rate of people without disability (4.6 per cent).[48] This also appears to align with the 2015 ABS data which showed that 29 per cent of autistic people aged 15–64 were permanently unable to work.[49]

3.30 A number of stakeholders also drew the committee's attention to the National Disability Insurance Agency (NDIA) report, *Outcomes for participants with Autism Spectrum Disorder*,[50] which found that:

- 13.8 per cent of participants aged 15–24 had a paid job, which was slightly lower than the average (16.6 per cent) and also lower than participants with intellectual disability (16 percent) or Down Syndrome (17.1 per cent); and

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[44] See, for example, Australian Autism Alliance, *Submission 52*, p. 35; OTARC, *Submission 55*, p. 17; Autism CRC, *Submission 46*, p. 27; Autism Spectrum Australia (Aspect), *Submission 64*, p. 15; Name withheld, *Submission 62*, p. 10; Commissioner for Children and Young People Western Australia, *Submission 42*, p. 6; Autism Awareness Australia, *Submission 47*, p. 9; Reframing Autism, *Submission 24*, [p. 9]; I CAN Network, *Submission 107*, p. 19; PEERS Australia, *Submission 108*, Attachment 1 - Select Committee on Autism 2020–21, [p. 32]; Name withheld, *Submission 126*, p. 4; Name withheld, *Submission 16*, [p. 2]; Mr Cameron Boyd, *Submission 157*, [p. 7]; Positive Youth Incorporated, *Submission 85*, p. 6; Coalition of Autistic Women, *Submission 125*, [p. 19]; JFA Purple Orange, *Submission 84*, p. 19.

[45] Scope-University of Melbourne Partnership, *Submission 83*, p. 20.

[46] Mr Rhett Ellis, *Submission 45*, [p. 1].

[47] Children and Young People with Disability Australia, *Submission 109*, p. 9. See also, Reframing Autism, *Submission 24*, [p. 10]. This figure is more than 2.5 per cent higher than for the general population.

[48] ABS, *Disability, Ageing and Carers, Australia: Summary of Findings*, www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/2018#autism-in-australia (accessed 19 October 2021).

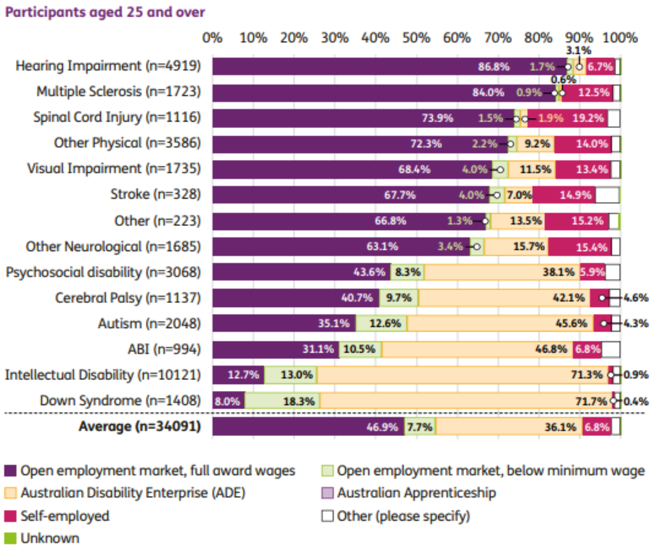
[49] National Disability Insurance Agency (NDIA), *Outcomes for participants with Autism Spectrum Disorder*, June 2018, p. 78.

[50] See, for example, Children and Young People with Disability Australia, *Submission 109*, p. 7; Autism Queensland, *Submission 129*, p. 24; JFA Purple Orange, *Submission 84*, p. 19.

- 25.7 per cent of participants aged over 25 had a paid job, which was slightly higher than the average (21.3 per cent) but lower than participants with intellectual disability (29.5 per cent) and Down Syndrome (32 per cent).[51]

3.31 The NDIA also found that of those autistic participants who were employed only 49.3 per cent of those aged 15–24 and 35.1 per cent of those aged over 25 were in open employment at full award wages—the third and fourth lowest percentages respectively of all participants. For those aged 15–24, a further 13.2 per cent were in open employment but paid less than award wages and 26.4 per cent were working in an Australian Disability Enterprise. For those aged over 25, the figures were 12.6 per cent and 45.6 per cent respectively (Figure 3.1).[52]

Figure 3.1 Type of employment by disability



Source: National Disability Insurance Agency, Employment Outcomes for NDIS Participants, December 2020, p. 45.

3.32 However, many National Disability Insurance Scheme (NDIS) participants not in paid employment would also like to work. According to the NDIA report, 61.5 per cent of autistic participants who didn't have a paid job (but would have liked one) had a work goal in their plan, which was equal to the average and higher than most other disabilities.[53]

3.33 This appears to align with the results of an Australian Autism Alliance (the Autism Alliance) survey, which found that of those respondents not in paid employment, 59.4 per cent would like to work.[54]

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[51] NDIA, *Employment Outcomes for NDIS Participants,* December 2020, pp. 29–30.

[52] NDIA, *Employment Outcomes for NDIS Participants,* December 2020, p. 45.

[53] NDIA, *Employment Outcomes for NDIS Participants,* December 2020, p. 89.

[54] Australian Autism Alliance, *Submission 52.2*, p. 10. The survey was conducted by Australian Catholic University (ACU) Engagement and involved 769 autistic adults and 3115 parents/carers (including

3.34 Stakeholders also identified underemployment of autistic people as a significant issue,[55] with many autistic people working below their potential and capacity.[56] This includes those employed in Australian Disability Enterprises, which can involve repetitive and low-paid work.[57]

3.35 High levels of unemployment and underemployment mean a significant proportion of autistic people are reliant on their families[58] and/or government funded services and benefits, such as income support payments.[59] The committee heard that around 50 per cent of people with disability aged 15–24 years rely on income support payments (compared to 14 per cent of people without disability).[60]

3.36 The committee heard that barriers to employment for autistic people ranged from low education attainment and limited work experience, social and communication difficulties, and sensory and executive function issues, through to anxiety with driving and accessing public transport, and difficulties managing life skills such as the need for a bank account and using an ATM.[61]

3.37 A range of external factors that may contribute to poor employment outcomes for autistic Australians were also highlighted, including unsuitable recruitment processes, negative employer perceptions of autistic people, unaccommodating workplace environments, a lack of appropriate workplace supports (including support to transition into the workplace), discrimination and bullying, and a lack of understanding about autism across workplaces and Disability Employment Service providers.[62]

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257 autistic adults who are also parents/carers of autistic people and completed the survey in both contexts).

[55] See, for example, Autism CRC, *Submission 46*, p. 19; Scope-University of Melbourne Partnership, *Submission 83*, p. 20; Specialisterne Australia, *Submission 67*, p. 3; Auticon, *Submission 160*, [p. 2]; Reframing Autism, *Submission 24*, [p. 10]; Name withheld, *Submission 120*, [pp. 7–8].

[56] Coalition of Autistic Women, *Submission 125*, [p. 19]; PEERS Australia, *Submission 108*, Attachment 1 - Select Committee on Autism 2020–21, [p. 35].

[57] Australian Autism Alliance, *Submission 52*, p. 35.

[58] OTARC, *Submission 55*, p. 17.

[59] See, for example, Northern Territory Office of the Public Guardian, *Submission 20*, [p. 5]; Specialisterne Australia, *Submission 67*, p. 4.

[60] Children and Young People with Disability Australia, *Submission 109*, p. 8.

[61] See, for example, Autism Queensland, *Submission 129*, p. 24; Marymead Autism Centre, *Submission 128*, p. 10; Different Journeys, *Submission 30*, p. 23.

[62] See, for example, Specialisterne Australia, *Submission 67*, p. 4; OTARC, *Submission 55*, p. 18; Australian Autism Alliance, *Submission 52*, p. 36; Autism CRC, *Submission 46*, p. 19; Commissioner for Children and Young People Western Australia, *Submission 42*, p. 6; Krofne, *Submission 57*, [p. 2]; Name withheld, *Submission 114*, [p. 2]]; Mr Cameron Boyd, *Submission 157*, [pp 9–10].

Housing outcomes

3.38 While accurate data on housing outcomes for autistic people appear to be lacking, evidence provided to the committee suggests that autistic people struggle to find suitable and sustainable accommodation.[63] As a result, it is thought that a large number of autistic adults remain in the family home until their parents' death.[64] Research also suggests that autistic people are at higher risk of homelessness than the general population.[65]

3.39 The committee heard that the difficulties experienced by autistic people relates primarily to a lack of appropriate, safe and affordable housing stock (particularly for those with more complex needs),[66] discrimination in the private rental market,[67] as well as the link between poor employment outcomes and the ability to access housing.[68]

Justice outcomes

3.40 As with housing, there is limited data available on justice outcomes for autistic Australians. However, a number of submissions pointed to the overrepresentation of people with disability in prison[69] and the barriers they experience in accessing justice services and interacting with the justice system.[70]

3.41 Stakeholders suggested a number of reasons for the overrepresentation of autistic people in the justice system, including a lack of understanding of autism within the system, communication and social difficulties experienced by autistic

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[63] See, for example, Yellow Ladybugs, *Submission 49*, pp. 21–22; Mr Phillip Gluyas, *Submission 8*, [pp. 5–6]; Name withheld, *Submission 131.2*, p. 2; Name withheld, *Submission 9*, p. 12; Name withheld, *Submission 131.2*, pp. 2–3; Name withheld, *Submission 60*, [p. 3]; Name withheld, *Submission 11*, [p. 9]; Name withheld, *Submission 38*, [p. 3].

[64] Autism Aspergers Advocacy Australia (A4), *Submission 54*, p. 22. See also, OTARC, *Submission 55*, p. 24. OTARC reported that only 10 per cent of young autistic adults live independently from family.

[65] A4, *Autistic people at greater risk of becoming homeless – new research*, 14 June 2018, https://a4.org.au/node/1782 (accessed 20 October 2021).

[66] See, for example, Tasmanian Government, *Submission 19*, p. 8; Northern Territory Office of the Public Guardian, *Submission 20*, pp. 5–6; St Vincent's Health Australia, *Submission 72*, p. 6; Name withheld, *Submission 119*, pp. 12–13; Name withheld, *Submission 11*, [p. 9]; Ethnic Disability Advocacy Centre (EDAC), *Submission 75*, p. 9; Name withheld, *Submission 60*, [p. 3].

[67] Name withheld, *Submission 131.2*, p. 1; Yellow Ladybugs, *Submission 49*, p. 10.

[68] Mr Cameron Boyd, *Submission 157*, [p. 10]; Name withheld, *Submission 123*, [p. 11].

[69] See, for example, NSW Government, *Submission 65*, p. 4; Government of Western Australia, *Submission 103*, p. 6; Spectrum Labor, *Submission 1*, [p. 11]; Name withheld, *Submission 126*, p. 23; Positive Youth Incorporated, *Submission 85*, p. 2; UNSW 3DN, *Submission 95*, p. 11; Queensland Family and Child Commission, *Submission 36*, p. 7.

[70] See, for example, Tasmanian Government, *Submission 19*, p. 4; Marymead Autism Centre, *Submission 128*, p. 9; Speech Pathology Australia, *Submission 87*, pp. 13–14; Yellow Ladybugs, *Submission 49*, p. 11; Name withheld, *Submission 131.1*, p. 2.

people, as well as their tendency towards compliance, difficulty processing information, and anxiety arising from changes in routine, unfamiliar situations or sensory overload.[71]

Social inclusion

3.42 The committee heard that autistic people and their families experience significant social isolation and discrimination.[72] A survey by the Autism Alliance found that:

- 67.5 per cent of autistic adults and 73.4 per cent of parents/carers feel socially isolated;
- 61.2 per cent of autistic adults and 63.4 per cent of parents/carers have lost friends because of the way the friends have responded to their autism or the person they care for;
- 47.5 per cent of autistic adults and 60.1 per cent of parents/carers sometimes feel unable to leave the house because of the fear of negative reactions; and
- 41.4 per cent of autistic adults have experienced discrimination or stigma.[73]

3.43 Using other measures of inclusion, some stakeholders cited research that found only 10 percent of autistic adults are in long-term sexual relationships or married, while 25 per cent reported only having a single friend.[74] For NDIS participants, it was reported that 34 per cent of autistic people aged 15–24 years and 41 per cent of those aged over 25 reported having no friends other than family or paid staff.[75]

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[71] See, for example, Aspect, *Submission 64*, pp. 15–16; Queensland Family and Child Commission, *Submission 36*, p. 7.

[72] See for example, The Autistic Realm Australia (TARA), *Submission 86*, p. 22; UNSW 3DN, *Submission 95*, p. 21; Name withheld, *Submission 81*, [p. 5]; Commissioner for Children and Young People Western Australia, *Submission 42*, p. 9.

[73] Australian Autism Alliance, *Submission 52*, p. 49.

[74] OTARC, *Submission 55*, p. 24. See, also, Australian Autism Alliance, *Submission 52*, pp. 45–46.

[75] JFA Purple Orange, *Submission 84*, p. 23.

3.44 Some of the factors contributing to low rates of social inclusion were autistic people's inherent challenges with communication and social engagement and the intersection with poor employment rates, a lack of community understanding of autism, limited opportunities to participate in the community and build social connections, unaccommodating built environments, reduced community mobility (such as access to transport), and low levels of independent living.[76]

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[76] See, for example, Australian Autism Alliance, *Submission 52*, pp. 49–50; TARA, *Submission 86*, p. 22; UNSW 3DN, *Submission 95*, p. 21; SDN Children's Services, *Submission 44*, p. 8; NDS, *Submission 98.1*, pp. 4–5; OTARC, *Submission 55*, p. 24. OTARC reported that living independently (either alone or as a couple) was related to better psychological quality of life and was an important factor in assessing social inclusion and participation in the community and economy.

Chapter 4
The cost of failing to provide adequate services and support

4.1 The preceding chapter detailed the unacceptably high cost, in terms of poor life outcomes, of failing to provide adequate services and support for autistic people.

4.2 This chapter seeks to identify the broader economic costs of failing to provide appropriate, timely and adequate support, as well as the financial, social and emotional costs borne by families and carers (including autistic parents). It also highlights key life stages and transition points where failure to provide appropriate supports can have a snowball effect in terms of the economic and social costs for autistic people, their families and the broader community.

Overview

4.3 The failure to provide adequate services and support comes at a significant cost to autistic individuals, their families, and society more broadly.[1] For individuals, these costs arise from lost potential, low employment rates, reduced independence and poor quality of life. For families, increased stress, social isolation, and relationship breakdowns can result in lower family income and increased health care expenditure. In broader economic terms, poor physical and mental health can lead to increased expenditure on health care and social services, while low education and employment levels can result in lost taxation revenue and an increased reliance on welfare support.[2]

4.4 The committee recognises there is a risk that a discussion about the cost of autism could be viewed as a negative reflection on the autistic community. In part this reflects the methodology of available research, which tends to quantify costs from a deficit perspective and does not identify the contribution of autistic people to the economy and society more broadly (or the fact that this contribution can be a function of their autistic traits).[3]

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[1] Mansfield Autism Statewide Services, *Submission 117*, [p. 4].

[2] Synergies Economic Consulting, *Economic Costs of Autism Spectrum Disorder in Australia (updated study)*, April 2011, pp. 7–8.

[3] This is acknowledged explicitly in some studies. See, for example, Synergies Economic Consulting, *Economic Costs of Autism Spectrum Disorder in Australia (updated study)*, April 2011, p. 3. This report acknowledges that identifying costs of autism could imply negative connotations about the condition. It also makes clear the intention of the study is not to diminish the contribution of autistic people to the community.

4.5 Therefore, the committee would like to make clear that the intent of this chapter, in concert with the preceding one, is to highlight the scale of the issues faced by autistic people and their families and point to where improved supports may offer the greatest benefit.

The economic cost

4.6 Estimates of the economic cost of autism in Australia appear to vary. Some of the figures provided to the inquiry include estimated lifetime costs ranging from \$6.7 million to \$9.2 million per person.[4] However, most submissions that referenced costs relied on Synergies Economic Consulting's *Economic Costs of Autism Spectrum Disorder in Australia* report (Synergies report),[5] which put the annual economic cost of autism in Australia at between \$8.1 billion and \$11.2 billion (2010 dollars) and cited an average per person cost of \$87 000.[6]

4.7 The Synergies report accounted for both direct and indirect costs, as well as quality of life costs. Proportionally, the impact on quality of life accounted for 40 per cent of the total cost, while employment costs and informal care costs (for adults) represented 26 per cent and 22 per cent respectively. Direct costs, including health care, social services and education, accounted for the remaining 12 per cent. Importantly, these figures represented incremental costs only—that is, those over and above costs incurred by non-autistic people.[7]

4.8 However, the Synergies report's authors noted that due to a lack of data, these figures also exclude a range of costs, including the cost of underemployment, comorbid conditions, alternative therapies, additional education and living support services, informal care for children, home modifications, and early intervention programs. The report also did not look at the costs of family breakdowns, or transfer effects such as reduced taxation revenue, reliance on welfare, or the impact on personal income. Therefore, it is likely that these cost estimates underestimate the true cost of autism in Australia.[8]

4.9 Accordingly, the report suggested that more systematic data collection and further research would be needed to understand the variance in individual

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[4] Mr Rhett Ellis, *Proof Committee Hansard*, 28 July 2020, p. 26; Dr Jose Molina, *Proof Committee Hansard*, 11 February 2021, p. 6.

[5] See, for example, Cooperative Research Centre for Living with Autism (Autism CRC), *Submission 46*, p. 19; Autism Queensland, *Submission 129*, p. 14; ABIA, *Submission 70*, p. 8; PEERS Australia, *Submission 108*, Attachment 1, [p. 34]; Spectrum Labor, *Submission 1*, Attachment 3.

[6] Synergies Economic Consulting, *Economic Costs of Autism Spectrum Disorder in Australia (updated study)*, April 2011, pp. 1 and 11. The report was originally prepared for the AEIOU Foundation in 2007 and was subsequently updated in 2011.

[7] Synergies Economic Consulting, *Economic Costs of Autism Spectrum Disorder in Australia (updated study)*, April 2011, p. 11.

[8] Synergies Economic Consulting, *Economic Costs of Autism Spectrum Disorder in Australia (updated study)*, April 2011, pp. 12–13 and 60–61.

outcomes and at what points services are likely to be needed, and by whom.[9] This sentiment was echoed by Ms Rosie Martin:

> I also wonder about the value of a deep and wide cost analysis of what costs later arise for not supplying enough support at the right time, in the early years. In this I am thinking about the expense of the challenges of mental illness and the criminal justice system. Maybe that money, if it had been spent early, would have been saved later down the track. I am not aware of there being a deep and wide cost analysis on that; I think it would be valuable.[10]

The cost to families and carers

4.10 BioAutism stated that through family relationships alone, it is estimated that approximately 6.5 per cent to 8.7 per cent of the Australian population are impacted by autism. As a result, failing to adequately support autistic people has flow on effects for a significant number of parents and carers, including autistic parents.[11]

4.11 This section outlines the financial, social and emotional impacts on families and carers, as well as the particular impacts on families of autistic people who show challenging behaviours, as well as autistic parents and carers.

Financial impacts

4.12 In terms of the direct financial impact on families, a 2014 Australian study estimated that the median cost to families was $34 900 per annum (or $38 198 in 2020). The study also reported that cost of autism symptoms was cumulative—that is, each additional symptom added approximately $1400 per annum.[12] However, given the limitations of the study,[13] the committee is aware that the actual cost to families may be higher. Indeed, some families provided evidence to the inquiry of significantly higher costs:

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[9] Synergies Economic Consulting, *Economic Costs of Autism Spectrum Disorder in Australia (updated study)*, April 2011, p. 108.

[10] Ms Rosie Martin, *Proof Committee Hansard*, 29 April 2021, p.21.

[11] BioAutism, *Submission 93*, pp. 21–22.

[12] Chiara Horlin, Marita Falkmer, Richard Parsons, Matthew A. Albrecht and Torbjorn Falkmer, 'The Cost of Autism Spectrum Disorders' in *PLoS ONE*, vol. 9 no. 9, 2014, p. 9, https://doi.org/10.1371/journal.pone.0106552. The 2020 figures were calculated using the Reserve Bank of Australia's Inflation Calculator, which is available at www.rba.gov.au/calculator/annualDecimal.html (accessed 19 May 2021).

[13] Chiara Horlin, Marita Falkmer, Richard Parsons, Matthew A. Albrecht and Torbjorn Falkmer, 'The Cost of Autism Spectrum Disorders' in *PLoS ONE*, vol. 9 no. 9, 2014, pp. 8–9, https://doi.org/10.1371/journal.pone.0106552. The study's authors acknowledge a number of limitations, including a low response rate, the use of current cost estimates (which may not be representative of historical costs), and the reporting of low costs due to an inability to afford treatment.

> Over the three or four years it's probably cost us, I hate to say it, but close to half a million dollars, believe it or not.[14]

4.13 The committee is also aware that cost estimates may be low as families are simply not able to access adequate and appropriate support. According to Irabina Autism Services (Irabina), 82.9 per cent of families with an autistic family member reported they did not receive some or all of the help they needed.[15]

4.14 In order to pay for supports and services, overseas research found that a number of parents borrowed money, cashed in retirement investments, used equity in their homes, and made other sacrifices (including going without meals).[16] This appears to be reflected in the Australian experience, with one submitter disclosing that, in order to care for her daughter, she had taken out a personal loan to cover a period of leave without pay (after exhausting her paid leave entitlements).[17]

4.15 In terms of indirect costs, a 2014 Australian study found that almost 90 per cent of the cost to families was the result of lost income from employment.[18] This was consistent with the Synergies report which found employment factors were the biggest indirect contributor to the cost of autism. This may be due to parents working fewer hours than they would like, working in a less skilled job than they would otherwise, or withdrawing from the workforce completely.[19] The indirect economic costs of caring are well known and were one of the factors that led to the establishment of the National Disability Insurance Scheme (NDIS).[20]

4.16 The impact of autism on parental employment was also a recurring theme across submissions to the inquiry.[21] For example, one parent reported being unable to work full time as behavioural issues meant they had to be on call to pick up their child from care when needed.[22] The need to reduce or abandon paid work to

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[14] Mr Domenic Mittiga, *Proof Committee Hansard*, 16 November 2020, p. 6.

[15] Irabina Autism Services, *Submission 130*, p. 9.

[16] Deanna Sharpe and Dana Baker, 'The Financial Side of Autism: Private and Public Costs' in *A Comprehensive Book on Autism Spectrum Disorders*, 2011, p. 283.

[17] Name withheld, *Submission 78*, p. 12.

[18] Chiara Horlin, Marita Falkmer, Richard Parsons, Matthew A. Albrecht and Torbjorn Falkmer, 'The Cost of Autism Spectrum Disorders' in *PLoS ONE*, vol. 9, issue 9, 2014, p. 9, https://doi.org/10.1371/journal.pone.0106552.

[19] Synergies Economic Consulting, *Economic Costs of Autism Spectrum Disorder in Australia (updated study)*, April 2011, pp. 1 and 59.

[20] The Productivity Commission estimated that about $1.5 billion per annum of economic benefits would occur from carers re-entering the workforce. See also, Name withheld, *Submission 126*, p. 3.

[21] Autism Queensland, *Submission 129*, p. 16; BioAutism, *Submission 93*, p. 25.

[22] Irabina Autism Services, *Submission 130*, p. 9.

care for an autistic child was also reported by a large proportion of respondents to a 2017 survey by Autism Queensland. This included:

- 68 per cent of parents whose children were yet to start school;
- 68 per cent of parents with primary school age children;
- 60 per cent of parents with secondary school age children; and
- 47 per cent of parents whose children had left school.[23]

4.17 In addition to the general impact of financial stress on health and family relationships,[24] reduced income from low employment also affects a family's ability to support their autistic child's development. This is a particular concern in relation to low-income families, who may have to limit their access to services, or may not seek support services at all.[25]

4.18 Given the substantial cost estimates associated with informal care provision,[26] the financial stress on parents without significant accumulated savings or superannuation is likely to continue well into retirement as they continue to care for adult children.[27]

4.19 This is likely to have a disproportionate impact on mothers, who are more likely to be the primary caregiver for their autistic child.[28] A population-based survey in the United Kingdom (UK) found that while 60–70 percent of mothers returned to the workforce after having a child, only 25 per cent from the sample of mothers with autistic children did the same.[29] The financial impact of being

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[23] Autism Queensland Limited, *Submission 129*, pp. 14–15.

[24] Synergies Economic Consulting, *Economic Costs of Autism Spectrum Disorder in Australia (updated study)*, April 2011, pp. 1 and 59.

[25] See, for example, Chiara Horlin, Marita Falkmer, Richard Parsons, Matthew A. Albrecht and Torbjorn Falkmer, 'The Cost of Autism Spectrum Disorders' in *PLoS ONE*, vol. 9 no. 9, 2014, pp. 8, 9 and 11, https://doi.org/10.1371/journal.pone.0106552. The journal article reported an association between increased costs and the severity of autism symptoms and suggested that early interventions that reduce expressed symptoms may improve families' productivity and, therefore, their financial situation.

[26] Synergies Economic Consulting, *Economic Costs of Autism Spectrum Disorder in Australia (updated study)*, April 2011, pp. 1 and 91. The estimated cost of caring for adult children ranged from $729 million to $3598 million (in 2010 dollars) depending on the assumed prevalence rate and calculation method.

[27] Chiara Horlin, Marita Falkmer, Richard Parsons, Matthew A. Albrecht and Torbjorn Falkmer, 'The Cost of Autism Spectrum Disorders' in *PLoS ONE*, vol. 9 no. 9, 2014, p. 8, https://doi.org/10.1371/journal.pone.0106552.

[28] Synergies Economic Consulting, *Economic Costs of Autism Spectrum Disorder in Australia (updated study)*, April 2011, pp. 1 and 55.

[29] Synergies Economic Consulting, *Economic Costs of Autism Spectrum Disorder in Australia (updated study)*, April 2011, pp. 1 and 55.

unable to work was described by one respondent to an Autism Queensland survey:

> My other children and I find ourselves in financially frightening circumstances. We cannot find another rental property because I am caring for my son, and we are almost destitute. I do not think other people/services realise how frightening this is.[30]

4.20 The committee is particularly concerned about the financial impact on women—and subsequently their children—given the gender gap in superannuation balances, the economic impact of marriage breakdown, and emerging evidence that women aged 65 and older are currently the fastest growing cohort among the homeless.[31]

Social and emotional impacts

4.21 The committee heard numerous accounts of social isolation, exhaustion and depression among parents and siblings of autistic people.[32] This aligns with research indicating that carers of people with disabilities report higher than normal levels of stress, depression and anxiety, along with reduced access to social activities and low levels of informal social support.[33]

4.22 Social isolation was identified as a significant source of stress for families. According to one participant, 51 per cent of autistic people and their families feel socially isolated, while 39 per cent feel unable to leave the house due to concerns about negative behaviours.[34] This was illustrated by another participant, who summarised many parents' feelings of being unwelcome at community events due to their children's behaviours:

> In particular they talked a lot about community sport and public transport. Some parents spoke about ... their struggles not being understood. Seventy per cent of respondents told us that they felt they weren't included as a

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[30] Autism Queensland Limited, *Submission 129*, p. 16.

[31] See, for example, Commonwealth of Australia, *Retirement Income Review Final Report, July 2020*, pp. 257 and 289. See also, I CAN Network, *Submission 107*, p. 11.

[32] See, for example, SDN Children's Services, *Submission 44*, pp. 18–20; Mansfield Autism Statewide Services, *Submission, 117*, [p. 4]; Autism Family Support Association, *Submission 22*, p. 3; Name withheld, *Submission 113*, [p. 3]; Name withheld, *Submission 131*, p. 3.

[33] K Nankervis, Andrea Rosewarne, and Maria Vassos, 'Why do families relinquish care? An investigation of the factors that lead to relinquishment into out-of-home respite care', *Journal of Intellectual Disability Research*, vol. 55 no. 4, 2011, p. 3, https://doi.org/10.1111/j.1365-2788.2011.01389.x.

[34] Mr Benjamin Biro, Community Member, Australian Autism Alliance, *Proof Committee Hansard*, 12 February 2021, p. 2.

> family, not just the child, and that that limited their child's opportunities and that they actually as a family felt isolated from community events.[35]

4.23 The challenge of accessing appropriate support services was identified as another source of stress, with one parent describing it as her 'second full-time job'.[36] More than one family described the process of accessing support as a battle[37] that favours those who have the ability and resources to fight.[38] The NDIS was seen as a particular source of anxiety and stress for parents:

> The NDIS is a fabulous scheme but … the stress we're putting on parents to navigate through that stream when they're trying to access services, supports and funding packages for their children is enormous…[39]

4.24 While the committee is unaware of any attempts to quantify the (likely avoidable) emotional and social costs of insufficient support, the cost is likely to be significant. For example, in 2018-19 the annual cost to the economy of mental ill-health in Australia was estimated to be up to $70 billion.[40]

Severe challenging behaviours

4.25 The cost of failing to provide appropriate services is even greater for families of autistic people who show severe challenging behaviours. These are behaviours that can result in injury (to themselves or others) or behaviours that impair functioning and health, and present in 5–10 per cent of autistic people with related neurodevelopmental disorders.[41]

4.26 Without appropriate support, severe challenging behaviours can escalate and further impair quality of life for autistic people. This can include limiting access to community and educational opportunities,[42] with the result that they are denied the chance to fulfil their potential. It was suggested to the committee that the opportunity cost of this lost potential was further magnified by the added

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[35] Ms Kay Turner, Chief Executive Officer, SDN Children's Services, *Proof Committee Hansard*, 28 July 2020, p. 40.

[36] La Trobe University – the Olga Tennison Autism Research Centre (OTARC), *Submission 55*, p. 17.

[37] Name withheld, *Submission 148*, [p. 1]; Mr Domenic Mittiga, *Proof Committee Hansard*, 16 November 2020, pp. 6–7.

[38] Speech Pathology Australia, *Submission 87*, p. 20; Name withheld, *Submission 155,* p. 8.

[39] Professor Cheryl Dissanayake, Director and Chair, Olga Tennison Autism Research Centre, *Proof Committee Hansard*, 12 February 2021, p. 29.

[40] Productivity Commission, *Mental Health*, Report no. 95, 2020, p. 149.

[41] Irabina Autism Services, *Submission 87*, p. 3. Examples of severe challenging behaviours include aggression, self-injury, property destruction, encopresis, enuresis, feeding disorders and absconding. See also, Learning for Life Autism Centre, *Submission 144*, p. 1.

[42] Irabina Autism Services, *Submission 87*, p. 3.

cost of services required to keep these autistic individuals (and those around them) safe as they become adults.[43]

4.27 While severe challenging behaviours present in a relatively small proportion of people, the impact on families can be severe:

> I see mothers present with black eyes or broken limbs, siblings that have been removed from their homes. I've got parents that have built a padded room for their child; a mother and a father that do not sleep at the same time because they are living in fear of the impact of that child on their sibling.[44]
>
> I've got siblings of one young fellow who can't go on play dates because the mother can't get them there and they certainly can't have play dates in the house. The mental health impact to those children is significant.[45]

4.28 Without appropriate support, the stress families experience can be extreme. For example, families have reported that the lack of appropriate services creates '"stress, worry, and guilt", "financial burden", and "hopelessness that engulfs all of us and our actions towards [our child], ourselves and each other"'.[46] The committee also heard that a significant number of parents meet the criteria for a provisional diagnosis of Post-Traumatic Stress Disorder, with parents most at risk being those whose children displayed challenging behaviours, including self-harm and physical aggression.[47]

4.29 In some cases, the stress and desperation resulting from a lack of access to appropriate support, including respite care, has led families to make the difficult decision to place their children into state care.[48] Media reports suggest that this occurs mainly in cases where children have high care needs, including 24-hour supervision due to severe challenging behaviours.[49] Parents in this situation

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[43] Learning for Life Autism Centre, *Submission 144*, p. 3.

[44] Ms Debra Goldfinch, Chief Executive Officer, Irabina Autism Services, *Proof Committee Hansard*, 11 February 2021, p. 5.

[45] Ms Debra Goldfinch, Chief Executive Officer, Irabina Autism Services, *Proof Committee Hansard*, 11 February 2021, p. 6.

[46] Irabina Autism Services, *Submission 130*, p. 9.

[47] Different Journeys, *Submission 30*, p. 6.

[48] Mansfield Autism Statewide Services, *Submission 117*, p. 4; Learning for Life Autism Centre, *Submission 144*, p. 3.

[49] See, for example, Neelima Choahan, 'Parents of child with severe autism say they will relinquish him unless given more support', *The Age*, 21 October 2017, www.theage.com.au/national/victoria/parents-of-child-with-severe-autism-say-they-will-relinquish-him-unless-given-more-support-20171018-gz39r6.html (accessed 25 May 2021); Richard Willingham, 'Advocates blame NDIS failures as families give up severely disabled children to child protection', *ABC News website*, 8 May 2019, www.abc.net.au/news/2019-05-09/families-with-severely-disabled-kids-giving-them-up-to-state/11092588 (accessed 25 May 2021); Carol Nader, 'State has 40 relinquished children', *Sydney Morning Herald*, 30 September 2010,

have spoken of being 'past the edge of physical, mental and financial crisis' and described how they 'sometimes felt suicidal or [like] simply walking away from lives that had become "nightmares"'.[50]

4.30 While the extent of this issue is not clear, in 2018, the Australian Institute of Health and Welfare estimated the percentage of children with disability in out of home care was approximately 14 per cent.[51] The committee heard that within this cohort, autistic children were over-represented 'due to a lack of available supports for families that are overwhelmed and unable to continue to cope in their caring role'.[52] Families report not receiving adequate support, therefore additional supports are critical to better prevent out of home care.

4.31 While not a cost borne directly by families, the Productivity Commission estimated that in 2019–20 the annual cost of supporting a young person in residential care in 2019–20 ranged from $445 023 to $847 379 per child.[53]

4.32 However, many costs related to severe challenging behaviours were considered avoidable. For example, Irabina argued that appropriate services could alter the trajectory for these individuals and provide 'improved quality of life, greater family stability, and participation in educational and community activities'.[54] This view was supported by other participants:

> We've got experiences where sibling relationships are massively improved. We have experiences where parents feel more confident taking their kids out in the community ... we can see that development and support in those really important formative years of a child's life, including school, has a greater impact on their ability to engage with the community as a whole.[55]

4.33 Despite this, Mansfield Autism Statewide Services noted that state government expenditure on out of home care services (in Victoria) has 'consistently exceeded spending on family support services intended to prevent children and young people from going into care'.[56]

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www.smh.com.au/national/state-has-40-relinquished-children-20100929-15xgp.html (accessed 25 May 2021).

[50] Bill Hoffman, 'Couple forced to give up son', *Sunshine Coast Daily*, 16 April 2011, www.sunshinecoastdaily.com.au/news/a-couples-heartbreak-disabled-son/826266/ (accessed 25 May 2021).

[51] The Queensland Family and Child Commission, *Submission 36*, p. 6.

[52] Autism Family Support Association, *Submission 22*, p. 3.

[53] Productivity Commission, *Report on Government Services 2021*, www.pc.gov.au/research/ongoing/report-on-government-services/2021 (accessed 22 October 2021).

[54] Irabina Autism Services, *Submission 130*, p. 9.

[55] Mrs Cindy Corrie, Founder and Board Director, The Sycamore School, *Proof Committee Hansard*, 3 March 2021, pp. 62–63.

[56] Mansfield Autism Statewide Services, *Submission 117*, p. 4.

Autistic parents

4.34 Autistic parents are doubly affected by a failure to provide adequate services and supports. In addition to being at higher risk of poor life outcomes themselves, autistic parents are also contending with the financial, social and emotional impacts of caring for an autistic child.

4.35 A number of submissions pointed to evidence showing that autistic mothers are more likely to have difficulties with multitasking, domestic responsibilities, creating social opportunities for their children, and communicating with professionals about their children.[57]

4.36 The challenge of accessing appropriate services is particularly magnified for autistic parents. For example, in addition to seeking their own supports, they are also required to navigate access to services for their children. One autistic parent described the constant advocacy as 'debilitating' and explained:

> I find myself communicating when I feel my communication is struggling and even wanting to adopt select mutism to recover, trying to build relationships when I want to withdraw and isolate…[58]

4.37 Discrimination was seen as another barrier to appropriate service provision.[59] It was reported that autistic parents can meet with 'unsupportive and even hostile responses' from providers, including criticisms of their parenting and accusations that they have caused their children's challenges.[60]

4.38 Discrimination can also lead to negative interactions with child and community services. For example, in the UK, around one in five mothers of an autistic child were assessed by social services and, of those, one in six had their child compulsorily placed for adoption.[61] Autistic mothers in Australia have described similar negative experiences:

> I went to a reputable psych clinic, for assessment of my oldest. They basically diagnosed me with refrigerator mum, told me I'm not implementing recommendations and the children's developmental delays are a result of my neglect. They called child protection, who've now taken my children. I am a good mother, I just feel let down by a system that is not built to support autistic women—I am still fighting this.[62]

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[57] See, for example, Coalition of Autistic Women, *Submission 125*, [p. 21]; Yellow Ladybugs, *Submission 49*, p. 5; Australian Autism Alliance, *Submission 52*, p. 21.

[58] Name withheld, *Submission 119*, p. 1.

[59] See, for example, Australian Autism Alliance, *Submission 52*, p. 21; Yellow Ladybugs, *Submission 49*, p. 5; Coalition of Autistic Women, *Submission 125*, [p. 25].

[60] The Autistic Realm Australia (TARA), *Submission 86*, p. 15.

[61] Australian Autism Alliance, *Submission 52*, p. 21.

[62] Yellow Ladybugs, *Submission 49*, pp. 5–6.

4.39 The committee heard that the challenge of accessing services, along with the fear of discrimination, can result in autistic parents being too afraid to seek help,[63] with significant costs for themselves and their children.

Key life transitions

4.40 Difficulties with communication and executive function, a tendency toward restricted interests, as well as cognitive and behavioural rigidity can make life transitions complex for autistic people.[64] Not surprisingly, a number of submissions identified key life transitions as critical points at which support is required.[65]

4.41 Failing to provide adequate services and supports at one or more transition points was also seen as having a compounding effect on life outcomes.[66] For example, poorly supported education transitions also decrease an individual's chances of employment. Unemployment can contribute to housing insecurity which may, in turn, increase the likelihood of an individual coming into contact with the justice system.[67]

4.42 While participants identified multiple transition points where support is required—such as transitions between living arrangements and between detention settings and the community,[68] the majority identified school transitions and post-school transitions (i.e. into further education and work) as key periods where support is currently lacking.[69]

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[63] Coalition of Autistic Women, *Submission 125*, [p. 21].

[64] PEERS Australia, *Submission 108*, pp. 3–4.

[65] See, for example, Commissioner for Children and Young People South Australia, *Submission 88*, p. 11; Queensland Family and Child Commission, *Submission 36*, p. 5; Australian Autism Alliance, *Submission 52*, p. 31; Marymead Autism Centre, *Submission 128*, p. 5; Autism Queensland, *Submission 129*, p. 24; PEERS Australia, *Submission 108*, p. 6, Name withheld, *Submission 126*, pp. 19 and 20.

[66] Assistance Dogs Australia, *Submission 43*, p. 4.

[67] Queensland Law Society, *Submission 124*, p. 5.

[68] See, for example, Positive Youth Incorporated, Submission 85, p. 6, Cameron Boyd, *Submission 157*, p. 11, Spectrum Labor, *Submission 1*, p. 15.

[69] OTARC, *Submission 55*, p. 11; AEIOU Foundation, *Submission 50*, [p. 5]; Australian Autism Alliance, *Submission 52*, p. 31; Positive Youth Incorporated, *Submission 85*, p. 6; Mr Cameron Boyd, *Submission 157*, [p. 10].

School transitions

4.43 The transition to school can be particularly difficult for autistic students[70] who face challenges that can disrupt their learning and social adjustment, particularly in new environments. These challenges arise primarily from:

- student characteristics – such as mental health and sensory, behavioural and adaptive functioning; and
- student interactivity – such as peer relations and social skills, communication, physical setting, logistics, and daily structure.[71]

4.44 The transition into primary school involves social-emotional, pre-literacy, and attention skills. Parents have reported difficulties with anxiety, communication with peers and teachers, and adapting to new routines.[72] Social-emotional challenges may be especially relevant, given that 'teachers rate social skills as more important than academic skills for successful kindergarten adjustment'.[73]

4.45 The subsequent transition between primary and secondary school brings additional challenges, such as increased academic demands and social pressures, as well as a more complex learning environment. This includes having to navigate multiple classroom settings and teachers.[74]

4.46 Successful school transitions were seen as having a positive impact on social adjustment and academic performance over the short term.[75] In addition, the

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[70] Annabel Marsh, Vanessa Spagnol, Rachel Grove, Valsamma Eapen, 'Transition to school for children with autism spectrum disorder: A systematic review', *World Journal of Psychiatry*, vol. 7 no. 3, 2017, p. 185, DOI: http://dx.doi.org/10.5498/wjp.v7.i3.184.

[71] Heather Joy Nuske, Elizabeth McGhee Hassrick, Briana Bronstein, Lindsay Hauptman, Courtney Aponte, Lynne Levato, Aubyn Stahmer, David S Mandell, Peter Mundy, Connie Kasari and Tristram Smith, ' Broken bridges—new school transitions for students with autism spectrum disorder: A systematic review on difficulties and strategies for success', *Autism*, Issue vol. 23 no. 1, February 2018, pp. 1 and 3, https://doi.org/10.1177/1362361318754529.

[72] Heather Joy Nuske, Elizabeth McGhee Hassrick, Briana Bronstein, Lindsay Hauptman, Courtney Aponte, Lynne Levato, Aubyn Stahmer, David S Mandell, Peter Mundy, Connie Kasari and Tristram Smith, ' Broken bridges—new school transitions for students with autism spectrum disorder: A systematic review on difficulties and strategies for success', *Autism*, Issue 23(1), February 2018, pp. 1–4, https://doi.org/10.1177/1362361318754529.

[73] Annabel Marsh, Vanessa Spagnol, Rachel Grove, Valsamma Eapen, 'Transition to school for children with autism spectrum disorder: A systematic review', *World Journal of Psychiatry*, vol. 7 no. 3, 2017, p. 185, DOI: http://dx.doi.org/10.5498/wjp.v7.i3.184.

[74] Dr Peter Walker, *Proof Committee Hansard*, 16 November 2020, p. 18; See also, Heather Joy Nuske, Elizabeth McGhee Hassrick, Briana Bronstein, Lindsay Hauptman, Courtney Aponte, Lynne Levato, Aubyn Stahmer, David S Mandell, Peter Mundy, Connie Kasari and Tristram Smith, 'Broken bridges—new school transitions for students with autism spectrum disorder: A systematic review on difficulties and strategies for success', *Autism*, vol. 23 no. 1, February 2018, pp. 1 and 3, https://doi.org/10.1177/1362361318754529.

[75] Scope-University of Melbourne Partnership, *Submission 83*, p. 16.

peer bonds and sense of belonging engendered by successful school transitions can decrease the likelihood of a young person coming into contact with the justice system.[76] Over the longer term, these benefits also generate cost savings related to improved employability and increased taxable income.[77]

4.47 Conversely, poor school transitions can have lifelong consequences for autistic students. According to the National Disability Insurance Agency (NDIA), issues of self-identity, social inclusion and bullying present a serious risk for autistic students, with isolation and negative experiences often leading to 'escalating behaviours of concern through this part of their life'.[78] In some cases, these experiences can result in autistic students disengaging completely from the education system.

4.48 The devastating impact of failing to support school transitions was highlighted by one submitter to the inquiry, who described the social and economic cost of this failure as irreversible—and not unique (Box 4.1).[79]

Box 4.1 Case study: failure to support school transitions

We experienced our own broken bridge before our child even got a chance to begin her secondary schooling. The combined experience of significantly rising anxiety with significantly reduced support triggered a rapid deterioration in our daughter's already fragile mental health. Not only did she experience exclusion because of the high school's decisions and omissions, she also experienced rejection by her peers. Soon after she communicated that she would no longer be going to this high school as planned, her friends were no longer accepting of her and stopped communicating with her both in person and online. She was not invited to her Grade 6 graduation party. We were officially in crisis.

The insomnia returned, so did worsening panic attacks. Obsessive compulsive disorder took hold. Her aggression escalated which jeopardised the safety of our family and for the first time emergency services were called to our daughter who really wanted to kill herself. She had become a mental health emergency and was taken to hospital in an ambulance with a police escort. Our daughter was seen by CAMHS (Child and Adolescent Health Service) and referred to a Psychiatrist. The wait was 12 weeks. We were unable to leave her side. In a matter of mere months, our daughter had progressed from a diagnosis of mild autism to be known as a complex case.

Our daughter exhibits frequent and intense behaviours of concern (aggression, disruption, inappropriate vocalisation and absconding) and is unable to attend school. As is often the case in Psychiatry, she requires multiple off label medications to function which attract no subsidies. Because I cannot leave her side,

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[76] Positive Youth Incorporated, *Submission 85*, p. 5.

[77] Scope-University of Melbourne Partnership, *Submission 83*, p. 16.

[78] National Disability Insurance Agency (NDIA), *Submission 56*, p. 12.

[79] Name withheld, *Submission 78*, p. 12.

> my leave entitlements have been exhausted and we took out a personal loan to cover my leave without pay. Our finances at breaking point, we could no longer fund the gaps for therapies using Medicare or Helping Children with Autism (HCWA) funding. We needed the NDIS (National Disability Insurance Agency) and the good news is, the NDIS has been nothing but positive for our child and family.

Transition to further education and work

4.49 A number of participants noted that successful post-school transitions can significantly improve an individual's long-term economic future, social inclusion and wellbeing.[80]

4.50 However, post-school transitions were identified as particularly challenging for young autistic people.[81] For example, pursuing further education can involve navigating a new environment, understanding and using new communication channels and adjusting to new teaching formats and expectations around self-sufficiency. Autistic students may also have limited access to social supports and experience difficulties managing routines and coping with anxiety and social interactions.[82]

4.51 In relation to seeking employment, a lack of appropriate support and adjustments place autistic people at a disadvantage, particularly when faced with generally unsuitable recruitment processes.[83] Once in the workplace, autistic people can struggle as a result of executive functioning challenges, sensory issues, as well as difficulties with, social interactions, communication, and self-regulation during stressful periods.[84]

4.52 As noted by the Cooperative Research Centre for Living with Autism (Autism CRC), those who fail to transition are 'at a significantly greater risk of long-term exclusion from the labour force as well as social isolation and physical and mental health issues'.[85] Despite this, it was observed by many participants that

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[80] See, for example, Autism CRC, *Submission 46*, p. 27; National Disability Services, *Submission 98,* p. 4; PEERS Australia, *Submission 108,* p. 16.

[81] See, for example, Autism CRC, *Submission 46*, p. 19; Scope-University of Melbourne Partnership, *Submission 83*, p. 9; OTARC, *Submission 55*, p. 11.

[82] See, for example, Mentoring Autism Community of Practice, *Submission 73*, [pp. 1–2]; Scope-University of Melbourne Partnership, *Submission 83*, p. 17; Professor Sandra Jones, Pro Vice-Chancellor, Engagement, Australian Catholic University, *Proof Committee Hansard,* 28 July 2020, p. 17.

[83] Untapped Holdings Pty Ltd, *Submission 92*, [p. 2]; Marymead Autism Centre, *Submission 128*, p. 10.

[84] Early Start Australia, *Submission 76*, p. 12; Marymead Autism Centre, *Submission 128*, p. 10.

[85] Autism CRC, *Submission 46*, p. 27.

the post-school transition is the point when services for autistic people 'fall off a cliff'.[86] The resulting impact of was described by one survey respondent:

> Lack of support means Autistic people may leave education early or stay in education for many additional years. Either way, this means we don't get jobs, develop financial independence or move out of home at the same rates as the general population. The cost to us is lack of independence, self-determination, financial stability.[87]

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[86] See, for example, Department of Developmental Disability Neuropsychiatry, University of New South Wales (UNSW 3DN) *Submission 95*, p. 19; Scope-University of Melbourne Partnership, *Submission 83*, p. 17; Autism Awareness Australia, *Submission 47*, p. 9; PEERS Australia, *Submission 108*, Attachment 1, [p. 37].

[87] TARA, *Submission 86*, p. 21.

Chapter 5

A National Autism Strategy

5.1 This chapter explores stakeholder support for a National Autism Strategy, sets out a number of guiding principles that could frame its development, and identifies a range of potential development mechanisms.

5.2 It should be noted that this chapter does not address the content of the national strategy, which will be presented alongside the discussion of key issues in following chapters.

Stakeholder support for a National Autism Strategy

5.3 There was overwhelming stakeholder support for the development of a National Autism Strategy.[1] For some, a cohesive national strategy that set 'clear goals and aspirations to change the quality of life of autistic people' was 'long overdue'.[2] Others highlighted the opportunity it presented to unify people around a 'nationally consistent approach'.[3]

5.4 These views were commonly held, with a National Autism Strategy deemed to be a much-needed mechanism for coordinating service delivery and investment

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[1] See, for example, Name withheld, Submission 7, [p. 2]; CliniKids, *Submission 15*, [p. 9]; Northern Territory Office of the Public Guardian, *Submission 20*, [p. 3]; Audiology Australia, *Submission 27*, [p. 1]; The Royal Australasian College of Physicians, *Submission 29*, p. 4; Different Journeys, *Submission 30*, p. 16; The Queensland Family and Child Commission, *Submission 36*, p. 8; Commissioner for Children and Young People – Western Australia, *Submission 42*, p. 4; Assistance Dogs Australia, *Submission 43*, p. 2; Cooperative Research Centre for Living with Autism (Autism CRC), *Submission 46*, p. 23; Autism Awareness Australia, *Submission 47*, p. 11; Yellow Ladybugs, *Submission 49*, p. 2; Australian Autism Alliance, *Submission 52*, p. 4; Autism Spectrum Australia (Aspect), *Submission 64*, p. 1; NSW Government, *Submission 65*, p. 4; Queensland Nurses and Midwives' Union, *Submission 69*, p. 3; Autism Behavioural Intervention Association (ABIA), *Submission 70*, p. 13; Ethnic Disability Advocacy Centre (EDAC), *Submission 75*, p. 3; Early Start Australia (ESA), *Submission 76*, p. 6; The Autistic Realm Australia (TARA), *Submission 86*, p. 3; Speech Pathology Australia, *Submission 87*, p. 21; Commissioner for Children and Young People South Australia, *Submission 88*, p. 2; Exercise & Sports Science Australia, *Submission 91*, p. 12; BioAutism Ltd, *Submission 93*, p. 1; Department of Developmental Disability Neuropsychiatry, University of New South Wales (UNSW 3DN), *Submission 95*, p. 2; Australian Association of Social Workers, *Submission 96*, p. 4; ND Australia, *Submission 97*, [p. 2]; Samaritans, *Submission 99*, p. 3; The Hon Coralee O'Rourke MP, Queensland Minister for Communities, Queensland Minister for Disability Services and Seniors, *Submission 101*, [p. 4]; Name withheld, *Submission 113*, [p. 1]; Name withheld, *Submission 116*, [p. 6]; Name withheld, *Submission 120*, [p. 8]; Queensland Law Society, *Submission 124*, p. 5; Mr Cameron Boyd, *Submission 157*, [p. 12].

[2] Ms Fiona Sharkie, Australian Autism Alliance, *Proof Committee Hansard*, 28 July 2020, p. 10.

[3] Mrs Cindy Corrie, Founder and Board Director, The Sycamore School, *Proof Committee Hansard*, 3 March 2021, p. 60.

at a national level.[4] As explained by the Australian Autism Alliance (the Autism Alliance), a National Autism Strategy would 'create an intentional and coherent approach to shifting the dial on outcomes for autistic people' by providing an agreed framework to drive 'coordinated and mutually reinforcing policy, research, service, and program responses across different domains and jurisdictions'.[5]

5.5 At the individual level, a National Autism Strategy was seen as a way to address gaps in support for autistic people across the spectrum and throughout their lives, including through key life transitions.[6] As summarised by Mr Paul Micallef, Co-chair of the Autism Alliance:

> We could talk about poor education and employment outcomes … poor mental health, social isolation of families, further neglected groups such as women and girls, older autistic adults, our First Nations people and other cultural minorities. But, at the end of the day, we autistic people are experts at falling through the cracks of systems designed to suit the neurotypical majority. So we need a plan—a top-down strategy—that aligns our efforts and ensures that all individual services are designed to actually help us succeed.[7]

5.6 In addition, a National Autism Strategy could also help to incentivise the development of complementary state and territory autism plans.[8] Ms Jenny Karavolos from Autism SA argued this could help bring greater consistency to what is currently a piecemeal approach:

> If there were a national autism strategy we'd have a framework and we'd be consistent at a state level. I know there needs to be ownership at a local level but … we're currently reviewing—to support different departments in parallel—25 different disability, action and inclusion plans. They've all got something in them but they are all disparate.[9]

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[4] Australian Association of Social Workers, *Submission 96*, pp. 4–5; Commissioner for Children and Young People South Australia, *Submission 88*, pp. 4–5; Speech Pathology Australia, *Submission 87*, p. 21; Ms Frances Scodellaro, Chief Operations Officer, Autism Queensland, *Proof Committee Hansard*, 3 March 2021, p. 33; Mr Andrew Davis, Chief Executive Officer, Autism CRC, *Proof Committee Hansard*, 3 March 2021, p. 8; Mrs Camilla Rowland, Chief Executive Officer, Marymead; Marymead Autism Centre, *Proof Committee Hansard*, 27 July 2020, p. 7.

[5] Australian Autism Alliance, *Submission 52*, p. 12.

[6] Australian Autism Alliance, *Submission 52*, p. 12.

[7] Mr Paul Micallef, Co-Chair, Australian Autism Alliance, *Proof Committee Hansard*, 12 February 2021, p. 1.

[8] Australian Autism Alliance, *Submission 52*, pp. 12–13.

[9] Ms Jenny Karavolos, Chief Executive Officer, Autism SA, *Proof Committee Hansard*, 16 November 2020, p. 15.

5.7 While support was widespread, some stakeholders stressed that a National Autism Strategy on its own was not enough to create change.[10] This view was shared by other stakeholders who recognised that its success would depend on both its content and the approach taken to implementation.[11] In this context, some viewed the specific delivery mechanism as a secondary issue.[12]

5.8 Other stakeholders were more cautious and questioned whether a strategy targeting one cohort might overwhelm the needs of other groups,[13] or whether a strategy aimed at neurodevelopmental conditions more broadly might be more productive.[14] However, submitters such as Amaze stressed that the 'dire outcomes' for people with autism necessitated 'urgent and dedicated action'.[15]

5.9 Accordingly, and as indicated previously, the majority of stakeholders were strongly in favour of a National Autism Strategy and highlighted its potential to make a meaningful difference to autistic people's lives. This was sentiment was summed up by Mr Benjamin Biro, who described the fears he held for his autistic son and the hope offered by a National Autism Strategy:

> The data is stark and harrowing. … That is why I am here today calling for a National Autism Strategy. Having that would signify that the government acknowledges that these outcomes are unacceptable and that the status quo has not worked, and it would commit to a better future, creating hope for autistic people. For me, I just hope to look at my son and think about the promise that his life could bring, rather than living in the fear that no matter what we do he will become just another statistic.[16]

Why a National Autism Strategy?

5.10 Evidence presented to the committee suggests that stakeholder support for a National Autism Strategy is driven by:

- the prevalence of autism and the lifelong nature of the condition;
- the poor life outcomes experienced by autistic people, even in comparison to other vulnerable groups;
- the failure of the current approaches to supporting autistic people; and

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[10] Professor Keith McVilly, Professor of Disability and Inclusion, School of Social and Political Sciences, University of Melbourne, *Proof Committee Hansard*, 12 February 2021, p. 23.

[11] Professor Katrina Williams, Professor of Paediatrics and Head of Department, Monash University, *Proof Committee Hansard*, 11 February 2021, p. 65.

[12] Autism Aspergers Advocacy Australia (A4), *Submission 54*, p. 25.

[13] Professor Julian Trollor, Chair, Intellectual Disability Mental Health; and Head, Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW Sydney, *Proof Committee Hansard*, 15 April 2021, p. 40.

[14] The Royal Australasian College of Physicians, *Submission 29*, p. 11.

[15] Amaze, *Submission 154.1*, p. 1.

[16] Mr Benjamin Biro, Community Member, Australian Autism Alliance, *Proof Committee Hansard*, 12 February 2021, p. 3.

- the introduction of similar strategies overseas.[17]

5.11 As the prevalence of autism, the lifelong nature of the condition, and life outcomes for autistic people are described in preceding chapters, the remainder of this section focuses on:

- the failure of current approaches to supporting autistic people; and
- the international experience of autism strategies.

The failure of current approaches

5.12 While some stakeholders acknowledged recent gains in support and resourcing for the disability sector as a whole, including the National Disability Insurance Scheme (NDIS),[18] there was also criticism of the failure of current approaches to improve the lives of autistic people.[19]

5.13 In particular, some submitters pointed to the failure of the *National Disability Strategy 2010–2020* (the *National Disability Strategy*) to drive better outcomes for the autistic community.[20] They also expressed frustration with the siloed and fragmented nature of the support available for autistic people,[21] including the poor integration between the NDIS, other disability supports and mainstream services.[22]

5.14 As dissatisfaction with the NDIS was a significant feature of evidence presented to the committee, issues specific to the NDIS will be addressed separately in Chapter 12.

The *National Disability Strategy*

5.15 For many stakeholders, the *National Disability Strategy* was seen as too generic to be an effective mechanism for supporting the autistic community.[23] It was also seen as lacking in both outcome measures and transparency around funding for implementation—aside from funding attached to the NDIS.[24]

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[17] See, for example, Australian Autism Alliance, *Submission 52*, p. 12; Name withheld, *Submission 120*, [p. 11]; Name withheld, *Submission 126*, p. 4.

[18] Australian Autism Alliance, *Submission 52*, p. 12; Ethnic Disability Advocacy Centre, *Submission 75*, p. 2.

[19] Australian Association of Social Workers, *Submission 96*, pp. 4–5.

[20] The Sycamore School, *Submission 118*, p. 7; A4, *Submission 54*, p. 25.

[21] See, for example, Irabina Autism Services, *Submission 130*, p. 8; A4, *Submission 54*, p. 21; EDAC, *Submission 75*, p. 5; Name withheld, *Submission 4*, [p. 6]; Name withheld, *Submission 59*, [p. 1].

[22] See, for example, Autism Awareness Australia, *Submission 47*, p. 10; Office of the Public Advocate Victoria, *Submission 80*, pp. 17–18; The Hon Coralee O'Rourke MP, Queensland Minister for Communities, Queensland Minister for Disability Services and Seniors, *Submission 101*, p. 3

[23] See, for example, The Sycamore School, *Submission 118*, p. 7; Name withheld, *Submission 126*, p. 4; NSW Government, *Submission 65*, p. 9.

[24] Australian Autism Alliance, *Submission 52*, p. 13.

Further, some stakeholders raised concerns that *National Disability Strategy* could be reinforcing misconceptions about the nature of autism as its only references to the condition are made in the context of early intervention for children.[25]

5.16 Not all stakeholders agreed. For example, People with Disability Australia (PWDA) suggested that the weakness of the *National Disability Strategy* was a lack of funding. Accordingly, it recommended greater investment in implementation of the *National Disability Strategy*, rather than a focus on any one particular cohort of people with disability. PWDA also argued that such a focus would be inconsistent with a social model of disability, which should look at 'barriers to disability in general, rather than focusing on one disability as a "problem" that needs to be solved'.[26]

5.17 However, other stakeholders, such as The Autistic Realm Australia (TARA), did not view a separate autism strategy as incompatible with a social model of disability. Instead, TARA supported a social model of disability as the basis for the plan and recommended that the National Autism Strategy adopt the same 'holistic policy approach' that underpinned the *National Disability Strategy.*[27]

5.18 Further, the Autism Alliance, argued that it was the ineffectiveness of generic approaches that necessitated more targeted action:

> General disability approaches are not working. We look at the data and see what's happening for people with disability and autism. Autistic people are far below even the outcomes of people with disability, which are poor compared to the population.[28]

5.19 Others agreed with this assessment and pointed to the failure of the decade-old *National Disability Strategy* to make inroads into closing the gap in outcomes for autistic people.[29] This lack of progress was noted by The Sycamore School, which suggested that the broad focus of the *National Disability Strategy* had allowed 'the particularly poor outcomes of the autistic population' to be overlooked.[30]

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[25] The Royal Australian and New Zealand College of Psychiatrists, *Submission 17*, [p. 2]; Family Planning NSW, *Submission 28*, p. 6.

[26] People with Disability Australia, *Submission 102*, p. 5.

[27] TARA, *Submission 86*, p. 24.

[28] Ms Fiona Sharkie, Co-Chair, Australian Autism Alliance, *Proof Committee Hans*ard, 12 February 2021, p. 3.

[29] See, for example, Mr Benjamin Biro, Community Member, Australian Autism Alliance, *Proof Committee Hansard*, 12 February 2021, p. 4; A4, *Submission 54*, p. 24.

[30] The Sycamore School, *Submission 118*, p. 7.

5.20 While work to design the new *National Disability Strategy 2021–2031* has involved consultation with the autistic community,[31] there is still scepticism about its ability to improve outcomes for autistic people. For example, Autism Aspergers Advocacy Australia (A4) said there was 'no sign' that the new *National Disability Strategy* would recognise the needs of the autistic community. It also suggested that relying on the new *National Disability Strategy* to drive change could delay improvements for another decade.[32]

5.21 While unconvinced about the ability of the *National Disability Strategy* to improve outcomes for autistic Australians, many stakeholders recognised the importance of aligning a potential National Autism Strategy with these broader national strategies.[33]

Fragmented services and support

5.22 Responsibility for delivering funded services and support for autistic people is shared between all Australian governments, the non-government sector, businesses and the wider community.[34] Stakeholders argued that this has resulted in a disjointed approach to policy and program delivery, with 'small, disconnected and fragmented initiatives' delivered through a multitude of systems across different levels of government.[35]

5.23 This fragmented landscape was seen to be 'failing' autistic people,[36] with many autistic people and their carers feeling confused and overwhelmed by 'the complex and multi-jurisdictional system, including NDIS, health, education, justice, housing and employment'.[37] More than one submitter used the expression 'falling through the cracks'[38] to describe the experience of trying to access services and support:

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[31] Department of Social Services, Department of Education, Skills and Employment, and Department of Health, *Submission 53*, p. 8.

[32] A4, *Submission 54*, p. 25.

[33] See, for example, NSW Government, *Submission 65*, p. 8; Commissioner for Children and Young People South Australia, *Submission 88*, p. 5; Northern Territory Office of the Public Guardian, *Submission 20*, [p. 8]; ND Australia, *Submission 97*, [p. 2]; Autism Awareness Australia, *Submission 47*, p. 11; Exercise and Sports Science Australia, *Submission 91*, p. 12; Name withheld, *Submission 126*, p. 4.

[34] Department of Social Services, Department of Education, Skills and Employment, and Department of Health, *Submission 53*, p. 20.

[35] Australian Autism Alliance, *Submission 52*, pp. 11–12.

[36] Marymead Autism Centre, *Submission 128*, p. 9; Ms Frances Scodellaro, Chief Operations Officer, Autism Queensland, *Proof Committee Hansard*, 3 March 2021, p. 32.

[37] Marymead Autism Centre, *Submission 128*, p. 5. This emerged as a key theme in the RSM Autism Community Needs Analysis Report prepared for Marymead Autism Centre.

[38] See, for example, Aspect, *Submission 64*, p. 13; Positive Youth Incorporated, *Submission 85*, p. 7; Ms Tamika Hicks, *Submission 14*, [p. 2]; Name withheld, *Submission 112*, [pp. 13 and 14]; Name

> The autism community sits in the middle of the Venn diagram of health, education and disability but rather than get the attention of all three areas of government, it is often lost and mismanaged between the cracks of these departments both at a state and federal level.[39]

5.24 Participants highlighted the challenges this poses for families seeking support. For example, in relation to diagnosis, it was 'not uncommon' for a service in one state to require a new diagnostic assessment for an autistic child who has moved from another state. In some cases, new diagnostic assessments were even required by different service sectors within the same state.[40]

5.25 Stakeholders also observed that the impact of service fragmentation was magnified for vulnerable and disadvantaged autistic cohorts such as Aboriginal and Torres Strait Islander peoples, LGBTQIA and culturally and linguistically diverse (CALD) communities, people in remote areas, those in the child protection and justice systems, and those with multiple and complex needs.[41]

5.26 A more detailed discussion of the issues associated with services and supports for autistic people occurs throughout the rest of this report.

International experience of national autism strategies

5.27 While Victoria is the only Australian state or territory to have a state-wide autism plan, the committee heard that a number of countries have introduced national autism strategies, with some on their second and third iterations.[42]

5.28 Two key strategies mentioned by participants were *The Scottish Strategy for Autism* and the United Kingdom's *National strategy for autistic children, young people and adults: 2021–2026* which was preceded by autism specific legislation.[43]

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withheld, *Submission 116*, [p. 4]; Name withheld, *Submission 141*, p. 3; Name withheld, *Submission 155*, p. 23; Name withheld, *Submission 37*, p. 3.

[39] Autism Awareness Australia, *Submission 47*, p. 6. See also, Autism Advisory and Support Service, *Submission 21*, p. 5.

[40] CliniKids, *Submission 15*, [p. 9]. For example, the education system will commonly require a reassessment for a child (at school age), despite the child having been diagnosed previously through the health system.

[41] See, for example, Royal Australasian College of Physicians, *Submission 29*, p. 6; Australian Association of Social Workers, *Submission 96*, pp. 4–5; Different Journeys, *Submission 30*, p. 16; Autism Advisory and Support Service, *Submission 21*, pp. 5–6; Yellow Ladybugs, *Submission 49*, p. 5; Name withheld, *Submission 126*, pp. 10–11.

[42] Amaze, *Submission 154.1*, p. 1. Countries with national autism strategies include England, Wales, Scotland, Northern Ireland, Malta, France, United States, Spain, Denmark and Hungary.

[43] See, for example, Amaze, *Submission 154.1*, pp. 7–9; Commissioner for Children and Young People South Australia, *Submission 88*, p. 5; Queensland Family and Child Commission, *Submission 36*, p. 8.

5.29 The Scottish strategy is a 10-year plan created to ensure national progress in delivering quality services for autistic children and adults,[44] while the United Kingdom (UK) strategy aims to create a society that truly understands and includes autistic people in all aspects of life and provides better access to the services autistic people need throughout their lives.[45] Summaries of these strategies appear at Appendices 3.B and 3.C.

5.30 While not a panacea, it was reported that having a national strategy did bring about positive change.[46] For example, one participant reported that prior to the introduction of autism specific legislation in the UK, 'most areas in England didn't have an adult diagnostic service—now 93 per cent do. Most councils now also have a designated individual who leads on autism services'.[47]

5.31 While acknowledging that the UK strategy has not met all its objectives,[48] it was suggested that a key benefit of the strategy was the greater accountability it imposed on the government, in particular by requiring it to:

- develop, review and report on the national strategy; and
- produce guidance to inform local implementation of the strategy.[49]

5.32 The importance of accountability in relation to national strategies was also highlighted by other participants. According to the Autism Alliance, public accountability—via strong evaluation and measurement—was identified by Autism Europe as critical to realising the benefits of a national autism strategy.[50]

5.33 As with the UK strategy, national guidance for local implementation was also cited as a feature of the Scottish Autism Strategy. In addition to creating a guide to available support and advice, the Scottish government mapped local autism services to improve coordination. This mapping also 'coincided with significant funding for local authorities and local and national organisations to develop projects, local autism strategies and action plans'.[51]

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[44] The Scottish Government, *The Scottish Strategy for Autism*, 2011, p. 1.

[45] HM Government, *The national strategy for autistic children, young people and adults: 2021–2026*, p. 7.

[46] Ms Fiona, Member, Australian Autism Alliance, *Proof Committee Hansard*, 28 July 2020, p. 15. See also, Name withheld, *Submission 126*, p. 4.

[47] Mr Philip Morris, Submission 25, [p. 2].

[48] Australian Autism Alliance, Submission 52, p. 12.

[49] Mr Philip Morris, *Submission 25*, [p. 2].

[50] Ms Fiona, Co-Chair, Australian Autism Alliance, *Proof Committee Hansard*, 12 February 2021, p. 4.

[51] Commissioner for Children and Young People South Australia, *Submission 88*, p. 11.

5.34 Other identified features of successful strategies included:

- a commitment to advancing the human rights and inclusion of autistic people (rather than taking a deficit-based approach);
- whole-of-life and whole-of-spectrum coverage;
- high quality information and training;
- links to the broader policy context;
- adequate and coordinated funding;
- strong accountability mechanisms (including clear targets and measures, an implementation plan, effective governance and timelines for review); and
- genuine co-production with the autistic community.[52]

Principles to guide development of a National Autism Strategy

5.35 While there were a range of views about what a National Autism Strategy should look like and what it should contain, the Cooperative Research Centre for Living with Autism (Autism CRC) suggested that its development should be guided by an agreed set of principles. These included that a National Autism Strategy should be:

- broad, inclusive and strengths-based;
- co-designed with all stakeholders—with autistic individuals and families at the centre of the process; and
- underpinned by strong accountability mechanisms.[53]

Broad, inclusive and strengths-based

5.36 It was noted that the diversity of the autism spectrum meant that any National Autism Strategy would have to cater for a broad cohort.[54] For example, one stakeholder argued for a focus on individuals with complex support requirements.[55] Conversely, another participant highlighted the need to support autistic people without profound challenges (but who still require some support and access to opportunities to succeed and live full lives).[56] In addition, there were also calls for a National Autism Strategy to consider the perspectives of service providers and researchers, alongside those of autistic people and their families.[57]

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[52] Amaze, *Submission 154.1*, pp. 5–6. The need to address the adverse impacts of the COVID-19 pandemic was also mentioned.

[53] Autism CRC, *Submission 46*, p. 5.

[54] Spectrum Labor, *Submission 1*, [p. 17].

[55] Name withheld, *Submission 38*, [p. 4].

[56] Name withheld, *Submission 6*, [p. 2].

[57] ABIA, *Submission 70*, p. 3.

5.37 Given the diversity of the autism spectrum, a number of stakeholders stressed the need for a broad, inclusive and strengths-based National Autism Strategy[58] that 'promotes the participation of people with autism as active citizens in all aspects of society'.[59] For example, TARA called for a National Autism Strategy to recognise the diversity of the autistic community and take a holistic policy approach based on a social model of disability.[60] Similarly, the Autism Behavioural Intervention Association (ABIA) suggested that a National Autism Strategy should:

> …recognise the human rights and unique strengths of people with autism, and should strive to create a more inclusive society that provides equal opportunity to individuals with autism.[61]

5.38 Stakeholders also underscored that taking a whole-of-life perspective would help to avoid a singular focus on service provision and ensure that people remain at the centre of a National Autism Strategy.[62] This view was shared by the Autism CRC, which proposed that a National Autism Strategy be both individual and family-centred as well as whole-of-life and whole-of-spectrum focused.[63] A person-centred approach was also seen as important to ensuring that the needs of individuals who have not yet been diagnosed are not overlooked in the development of a National Autism Strategy.[64]

5.39 Within the broad framework of a National Autism Strategy, a number of stakeholders identified a need for targeted action to support particularly vulnerable cohorts.[65] These cohorts, who may face additional challenges and compounding disadvantage, include:

- girls and women;
- Aboriginal and Torres Strait Islander peoples;

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[58] Autism CRC, *Submission 46*, p. 5

[59] Commissioner for Children and Young People South Australia, *Submission 88*, p. 4. See also, Australian Association of Social Workers, *Submission 96*, p. 5.

[60] TARA, *Submission 86*, pp. 3 and 24. The social model understands disability as barriers preventing engagement and participation (e.g. physical barriers, attitudinal barriers, communication barriers, and systematic barriers) rather than as a deficit located within the person themselves.

[61] ABIA, *Submission 70*, p. 3.

[62] Ms Helen Connolly, Commissioner for Children and Young People, South Australia, *Proof Committee Hansard*, 16 November 2020, p. 38.

[63] Autism CRC, *Submission 46*, p. 23.

[64] Mr Andrew Davis, Chief Executive Officer, Autism CRC, *Proof Committee Hansard*, 3 March 2021, p. 6. This recognises that diagnosis is a journey and that support should be available to those people who may not yet have a diagnosis but would meet the criteria, as well as those who have shown signs of neurodevelopmental conditions.

[65] See, for example, Queensland Family and Child Commission, *Submission 36*, pp. 8–9; TARA, *Submission 86*, p. 25; Queensland Law Society, *Submission 124*, p. 5.

- LGBTQIA communities;
- culturally and linguistically diverse communities;
- people in regional and remote areas;
- individuals in the child protection and justice systems; and
- autistic people with multiple and complex needs.[66]

5.40 For example, service provision is currently limited for autistic people living in remote communities, including autistic Aboriginal and Torres Strait Islander people. While support may be accessed by relocating to a regional centre, this separates Aboriginal and Torres Strait Islander peoples from kinship ties, culture and country, which can adversely impact health and wellbeing. Accordingly, a National Autism Strategy may need to include specific considerations for this cohort.[67]

5.41 Similarly, particular considerations may also be needed for autistic people with complex needs[68] as they may not benefit from broader actions to address the needs of autistic people.[69] For example, one participant cautioned that a broad neurodiversity perspective would be inappropriate for autistic people with profound intellectual disability and 'debilitating' co-occurring conditions. At worst, they argued, it could 'put them at very high risk of being misunderstood, left behind, in some cases worse off and inevitably hidden'.[70]

Co-design with all stakeholders

5.42 Consultation and co-design were consistent themes across submissions to the inquiry.[71] The idea of co-design and co-production—not simply consultation—was seen as critical to the acceptance and success of a national strategy. For example, Mr Andrew Davis of the Autism CRC argued that a National Autism Strategy:

> …should be developed by all stakeholders in co-production. That is the approach that we've taken with all the things that we've done. That's how

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[66] See, for example, Royal Australasian College of Physicians, *Submission 29*, p. 6; Australian Association of Social Workers, *Submission 96*, pp. 4–5; Different Journeys, *Submission 30*, p. 16; Autism Advisory and Support Service, *Submission 21*, pp. 5-6; Yellow Ladybugs, *Submission 49*, p. 5; Name withheld, *Submission 126*, pp. 10–11.

[67] Northern Territory Office of the Public Guardian, *Submission 20*, [p. 9].

[68] Irabina Autism Services, *Submission 130*, p. 12.

[69] Name withheld, *Submission 31*, p. 3. This submission notes that similar considerations were made in the Victorian Autism Plan, including processes for bringing expertise on complex needs into any relevant policy work.

[70] Name withheld, *Submission 31*, p. 4.

[71] See, for example, Autism CRC, *Submission 46*, p. 5; Queensland Family and Child Commission, *Submission 36*, p. 9; The Hon Coralee O'Rourke MP, Queensland Minister for Communities, Queensland Minister for Disability Services and Seniors, *Submission 101*, [p. 4].

> you end up with defined needs, a means of conducting work and getting something implemented that is accepted.[72]

5.43 A number of stakeholders emphasised the importance of engaging autistic people in the design of a National Autism Strategy,[73] including autistic children and young people and those from vulnerable or marginalised cohorts.[74] This view was shared by Ms Fiona Sharkie, Co-Chair of the Australian Autism Alliance, who took the view that true engagement happens when autistic people and their families have a seat at the table and are 'actually asked their views about what they need and how they would like their lives to be different'.[75]

5.44 The need to centre the experiences of autistic people was highlighted by stakeholders who were concerned that their perspectives 'are too often regarded as secondary to those presented by medical professionals or non-autistic parents of autistic children'.[76]

5.45 However, other stakeholders highlighted the importance of multiple representations, particularly given the diversity of need across the spectrum, high levels of informal care provision, and the important role played by families and carers.[77] For example, while noting the importance of the autistic voice in developing a National Autism Strategy, Ms Mel Spencer from Different Journeys expressed concerns that 'the carers are getting lost and not being heard and validated, and that's something that needs to be included'.[78]

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[72] Mr Andrew Davis, Chief Executive Officer, Autism CRC, *Proof Committee Hansard*, 3 March 2021, p. 1.

[73] See, for example, The Autistic Realm Australia, *Submission 86*, pp. 24–25; Australian Autism Alliance, *Submission 52*, p. 13; Name withheld, *Submission 120*, [p. 8]; Mr David Staples, *Submission 143*, p. 19.

[74] See, for example, Queensland Family and Child Commission, *Submission 36*, p. 9; Commissioner for Children and Young People South Australia, *Submission 88*, p. 4; Mrs Natasha Staheli, Strategic Relationships and Policy Adviser, Yellow Ladybugs, *Proof Committee Hansard*, 11 February 2021, p. 38; The Hon Coralee O'Rourke MP, Queensland Minister for Communities, Queensland Minister for Disability Services and Seniors, *Submission 101*, [p. 4].

[75] Ms Fiona Sharkie, Co-Chair, Australian Autism Alliance, *Proof Committee Hansard*, 12 February 2021, p. 9.

[76] TARA, *Submission 86*, pp. 24–25.

[77] Ms Mel Spencer, Executive Officer & Co-founder, Different Journeys, *Proof Committee Hansard*, 11 February 2021, p. 31.

[78] Ms Mel Spencer, Executive Officer & Co-founder, Different Journeys, *Proof Committee Hansard*, 11 February 2021, p. 31.

Strong accountability mechanisms

5.46 The lack of an outcomes framework was identified as a 'fundamental flaw' of the *National Disability Strategy*.[79]

5.47 This aligned with international experiences,[80] which numerous stakeholders stated underscored the importance of strong accountability mechanisms to the success of a National Autism Strategy. Commonly cited measures included:

- a comprehensive, meaningful and measurable outcomes framework;
- an implementation plan with clearly defined targets, milestones and responsibilities;
- appropriate and transparent funding to support implementation; and
- regular monitoring and reporting on outcomes.[81]

Potential development mechanisms

5.48 More than one stakeholder raised the idea of convening a national taskforce (or peak body) to develop a National Autism Strategy and oversee its implementation.[82] For example, Ms Nicole Rogerson from Autism Awareness Australia expressed fears that without such an approach, this inquiry's recommendations would just end up 'on a shelf somewhere'.[83]

5.49 In terms of membership, some stakeholders suggested the taskforce should be chaired by someone with lived experience of autism[84] and should include members of the autism community, as well as leading researchers and clinicians.[85] Others highlighted the importance of including autistic people in a range of key roles covering development, implementation and monitoring.[86]

5.50 It was also recognised that to be successful, a taskforce would need to include people with a proven ability to deliver cross-jurisdictional projects.[87]

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[79] Australian Autism Alliance, *Submission 52*, p. 13.

[80] Australian Autism Alliance, *Submission 52*, p. 12.

[81] See, for example, Australian Autism Alliance, *Submission 52*, p. 13; Commissioner for Children and Young People South Australia, *Submission 88*, p. 5; Mr Bob Buckley, Convener, Autism Aspergers Advocacy Australia, *Proof Committee Hansard*, 27 July 2020, p. 18; Commissioner for Children and Young People Western Australia, *Submission 42*, pp. 19–20; The Royal Australasian College of Physicians, *Submission 29*, p. 11.

[82] Autism Awareness Australia, *Submission 47*, p. 6; ND Australia, *Submission 97*, [p. 2]; Different Journeys, *Submission 30*, p. 25.

[83] Ms Nicole Rogerson, Chief Executive Officer, Autism Awareness Australia, *Proof Committee Hansard*, 28 July 2020, p. 2.

[84] Autism Awareness Australia, *Submission 47*, p. 6.

[85] ND Australia, *Submission 97*, [p. 2].

[86] TARA, *Submission 86*, p. 3.

[87] ND Australia, *Submission 97*, [p. 2].

The development mechanism would also need to facilitate cooperation between different levels of government, as well as intra-government collaboration between departments with responsibility for health, disability, education, justice and social services.[88]

5.51 Given the extent of collaboration and coordination required, the Autism Alliance suggested that the approach taken to the 'refreshed' Closing the Gap Strategy could be used as a possible model for the development of a National Autism Strategy (see Box 5.1).[89]

5.52 Alternative mechanisms identified by the committee could include a dedicated taskforce under the National Federation Reform Council, a working group reporting to the Disability Reform Ministers' Meeting, or a time-limited Ministers' Meeting established specifically to drive development of a National Autism Strategy.[90]

Box 5.1 Closing the Gap in partnership

Established in March 2019, the *Closing the Gap Partnership Agreement* is a formal agreement between Commonwealth, state and territory governments, the National Coalition of Aboriginal and Torres Strait Islander Peak Organisations, and the Australian Local Government Association.

The Coalition of Peaks comprises over fifty Aboriginal and Torres Strait Islander peak organisations, formed for the purpose of negotiating with governments to develop the National Agreement. The Coalition of Peaks represent the Aboriginal and Torres Strait Islander community-controlled service sector. Members of the Coalition of Peaks are accountable to their communities.

The *Closing the Gap Partnership Agreement* recognises that shared decision making with Aboriginal and Torres Strait Islander peoples, through their representative organisations, in the design, implementation, monitoring and evaluation of the Closing the Gap framework is essential to closing the gap in life outcomes between Indigenous and non-Indigenous Australians.

Source: Australian Government, Closing the Gap in Partnership, www.closingthegap.gov.au/partnership *(accessed 31 October 2021).*

Committee view

5.53 The committee strongly believes that all Australians should have the opportunity to fulfil their potential and lead healthy, safe and productive lives.

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[88] Early Start Australia, *Submission 76*, p. 13; Ms Nicole Rogerson, Chief Executive Officer, Autism Awareness Australia, *Proof Committee Hansard*, 28 July 2020, p. 2.

[89] Australian Autism Alliance, *Submission 52*, p. 13.

[90] Department of Prime Minister and Cabinet, *Australian Federal Relations Architecture*, www.pmc.gov.au/sites/default/files/federal-relations-architecture-diagram.pdf (accessed 1 November 2021).

However, this is an opportunity currently denied to many autistic people and their families.

5.54 Despite its prevalence—and the fact that autistic people make up the largest single disability group within the NDIS—autism appears to be poorly understood and not adequately supported.

5.55 During the course of the inquiry, the committee heard first-hand accounts of the devastating impact that a lack of support has on the lives of autistic people and their families. Alarmingly, research shows that these accounts are not isolated incidents. Autistic people continue to experience life outcomes that are worse than both the general population and other disability groups.

5.56 The committee notes that, in addition to the impact on autistic individuals, the failure to provide adequate supports for autistic people also comes at an enormous social and economic cost to families, communities and society as a whole.

5.57 The ongoing failure of the system to improve outcomes for autistic people means that there is little value in continuing to do more of the same. Something must change.

A National Autism Strategy

5.58 The committee agrees with the widely held view that generic disability approaches will not deliver the change needed to improve outcomes for autistic people and their families. This includes the *National Disability Strategy*—although the committee commends the positive steps taken to ensure consultation with autistic people around design of the new *Australia's Disability Strategy 2021–2031*.

5.59 The committee also acknowledges the overwhelming support expressed for a National Autism Strategy. Multiple participants highlighted the failure of current approaches and called for an autism-specific strategy that would increase understanding of autism, enhance service coordination and integration, increase the use of evidence-based supports and interventions, and drive a national autism research agenda. In addition, international experience shows that national strategies, while not a panacea, do lead to improved outcomes. Importantly, they serve to establish a baseline against which progress can be measured and reported.

5.60 Accordingly, the committee supports the development of a National Autism Strategy that is both person and family-centred and addresses whole-of-life needs for people across the breadth of the spectrum. To ensure consistency—and to enable its use as a model for future state-based strategies—the National Autism Strategy should align with other national strategies, including the *National Disability Strategy*.

5.61 The content of the National Autism Strategy, including any priority actions, should be guided by the recommendations of this inquiry.

Recommendation 1

5.62 The committee recommends that the Australian Government develop a National Autism Strategy and accompanying implementation within 12 months to drive nationally-coordinated action to improve services and supports for autistic Australians. The National Autism Strategy should:

- **be both person- and family-centred;**
- **address whole-of-life needs for people across the breadth of the spectrum;**
- **align with other national strategies, including the National Disability Strategy; and**
- **be informed by the recommendations of this inquiry and the Disability Royal Commission.**

Approach to development

5.63 While recognising that there are diverse views within the autism community on a number of issues, the committee believes a National Autism Strategy has the potential to find common ground and unify the broader autism community around a common set of goals.

5.64 To this end, the committee considers that development of the National Autism Strategy—as well as any associated plans and frameworks—must adopt a co-design approach and that autistic people's voices must be central to this process.

5.65 However, the committee also understands that there are genuine fears some voices could get lost in the development process, including those of parents and carers, as well as autistic people with multiple and complex needs, who may be unable to advocate for themselves. For this reason, the committee believes the co-design process must be inclusive of multiple perspectives.

5.66 The committee also notes that the development process must also include the policy and decisions makers who will be responsible for implementing many of the actions arising from the National Autism Strategy. To this end, the committee believes that utilising the Australian Federal Relations Architecture to drive development would be an appropriate approach.

Recommendation 2

5.67 The committee recommends that development of a National Autism Strategy be driven by a national taskforce established under the auspices of the National Federation Reform Council. The taskforce should adopt a co-design approach drawing on the autistic community, as well as parents, carers, researchers, and policy makers. The definition of co-design, and the

principles underpinning it, should be agreed at the start of the development process.

Accountability

5.68 Evidence presented to the committee about international experiences of autism strategies highlights the link between strong accountability measures and success of a national strategy.

5.69 Therefore, the committee believes that a combination of accountability measures be adopted as part of the National Autism Strategy, including:

- clear and measurable actions, targets and milestones;
- an implementation plan with clearly defined responsibilities;
- ongoing monitoring and reporting requirements; and
- built in timelines for review and renewal of the strategy.

5.70 For consistency, and to avoid unnecessary duplication, outcomes and targets developed for the National Autism Strategy should align with those in other national strategies wherever possible.

Recommendation 3

5.71 The committee recommends that the National Autism Strategy and accompanying implementation plan include an outcomes framework, as well as specific and measurable actions, targets and milestones. Where appropriate, the framework and measurable items should align with those in other national strategies.

Recommendation 4

5.72 The committee recommends that the taskforce monitor and report annually on the implementation of the National Autism Strategy.

Recommendation 5

5.73 The committee recommends that an independent review of the National Autism Strategy be undertaken three years after implementation begins, with the findings to be publicly released and used to inform the next iteration of the strategy.

Chapter 6
The adequacy of available services and supports

6.1 This chapter describes general concerns raised by participants about the overall adequacy and availability of services and supports for autistic people in Australia, including through the National Disability Insurance Scheme (NDIS). It also provides an overview of the barriers to adequate service provision that are common to many—if not all—service sectors. In addition, it also includes discussion of stakeholder concerns in relation to gaps in support for social inclusion.

6.2 This chapter does not canvas issues that are specific to individual service areas such as diagnosis, early intervention (including the NDIS Early Childhood Approach[1]), education and employment. Nor does it identify the additional challenges faced by particular cohorts of autistic people in relation to adequate supports. These issues are addressed in subsequent chapters.

Support for autistic Australians

6.3 The social and economic costs of failing to support autistic people and their families were described in Chapters 3 and 4. However, as one autistic participant described, providing adequate support for autistic people is 'not only about reducing our suffering but about gleaning the unique potential that our differences enable'.[2] This point was also made by the Northern Territory Office of the Public Guardian which highlighted the wasted potential arising from a lack of adequate support.[3]

6.4 However, Mr Paul Micallef, Co-chair of the Australian Autism Alliance, cautioned that even successful outcomes for autistic people can come at a significant cost if not supported adequately:

> A typical story is that even outward success comes at a huge internal price and, sooner or later, we just can't do it anymore. The mask breaks, resulting in problematic behaviour—to say the least. That's what it looks like on the outside. There's severe burnout and mental breakdown, and it can end jobs, destroy marriages and alienate friends and family.[4]

6.5 Support for autistic people in Australia can be provided through a sometimes complex mix of disability supports funded by the NDIS, non NDIS-funded

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[1] Formerly the Early Childhood Early Intervention approach.

[2] Name withheld, *Submission 112*, [p. 4].

[3] Northern Territory Office of the Public Guardian, *Submission 20*, [p. 6].

[4] Mr Paul Micallef, Co-Chair, Australian Autism Alliance, *Proof Committee Hansard*, 12 February 2021, p. 2.

mainstream and community services and supports, as well as informal supports provided by families, carers, and friends.[5]

6.6 The majority of funded support for autistic people is provided through the NDIS (see Box 6.1). The most recent quarterly report indicated that the NDIS is supporting over 144 000 active autism participants, representing approximately 32 per cent of all active plans. For autistic NDIS participants, evidence suggests that the amount of committed funding increases with age and it has been estimated that the lifetime support costs for an autistic person is $6.7 million per NDIS participant to age 70 years.[6]

6.7 The under representation of females is also reflected in NDIS plans for autistic people. 105 925 of the 144 154 active participants in the scheme with autism are male and 36 197 are female. This represents a male to female ratio of just under 3:1 for active participants in the NDIS with autism.[7]

Box 6.1 National Disability Insurance Scheme

The NDIS was established in 2013 through the *National Disability Insurance Scheme Act 2013*. It represents a social insurance model of care for eligible Australians with a disability and is managed by the National Disability Insurance Agency (NDIA).[8]

The NDIS provides eligible individuals with a permanent and significant disability access to the reasonable and necessary supports they need 'to achieve their goals and aspirations'.[9] The decision on what supports or therapies are deemed reasonable and necessary for an individual with autism depends on the supports and services already available to the participant.[10] The NDIS is not intended to replace all the services and supports provided elsewhere by governments or the community.[11] Of the estimated 4.4 million Australians with a disability, around 500 000 receive individualised supports under the scheme.[12]

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[5] See, for example, National Disability Insurance Agency (NDIA), *Submission 56*, p. 21. Mainstream and community supports are those available to all Australians regardless of whether they have a disability or not, such as health, education and transport. Informal supports are those provided by carers, families and friends. NDIS plans may include supports provided by mainstream, community and informal networks.

[6] Autism Aspergers Advocacy Australia (A4), *Submission 54*, p. 17.

[7] NDIA, *NDIS Quarterly Report: 2020-21 Q3*, p. 116.

[8] Department of Social Services, Department of Health, Department of Education, Skills and Employment, *Submission 53*, p. 20.

[9] Department of Social Services, Department of Health, Department of Education, Skills and Employment, *Submission 53*, p. 20.

[10] National Disability Insurance Agency, *Submission 56*, p. 10.

[11] Department of Social Services, Department of Health, Department of Education, Skills and Employment, *Submission 53*, p. 7.

[12] Department of Social Services, Department of Health, Department of Education, Skills and Employment, *Submission 53*, p. 20.

From 1 July 2020, the NDIS became available nationally. As part of this, Commonwealth disability programs have been transitioning funds and clients to the NDIS, including the individualised components of the Helping Children with Autism (HCWA) program.[13]

6.8 Informal care also plays a significant role in supporting autistic individuals. For example, according to the Australian Bureau of Statistics (ABS), the majority of care in the core areas of self-care, mobility and communication is provided by informal carers.[14]

Concerns raised by stakeholders

6.9 There was almost universal stakeholder concern about the adequacy of current services and supports for autistic people, including high levels of unmet demand, as well as service gaps and inadequacies.[15]

6.10 In terms of unmet demand, the ABS found that many autistic people were not receiving either some or all of the assistance they needed, with over half indicating they needed more help with at least one activity. According to the ABS, the unmet need for assistance was greatest for cognitive and emotional support (40.8 per cent), household chores (36.8 per cent), communication (34.3 per cent) and transport (30.3 per cent).[16]

6.11 Similarly, a survey by La Trobe University's Olga Tennison Autism Research Centre (OTARC) identified 'significant problems with accessibility and adequacy of services'. This included:

- difficulty locating available services, particularly after high school;
- lack of curriculum adaptation to cater for individual needs of autistic students in education settings;
- lack of support to acquire employability and upskilling;
- lack of day programs;
- lack of practical supports and accommodations at university;
- lack of supports in fostering decision making, living skills and self-advocacy;

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[13] Department of Social Services, Department of Health, Department of Education, Skills and Employment, *Submission 53*, p. 7.

[14] Australian Bureau of Statistics (ABS), *Disability, Ageing and Carers, Australia: Summary of Findings 2018*, www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/2018#autism-in-australia (accessed 3 November 2021).

[15] SDN Children's Services, *Submission 44*, p. 6; Marymead Autism Centre, *Submission 128*, pp. 12–13; Northern Territory Office of the Public Guardian, *Submission 20*, [pp. 4–5].

[16] ABS, *Disability, Ageing and Carers, Australia: Summary of Findings 2018*, www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/2018#autism-in-australia (accessed 2 November 2021).

- difficulty navigating the system if you do not fit typical categories of support; and
- a lack of post diagnosis supports.[17]

6.12 Many stakeholders also observed the compounding nature of inadequate service provision and noted that failures in one sector, particularly early in life, were likely to increase the need for services in other sectors.[18]

6.13 While the cost of services was also a concern, this related primarily to specific services areas (such as the cost of diagnosis), as well as the cost of services for people without a diagnosis, or people who do not qualify for support under the NDIS.[19] Accordingly, the primary discussion of costs appears in those chapters dealing with relevant service sectors.

Specific concerns about the NDIS raised by stakeholders

6.14 Stakeholder support for the operation of and services provided to autistic participants by the NDIS was mixed.[20]

6.15 While some autistic participants and their carers have benefited from being able to access the NDIS,[21] a number were critical of the lack of general understanding about autism within the NDIA and the absence of tailored supports to assist autistic people access, navigate and benefit from NDIS funding. For example, the AEIOU Foundation (AEIOU), one of Australia's largest providers of autism-specific early intervention, outlined their concerns about a lack of understanding:

> AEIOU believes there is a lack of understanding at agency level regarding autism and evidence-based treatments for children up to six years, perhaps viewing it as a more transient condition rather than a permanent disability which warrants long-term investment. The alternative is there is a lack of understanding about what can be achieved for these children via quality, evidence-based intervention and both the personal and cost benefit over the course of an individual's lifespan.[22]

6.16 General concerns were also raised by participants and their carers as to whether the NDIS was meeting the principles in the Participant Service Charter (see Box 6.2). For example, Dr Nancy Sadka, an autism researcher and parent to two autistic boys, shared her experience which as well as appearing exhausting also

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[17] La Trobe University – the Olga Tennison Autism Research Centre (OTARC), *Submission 55*, p. 10.

[18] Commissioner for Children and Young People South Australia, *Submission 88*, pp. 10–11; Queensland Law Society, *Submission 124*, p. 5.

[19] Marymead Autism Centre, *Submission 128*, p. 12.

[20] See, for example, the variety of family insights contained in SDN Children's Services, *Submission 44*.

[21] See, for example, Name withheld, *Submission 113*, [p. 2]; Name withheld, *Submission 116*, [p. 3]; Name withheld, *Submission 122*, [p. 1]; Name withheld, *Submission 126*, p. 10.

[22] AEIOU Foundation, *Submission 50*, [p. 4].

did not seem to be transparent, responsive, respectful, empowering or connected:

> …navigating the NDIS is a long and challenging process. It took me a year to prepare for our support planning meeting to ensure adequate funding. I accounted for every hour of every day, 365 days, 8,760 hours, and it did not stop there. Receiving an adequate plan is only the first step, trying to implement the plan is another matter. I fight with providers who are lacking in knowledge on how to operate under the NDIS. I recruit support staff, provide monthly rosters for support staff, check signatures against hours provided, document and lodge them weekly, approve invoices against line items, keep an expense ledger, budget funding so it will last for the duration of his plan, keep up with NDIS changes, and get ready for the next year's plan review. So if you think that the NDIS is all about funding the individual, think again. It is my second full time job.[23]

6.17 Similarly, a family contribution to the SDN Children's Services' submission also appeared inconsistent with the expectations arising from the Participant Services Charter:

> NDIS' insistence they will only fund 'disability specific' programs means our kids miss therapeutic opportunities that would also help them build social connections in the community. Any attempt to raise issues with the NDIS makes us feel voiceless and powerless. If the aim was to design a system to isolate families with disabilities, undermine their mental health and disempower them the NDIS is doing a bang-up job.[24]

Box 6.2 The NDIS Participant Service Charter

The Participant Service Charter sets out what participants can expect from the NDIA and the Partners in the Community Organisations.

The Participant Service Charter is based on five principles for our engagement with participants:

- Transparent – easy to access and understand information and decisions
- Responsive – respond to individual needs and circumstances
- Respectful – recognise your individual experience and acknowledge you are an expert in your own life
- Empowering – easy to access information and be supported by the NDIS to lead your life
- Connected – support you to access the services and supports you need.[25]

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[23] OTARC, *Submission 55*, p. 17.

[24] SDN Children's Services, *Submission 44*, p. 8.

[25] NDIS, *Participant Service Charter*, September 2020, p. 4.

6.18 Stakeholders (both individuals and organisations) who submitted to the inquiry also identified specific concerns relating to the support provided by the NDIS to autistic individuals. These concerns can be broadly categorised as:

- lack of information and support to autistic individuals and/or their families when applying and navigating the NDIS;
- lack of knowledge regarding autism and best practice among NDIS planners who are the main contacts for families with children with autism;
- inadequate plan funding and trouble accessing services once plans are received.

Lack of information and support when applying and navigating the NDIS

6.19 The committee heard concerns around the lack of information and support to autistic individuals when applying and navigating the NDIS. This was particularly an issue for families having to navigate multiple service sectors to address the specific needs of their children.

6.20 For example, Children and Young People with Disability Australia (CYDA) observed that 'families of children and young with disability often encounter challenges with eligibility criteria and difficulty obtaining medical diagnostic reports and assessments'. It argued that:

> This leads to significant costs and stress to families, and means there is inequitable access for children living in families experiencing poverty or hardship. Many find it hard to access to the Scheme without support or advocacy services. Families are also concerned their child only receives support for what is considered the 'primary disability' rather than support for their full spectrum of needs.[26]

6.21 CYDA also noted that:

> Information about accessing the Scheme, and throughout the planning and implementation processes is often confusing. Families are unclear on what the Scheme can and cannot fund and are not supported to access services and supports outside the NDIS when these are not included in the NDIS plan. The interface issue with the NDIS and other systems such as health and education need to be urgently resolved by the NDIA and state and territory governments.[27]

6.22 Another submitter, who did not wish to be identified, argued that the NDIS should engage with autistic people and their families openly about seeking options to reduce potential cost blowouts, should they exist, rather than give the perception it is trying to limit or take away access to services.[28]

6.23 In addition, AEIOU argued that 'the current system relies heavily on parents understanding what services are available before they get to see their planner,

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[26] Children and Young People with Disability Australia, *Submission 109*, p. 11.

[27] Children and Young People with Disability Australia, *Submission 109*, p. 11.

[28] Name withheld, *Submission 126*, p. 15.

what evidence-based practices are, and how to advocate for them, all at a time that is often guided by stress and grief'.[29]

6.24 Another submitter suggested that the NDIS should assist by publishing 'transparent guides to NDIS planning for carers of people with Autism that identifies what sort of goals will be supported and what types of therapy and other support will be funded'.[30]

6.25 The Queensland Government voiced concerns about delays in children being able to access Early Childhood Early Intervention (ECEI) services and contended that the NDIS does not recognise delegated decision making by more than one individual and does not recognise entities or individuals acting in their professional capacity under child protection legislation.[31]

6.26 Stakeholders also raised concerns in relation to the NDIS website. For example, one submitter noted:

> …if you are self managed but like me for physiotherapy want to use a Registered NDIS Service Provider you can't do it via the NDIS website you still have to put a Private Service Agreement in place and book your appointments privately and pay up front then claim back instead of being able to do it via the NDIS website. Some Registered NDIS Service Providers won't take self managed clients because their systems for managing NDIS clients is done totally through the NDIS website and self managed NDIS is not accessible to them for booking/billing.[32]

6.27 The Coalition of Autistic Women also highlighted the 'difficulties in navigating the NDIS website by participants, particularly for those participants with limited reading or comprehension skills'.[33]

6.28 Marymead Autism Centre reported that its clients experienced confusion and feelings of being overwhelmed when accessing and navigating the complex system and contended that a lack of information figures strongly in the reasons given by people not applying for the NDIS.[34]

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[29] AEIOU Foundation, *Submission 50*, pp. 3 and 7.

[30] Name withheld, *Submission 81*, p. 4. See also, Name withheld, *Submission 126*, p. 13.

[31] Queensland Government, *Submission 101*, p. 10.

[32] Name withheld, *Submission 9*, p. 6. See also, Royal Australasian College of Physicians, *Submission 29*, p. 10.

[33] Coalition of Autistic Women, *Submission 125*, pp. 12–13 and 25.

[34] Marymead Autism Centre, *Submission 128*, pp. 7 and 12.

A lack of knowledge regarding autism and best practice among planners

6.29 Many stakeholders expressed concerns around a lack of knowledge regarding autism among NDIS planners who are the main contacts for families with autistic children.[35]

6.30 Autism Awareness Australia advised that the families it interacts with often report that NDIS planners have a 'poor understanding' of autism. It explained:

> Given the wide spectrum and multiple presentations of ASD, this is not surprising, but it does raise significant issues. Understanding suitable interventions and supports for different children with varied presentations of autism are critical.[36]

6.31 Similarly, The Autistic Realm Australia (TARA) advised that:

> Many NDIS planners do not appear to have training in Autism and how it manifests in both children and adults, and as a result make decisions for our plans that are inappropriate and contrary to the recommendations of our medical professionals.[37]

6.32 Issues with planners were identified early in the NDIS rollout and appear to persist today. For example, the Australian Medical Association (AMA) noted that concerns were flagged about the capacity for providing appropriate and timely support to those with autism in the early phases of the NDIS.[38] It observed that concerns remain, particularly around the wide variation of support packages provided to people with autism:

> While it is true that support needs [for individuals with ASD] can differ, there continues to be anecdotal stories of people with similar support needs receiving vastly different packages of support. There may be a range of factors contributing to this disparity but improving the NDIS Planners understanding of Autism Spectrum Disorder is one aspect that may improve the situation.[39]

6.33 Similarly, the Royal Australasian College of Physicians (RACP) observed:

> The experience, expertise and qualifications of NDIS staff can vary greatly. Some RACP Fellows report that the level of understanding of a client's impairments tends to vary greatly which can lead to different funding levels for similar clients, both in terms of core supports and capacity building supports. Planners have also been reported to act independently in deciding

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[35] In addition to the examples presented in this section, see also South Australian Commissioner for Children and Young People, *Submission 88*, p. 7; Autism Spectrum Australia (Aspect), *Submission 64*, pp. 10, 17, 19, and 21.

[36] Autism Awareness Australia, *Submission 47*, p. 10.

[37] The Autistic Realm Australia (TARA), *Submission 86*, p. 17.

[38] Australian Medical Association (AMA), *Submission 40*, p. 2. See also, Spectrum Labor, *Submission 1*, p. 15.

[39] AMA, *Submission 40*, p. 2.

> which requests will be funded and often do not necessarily accept the recommendations of experienced clinicians.[40]

6.34 The Tasmanian Government also shared these concerns:

> NDIS planners do not always have the skills, knowledge, and understanding to effectively support people with autism. This can result in the development of plans deficient in the types of and level of supports needed. Introduction of draft plans may assist in supporting NDIS planners and participants to develop appropriate plans.[41]

6.35 In addition, the Northern Territory Office of the Public Guardian noted that 'planners are not always able to understand the complexities of a participant's disability and therefore the required level of supports is not incorporated in the participant's plan'. It went on to argue that:

> The growth of the human services support industry in the Northern Territory is dependent upon NDIS planners having an understanding of both the supports that are currently available as well as what supports could be provided to the participant. This is particularly relevant to NDIS plans for people with autism where the growth of specialist and holistic services is essential to meet the needs of this group.[42]

6.36 A submitter, who did not wish to be identified, argued that the knowledge of autism within the NDIA and its contracted client management firms as it relates to 'teens, young adults and adults especially females is somewhere between little and totally non-existent'.[43]

6.37 Carers Australia also commented on eligibility barriers and argued that the eligibility of participants with mild to moderate disability can be difficult to establish due to the absence of sound and fair judgements as to need by planners. Moreover, the review process to challenge decisions is often time consuming and complex.[44]

6.38 Given these concerns, the South Australian Commissioner for Children and Young People recommended that:

> Given that one third of NDIS participants are people with autism, autism-specific training should be prioritised and provided for NDIS planners and all individuals and services that interface with the NDIS.[45]

6.39 Several stakeholders raised concerns regarding the lack of understanding on best practice and evidence-based treatments for people with autism.

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[40] Royal Australasian College of Physicians, *Submission 29*, p. 9.

[41] Tasmanian Government, *Submission 19*, p. 5.

[42] Northern Territory Office of the Public Guardian, *Submission 20*, p. 6.

[43] Name withheld, *Submission 9*, p. 6.

[44] Carers Australia, *Submission 71*, pp. 2–3. See also Carers NSW, *Submission 71*, pp. 3–4.

[45] South Australian Commissioner for Children and Young People, *Submission 88*, p. 7. See also, Aspect, *Submission 64*, pp. 10, 17, 19, and 21.

For example, CYDA noted concerns from families that 'NDIS plans consider children and young people in isolation from their families despite extensive research which shows the development and wellbeing of children and young people is facilitated through supportive home learning and support environments'. It argued:

> Families can be denied support and services as these are considered to be 'parental responsibility', and there is a push to medicalise the supports in the plan rather than consider the natural environments and supports in the community which promote the wellbeing and development of children and young people.[46]

6.40 Autism Aspergers Advocacy Australia (A4) noted that 'few autistic children in Australia are diagnosed in time to access good or best practice early intervention before the NDIS's premature cut-off at school entry of age 7 years'. It observed:

> Since the NDIS caused the demise of the national Autism Advisor Scheme that was part of the Helping Children with Autism package, few parents are informed about good practice for autistic children so they are unable to make an informed choice for their autistic child. And the NDIS often resists requests for evidence-based supports for young autistic children: families may have to take their service request to the Administrative Appeals Tribunal to get their child's needs met.[47]

6.41 Stakeholders also reported the need to improve the participation of people with autism in the NDIS planning process. For example, the Northern Territory Office of the Public Guardian argued:

> …the planning process does not always draw optimal outcomes because of the general nature and structure of the meetings. In addition to this, the assessment tools that are used are not meaningful in all situations but particularly for people with autism, nor is the process coming from a strengths approach. Instead, participants are asked to justify their deficits to enable funding to be allocated, which is very difficult for participants, family and carers and support providers. Inappropriately worded questions can exacerbate the existing discomfort of a participant who is not comfortable talking to a stranger about personal matters leading to critical information not being disclosed and basic supports not being included in plans.[48]

6.42 Likewise, a submitter who did not wish to be identified, noted:

> Planners have varying levels of autism understanding, and their personal perspectives on the types of support required and the way they view autism generally may be at odds with the autistic person and their family or carers. The submission of plans is not transparent, and the effort put into providing evidence of supports needed is overridden by the planner/or someone else

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[46] Children and Young People with Disability Australia, *Submission 109*, p. 11.

[47] A4, *Submission 54*, p. 16.

[48] Northern Territory Office of the Public Guardian, *Submission 20*, p. 7. See also, Autism Advisory and Support Service, *Submission 21*, p. 7.

> who approves the plan. The review process is confusing and takes far too much time.[49]

6.43 Another submitted suggested that, given the special nature of autism, a dedicated autism stream be developed within the NDIS to provide for more timely, specialised and appropriate diagnosis and provision of services.[50]

Difficulty accessing services and inadequate funding

6.44 Once plans and funding have been finalised, stakeholders commented on the difficulty they then had accessing services and highlighted that funding was often not sufficient to provide the services and supports required.

6.45 At least one submitter suggested that a lack of support coordination is a contributing factor to the underutilisation of plans[51] and is one reason the full benefits of the NDIS are not being realised.[52] According to CYDA, 'many families are not aware how to start using the funds once the plan is approved, where to find support workers and what to ask providers to compare services'.[53] This was reflected in the experience of one mother, who described a lack of support coordination as a major impediment to getting the most out of her children's funded supports.[54]

6.46 The NDIA acknowledged the difficulties autistic people experience in trying to interact with the multiple agencies and service sectors involved in their support.[55] It also indicated that support coordination is currently provided through:

- Local Area Coordinators (LACs), who provide information about, and referrals to, mainstream services for both NDIS participants and non-participants; and
- support coordination, which can be funded and may comprise:
  - support connection (to build an individual's ability to connect with informal, community and funded supports);
  - support coordination (to build the skills needed to understand, implement and use an NDIS plan); and

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[49] Name withheld, *Submission 59*, p. 2.

[50] Name withheld, *Submission 81*, p. 3.

[51] Children and Young People with Disability Australia, *Submission 109*, p. 19.

[52] Name withheld, *Submission 126*, p. 13.

[53] Children and Young People with Disability Australia, *Submission 109*, p. 19.

[54] Name withheld, *Submission 112*, p. 12.

[55] NDIA, *Submission 56*, p. 14.

- specialist support coordination (for people with complex situations who need help managing challenges in the support environment).[56]

6.47 In addition, the NDIA highlighted that it now has dedicated Health Liaison Officers and Justice Liaison Officers, who can support people who are 'moving into and out of these state systems'.[57]

6.48 However, the committee heard mixed views about the availability and quality of the NDIS support coordination. For example, one mother described the lack of support provided by her LAC while she struggled to make use of her children's plans:

> I was expected to coordinate the supports of my children, despite not being qualified to identify what supports were needed, or to identify what supports were available. I had no hope of putting those two things together and making good use of their funding. None. And the LAC let it ride for three years - three plan reviews, and would have let it go for another, and probably indefinitely. And every time I asked for help in locating a suitable support service, she'd handball the task back to me, essentially telling me to Google. Or Googling and sending me the first page of results as an email. Or a list of phone numbers to call, none of which were for organisations that provided the support or service I needed. And she refused to ask for a specific support in my daughter's plan Three Times, because she said that the NDIS didn't provide that kind of support, despite it being a line item in the price guide…[58]

6.49 The mother went on to describe how her experience was turned around by a support coordinator who recognised that she was unable to cope and volunteered to advocate for her. With this support, the mother was able to access 'the help and support we should have had all along in dealing with the NDIS'.[59]

6.50 As a result, the committee heard calls for support coordination funding to be increased, particularly for disadvantaged and vulnerable cohorts.[60] There were also calls for support coordination to be a 'default' inclusion for NDIS plans.[61]

6.51 Other stakeholders expressed frustration at NDIS policies that led to inadequate plan funding. For example, one family outlined how difficulty accessing

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[56] NDIA, *Submission 56*, p. 14. See also, National Disability Insurance Agency, *Support coordination*, www.ndis.gov.au/participants/using-your-plan/who-can-help-start-your-plan/support-coordination (accessed 8 November 2021).

[57] NDIA, *Submission 56*, p. 15.

[58] Name withheld, *Submission 112*, p. 12.

[59] Name withheld, *Submission 112*, p. 12.

[60] Autism Advisory and Support Service, *Submission 21*, p. 5.

[61] Name withheld, *Submission 112*, p. 13. See also, Children and Young People with Disability Australia, *Submission 109*, p. 19.

services in one year had led to inadequate funding the following year when services were available:

> We were unable to get a psychologist for the 12 months and NDIS reduced our funding down as we hadn't been able to use the services. The next year when we were able to get a psychologist, but we are limited to how many sessions we can have as we don't have enough funding now.[62]

6.52 Other participants and providers indicated that plan funding is often inadequate to access the supports needed.[63] Indeed, responses to the Australian Autism Alliance (the Autism Alliance) survey indicated that:

> Just over one-third of respondents with a current or pending NDIS plan report that their NDIS funding is inadequate.[64]

6.53 Submitters also raised concerns with plan funding allocation, noting that families and carers are allocated funding for specific purposes but may find they do not have access to the provider or service specified. For example, one submitter was told they were unable to use plan funding for a teacher's aide if their state education department would not fund the support.[65]

Common barriers to the provision of adequate services and supports

6.54 Consistent with the issues raised in the previous section, stakeholders noted that the barriers to adequate service provision are interconnected and cut across multiple service sectors. Overall, some of the issues most commonly identified were:

- the lack of integration across service sectors and between levels of government, including the intersection of NDIS and mainstream supports; and poor service coordination support;
- poor understanding of autism in both community and professional settings;
- inappropriate service provision;
- workforce shortages.[66]

Lack of service integration

6.55 Responsibility for ensuring people with autism are included in the community and are able to access the services they need is shared between all Australian

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[62] SDN Children's Services, *Submission 44*, p. 8

[63] Australian Autism Alliance, *Submission 52*, p. 45; Name withheld, *Submission 145*, p. 2; AEIOU Foundation, *Submission 50*, p. 2; Queensland Family and Child Commission, *Submission 36*, pp. 5–6.

[64] Australian Autism Alliance, *Submission 52*, p. 45.

[65] Name withheld, *Submission* 113, [p. 4].

[66] See, for example, Australian Autism Alliance, *Submission 52*, p. 11; Autism Awareness Australia, *Submission 47*, pp. 2–3 and 6; A4, *Submission 54*, p. 17, 19 and 21; Autism Behavioural Intervention Association (ABIA), *Submission 70*, pp. 6–7; TARA, *Submission 86*, p. 15.

governments, the non-government sector, businesses and the wider community.[67] The Autism Alliance claimed this had contributed to a piecemeal policy and program delivery landscape, with 'small, disconnected and fragmented initiatives' delivered through a multitude of systems across different levels of government.[68]

6.56 According to CliniKids, the disconnect is apparent within and across different levels of government, between various service sectors, and across NDIS-funded and mainstream services (including privately provided services and those in the community and not for profit sectors).[69] According to some stakeholders, this had led to both gaps in, and duplication of, services for autistic people.[70] Overall, the Northern Territory Office of the Public Guardian observed that:

> …none of the service sectors provide either a comprehensive service to address the needs of people with autism or provide a seamless transition between service sectors. It appears difficult for service sectors to accommodate the range of complex needs that exist across the autism spectrum…[71]

6.57 The complexity of this approach was described as 'failing' autistic people[72] and Marymead Autism Centre reported that members of the autism community felt confused and overwhelmed by 'the complex and multi-jurisdictional system, including NDIS, health, education, justice, housing and employment'.[73]

6.58 Stakeholders also expressed frustration at having to deal with multiple agencies.[74] For example, one autistic submitter described interacting with the current system as a 'referral-go-round', where they were referred from one organisation to another multiple times, only to end up back where they started.[75] In addition to affecting the quality of service provision, this also creates

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[67] Department of Social Services, Department of Education, Skills and Employment, and Department of Health, *Submission 53*, p. 20.

[68] Australian Autism Alliance, *Submission 52*, pp. 11–12.

[69] CliniKids, *Submission 15*, [p. 9].

[70] Cooperative Research Centre for Living with Autism (Autism CRC), *Submission 46*, p. 17; Samaritans, *Submission 99*, p. 7; Commissioner for Children and Young People, South Australia, *Submission 88*, p. 10.

[71] Northern Territory Office of the Public Guardian, *Submission 20*, [pp. 4-5].

[72] Marymead Autism Centre, *Submission 128*, p. 9; Ms Frances Scodellaro, Chief Operations Officer, Autism Queensland, *Proof Committee Hansard*, 3 March 2021, p. 32.

[73] Marymead Autism Centre, *Submission 128*, p. 5. This emerged as a key theme in the RSM Autism Community Needs Analysis Report prepared for Marymead Autism Centre.

[74] See, for example, Ethnic Disability Advocacy Centre, *Submission 75*, p. 5; TARA, *Submission 86*, pp. 14–15; Name withheld, *Submission 120*, [p. 5].

[75] Name withheld, *Submission 112*, [pp. 3 and 9-10].

unnecessary stress and increases the psychological and emotional burden on people seeking support:

> Because phone calls are very hard and draining for me, I may find that I have spent weeks of mental energy on a circular exploration in which every organisation has ended the call satisfied that they have genuinely helped me to address my problem—a job well done—but my problem has not even remotely been addressed. It's kind of mind-bending when you're having problems with anxiety, depression, or both.[76]

6.59 The committee heard that service segregation had even created 'rail gauge' issues for autistic people and their families when they move interstate—or even between services within the same state. CliniKids observed that it was 'not uncommon' for service sectors in one state not to recognise an autism diagnosis from another state, or for the education system to require an assessment for a child, despite that child already having a diagnosis from the health system in the same state.[77]

6.60 For some stakeholders, it appeared that this service segregation was viewed as a consequence of the move to a market-based service provision model, where, in the absence of willing providers, governments no longer own the duty of care for providing services to people with disability.[78] However, others suggested it was the breadth of services required by autistic people and the dispersal of responsibility for those services that allowed people to fall through the cracks:

> …autism has sat in the Venn diagram of health, disability and education for too long at the state and federal levels. There are six departments, at bare minimum, that deal with us. You would think that means we get six levels of concentration and effort, but it doesn't; it's quite different. We fall in the middle of those things.[79]

6.61 As some participants noted, a specialised and segregated service environment works against the ability of providers to meet intersectional service needs and provide the holistic 'wraparound' services required by autistic people and their families.[80] For example, the Scope-University of Melbourne Partnership stated that women with disability who experience domestic violence are often underserved—caught at the intersection of disability services which do not provide adequate support and mainstream domestic violence services that are

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[76] Name withheld, *Submission 112*, [p. 10].

[77] CliniKids, *Submission 15*, [p. 9].

[78] Office of the Public Advocate Victoria, *Submission 80*, p. 21.

[79] Ms Nicole Rogerson, Chief Executive Officer, Autism Awareness Australia *Proof Committee Hansard*, 28 July 2020, p. 2.

[80] See, for example, Commissioner for Children and Young People South Australia, *Submission 88*, pp. 10–11; TARA, *Submission 86*, p. 14; Positive Youth Incorporated, *Submission 85*, p. 4.

inaccessible to them.[81] Likewise, there appears to be significant unmet demand for wraparound services, with Mansfield Autism Statewide Services—one of the few organisations that offers such services—having described itself as 'bursting at the seams'.[82]

6.62 Multiple submitters stated that the impact of service fragmentation was magnified for vulnerable and disadvantaged cohorts such as First Nations people, non-heterosexual and gender diverse people, and culturally and linguistically diverse communities, as well as people in remote areas, those in the child protection and justice systems, and those with multiple and complex needs.[83]

Intersection between the NDIS and mainstream supports

6.63 According to the NDIA, NDIS supports are designed to:

> …work in concert with, but not replace, existing services that are offered to participants, such as those provided by educational institutions, public or private hospitals, or correctional facilities.[84]

6.64 However, the intersection between the NDIS and mainstream supports was singled out by stakeholders as particularly problematic,[85] despite some having reported positive experiences with the NDIS since its introduction.[86] As described by one witness:

> …we are seeing vulnerable people falling through the cracks, because it doesn't fit under education, it doesn't fit under the NDIS, and it doesn't fit under health. Where does it go?[87]

6.65 It was also suggested that the NDIS may have escalated service segregation and specialisation. For example, the Samaritans argued that as a result of including early intervention in NDIS plans, many early intervention services have become

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[81] Scope-University of Melbourne Partnership, *Submission 3*, p. 24.

[82] Mansfield Autism Statewide Services, *Submission 117*, [p. 2].

[83] See, for example, Royal Australasian College of Physicians, *Submission 29*, p. 6; Australian Association of Social Workers, *Submission 96*, pp. 4–5; Different Journeys, *Submission 30*, p. 16; Autism Advisory and Support Service, *Submission 21*, pp. 5–6; Yellow Ladybugs, *Submission 49*, p. 5; Name withheld, *Submission 126*, pp. 10–11.

[84] NDIA, *Submission 56*, p. 14.

[85] See, for example, Children and Young People with Disability Australia, *Submission 109*, p. 13; SDN Children's Services, *Submission 44*, p. 6. See also, Mr Shawn Stevenson, *Submission 115*, [p. 4].

[86] See, for example, Northern Territory Office of the Public Guardian, *Submission 20*, [p. 4]; Name withheld, *Submission 16*, [p. 4]; Name withheld, *Submission 113*, [p. 2]; Name withheld, *Submission 116*, [pp. 3 and 5]; The Sycamore School, *Submission 118*, p. 6.

[87] Ms Frances Scodellaro, Chief Operations Officer, Autism Queensland, *Proof Committee Hansard*, 3 March 2021, p. 33.

providers of a 'therapy type', rather than services that look more holistically at children's needs.[88]

6.66 According to Speech Pathology Australia (SPA), the 'hard line' between the NDIS and other services means that autistic people are 'often caught in the middle of debates between the disability and health sectors regarding who should provide funding for the wrap-around or integrative services, or for transition to home'.[89]

6.67 In response, the Department of Social Services, Department of Education, Skills and Employment and Department of Health (the departments) pointed to ongoing work to 'clarify the interface between the NDIS and funding and delivery responsibilities across a number of key service systems'.[90] According to the departments, this builds on the *Applied Principles to Determine the Responsibilities of the NDIS and other Service Systems* (the APTOS Principles), which were agreed in 2015.[91]

6.68 The departments also noted that, while NDIS participants could access support from both mainstream and disability services concurrently, 'they will not be able to access the same funded services under more than one program at the same time'.[92] The NDIA also stressed that simply because a service was not funded by a particular sector (e.g. the health system), that 'does not make the provision of such a support the responsibility of the NDIS'. Instead, the NDIA emphasised that its decisions were guided by Schedule 1 of the *National Disability Insurance Scheme (Supports for Participants) Rules 2013* (see Box 6.3), which is derived from the APTOS Principles.[93]

Box 6.3 Schedule 1 of the *National Disability Insurance Scheme (Supports for Participants) Rules 2013*

The *National Disability Insurance Scheme (Supports for Participants) Rules 2013* (the Rules) guides the assessment and determination of the reasonable and necessary supports that will be funded for participants under the NDIS.

Schedule 1 to the Rules sets out the considerations that must be taken into account in deciding whether a support is more appropriately funded by the NDIS or

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[88] Samaritans, *Submission 99*, p. 7.

[89] Speech Pathology Australia, *Submission 87*, p. 19.

[90] Department of Social Services, Department of Education, Skills and Employment, Department of Health, *Submission 53*, p. 22.

[91] Department of Social Services, Department of Education, Skills and Employment, Department of Health, *Submission 53*, p. 22.

[92] Department of Social Services, Department of Education, Skills and Employment, Department of Health, *Submission 53*, p. 22.

[93] NDIA, *Submission 56*, p. 24.

another service system (for example, as part of a universal services obligation or in accordance with reasonable adjustments required by law).

Considerations are described in relation to the interaction of the NDIS with the following service systems:

- health (excluding mental health);
- mental health;
- early childhood development;
- child protection and family support;
- school education;
- higher education and vocational education and training;
- employment;
- housing and community infrastructure;
- transport; and
- justice.

Source: Schedule 1, National Disability Insurance Scheme (Supports for Participants) Rules 2013.

6.69 However, some stakeholders raised doubts about how well the APTOS Principles were being applied, as well as the transparency of the process to resolve interface issues. For example, the Office of the Public Advocate Victoria called for governments to abide by the APTOS Principles,[94] while Children and Young People with Disability claimed there was 'little publicly available information' about progress in clarifying the interface between the NDIS and mainstream supports.[95]

6.70 There were also concerns that the NDIS had allowed state, territory and local governments to reduce the level of service they provide. While the departments noted that some state and territory service provision was absorbed into the NDIS by design,[96] there was a view that, following the introduction of the NDIS, many important supports—such as advice, respite, sibling and parent programs—ceased to exist as they were no longer funded.[97] Similarly, A4 claimed that state and territory governments had 'abandoned as much of their support for autistic people as they could', with the expectation that the NDIS would fill the gap.[98]

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[94] Office of the Public Advocate Victoria, *Submission 80*, p. 18.

[95] Children and Young People with Disability, *Submission 109*, p. 22.

[96] Department of Social Services, Department of Education, Skills and Employment, Department of Health, *Submission 53*, pp. 4 and 7. The submission notes that the NDIS is not intended to replace all services for people with disability previously funded by state and territory governments. These governments retain responsibility for many of the service systems that support autistic people, including primary health services (excluding general practitioners) and education.

[97] See, for example, Autism Queensland, *Submission 129*, p. 17; Mr David Staples, *Submission 143*, [p. 18]; Samaritans, *Submission 99*, p. 7.

[98] A4, *Submission 54*, p. 20.

6.71 Unsurprisingly, the committee heard multiple pleas for greater clarity, coordination and integration of services in order to provide a holistic approach to providing support for autistic people and their families.[99] Many stakeholders also highlighted the role a National Autism Strategy could play in guiding better service coordination and integration between jurisdictions and across service sectors, including where NDIS and mainstream services intersect.[100] For example, a number of stakeholders spoke of the potential for a National Autism Strategy to connect specific sectors, such as health, education, community services and justice,[101] while others highlighted the potential for a National Autism Strategy to generate consistent guidelines and service standards,[102] and address inconsistencies in how services for autistic people are funded.[103]

Support coordination

6.72 More than one stakeholder described trying to access services for their children as a 'fight' or a 'battle'.[104] According to Speech Pathology Australia, the outcome of this fight varies according to who is 'more willing, or able, to fight harder or for longer'.[105] This view was shared by one parent of an autistic child who argued that access to adequate services was inequitable and dependent on the 'resourcefulness of parents/carers'.[106]

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[99] See, for example, Northern Territory Office of the Public Guardian, *Submission 20*, [p. 5]; Commissioner for Children and Young People South Australia, *Submission 88*, p. 11; Scope-University of Melbourne Partnership, *Submission 83*, p. 34.

[100] See, for example, Autism Awareness Australia, *Submission 47*, p. 6; Autism CRC, *Submission 46*, p. 23; The Hon Coralee O'Rourke MP, Queensland Minister for Communities, Queensland Minister for Disability Services and Seniors, *Submission 101*, p. 4; CliniKids, *Submission 15*, [p. 9]; Northern Territory Office of the Public Guardian, *Submission 20*, [p. 8]; Speech Pathology Australia, *Submission 87*, p. 19; Mr Cameron Boyd, *Submission 157*, [p. 12].

[101] NSW Government, *Submission 65*, p. 4; Australian Autism Alliance, *Submission 52*, p. 12; Mrs Camilla Rowland, Chief Executive Officer, Marymead Autism Centre, *Proof Committee Hansard*, 27 July 2020, p. 7; Name withheld, *Submission 120*, [p. 8].

[102] Commissioner for Children and Young People South Australia, *Submission 88*, p. 6; Queensland Family and Child Commission, *Submission 36*, p. 8; Early Start Australia, *Submission 76*, p. 6.

[103] Speech Pathology Australia, *Submission 87*, p. 21.

[104] Mr Domenic Mittiga, *Proof Committee Hansard*, 16 November 2020, pp. 6–7; Speech Pathology Australia, *Submission 87*, p. 21; Name withheld, *Submission 148*, [p. 1].

[105] Speech Pathology Australia, *Submission 87*, p. 20.

[106] Name withheld, *Submission 120*, [p. 4].

6.73 A lack of support coordination assistance was seen to exacerbate this situation.[107] For example, one parent described the 'constant issue' of trying to decipher 'which department or support system is responsible for supports for my son, between the NDIS, the Department of Education, Medicare and the public health system'.[108]

6.74 For autistic individuals themselves, the characteristics of autism itself—including executive functioning difficulties—can make navigating and coordinating the disconnected service environment even more challenging.[109]

Understanding of autism

6.75 Poor understanding of autism was a common theme that emerged from the evidence presented to the committee.[110] This lack of understanding, as well as misconceptions about autism and stereotypical views of autistic people, were also cited as barriers to the inclusion of autistic people within the community.[111]

6.76 Even more worryingly, a lack of understanding of autism also extends to various professionals—including general practitioners, paediatricians, psychiatrists, early childhood educators and school teachers—who are often the first point of contact for autistic people and their families.[112] The Australian Association of Social Workers described the impact this has on autistic people:

> Our members highlight a concerning lack of understanding held by … professionals that contribute to a concerning lack of consistency in supports. … This lack of widely available consistent, relevant and accurate information means that these important (in gate-keeping roles) and highly influential professionals can compromise and impede therapeutic supports, and capacity to access appropriate community resources in a timely manner, that further reduces best practice and optimal outcomes.[113]

6.77 As a result, multiple submissions recommended that a public education campaign be undertaken to promote community understanding of autism, employment of autistic people, and inclusion of autistic people in a broad range

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[107] See, for example, Marymead Autism Centre, *Submission 128*, p. 9; Autism Advisory and Support Service, *Submission 21*, pp. 5–6; Children and Young People with Disability Australia, *Submission 109*, p. 19; Name withheld, *Submission 112*, [pp. 12–13].

[108] Name withheld, *Submission 148*, p. 3.

[109] NDIA, *Submission 56*, p. 14.

[110] See, for example, Australian Association of Social Workers, *Submission 96*, p. 5; Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 4]; Aspergers Victoria, *Submission 90*, [p. 5].

[111] See, for example, Mr David Staples, *Submission 143*, [p. 9]; Name withheld, *Submission 5*, [p. 1]; Name withheld, *Submission 6*, [pp. 1 and 2]; Name withheld, *Submission 7.1*, [p. 1]; Name withheld, *Submission 155*, p. 16.

[112] Australian Association of Social Workers, *Submission 96*, p. 5.

[113] Australian Association of Social Workers, *Submission 96*, p. 5.

of settings.[114] A number of submissions also suggested that this should complement, or be a central component of, a National Autism Strategy.[115]

6.78 The committee heard that a coordinated focus on autism driven by a National Autism Strategy would help build the capacity of the community to recognise and respond to the needs of autistic individuals—rather than having the adjustment burden rest solely with autistic people themselves. Ms Jenny Karavolos, the Chief Executive Officer of Autism SA, explained:

> Understanding and education are critical. …because that's the capacity building of all the interfaces of society. The world isn't built for people with autism, but it can be adjusted. With some small tweaks, I think we can make great gains.[116]

6.79 Some stakeholders cited the Amaze *Change Your Reactions* public education campaign as an example for future campaigns.[117] According to Amaze, the campaign was very successful:

> For neurotypical viewers, 90 per cent felt concerned about how autistic people were treated; 85 per cent intended to refrain from being judgmental; and 81 per cent were made to stop and think. Importantly, of those who saw the campaign, 68 per cent reported having a better understanding of autism.[118]

6.80 Calls for greater understanding also extended to the need for better education and training for professionals involved in supporting autistic people in all service settings, including healthcare, education, disability support as well as first responders, such as police and paramedics.[119]

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[114] See, for example, Commissioner for Children and Young People Western Australia, *Submission 42*, p. 10; Children and Young People with Disability Australia, *Submission 109*, p. 14; Australian Autism Alliance, *Submission 52*, p. 50; JFA Purple Orange, *Submission 84*, p. 28; Autism Advisory and Support Service, *Submission 21*, p. 8; TARA, *Submission 86*, p. 2; Spectrum Labor, *Submission 1*, [p. 19]; Dr Kerry Chillemi, *Submission 18*, p. 2; Dr Bruce Baer Arnold, *Submission 39*, p. 8; Name withheld, *Submission 141*, p. 6; Name withheld, *Submission 155*, p. 24.

[115] See, for example, Amaze, *Submission 154*, [p. 2]; Queensland Family and Child Commission, *Submission 36*, p. 8; Commissioner for Children and Young People South Australia, *Submission 88*, p. 5; Exercise & Sports Science Australia, *Submission 91*, p. 12; Name withheld, *Submission 2*, p. 3; Name withheld, *Submission 7.1*, p. 1.

[116] *Proof Committee Hansard*, 16 November 2020, p. 14.

[117] See, for example, Australian Autism Alliance, *Submission 52*, p. 49; Commissioner for Children and Young People Western Australia, *Submission 42*, p. 8; TARA, *Submission 86*, p. 19.

[118] Amaze, *Submission 154*, [p. 2].

[119] See, for example, Commissioner for Children and Young People Western Australia, *Submission 42*, p. 4; TARA, *Submission 86*, p. 2; Exercise & Sports Science Australia, *Submission 91*, p. 12; Aspect, *Submission 64*, p. 4; Ashton's Place, *Submission 58*, [p. 7]; A4, *Submission 54*, p. 7; The Hon Coralee O'Rourke MP, Queensland Minister for Communities, Queensland Minister for Disability Services and Seniors, *Submission 101*, p. 4.

6.81 The Commissioner for Children and Young People South Australia (SA Commissioner) suggested that an autism-specific training framework be developed as part of a National Autism Strategy with the aim of equipping all workers with the 'skills to support the varied and complex communication, social interaction, sensory regulation and cognitive needs of autistic people'. The SA Commissioner also called for training to be prioritised for NDIS planners, as well as individuals and services that interact with the NDIS. This was in response to the Autism Alliance finding that 65 per cent of autistic NDIS participants (or their carers) 'rated their planner's knowledge and understanding of autism as "None" to "Moderate"'.[120]

6.82 In response, the NDIA acknowledged that it had a role in 'leading and encouraging inclusive practices' and was in the process of developing an Autism Staffing and Recruitment Strategy to enable it to better support autistic participants.[121] The committee is also aware of work underway to implement the NDIS Workforce Capability Framework which 'articulates the Australian Government's expectations about the attitudes, skills and knowledge of all workers funded under the NDIS'.[122]

6.83 More broadly, some submitters noted that a greater awareness and understanding of autism could also play a role in encouraging the development of autism-friendly 'public spaces, buildings, workplaces and events'.[123]

Inappropriate service provision

6.84 Inappropriate service provision was identified as another barrier to the provision of adequate supports. Inappropriate service provision was seen to arise primarily from:

- a lack of services designed specifically for autistic people, including a lack of autism-friendly environments; and
- misinformation and non evidence-based practices.

Services not designed for autistic people

6.85 Given the breadth of presentation across the autism spectrum, stakeholders such as Marymead Autism Centre highlighted the importance of nuanced systems and services that are capable of responding to individual needs.[124] Services also need to adjust for specific autistic characteristics. For example, as

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[120] Commissioner for Children and Young People South Australia, *Submission 88*, p. 7.

[121] NDIA, *Submission 56*, p. 18.

[122] Commonwealth of Australia (National Disability Insurance Scheme Quality and Safeguards Commission), *NDIS Workforce Capability Framework*, 2021, p. 8.

[123] Commissioner for Children and Young People South Australia, *Submission 88*, p. 5. See also, Australian Autism Alliance, *Submission 52*, p. 38.

[124] Marymead Autism Centre, *Submission 128*, p. 1.

noted by TARA, executive functioning and communication challenges mean that autistic people may need more time to absorb information or may have trouble grasping information delivered verbally.[125]

6.86 However, the committee also heard evidence about a lack of services designed specifically to meet the needs of autistic people.[126] More than one submitter contended that autistic people have to 'make do' with generic services, or with services 'designed for people with intellectual and cognitive disabilities' which are often not aligned with their needs.[127] This was reflected in the results of a survey by TARA, which found many respondents reported that services:

> …do not understand the needs of autistic people, and are predicated on highly medicalised and deficit-focused approaches to autism that not only fail to meet our needs, but can be actively alienating or upsetting...[128]

6.87 Issues with service design also extend to physical service environments and social norms that are not adapted for autistic people. For example, Aspergers Victoria highlighted general expectations which many autistic people find challenging, such as networking in office environments, making eye contact during job interviews, or keeping still during school assemblies.[129]

6.88 Similarly, the Tasmanian Government noted that busy and noisy environments can be 'inappropriate for people who need to avoid sensory overload'.[130] Sensory processing disorders were also mentioned by the Coalition of Autistic Women as a barrier to accessing care. It described the experience of an autistic woman who was unable to proceed with a medical examination after being ridiculed for wanting to sit on her own clothing (rather than the plastic sheet).[131]

6.89 In response, it was suggested that services should implement adjustments that would allow them to better accommodate the needs of autistic clients. OTARC suggested this should include 'longer consultation times and reduced wait times (expedited triage of care), reduced sensory stimulation in waiting and testing rooms'.[132]

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[125] TARA, *Submission 86*, p. 14.

[126] A4, *Submission 54*, p. 20.

[127] Tasmanian Government, Submission 19, p. 4; Autism Aspergers Advocacy Australia, *Submission 54*, p. 19.

[128] TARA, *Submission 86*, p. 15.

[129] Aspergers Victoria, *Submission 90*, [p. 8].

[130] Tasmanian Government, *Submission 19*, p. 4.

[131] Coalition of Autistic Women, *Submission 125*, [p. 13].

[132] OTARC, *Submission 55*, p. 2.

6.90 In addition, Autism Spectrum Australia suggested the development of 'national standards for autism friendly environments and services across government, business and community organisations'.[133]

6.91 According to the Cooperative Research Centre for Living with Autism (Autism CRC), improving physical environments can have positive impacts for all people and can create 'options for independent living, education, employment and health'. It cited one study related to school education which found that built environment factors contributed up to 16 per cent to students' learning progression. The Autism CRC also highlighted the role assistive technologies could play in supporting communication and inclusion—particularly for the 20–30 per cent of non-verbal autistic people. [134]

6.92 Stakeholders also noted that adjustments to physical environments can also have positive impacts in terms of social inclusion and participation in the community. For example, Mr Shawn Stevenson reported seeing parents' 'tears of joy' while watching a sporting event with their children from the sensory/chill room at Melbourne Arena—something they had been unable to do for over a decade.[135]

6.93 To this end, the Autism Alliance pointed to an app being developed by the Autism Association of South Australia which will 'map autism friendly spaces, activities, businesses and services'. The Autism Alliance suggested there would be value in monitoring its impact on the participation of autistic people in the community.[136]

Misinformation and non evidence-based practices

6.94 ND Australia highlighted the importance of providing policy makers, families and autistic people with accurate and evidence-based information to inform their decisions about interventions and support.[137] However, other submitters noted the current prevalence of misinformation about autism, as well as gaps in the available evidence.[138] This included gaps in relation to 'which interventions or treatments are the most appropriate for the age and level of ability of the

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[133] Aspect, *Submission 64*, p. 13.

[134] Autism CRC, *Submission 46*, p. 28.

[135] Mr Shawn Stevenson, *Submission 115*, [p. 1].

[136] Australian Autism Alliance, *Submission 52*, p. 50.

[137] ND Australia, *Submission 97*, [pp. 1 and 5].

[138] See, for example, AMA, *Submission 40*, p. 2; Monash University, *Submission 94*, p. 21; Australian Association of Social Workers, *Submission 96*, p. 5; Name withheld, *Submission 111*, [p. 2]; Name withheld, *Submission 59*, [p. 1]; Name withheld, *Submission 62*, p. 5.

individual or what the most effective pathways might be as a child progresses through life'.[139]

6.95 It was suggested that this lack of information left people susceptible to 'expensive marketed interventions'.[140] This was reflected in commentary about 'widespread' use of non-evidence-based interventions in Australia,[141] as well as calls for only evidence-based therapies to be publicly funded.[142]

6.96 A lack of information was also cited as an issue in relation to NDIS-funded supports. For example, the NDIA acknowledged that gaps in evidence and guidance 'in a market driven insurance scheme can lead to highly contested interpretations of reasonable and necessary supports'. It also noted this also creates confusion for participants, families and carers 'who may receive conflicting information about different practices, particularly in the early childhood space'.[143]

6.97 As a result, a number of stakeholders felt that a National Autism Strategy should be used to drive an evidence-based or best practice approach to service provision.[144] The AMA also suggested prioritising the production of 'clear and regularly updated evidence summaries' that seek to address misinformation.[145]

6.98 In addition to policy makers and service providers, submitters also stressed the importance of providing accurate information aimed at autistic people and their families. For example, one mother described the struggle to find trustworthy information and credited the Raising Children website with helping her to 'separate the useful advice, from the reckless and potentially dangerous information. Particularly the database of therapies that outlines the science (or lack thereof) behind it'.[146]

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[139] ND Australia, *Submission 97*, [p. 5].

[140] Monash University, *Submission 94*, p. 21.

[141] CliniKids, *Submission 15*, [p. 7].

[142] Australian Psychological Society, *Submission 110*, p. 7. Treatments referred to as non-evidence based included chelation therapy, bleach therapy, stem cell therapy and facilitated communication. See also, Professor Andrew Whitehouse, Research Strategy Director, Autism CRC, *Proof Committee Hansard*, 3 March 2021, p. 12.

[143] NDIA, *Submission 56*, p. 18.

[144] See, for example, Autism CRC, *Submission 46*, p. 5; Early Start Australia, *Submission 76*, p. 13; ND Australia, *Submission 97*, [p. 2]; Different Journeys, *Submission 30*, p. 25; Commissioner for Children and Young People Western Australia, *Submission 42*, p. 7; Commissioner for Children and Young People South Australia, *Submission 88*, p. 5; ABIA, *Submission 70*, p. 13; Samaritans, *Submission 99*, p. 8.

[145] AMA, *Submission 40*, p. 2.

[146] Name withheld, *Submission 111*, [p. 2].

Workforce shortages

6.99 Various stakeholders noted the impact of workforce shortages on the provision of adequate supports for autistic people.[147] While this section discusses workforce shortages in a general sense, the committee also heard about specific shortages affecting individual sectors, particularly diagnosis and early intervention.[148] Sector-specific shortages are discussed in relevant chapters later in the report.

6.100 Against the backdrop of general workforce shortages, submitters also indicated there is a shortage of professionals with sufficient knowledge of autism to provide adequate services to individuals and their families.[149] Together, these challenges serve to increase waiting lists for services, decrease service choice, and lead to people using poor quality services. As described to CYDA by one family:

> There is a severe shortage of therapist, support workers, treating doctors and long wait lists. Even when signed up with a service, there is a shortage of available appointments. We have accepted, in desperation, untrained and (previously) unacceptable support workers just to have another pair of hands on board. All the wonderful skill development that we previously could work on has now become purely survival.[150]

6.101 The committee understands that the workforce shortages affecting the autism community are a reflection of issues facing the broader disability workforce. Indeed, the *NDIS National Workforce Plan: 2021–2025* (the NDIS Workforce Plan) states that the NDIS needs to attract approximately 83 000 net additional workers by 2024. However, it also identified a number of challenges to growing the care and support workforce, including:

- perceptions of lower job prestige, pay and fewer opportunities for career progression compared to other sectors;
- difficulties attracting and retaining culturally and linguistically diverse workers and Aboriginal and Torres Strait Islander workers;
- higher rates of workforce casualisation than other sectors such as aged care;
- difficulties identifying and matching suitable workers to positions;
- limited opportunities for entry-level workers to enter the NDIS;

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[147] See, for example, Children and Young People with Disability, *Submission 109*, p. 18; ABIA, *Submission 70*, p. 6; Name withheld, *Submission 116*, [p. 2].

[148] See, for example, Government of Western Australia, *Submission 103*, p. 2; Tasmanian Government, *Submission 19*, p. 5; Australian Medical Association, *Submission 40*, p. 2; Name withheld, *Submission 126*, p. 16.

[149] See, for example, Monash University, *Submission 94*, p. 26; Department of Developmental Disability Neuropsychiatry, University of New South Wales (UNSW 3DN), *Submission 95*, p. 13; Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 4].

[150] Children and Young People with Disability, *Submission 109*, p. 18.

- the struggle of providers to provide necessary staff training and supervision due to lack of time and resources;
- training that is not matched to workers' needs or preferences, including the desire for training that is treatment or support specific (as opposed to general training or traditional qualifications);
- administrative burden; and
- a lack of information on the care and support market that could help providers identify areas of unmet demand and opportunities for growth.[151]

6.102 The NDIS itself may have also played a role in intensifying workforce shortages in certain areas. For example, the NDIS Workforce Plan indicates that the introduction of the NDIS may have disrupted pathways between education and industry, with subsequent impacts on the disability workforce pipeline. Likewise, the Tasmanian Government suggested that the NDIS had created an incentive for allied health professionals to leave they public system and set up private practices to deliver services to NDIS participants.[152]

6.103 These challenges present particular difficulties in thin markets, such as those in regional and remote locations and in certain service sectors (including those providing support for people with complex needs). For example, the NDIS Workforce Plan states that filling disability vacancies in regional areas takes 22 per cent longer than in metropolitan areas and there are 55 per cent fewer suitable applicants for each job. In addition, workers may leave regional and remote locations to access better supervision, support and training opportunities. Similarly, there are difficulties in attracting and retaining skilled, experienced workers to support participants with complex and/or high care needs (including those with psychosocial disability).[153] The contribution of thin

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[151] Commonwealth of Australia (Department of Social Services), *NDIS National Workforce Plan: 2021–2025*, pp. 11 and 15–18. Key statistics include:

- 51 per cent of Australians would prefer retail work over disability work and 32 per cent would prefer to work in aged care;
- 34 per cent of disability sector workers are employed casually, compared with 14 per cent in aged care. While casual employment is attractive for some workers, others would like the opportunity to work regular full time hours;
- a lack of suitable or qualified candidates (43 per cent) and candidates being unable or unwilling to meet specific job requirements (29 per cent) were the main reasons for unfilled NDIS vacancies;
- 20 per cent of providers said that staff members were not paid for all the time spent to attend training and development activities; and
- only 31 per cent of workers strongly agreed that their skills were well matched to the work they are asked to do. NDIS participants also expressed a preference for workers who have been trained in supports which respond to their unique requirements.

[152] Tasmanian Government, *Submission 19*, p. 5.

[153] Commonwealth of Australia (Department of Social Services), *NDIS National Workforce Plan: 2021–2025*, p. 20.

markets to inadequate supports for autistic people was also recognised by submitters to the inquiry.[154]

6.104 In response, stakeholders identified a range of possible actions that could be taken to address workforce shortages, including as part of a National Autism Strategy.[155] For example, some proposed longer-term solutions, such as promotion of relevant career pathways in schools, or training more professionals in areas of workforce shortages.[156] Others suggested short to medium term actions such as:

- creating a national training centre and resources clearinghouse;
- including autism content in undergraduate training courses;
- upskilling the existing workforce;
- providing visas for overseas specialists to work in Australia; and
- expanding the range of professionals that can provide certain services, such as diagnosis.[157]

Support for social inclusion within the community

6.105 As described by OTARC, social inclusion involves:

> …feeling accepted within your local community and being able to contribute to society in a meaningful way through participation in mainstream activities like employment and education.[158]

6.106 While education and employment were cited as important enablers of inclusion by stakeholders,[159] they are not addressed in this section. Instead, issues relating to education and employment are be discussed in Chapters 12 and 13.

6.107 According to stakeholders such as JFA Purple Orange, poor social inclusion is linked to increased loneliness, depression and anxiety.[160]

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[154] See, for example, Government of Western Australia, *Submission 103*, p. 2; Children and Young People with Disability Australia, *Submission 109*, p. 12; Name withheld, *Submission 126*, p. 15.

[155] See, for example, Name withheld, *Submission 120*, [p. 8].

[156] See, for example, Mr Shawn Stevenson, *Submission 115*, [p. 3]; Name withheld, *Submission 116*, [p. 2]; Name withheld, *Submission 32*, [p. 3].

[157] See, for example, UNSW 3DN, *Submission 95*, p. 15; Autism CRC, *Submission 46*, p. 4; St Vincent's Health Australia, *Submission 72*, p. 6; Mindful, *Submission 162*, pp. 1–2; Autism Family Support Association, *Supplementary Submission 22.1*, Emerging Minds, *Submission 89*, [p. 9]; Australian College of Nurse Practitioners, *Submission 127*, [p. 2]; Name withheld, *Submission 116*, [p. 2].

[158] OTARC, *Submission 55*, p. 23.

[159] See, for example, Autism CRC, *Submission 46*, p. 27; Northern Territory Office of the Public Guardian, *Submission 20*, [p. 8]; People with Disability Australia, *Submission 102*, p. 25; Learning for Life Autism Centre, *Submission 144*, p. 4; The Sycamore School, *Submission 118*, p. 9; Name withheld, *Submission 9*, p. 8.

[160] JFA Purple Orange, *Submission 84*, p. 22. See also, Mr Cameron Boyd, *Submission 157*, [p. 12].

Concerningly, multiple stakeholders provided evidence about the poor inclusion of autistic people and their families within the community.[161] For example, when SDN Children's Services asked families about their experiences, 77 per cent of respondents described feeling isolated, being excluded, and having limited opportunities for their child.[162] Similarly, JFA Purple Orange reported that a 2018 survey found that 52 per cent of respondents felt socially isolated.[163]

6.108 According to TARA, autistic people are particularly vulnerable to social isolation due to challenges with communication and social engagement, as well as ignorance and discrimination within the community.[164] Other factors contributing to social isolation included a lack of autism-friendly spaces and activities, difficulties accessing transport, and financial barriers to participation.[165]

6.109 As a result, some stakeholders called for strategies to increase community understanding of autism, develop autism-friendly public spaces and services that accommodate the sensory and social difficulties associated with autism, make better use of assistive technologies, and improve access to public and private transport.[166]

6.110 The Northern Territory Office of the Public Guardian also pointed to a shortage of services to help autistic people develop social skills and friendships and participate in the community.[167] Accordingly, more than one submitter raised the importance of after school activities, including out of school hours care, to increasing social inclusion.[168] However, they also noted issues with the accessibility of these activities for autistic children:

> We have tried, and reluctantly ceased when it was clear these weren't able to make adjustments for our son's autism: after school care, music lessons, martial arts lessons and non-special needs babysitters.[169]

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[161] See, for example, UNSW 3DN, *Submission 95*, p. 21; Positive Youth Incorporated, *Submission 85*, p. 6; TARA, *Submission 86*, p. 22; Name withheld, *Submission 120*, [p. 9].

[162] SDN Children's Services, *Submission 44*, p. 8.

[163] JFA Purple Orange, *Submission 84*, p. 23.

[164] TARA, *Submission 86*, p. 22.

[165] See, for example, Mr Philip Gluyas, *Submission 8*, [p. 3]; Name withheld, *Submission 113*, [p. 4]; Name withheld, *Submission 116*, [p. 6]; Name withheld, *Submission 81*, [p. 5].

[166] See, for example, Northern Territory Office of the Public Guardian, *Submission 20*, [p. 8]; The Queensland Family and Child Commission, *Submission 36*, p. 9; Autism CRC, *Submission 46*, p. 28; Australian Autism Alliance, *Submission 52*, p. 50.

[167] Northern Territory Office of the Public Guardian, *Submission 20*, [p. 4].

[168] Name withheld, *Submission 62*, [p. 9].

[169] Name withheld, *Submission 113*, [p. 4].

6.111 Similarly, while sport was also seen as important for social interaction,[170] it was noted that sports were targeted either at neurotypical children or autistic children, with few truly inclusive options available.[171] This reflected evidence provided to the committee that community organisations are not well-equipped to cater for autistic people.[172]

6.112 However, it was also noted that social inclusion can be complex for autistic people. For example, autistic individuals may desire inclusion but may not want 'lots of social connection'[173] or may need the ability to 'withdraw quickly and feel safe doing so'.[174]

6.113 To this end, some stakeholders noted the importance of peer communities to fostering a sense of acceptance and self-worth.[175] For example, the Commissioner for Children and Young People Western Australia reported that young autistic people felt that peer support networks allowed them to 'be themselves, share experiences, support each other'.[176] JFA Purple Orange also noted the importance of peer networks, which are 'safe' and remove the pressure on autistic people to 'play the role of educator'.[177]

Committee view

6.114 The committee acknowledges the near universal concern among stakeholders in relation to the adequacy of services and supports for autistic people and their families. While there is evidence of good practice across all sectors, the committee agrees with the sentiment that, overall, the current arrangements are not adequately supporting autistic people.

6.115 While noting that the ABS statistics about the unmet needs of autistic people are already concerning, the committee expects the rate of unmet need may be even higher given the known issues with underdiagnosis of autism—particularly among more vulnerable and disadvantaged cohorts.

6.116 The committee is also concerned that families and carers are shouldering an undue burden because of the high reliance on informal supports for autistic people, as well as the challenges of navigating a complex service environment.

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[170] SDN Children's Services, *Submission 44*, pp. 18 and 19; Mr Shawn Stevenson, *Submission 115*, [p. 2].

[171] SDN Children's Services, *Submission 44*, p. 19; Name withheld, *Submission 116*, [p. 6].

[172] Name withheld, *Submission 81*, [p. 5].

[173] JFA Purple Orange, *Submission 84*, p. 24.

[174] A4, *Submission 54*, p. 26.

[175] See, for example, Commissioner for Children and Young People Western Australia, *Submission 42*, p. 9; A4, *Submission 54*, p. 26; TARA, *Submission 86*, p. 22.

[176] Commissioner for Children and Young People Western Australia, *Submission 42*, p. 9.

[177] JFA Purple Orange, *Submission 84*, pp. 26 and 27.

6.117 The committee recognises that many of the reasons for inadequate service provision are deeply intertwined and cut across multiple service sectors. However, the committee does not believe these problems are intractable. Significant inroads could be made by taking action to improve service integration and access, increase understanding of autism in both community and professional settings, encourage the development of autism-specific and autism-friendly services, and build workforce capacity and capability.

National Disability Insurance Scheme (NDIS) services

6.118 Given that there are almost 150 000 autistic participants, the committee is concerned that the NDIS is not providing autistic children and adults with the services and supports that they need and are entitled to receive. It is particularly troubling that many NDIA staff and service providers seem to lack a basic understanding of how autism presents and suitable interventions consistent with best practice. Further, the experiences of some autistic participants and their carers when interacting with the NDIS do not seem to be consistent with the Participant Service Charter.

6.119 Many of the issues raised in this inquiry are symptomatic of broader problems with the NDIS which have been consistently raised through work undertaken by the Joint Standing Committee on the NDIS.

6.120 The committee notes that resolving the access, planning and service issues associated with providing reasonable and necessary supports for autistic participants requires further consideration. In addition, it is too early to tell whether the reset of the Early Childhood Approach is better meeting the needs of young autistic children. For these reasons, the committee recommends that the Joint Standing Committee on the NDIS undertake a comprehensive review of how the NDIS supports autistic children and adults.

Recommendation 6

6.121 The committee recommends that the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) undertake an inquiry into the experiences of autistic participants in the NDIS with particular focus on:

- **the level of reasonable and necessary supports required by autistic participants across the course of their life;**
- **whether the NDIS is currently funding these reasonable and necessary supports;**
- **the implementation of the new Early Childhood Approach;**
- **whether adequate information and support is being provided to participants and prospective participants in a timely manner;**
- **how autism diagnosis is recognised by the NDIS;**

- **the ability and capacity of NDIS planners to make informed decisions regarding the reasonable and necessary supports to be funded by the NDIS;**
- **the level of under-utilisation in NDIS plans for autistic participants;**
- **ensuring there is sufficient service capacity to deliver funded supports; and**
- **how the NDIS interacts with other government funded support services—such as education, employment and health services—to provide coordinated and holistic care for autistic participants.**

Service integration

6.122 Many stakeholders described their experience of trying to access services as one of 'falling between the cracks'. This seems to be driven by a combination of the complexity of autistic people's needs and highly siloed service delivery sectors that do not deal well with that complexity.

6.123 The committee also heard the process of accessing services described as a 'fight' or a 'battle', with the outcome often dependent on the knowledge, capacity and resources of autistic individuals and their families. Also, while the NDIS is a critical source of support, the process of engaging with the NDIA has significantly increased the administrative burden on autistic people and their families. Indeed, the committee heard that the time and effort required to successfully navigate the NDIS can be equivalent to a full-time job.

6.124 In the committee's view, it simply shouldn't be this hard. Autistic people and their families should not have to fight for the services and supports they require. They should not be shuffled between agencies when their support needs don't fit neatly into a particular service delivery box. They should not be required to pay twice for services, such as diagnosis, simply because they move from one state to another.

6.125 While acknowledging that there are inherent challenges to service delivery within a federation, it is the committee's view that the current service environment is unnecessarily fragmented and overly difficult for autistic people and their families to navigate.

6.126 The committee acknowledges the departments' evidence that NDIS system interface issues are the subject of an ongoing clarification process. However, it is hard not to question the commitment and resolve of the parties involved when—after eight years of operation—little progress appears to have been made and autistic people continue to pay the price.

6.127 As a priority, the National Autism Strategy should identify actions to drive better integration between federal and state systems, including NDIS and mainstream services.

Recommendation 7

6.128 **The committee recommends that the National Autism Strategy identify actions to drive better integration between federal and state service systems, including a roadmap to better integrate NDIS and mainstream services. This roadmap should be consistent with the recommendations made by the Joint Standing Committee on the NDIS in relation to service integration and overlap with other systems.**

Recommendation 8

6.129 **The committee recommends that the National Disability Insurance Agency provide support coordination assistance as a default inclusion in plans for autistic NDIS participants who:**

- **have complex or high care needs;**
- **are from other identified disadvantaged and vulnerable cohorts; and**
- **have significantly underutilised plans.**

6.130 **One year of support coordination assistance should also be a default inclusion in plans for all new NDIS participants.**

Recommendation 9

6.131 **The committee recommends that the National Disability Insurance Agency continue to improve the capacity of its staff, including Local Area Coordinators, to provide better support to autistic people. This should include a focus on both understanding and meeting autistic participants' support coordination needs.**

Understanding of autism

6.132 The need to increase autism understanding was raised repeatedly by stakeholders. The committee heard that ignorance of autism within the community, as well as misconceptions about autistic people, are significant barrier to the inclusion of autistic people and their families in the community, at school, as well as in workplaces. Accordingly, the committee sees value in a public education campaign to increase awareness and understanding of autism in the community. The committee notes that this will align with the policy priority contained in *Australia's Disability Strategy 2021–2031* in relation to improving community attitudes to people with disability.[178]

6.133 Recommendations related to improving autism understanding in specific service sectors are addressed in later chapters.

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[178] Department of Social Services, *Australia's Disability Strategy 2021–2031*, p. 33.

Recommendation 10

6.134 The committee recommends that a National Autism Strategy identify actions to increase community understanding of autism. This should include consideration of a public education campaign that portrays the diversity of the spectrum and helps improve inclusion across a range of settings, including schools, workplaces and in the general community. All materials should be tailored and accessible to First Nations and Culturally and Linguistically Diverse audiences.

Appropriate services

6.135 A lack of autism understanding means there are very few services that are designed with the specific sensory and communication challenges of autistic people in mind. In many cases, the changes required to improve service provision are minimal and easily implemented—for example, reduced sensory stimulation in health care waiting rooms.

6.136 Given the ease with which many adjustments could be made, the committee was disturbed to hear reports of autistic people being subjected to unnecessarily traumatic care experiences—including being ridiculed after advocating for small adjustments to the service environment.

6.137 The committee is also concerned that poor autism knowledge is leaving autistic people and their families vulnerable to misinformation. This includes the marketing of expensive therapies that are unsupported by evidence and are, at best, ineffective and, at worst, dangerous.

Recommendation 11

6.138 The committee recommends that the National Autism Strategy identify actions to promote awareness of, and access to, quality, evidence-based information about autism for autistic people, their families, and professionals in autism-related sectors.

Recommendation 12

6.139 The committee recommends that the Australian Government develop guidelines on autism-friendly service design through the National Autism Strategy in order to help service providers tailor services and service environments to meet the needs of autistic individuals.

Workforce

6.140 It is apparent to the committee that there is a critical shortage of professionals with the skills, knowledge and experience to provide services that meet the needs of autistic people. This relates both to the skills of the existing workforce, as well as shortages of professionals in specific sectors and locations.

6.141 However, the committee remains cognisant that this is an issue for the broader disability workforce as a whole. Accordingly, the committee sees value in developing a national autism workforce plan that aligns with other relevant workforce strategies, such as the *NDIS National Workforce Plan: 2021–2025*—noting, however, the recent recommendation of the Joint Standing Committee on the NDIS in relation to the need to prioritise the development of clear and measurable outcomes for that plan.

6.142 At the same time, skilled migration arrangements should be reviewed with an autism lens to ensure they are matched to current areas of need. Additional recommendations to address to workforce issues in specific sectors are dealt with in later chapters.

Recommendation 13

6.143 The committee recommends that a National Autism Workforce Plan be developed under the auspices of the National Autism Strategy to ensure the supply of a suitable and appropriate workforce to deliver services for autistic people. The National Autism Workforce Plan should identify actions, accompanied by clear and measurable outcomes, to:

- **improve data around current and future workforce gaps and shortages (as they relate to the needs of the autism community);**
- **attract, train and retain workers in identified areas of shortage (both geographic and sector/profession-specific);**
- **increase autism content in relevant undergraduate training courses;**
- **develop accredited autism-specific short courses (or promote existing accredited courses) for current workers; and**
- **embed autism as part of ongoing professional development requirements related to professional registration.**

6.144 Where appropriate, the National Autism Workforce Plan should align with existing workforce strategies, including the *NDIS National Workforce Plan: 2021–2025*.

Recommendation 14

6.145 The committee recommends that the Department of Home Affairs work with the Departments of Social Services, Health, and Education, Skills and Training, as well as the National Disability Insurance Agency, to ensure current skilled migration arrangements facilitate migration to fill identified autism workforce shortages.

Social inclusion

6.146 *Australia's Disability Strategy 2021–2031* identifies the full participation of people with disability in social, recreational, sporting, religious and cultural life as a policy priority.[179]

6.147 However, inclusion of autistic people in the community is poor, with many experiencing loneliness, isolation, exclusion and depression. The committee is particularly alarmed at the high proportion of autistic people who report feeling isolated and the significant proportion of autistic NDIS participants who report having no friends other than family or paid staff. Given these concerning statistics, the committee believes the National Autism Strategy should include play a role in monitoring progress on social inclusion.

6.148 The committee accepts that improving social inclusion requires support and opportunities for autistic people to engage in mainstream activities, as well as the opportunity to participate in peer networks.

6.149 The committee heard that current efforts to support participation in mainstream activities are hampered by the fact that community groups are generally not well-equipped to cater for autistic people. This was identified as a particular issue for parents in relation to after school activities, including sport and out of school hours care.

6.150 Multiple stakeholders also highlighted the importance of participation in education and employment to increasing the inclusion of autistic people, along with the need to increase community understanding of autism and promote development of more autism-friendly spaces and events. Recommendations relating to these issues are addressed in following chapters.

Recommendation 15

6.151 The committee recommends that the National Autism Strategy include measures to allow for monitoring and reporting of the social inclusion of autistic people within the community.

Recommendation 16

6.152 The committee recommends that peer-to-peer networking and support projects continue to be funded as a priority under the Department of Social Security's Information, Linkages and Capacity Building program.

Recommendation 17

6.153 The committee recommends that online resources be developed by existing autism education and advocacy organisations—funded through the Department of Social Security's Information, Linkages and Capacity Building

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[179] Department of Social Services, *Australia's Disability Strategy 2021–2031*, p. 11.

program—and made widely available to help community organisations understand how they can actively support and include autistic people.

Chapter 7
Services and supports for specialist groups

7.1 While the previous chapter discussed barriers to adequate service provision for autistic people and their families, this chapter describes the particular challenges faced by identified cohorts, including:

- autistic adults;
- autistic women and girls;
- families and carers of autistic people; and
- disadvantaged and vulnerable cohorts.

Autistic adults

7.2 While not disagreeing with the importance of early diagnosis and intervention for autistic children, many stakeholders raised concerns there was no corresponding focus on support for autistic adults—despite the lifelong nature of the condition.[1] According to multiple stakeholders, the main drop off point occurs at the end of formal schooling, when services for autistic youth are said to 'fall off a cliff'.[2]

7.3 In part, this may be driven by the persistent misconception that autism is a 'childhood condition'. For example, one autistic adult recounted their experience with a receptionist at a service provider who questioned why they would need occupational therapy assessment and assistance for autism as '"it's a childhood illness"'.[3]

7.4 In addition, this perception may also have contributed to the current under-diagnosis of autistic adults—noting that lack of a diagnosis is itself a barrier to service access.[4] However, even when adults are diagnosed, there is still a lack of appropriate services. According to Autism Aspergers Advocacy Australia (A4),

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[1] See, for example, St Vincent's Health Australia, *Submission 72*, p. 1; Autism Aspergers Advocacy Australia (A4), *Submission 54*, p. 19; Autism Advisory and Support Service, *Submission 21*, p. 5; Royal Australian and New Zealand College of Psychiatrists, *Submission 17*, [p. 2]; Name withheld, *Submission 7*, [p. 1].

[2] See, for example, Department of Developmental Disability Neuropsychiatry, University of New South Wales (UNSW 3DN), *Submission 95*, p. 19; Scope-University of Melbourne Partnership, *Submission 83*, p. 17; Autism Awareness Australia, *Submission 47*, p. 9; PEERS Australia, *Submission 108*, Attachment 1, [p. 37].

[3] Name withheld, *Submission 9*, p. 6.

[4] See, for example, Government of Western Australia, *Submission 103*, pp. 4 and 7; National Aboriginal Community Controlled Health Organisation (NACCHO), *Submission 104*, [p. 4]; Coalition of Autistic Women, *Submission 125*, [p. 12]; Samaritans, *Submission 99*, p. 6; Name withheld, *Submission 112*, [p. 8].

'these services do not yet exist' and there are 'neither plans nor policies to create essential services that autistic adults need'.[5]

7.5 This view was reflected in evidence presented to the committee about a lack of research into, and understanding of, the supports and services required by autistic adults.[6]

7.6 Stakeholders, including the Department of Developmental Disability Neuropsychiatry, University of New South Wales (UNSW 3DN), also highlighted the particular difficulties faced by autistic adults who may not qualify for the National Disability Insurance Scheme (NDIS) but still have significant impairments that mean they struggle with daily life, including maintaining employment and relationships.[7] Without access to independent financial resources these individuals can find it difficult to access necessary supports:

> "At present, you can have a well supported autistic life if you are in a great financial place. If you are struggling to make ends meet, affordable wrap around services just don’t exist." – Lisa, 50.[8]

Autistic women and girls

7.7 As with autistic adults, the misconception that autism is both a childhood illness and one that only affects males is persistent.[9] The historic focus on autism as a childhood condition primarily affecting boys also means that much of the research—and consequently, the approach to services and supports—is based on the needs of male autistic children.[10]

7.8 As described in Chapter 2, this has meant that autistic women and girls are likely to be under-diagnosed and, therefore, also underrepresented in existing support services.[11] Autistic females are also often wrongly diagnosed and, in some cases, are even inappropriately medicated.[12] This is consistent with research showing

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[5] A4, *Submission 54*, p. 19.

[6] See, for example, UNSW 3DN, *Submission 95*, p. 4; Scope-University of Melbourne Partnership, *Submission 83*, p. 23; La Trobe University – the Olga Tennison Autism Research Centre (OTARC), *Submission 55*, p. 22.

[7] UNSW 3DN, *Submission 95*, p. 19.

[8] The Autistic Realm Australia (TARA), *Submission 86*, p. 15.

[9] See, for example, Queensland Centre for Intellectual and Developmental Disability, University of Queensland, *Submission 51*, [p. 3]; Mr Cameron Boyd, *Submission 157*, [p. 7]; Name withheld, *Submission 62*, p. 6.

[10] See, for example, CliniKids, *Submission 15*, [p. 5]; Queensland Law Society, *Submission 124*, p. 3; The Sycamore School, *Submission 118*, p. 6.

[11] The Sycamore School, *Submission 118*, p. 6.

[12] Cooperative Research Centre for Living with Autism (Autism CRC), Name withheld, *Submission 119*, p. 5; Name withheld, *Submission 9*, pp. 4–5.

that 'red flags' for females were 'often dismissed by health professionals, leading to later diagnosis'.[13] As one participant described, this can have potentially fatal consequences:

> My daughter began seeing a psychiatrist in September 2014 – age 13 (due to extreme social anxiety and withdrawal) and despite him being informed, on many occasions, that we had autism in the family, she was diagnosed with, and treated for, clinical depression only. Over the next few years, she was prescribed many different drugs and attempted to take her life. After 4 years, we took her to another psychiatrist – she was then given an ASD diagnosis.[14]

7.9 Even when diagnosed as autistic, stereotypes about autism can affect the adequacy of the services females receive. For example, the committee heard of a Disability Employment Service Provider refusing to believe a person was autistic because they were female and an adult.[15] Another participant reported having their diagnosis questioned by professionals, or brushed aside, with comments such as 'everyone is a little bit autistic'.[16]

7.10 A number of stakeholders referred to the different way autism presents in females[17] and at least one suggested that different approaches to service delivery may be required.[18] The Cooperative Research Centre for Living with Autism (Autism CRC) noted that while research in this area has been significant over recent years, it appears that this has not yet translated into better service provision.[19]

Autistic mothers

7.11 Some stakeholders made particular reference to the need for better support for autistic mothers, who have particular support needs but report significant discrimination when seeking services for themselves and their children.[20] For example, The Autistic Realm Australia (TARA) described parents being 'criticised for their parenting, and being accused of exacerbating or even causing

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[13] Autism CRC, *Submission 46*, p. 11.

[14] Name withheld, *Submission 16*, [p. 4].

[15] Name withheld, *Submission 9*, p. 11.

[16] Name withheld, *Submission 119*, p. 4.

[17] See, for example, CliniKids, *Submission 15*, [p. 5]; Australian Psychological Society, *Submission 110*, p. 8; Coalition of Autistic Women, *Submission 125*, [p. 7]; Marymead Autism Centre, *Submission 128*, p. 6; The Sycamore School, *Submission 118*, p. 6; Ms Alexa McLaughlin, *Submission 142*, [p. 1]; Name withheld, *Submission 9*, p. 4; Name withheld, *Submission 119*, p. 4; Name withheld, *Submission 12*, [p. 1].

[18] Name withheld, *Submission 9*, p. 4.

[19] Autism CRC, *Submission 46*, p. 12.

[20] See, for example, Coalition of Autistic Women, *Submission 125*, [p. 20]; TARA, *Submission 86*, p. 15; Yellow Ladybugs, *Submission 49*, p. 5.

their children's challenges'.[21] The Coalition of Autistic Women referred to the 'catastrophic' impact of discrimination, with evidence showing that in family court cases, autistic mothers have had their children removed for 'no other reason than their disability'.[22]

Disadvantaged and vulnerable cohorts

7.12 As described in Chapter 3, there is evidence that autistic individuals from disadvantaged and vulnerable cohorts can face worse life outcomes than the broader autistic population.[23] The Commissioner for Children and Young People in Western Australia also noted that these cohorts face additional challenges in relation to accessing adequate services and supports.[24]

7.13 While these groups also face disadvantage in the general population, in this case their difficulties are compounded by the intersection between their autism and other factors such as their socio-economic status, geographical location, and/or cultural, linguistic background.[25]

7.14 This section provides an overview of identified service provision issues for the following cohorts:

- people from lower socio-economic backgrounds;
- people in regional and remote locations;
- First Nations people;
- people from culturally and linguistically diverse backgrounds;
- gender diverse and LGBQTI people; and
- people with complex needs.

Socio-economic background

7.15 More than one submitter highlighted the difficulties that autistic people from lower socio-economic backgrounds have in accessing services, particularly diagnostic services, and argued for additional supports to ensure more equitable access to services.[26] For example, Positive Youth Incorporated (Positive Youth) pointed to research that found families from lower socio-economic backgrounds often experience delayed diagnosis as a result of long waiting lists in the public system and the high cost of private diagnosis.[27] According to UNSW 3DN,

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[21] TARA, *Submission 86*, p. 15.

[22] Coalition of Autistic Women, *Submission 125*, [p. 20].

[23] Australian Autism Alliance, *Submission 52*, p. 11.

[24] Commissioner for Children and Young People Western Australia, *Submission 42*, p. 2.

[25] See, for example, Autism Advisory and Support Service, *Submission 21*, pp. 5–6; Different Journeys, *Submission 30*, p. 16; Coalition of Autistic Women, *Submission 125*, [p. 22].

[26] UNSW 3DN, *Submission 95*, p. 11; Positive Youth Incorporated, *Submission 85*, p. 3.

[27] Positive Youth Incorporated, *Submission 85*, p. 3.

research also found better access to early intervention services in more affluent neighbourhoods.[28]

7.16 The impact of financial hardship on access to services was also borne out by stakeholder experiences. Speech Pathology Australia (SPA) reported that in one case, after waiting a year for a diagnosis, a single mother took out an advance on her Centrelink payments in order to access a private diagnosis (so that people would understand her son had anxiety and significant sensory difficulties and was not just naughty or violent). In another case, a six-year-old boy attempted suicide at school because 'he felt so stupid and misunderstood' while waiting over three years for a diagnosis.[29]

7.17 Children and Young People with Disability Australia (CYDA) reflected that inadequate access to timely diagnosis also makes it harder to gain entry to the NDIS and/or receive supports that would enable participation in mainstream health and education services.[30]

7.18 As noted by Positive Youth, without diagnosis and intervention, autistic people from lower socio-economic backgrounds may be more at risk of becoming involved with the justice system.[31] A lack of adequate supports may also reduce employment opportunities—itself a risk factor for increased poverty[32]—and limit autistic people's participation in the community.[33] The inability to afford therapies and supports was described by one autistic parent:

> You have kids to care for, a household to run on a tiny budget. You are too crucial, too stretched, and too fragile to take the risk of anything going wrong. And you’re not actually suicidal. You’re just suffering the natural, whole wheat, 100% organic, acute on chronic stress of living, unassisted, with autism.[34]

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[28] UNSW 3DN, *Submission 95*, p. 11.

[29] Speech Pathology Australia, *Submission 87*, p. 8.

[30] Children and Young People with Disability Australia (CYDA), *Submission 109*, p. 9.

[31] Positive Youth Incorporated, *Submission 85*, p. 3.

[32] See, for example, Name withheld, *Submission 155*, p. 17; Aspergers Victoria, *Submission 90*, [p. 5]; Reframing Autism, *Submission 24*, p. 10; TARA, *Submission 86*, p. 8.

[33] Reframing Autism, *Submission 24*, p. 10.

[34] Name withheld, *Submission 112*, [p. 14].

Regional and remote locations

7.19 Stakeholders presented evidence about the difficulty with service provision in regional and remote locations that may encompass large geographic areas with fluctuating populations, limited infrastructure and diverse demographics.[35] Along with thin markets, this has led to a lack of clinicians and service providers in these areas. As stated by the Government of Western Australia, this places more reliance on government services, which in regional and remote areas may be dependent on visits by city-based clinicians.[36]

7.20 As discussed in the previous chapter, there are noted service shortages and long wait times for those in regional and remote areas, as well as the complete absence of some therapies and supports, such as the NDIS Early Childhood Early Intervention pathway.[37] Mindful argued that specific issue relating to disadvantage in rural areas included fewer skilled staff, less effective utilisation of skilled autism practitioners, limited access to private or public services for ongoing care and treatment, and a lack of access to allied health disciplines.[38]

7.21 The committee heard that the lack of services also resulted in people travelling long distances (often taking time away from work and family) or relocating to access city-based services.[39] As described by one submitter, this can be a heartbreaking decision:

> Regional families are often forced to face the decision to leave their lives behind in order to get their children the best care. This is a heartbreaking decision and it's one no family should be forced to make. We need to be supporting our regional communities and not deserting them in times of crisis.[40]

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[35] See, for example, Government of Western Australia, *Submission 103*, p. 1; Northern Territory Office of the Public Guardian, *Submission 20*, [pp. 3 and 4]; Name withheld, *Submission 126*, p. 15; Mindful, *Submission 162*, pp. 4–5.

[36] Government of Western Australia, *Submission 103*, p. 1.

[37] See, for example, NACCHO, *Submission 104*, [p. 8]; Australian Autism Alliance, *Submission 52*, pp. 15 and 45; The Royal Australasian College of Physicians, *Submission 29*, p. 6; Queensland Family and Child Commission, *Submission 36*, p. 5; CYDA, *Submission 109*, p. 12.

[38] Mindful, *Submission 162*, p. 5.

[39] Commissioner for Children and Young People Western Australia, *Submission 42*, p. 3; Autism Spectrum Australia (Aspect), *Submission 64*, p. 3.

[40] Name withheld, *Submission 122*, [p. 1].

7.22 Accordingly, numerous stakeholders identified a need for better support for people living in regional and remote areas,[41] including investigation of effective ways to build regional capacity, as well as deliver services remotely.[42]

First Nations peoples

7.23 The National Aboriginal Community Controlled Health Organisation (NACCHO) noted that First Nations peoples are both less likely to access services, as well as more likely than other Australians to require support in order to access and participate in disability services.[43]

7.24 The reasons for this include low awareness of autism, a lack of services—particularly in regional and remote areas—as well as a lack of culturally appropriate information, support and services.[44] Other factors that can deter First Nations people from seeking help include poverty, limited access to transport, cultural and language barriers, shame and stigmatisation around disability, a lack of trust in government, and experiences of racism in mainstream services.[45]

7.25 In addition, NACCHO indicated that First Nations peoples are often undiagnosed or misdiagnosed, which has implications for timely and appropriate interventions and treatment.[46] The Ethnic Disability Advisory Centre relayed their experiences in this area:

> We have also observed that some Aboriginal clients have not been diagnosed with autism at a younger age so by the time they are in the justice system they are diagnosed with cognitive impairment.[47]

7.26 The Commissioner for Children and Young People Western Australia also advised that Aboriginal children are more likely than non-Aboriginal children to have unmet needs post-diagnosis.[48]

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[41] See, for example, The Hon Coralee O'Rourke MP, Queensland Minister for Communities, Queensland Minister for Disability Services and Seniors, *Submission 101*, p. 4; Northern Territory Office of the Public Guardian, *Submission 20*, [p. 4]; Aspect, *Submission 64*, pp. 3–4, 5 and 9.

[42] NACCHO, *Submission 104*, [p. 4]; Government of Western Australia, *Submission 103*, p. 1; Queensland Law Society, *Submission 124*, p. 5; Australian College of Nurse Practitioners (ACNP), *Submission 127*, [p. 3]; Family Planning NSW, *Submission 28*, p. 2; Aspect, *Submission 64*, p. 4.

[43] NACCHO, *Submission 104*, [p. 5].

[44] See, for example, NACCHO, *Submission 104*, [pp. 3 and 4]; The Royal Australasian College of Physicians, *Submission 29*, p. 6; TARA, *Submission 86*, p. 9.

[45] See, for example, NACCHO, *Submission 104*, [p. 4]; The Royal Australasian College of Physicians, *Submission 29*, pp. 6–7; Queensland Family and Child Commission, *Submission 36*, p. 5.

[46] NACCHO, *Submission 104*, [p. 5].

[47] Ethnic Disability Advisory Centre, *Submission 75*, p. 4.

[48] Commissioner for Children and Young People Western Australia, *Submission 42*, p. 2.

7.27 As with the general population, a lack of services in regional and remote areas can necessitate travel or relocation for diagnosis or therapy. As recognised by the Northern Territory Office of the Public Guardian, this separation from kinship ties, country and culture can adversely affect the health and wellbeing of First Nations peoples.[49]

7.28 While stakeholders identified the need for additional support, this is currently hampered by a lack of research about, and understanding of, how First Nations peoples experience autism, the supports available to them and the impact of culture and language on diagnosis.[50]

7.29 However, the need for more investment in culturally appropriate information and services was recognised in a number of submissions.[51] In line with the preference of First Nations peoples to use Aboriginal and Torres Strait Islander services, NACCHO suggested:

- increasing the capacity of Aboriginal Community Controlled Health Organisations (ACCHOs) to provide services;
- building relationships between ACCHOs and disability service providers to improve care integration;
- commissioning ACCHOs to train mainstream services staff to increase the cultural competence; and
- encouraging ACCHOs to register with the NDIS to perform a support coordination role.[52]

7.30 NACCHO also stressed the need to develop integrated models of care. In doing so, it pointed to the work of the Gidgee Healing Aboriginal Corporation in relation to Foetal Alcohol Spectrum Disorder (FASD) as a potential model for autism services (see Box 7.1).[53]

Box 7.1 Gidgee Healing Aboriginal Corporation – FASD program

The program worked with community over 12–18 months to understand what community needed from a FASD program, and how Gidgee Healing, in partnership with Griffith University, could deliver an improved FASD model that is integrated into its holistic model of care.

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[49] Northern Territory Office of the Public Guardian, *Submission 20*, [p. 9].

[50] See, for example, NACCHO, *Submission 104*, [p. 9]; The Royal Australasian College of Physicians, *Submission 29*, p. 4; Queensland Family and Child Commission, *Submission 36*, pp. 4–5; BioAutism Ltd, *Submission 93*, p. 16.

[51] Government of Western Australia, *Submission 103*, pp. 1–2; NACCHO, *Submission 104*, [p. 5]; The Royal Australasian College of Physicians, *Submission 29*, p. 6; TARA, *Submission 86*, p. 9; Queensland Family and Child Commission, *Submission 36*, p. 5.

[52] NACCHO, *Submission 104*, [p. 8].

[53] NACCHO, *Submission 104*, [p. 9].

> The strength of the model is that it is driven and managed by community. This shifted the focus from a clinical specialist setting to a holistic primary health care model run by Aboriginal and Torres Strait Islander heath workers and practitioners from that community.
>
> The project demonstrated that there is another way to support children and families affected by FASD which transfers a traditionally clinical approach into a community health approach.
>
> The long-term outcome of this approach is not yet known, however the logical impact of the community driving the response is that the community has greater awareness and understanding of the causes of FASD and the best ways to support children and families impacted by it.

Source: National Aboriginal Community Controlled Health Organisation, Submission 104, [p. 9].

Culturally and linguistically diverse (CALD) communities

7.31 The Autism Advisory and Support Service noted that autistic people from culturally and linguistically diverse (CALD) backgrounds face additional challenges in accessing adequate services, including coordination support. These challenges include language barriers, a lack of local informal support networks, low computer literacy, and a lack of trust in government agencies.[54]

7.32 BioAutism Ltd also suggested that some people from CALD backgrounds may be unfamiliar with autistic presentations,[55] while another stakeholder commented that some cultures associate disability with shame and fear.[56] For example, according to one submitter, an autistic child can be seen as the fault of the mother or even 'as being punished by God'.[57]

7.33 The Ethnic Disability Advocacy Centre suggested that a lack of awareness, as well as language barriers that make it difficult to understand the assessment process, contributes to the late diagnosis of autistic people from CALD backgrounds:

> Often, the assessments involve an interpreter. Some parents skip assessment because they do not understand the reason for the rigorousness of the assessment process.[58]

7.34 Accordingly, stakeholders highlighted the need for information about autism to be presented in languages other than English, as well as positive portrayals of

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[54] Autism Advisory and Support Service, *Submission 21.1*, pp. 7–8.

[55] BioAutism Ltd, *Submission 93*, p. 13.

[56] Name withheld, *Submission 62*, p. 5.

[57] Name withheld, *Submission 2*, p. 11.

[58] Ethnic Disability Advocacy Centre, *Submission 75*, p. 4.

autistic people to change perceptions.[59] Submitters also noted a lack of research about how autism impacts CALD communities[60] and suggested this as an area for further investigation.[61]

Gender diversity and sexual orientation

7.35 As described in Chapter 2, there is growing awareness of increased rates of gender variance and non-heterosexual orientation in autistic people compared to the general population. Stakeholders, such as the Australian Psychological Society and the I CAN Network, also reported that this group is more likely to experience mental health issues such as depression and anxiety than heteronormative populations.[62]

7.36 According to the Coalition of Autistic Women, these cohorts also experience abuse and discrimination.[63] The impact in terms of access to appropriate supports was described to Yellow Ladybugs by a young, queer, gender diverse autistic person:

> The areas in which I have found this problematic have been when I have been attempting to access and use services essential to me. One of the most notable being that my previous mainstream high school was completely unwilling to make changes for my access needs to the extent that I was heavily bullied for various parts of my existence that challenged the norm as well as my mental health further deteriorated to the point where I could not attend school whatsoever. I was forced to drop out of school.[64]

7.37 Yellow Ladybugs also identified the impact of inadequate mental health services as a concern, driven in part by a lack of expertise in dealing with gender diverse and non-heterosexual autistic individuals.[65] This view was shared by SPA and CYDA, which saw a need to build greater understanding of the needs of these cohorts across relevant workforces.[66]

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[59] See, for example, Ethnic Disability Advocacy Centre, *Submission 75*, p. 11; CYDA, *Submission 109*, p. 12; Name withheld, *Submission 2*, p. 11.

[60] Ethnic Disability Advocacy Centre, *Submission 75*, p. 10; TARA, *Submission 86*, p. 9.

[61] Australian Psychological Society, *Submission 110*, p. 9; Australian Autism Alliance, *Submission 52*, p. 13; Speech Pathology Australia, *Submission 87*, p. 21; Spectrum Labor, *Submission 1*, [p. 18].

[62] Australian Psychological Society, *Submission 110*, p. 8; I CAN Network, *Submission 107*, p. 10.

[63] Coalition of Autistic Women, *Submission 125*, [p. 16].

[64] Yellow Ladybugs, *Submission 49*, p. 8.

[65] Yellow Ladybugs, *Submission 49*, p. 4.

[66] Speech Pathology Australia, *Submission 87*, p. 26; CYDA, *Submission 109*, p. 14.

7.38 As with other vulnerable and disadvantaged groups, there were also calls for more research into gender diverse and non-heterosexual individuals and their experiences of autism.[67]

Complex needs

7.39 While services to support autistic people are generally siloed and poorly coordinated, these issues are often exacerbated for people who have complex care needs that require supports across multiple service sectors.

7.40 The Autism Advisory and Support Service pointed to the difficulties families face in accessing holistic supports as a result of complex care needs that can span multiple government departments. Similarly, Marymead Autism Centre also reported families' desire for 'greater cooperation and liaison between jurisdictions of health, education, housing, mental health, justice and out of home care'.[68]

7.41 Professor Julian Trollor, UNSW, concurred and referred to people with complex needs as 'falling through the cracks between service sectors'. He stated that this 'fundamentally relates back to a lack of cohesive and integrated policy and legislative frameworks and then service system frameworks that don't really speak to one another or historically haven't'.[69]

7.42 In addition to raising concerns about the lack of a coordinated model of care for this cohort, Irabina Autism Services (Irabina) was also critical of the tendency for state-based agencies to spend time and resources 'disputing the mandates and remits of each particular agency' rather than collaborating to meet the needs of autistic people and their families.[70]

7.43 According to Irabina, the lack of support coordination services put families 'in the position of having to identify, evaluate, and approach the multiple services required by individuals', as well as holding agencies accountable if they fail to provide the necessary support. Irabina described the impact on families:

> These gaps in the system create a situation in which those who are most vulnerable are further victimised, discriminated against, or traumatised by interacting with a system that is incapable of providing a unified approach to treatment, care, and support.[71]

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[67] Autism CRC, *Submission 46*, p. 25; Family Planning NSW, *Submission 28*, p. 6; Spectrum Labor, *Submission 1*, [p. 18]; Name withheld, *Submission 2*, p. 4.

[68] Marymead Autism Centre, *Submission 128*, p. 9.

[69] Professor Julian Trollor, Chair, Intellectual Disability Mental Health; and Head, Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW Sydney, *Proof Committee Hansard*, 15 April 2021, p. 37.

[70] Irabina Autism Services, Submission 130, p. 8.

[71] Irabina Autism Services, *Submission 130*, p. 8.

7.44 Concerns were also raised about the lack of services that are both willing and able to support individuals with complex needs. For example, Irabina explained that generalist services are 'unequipped, untrained, and often unwilling to support clients with complex behavioural presentations,' particularly when there is no financial incentive for doing so.[72]

7.45 The lack of services is also reflected in a shortage of crisis supports for individuals and families with complex needs.[73] Aspergers Victoria described the impact of this shortage on families struggling to manage their child's 'escalating violent and aggressive behaviours':

> For those who call an ambulance, they are given a sedative and by the time they reach the hospital, they are calmer and are told to go home. For those with no informal supports they are faced with nowhere to turn and an on-going cycle in and out of hospitals and mental health wards.[74]

7.46 This concern was shared by the Office of the Public Advocate Victoria, which warned that the lack of adequate support for this cohort was leading to prisons becoming proxy institutions for people with cognitive disability and mental illness.[75] The Tasmanian Government expressed similar fears in relation to hospital admissions being used to keep autistic people safe when supports for their exceptionally complex needs have been withdrawn.[76]

7.47 Like other vulnerable groups, there was a call for research to provide insights into the experiences and needs of families with complex needs.[77]

Families and carers of autistic people

7.48 As described in Chapter 4, autism has a significant impact on families and carers. Multiple submissions described experiences of stress and depression, sleep deprivation, social isolation, loss of employment, the inability to buy a home (or having to sell the family home or take on additional debt to afford services), and the impact on relationships and siblings' quality of life.[78]

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[72] Irabina Autism Services, *Submission 130*, p. 11. According to Irabina, services capable of supporting individuals with complex needs would need to be staffed by highly specialised professionals and clinicians with specific qualifications and experience in behavioural intervention and support. They would also require appropriate resources, facilities and training to safely provide support, assistance and treatment.

[73] Marymead Autism Centre, *Submission 128*, p. 4.

[74] Aspergers Victoria, *Submission 90*, [p. 21].

[75] Office of the Public Advocate Victoria, *Submission 80*, p. 15.

[76] Tasmanian Government, *Submission 19*, p. 4.

[77] Irabina Autism Services, *Submission 130*, p. 6.

[78] See for example, Name withheld, *Submission 62*, p. 3; Name withheld, *Submission 111*, pp. 3–4; Name withheld, *Submission 81*, [p. 2]; Name withheld, *Submission 113*, [p. 3]; Name withheld, *Submission 120*, [p. 2]; Name withheld, *Submission 147*, [p. 1].

7.49 This reflects the significant and often intensive role played by families and carers in providing informal supports for autistic family members.[79] More than one stakeholder cited high levels of dependence on informal supports in Australia,[80] including A4, which suggested there was 'an over-reliance on informal supports' for autistic people.[81] The breadth of support was described by Carers NSW which argued that, in addition to direct personal care, support also includes 'navigating and coordinating services, supports and decision making with, or on behalf of, the person they care for,' as well as facilitating their 'social and economic participation'.[82]

7.50 In addition to the impact on the broader family, a lack of support for parents and carers was also identified as impacting on the quality of supports for autistic individuals. For example, Exercise and Sports Science Australia reported that parents and carers who are 'already at capacity in their caring role' can find it difficult to make time for home therapy sessions. This, in turn, can result in their child not achieving outcomes that would otherwise be possible.[83]

7.51 Stakeholders also reminded the committee that inadequate supports for families also affects autistic parents and carers. One autistic submitter described the challenges of trying to access support for their autistic children:

> All organisations, policies and people I interface with about these issues operate under the default assumption that there is a competent adult in charge. But there's only me. Trying to cope is progressively damaging me, making it harder to cope, and coping more damaging. I'm terrified that I will burn out entirely and not recover.[84]

7.52 In response, there was a broad view that more needed to be done to support the families and carers of autistic people.[85] More specifically, stakeholders raised the need for action to address service gaps in relation to:

- respite care;
- family-centred services and wraparound supports; and

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[79] See, for example, Name withheld, *Submission 11*, [p. 11]; Name withheld, *Submission 111*, [p. 4]; Name withheld, *Submission 113*, [p. 3].

[80] See for example, Carers NSW, *Submission 71*, [p. 2]; Different Journeys, *Submission 30*, p. 3; Speech Pathology Australian, *Submission 87*, p. 22.

[81] A4, *Submission 54*, p. 18.

[82] Carers NSW, *Submission 71*, [p. 2].

[83] Exercise and Sports Science Australia (ESSA), *Submission 91*, p. 12.

[84] Name withheld, *Submission 112*, p. 9.

[85] See for example, Monash University, *Submission 94*, pp. 29–30; I CAN Network, *Submission 107*, p. 11; Mansfield Autism Statewide Services, *Submission 117*, [p. 1]; Exercise and Sports Science Australia, *Submission 91*, p. 12; Name withheld, *Submission 2*, p. 5; Name withheld, *Submission 81*, [p. 2].

- better support for families and carers under the NDIS.

Respite care

7.53 Stakeholders highlighted the importance of respite care for the wellbeing of families and carers, as well as the individuals in their care.[86] More than one submitter also emphasised that well-supported parents and carers equated to better supported children and more functional families.[87]

7.54 The need for respite care is particularly important for the families of people with high care needs. For example, one submitter stated that the 'intertwining' of the autistic individual's wellbeing with that of the carer increases in line with the degree of support needed by the individual.[88] As noted by another stakeholder, without support, the risk of carer burnout is high:

> Having an autistic child, or children if there is more than one diagnosed child in the family, is more than a 24/7 job. Autistic children require such a high level of care, that parent/carer burnout is inevitable in most cases. Once the parent/carer is burnt out that greatly impedes the quality of care and attention the autistic child is able to receive.[89]

7.55 However, according to Autism Queensland, the introduction of the NDIS resulted in the defunding and closure of 'many important supports for families such as respite, sibling programs and parent programs'.[90]

7.56 As a result, stakeholders such as Mansfield Autism Statewide Services (MASS) called for greater 'availability and quality of planned respite care' to help prevent carer fatigue that can lead to family breakdown and relinquishment'.[91]

7.57 Flexibility in respite care was also important, with one participant suggesting that respite could include options for either the parents or child to have time away from the home, depending on the circumstances:

> Respite needs to be flexible, particularly when we are dealing with autistic adults who may be 'high functioning' enough to look after themselves for a night or two with appropriate supports. It cannot just be about sending the autistic person out of their familiar setting, into an unfamiliar one. Respite can also look like this: the **parent/s** or **carer/s** having some time away.[92]

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[86] NACCHO, *Submission 104*, [p. 6]; Name withheld, *Submission 113*, [p. 3].

[87] Name withheld, *Submission 111*, [p. 4]; Name withheld, *Submission 116*, pp. 5–6.

[88] Name withheld, *Submission 126*, p. 14.

[89] Name withheld, *Submission 116*, pp. 5–6.

[90] Autism Queensland, *Submission 129*, p. 17.

[91] Mansfield Autism Statewide Services, *Submission 117*, [p. 1].

[92] Name withheld, *Submission 11*, [p. 10].

Family-centred services and wraparound supports

7.58 A family-centred approach to services involves working in partnership with families to understand their situation and determine what strategies will best meet their needs. It is based on a number of principles, including that:

- support works best when it is based on an understanding of a family's goals, expectations, values and everyday life;
- parents know their children and their family best;
- families learn and grow best when using their strengths;
- children's wellbeing and development depends on the wellbeing of all other family members and of the family as a whole; and
- family wellbeing depends on the quality of informal social supports and the availability of formal support services.[93]

7.59 According to Positive Youth, a wraparound approach to supports generally involves collaboration between people from different service sectors to meet a person's needs.[94]

7.60 A number of stakeholders cited the importance of both family-centred and wraparound supports for families. For example, Marymead Autism Centre argued that a focus 'on the entire family dynamic is necessary to address the complexities of the family and everyday life challenges,' which may include multiple children or parents with disability or health challenges, isolation and/or unemployment.[95] This view was shared by one parent who noted the link between a family-centred approach and outcomes for their autistic child:

> I ask that the committee consider the family as a whole when making policy decisions regarding funding, respite and support workers, not just the needs of the child. If the parents and family unit are functioning well, they are better equipped to make better choices for their autistic child.[96]

7.61 However, the committee heard that services combining family-centred approaches with integrated wraparound services are rare. One provider—MASS—stated that it may be the only provider in Australia offering this unique approach to service delivery (see Box 7.2). As a result, MASS revealed it was 'often in the heartbreaking position of advising parents that we are at capacity, with all of our programs being full for the next 12 months'.[97]

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[93] Raising Children website, *Professionals: a family-centred approach to working with parents*, www.raisingchildren.net.au/for-professionals/working-with-parents/about-working-with-parents/professionals-a-family-centred-approach (accessed 6 November 2021).

[94] Positive Youth Incorporated, *Submission 85*, p. 4.

[95] Marymead Autism Centre, *Submission 128*, pp. 3 and 13.

[96] Name withheld, *Submission 111*, [p. 5].

[97] Mansfield Autism Statewide Services, *Submission 117*, [pp. 3 and 4].

Box 7.2 Mansfield Autism Statewide Services

Mansfield Autism Statewide Services provides a range of integrated wraparound services that aim to keep families together by working with the whole family, not just the child. Its services include:

- day and term therapeutic residence schools;
- respite, crisis and full-time care;
- family camps;
- in-home practitioners (Mansfield Autism Practitioners – MAPs);
- entry to school and work transition programs;
- professional development for teachers;
- allied health industry placements; and
- bespoke disability housing.

The MASS approach was acknowledged in the Victorian Parliamentary Inquiry into Services for People with Autism Spectrum Disorder, which recommended that the Victorian Government fund the expansion of the MASS model, including the travelling teacher scheme (now MAPs), across regional Victoria.

The MAPs program offers practical, autism-specific support in the family home, with MAPs living in the family home for 3–5 days at a time, multiple times per year.

A cost benefit analysis of the MAPs service undertaken in 2011 showed a return of $4.83 for every dollar spent.

Source: Mansfield Autism Statewide Services, Submission 117, [pp. 2, 3 and 5]; Mansfield Autism Statewide Services, Strategic Plan 2021-2023; Mansfield Autism Statewide Services, Mansfield Autism Practitioners, www.autismmansfield.org.au/mansfield-autism-practitioners-maps/, (accessed 6 November 2021).

NDIS support for families and carers

7.62 Many stakeholders raised concerns with the support available for families and carers under the NDIS. This included concerns in relation to respite care, as well as the availability of family-centred and wraparound approaches to supports.

Respite care

7.63 Stakeholders were critical of the support provided for families and carers within the NDIS, particularly in relation to respite care.[98] According to CYDA, families report feeling 'invisible' in the NDIS, with NDIS plans failing to recognise the role they play in supporting their child.[99] Autism Queensland concurred and asserted that neglecting the family context can negatively affect a family's ability to support their child.[100]

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[98] See, for example, Name withheld, *Submission 111*, [p. 4]; Name withheld, *Submission 113*, [p. 3]; Name withheld, *Submission 112*, [pp. 14–15].

[99] CYDA, *Submission 109*, Appendix B (CYDA's submission to the 2019 review of the *National Disability Insurance Scheme Act 2013* [Tune Review], October 2019), p. 14.

[100] Autism Queensland, *Submission 129*, p. 17.

7.64 However, in its submission, the National Disability Insurance Agency (NDIA) recognised the importance of sustainable informal support and noted that 'the ongoing capacity of families and carers is critical to the wellbeing of some participants'.[101]

7.65 The government's response to the final report of the Joint Standing Committee on the National Disability Insurance Scheme on its inquiry into NDIS planning also committed to improving support for informal carers:

> The NDIA has worked with Carers Australia to develop internal guidance for NDIA planners and Partners in the Community to support improved outcomes for participants, families and carers by ensuring all planning staff understand the valuable role played by caregivers and families.[102]

7.66 That said, the NDIA also emphasised that funded supports are 'not intended to displace the ordinary role of parents, families and carers'.[103]

7.67 The NDIA's application of the 'ordinary parental responsibility' principle was criticised by some stakeholders. For example, CYDA argued that the NDIS has 'little understanding' of the level of support provided by families to meet their child's daily needs.[104] This view was shared by Autism Spectrum Australia which also pointed to a lack of understanding about the support families require to 'maintain their caregiving roles', as well as the 'intensive support' young autistic children need to develop early skills.[105]

7.68 The experience of one family was relayed by CYDA:

> Respite was difficult to get as 'parental responsibility' kept getting quoted, even though the single parent was not able to do these parental responsibility [sic] due to physical & mental health issues.[106]

7.69 Another submitter claimed that she had been advised not to expect support 'for circumstances that would be reasonable for all parents'. Given the additional challenges involved in parenting an autistic child, she argued that the NDIA's 'ordinary role of parents' principle minimised the experience of parents and carers:

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[101] National Disability Insurance Agency, *Submission 56*, p. 23.

[102] Senator the Hon Richard Colbeck, Minister for Senior Australians and Aged Care Services and Minister for Sport, *Senate Hansard*, Tuesday 23 February 2021, p. 1328.

[103] NDIA, *Submission 56*, p. 23.

[104] CYDA, *Submission 109*, Appendix B (CYDA's submission to the 2019 review of the *National Disability Insurance Scheme Act 2013* [Tune Review], October 2019), p. 14. For example, the submission noted that parents would like to work but are unable to because caring for their child is seen as their parental responsibility.

[105] Aspect, *Submission 64*, p. 16.

[106] CYDA, *Submission 109*, Appendix B (CYDA's submission to the 2019 review of the *National Disability Insurance Scheme Act 2013* [Tune Review], October 2019), p. 14.

> All parents take their children to activities, supervise and assist in their daily living. Special needs parents are carers, advocates and personal assistants to their child in addition to all other parenting responsibilities. … All parents deal with challenging behaviours such as temper tantrums. Special needs parents manage meltdowns that can last for hours and become violent and place other family members at risk of harm.[107]

7.70 There was also frustration with the NDIA's application of the ordinary role of parenting principle and its use of existing support networks to deny respite care. For example, the committee heard of one family who were denied respite by the NDIA because the family was seen to have a support network—despite this network providing minimal support (as well as being unequipped to do so):

> Our son has been in the care of someone other than myself and my husband for a total of three hours in the past two years, and that was because I was rushed to hospital … and my husband was required to be at the hospital and children weren't allowed in.[108]

7.71 In response, more than one submitter suggested the creation of a category of NDIS funding to better support informal care givers.[109]

Family-centred services and wraparound supports

7.72 While the NDIA indicated that its Early Childhood Early Intervention approach places a strong focus on family-centred planning,[110] this was not reflected in feedback about NDIS planning processes more broadly. For example, while Autism Queensland argued that children need 'family-centred plans that identify and support active family engagement in the child's early intervention', it claimed that '[m]any wrap around supports for families are either not funded or not adequately funded under the child's individual funding package'.[111]

7.73 This was also reflected in evidence from the Marymead Autism Centre, which stated that children were considered in isolation from their families 'despite extensive research which shows the development and wellbeing of children and young people is facilitated through supportive home learning and support environments'.[112]

Committee view

7.74 This chapter has focused on stakeholder concerns that, within the broader autistic community, there are certain cohorts that are at even greater risk of

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[107] Name withheld, *Submission 111*, [p. 4].

[108] Name withheld, *Submission 116*, pp. 5–6. During the NDIS planning process the parents mentioned that their son had godparents, a grandparent, an aunt and two cousins in his life.

[109] Marymead Autism Centre, *Submission 128*, p. 13; Name withheld, *Submission 11*, [p. 11].

[110] NDIA, *Submission 56*, p. 12.

[111] Autism Queensland, *Submission 129*, p. 17.

[112] Marymead Autism Centre, *Submission 128*, p. 12.

missing out on services and supports. In these cases, the committee contends that additional scaffolding and support is required to ensure they receive the services they require.

Disadvantaged and vulnerable cohorts

7.75 The committee notes that gaps in services and inadequate provision are likely to have a disproportionate impact on the following cohorts, given the complexity of their needs and/or the intersection between their autism and other factors:

- people from lower socio-economic backgrounds;
- people in regional and remote locations;
- First Nations people;
- people from culturally and linguistically diverse backgrounds;
- gender diverse and non-heterosexual people; and
- people with complex needs.

7.76 Additional challenges also exist for autistic adults, women and girls, as well as the families and carers of autistic individuals. As such, the committee accepts that there will be a need for the National Autism Strategy to focus on meeting the needs of all autistic people—including the most vulnerable and disadvantaged groups. This should include actions to ensure that autism information and services are:

- accessible regardless of geographic location; and
- tailored to meet the needs of individual cohorts.

7.77 Encouragingly, the committee heard evidence about the potential of remote service delivery and the use of local networks and integrated care models to deliver better services for First Nations people and those in regional and remote locations. However, the committee notes that further investigation of the needs of all vulnerable cohorts—and the most effective ways to meet those needs—will be required to inform specific policy responses, as well as any potential actions under the National Autism Strategy.

7.78 Despite this progress, the committee remains deeply concerned about the adequacy of supports for individuals with complex needs, particularly in times of crisis. While recognising the role earlier and better intervention play in preventing crises, the committee is disturbed by evidence suggesting that prisons and hospitals are being used to fill the gaps in appropriate supports, including providers of last resort. Accordingly, in addition to the recommendations below, further recommendations in relation to the National Disability Insurance Scheme (NDIS) complex needs pathway and provider of last resort arrangements appear in Chapters 14 and 16.

Recommendation 18

7.79 **The committee recommends that the National Autism Strategy include a focus on meeting the needs of all autistic people. This should include a particular focus on the provision of adequate and appropriate services for autistic adults, women and girls, as well as disadvantaged and vulnerable cohorts of autistic people such as:**

- **people from lower socio-economic backgrounds;**
- **people in regional and remote locations;**
- **First Nations people;**
- **people from culturally and linguistically diverse backgrounds;**
- **gender diverse and non-heterosexual people; and**
- **people with complex needs.**

Recommendation 19

7.80 **The committee recommends that the National Autism Strategy include specific actions to improve access to services in regional and remote areas. This should include options for remote service delivery (such as telehealth), as well as working with relevant medical colleges and professional bodies to increase the supply and retention of clinicians and allied health professionals available to work in regional and remote locations.**

Recommendation 20

7.81 **The committee recommends that the National Autism Strategy include specific actions to improve access to services for First Nations peoples. This should include building the capacity of Aboriginal Community Controlled Health Organisations to deliver autism services in First Nations communities, as well as trialling the use of alternative care models, such as those in place to support individuals with Foetal Alcohol Spectrum Disorders.**

7.82 **In addition, the taskforce established to develop the National Autism Strategy should include First Nations representation.**

Recommendation 21

7.83 **The committee recommends that, as a priority, all governments through the National Federation Reform Council review their approaches to coordinating service delivery for autistic people with complex needs and implement actions to ensure integrated and appropriate support for individuals and families with complex support needs, particularly during times of crisis.**

Support for families and carers

7.84 The committee is aware that tension exists in the autism community in relation to the role of non-autistic parents and carers as advocates for autistic individuals. However, the critical role of parents and carers cannot be separated from the success of autistic individuals. As the committee heard, parents and carers:

> …guide and teach children, they offer encouragement and supports through the transition to adulthood, are their children's strongest advocates, navigate government supports and the education system and are crucial to an individual's social support system.[113]

7.85 In addition, the high reliance on informal supports for autistic people means that their families, parents and carers shoulder a significant caring load. Despite the wellbeing of parents and carers being critical to the success of autistic people, the committee heard overwhelming evidence of inadequate support for people in these important caring roles. The impact of inadequate support for families and carers can be debilitating, both financially and emotionally. Accordingly, the need to acknowledge and support informal care arrangements is recognised as a policy priority within *Australia's Disability Strategy 2021-2031*.[114]

7.86 While the committee also recognises the role of the Carer Gateway in providing advice, services and supports for carers, the evidence provided to the committee suggests that there are still gaps in supports for families and carers in relation to respite care, as well as a lack of services that are family-centred and offer wraparound supports. The committee notes particular concerns in relation to the support available under the NDIS, specifically that there is:

- a lack of clarity and consistency in how the principle of not supporting the 'ordinary role of parenting' is applied by the NDIA;
- an assumption that the existence of a support network can be sufficient grounds for denying respite care, regardless of the actual support provided by that network; and
- a mismatch between the stated aim of providing family-centred planning under the Early Childhood Approach and the lack of family-centred approaches for all clients.

7.87 The committee also welcomes the government's response to the NDIS planning inquiry regarding internal guidance developed by NDIA with Carers Australia. However, this should be published for transparency and consistency.

7.88 The committee acknowledges that the provision of respite and support services for parents is not solely the preserve of the NDIA but the committee heard evidence that many state-based supports for families and carers have disappeared since the introduction of the NDIS. As such, there is also an urgent need to address deficiencies in state-based services for parents and carers.

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[113] OTARC, *Submission 55*, p. 25.

[114] Department of Social Services, *Australia's Disability Strategy 2021–2031*, p. 20.

Recommendation 22

7.89 **The committee recommends that the National Autism Strategy recognise the vital role that families, parents and carers play in supporting autistic individuals.**

Recommendation 23

7.90 **The committee recommends that the National Disability Insurance Agency work with stakeholders and experts to:**

- **clarify the operation of the 'ordinary role of parenting' principle, recognising the significant additional responsibilities borne by parents and carers of autistic individuals; and**
- **institute a family-centred approach to planning that extends beyond the Early Childhood Approach and is supported by training in family-centred approaches for National Disability Insurance Scheme Planners, Local Area Coordinators, and Support Coordinators.**

Recommendation 24

7.91 **The committee recommends that the National Disability Insurance Agency publish its guidance for planners regarding the role of caregivers and families to improve transparency and consistency of support provided.**

Recommendation 25

7.92 **The committee recommends that state and territory governments undertake a mapping of respite and support services for parents and work with government and non-government providers to address identified gaps in support.**

Chapter 8
Research and data collection

8.1 This chapter provides an overview of the current funding for autism research, as well as discussion of stakeholder views in relation to:

- existing research gaps;
- the need for a national autism register; and
- the need for a national autism research framework;

Overview

8.2 According to the Department of Social Services, Department of Education, Skills and Employment, and the Department of Health (the departments), funding for autism research at a national level is provided through the Cooperative Research Centre for Living with Autism (Autism CRC), the National Health and Medical Research Council (NHMRC), the Autism Specific Early Learning and Care Centres (ASELCCs), and the Medical Research Future Fund, as well as two initiatives under the national Disability Research Strategy—the National Disability Data Asset and the National Disability Research Partnership.[1] Further detail about these initiatives appears at Appendix 3.D.

8.3 Research funding is also provided at a state and territory level, as well as by non-government organisations, private companies and philanthropic sources.

8.4 However, multiple stakeholders identified a need for increased autism research funding.[2] For example, CliniKids, the Autism CRC and the Australian Autism Alliance (the Autism Alliance) all claimed that autism research currently receives a 'disproportionately' small funding allocation—particularly given the prevalence of the condition within the community and the National Disability Insurance Scheme (NDIS), as well as its lifelong nature.[3]

8.5 CliniKids highlighted analysis showing that during the period 2013–2017, the NHMRC allocated $19.3 million to autism research projects—a 'very small fraction' of the approximately $3 billion in research funding allocated by the

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[1] Department of Social Services, Department of Education, Skills and Employment, Department of Health, *Submission 53*, pp. 25-27.

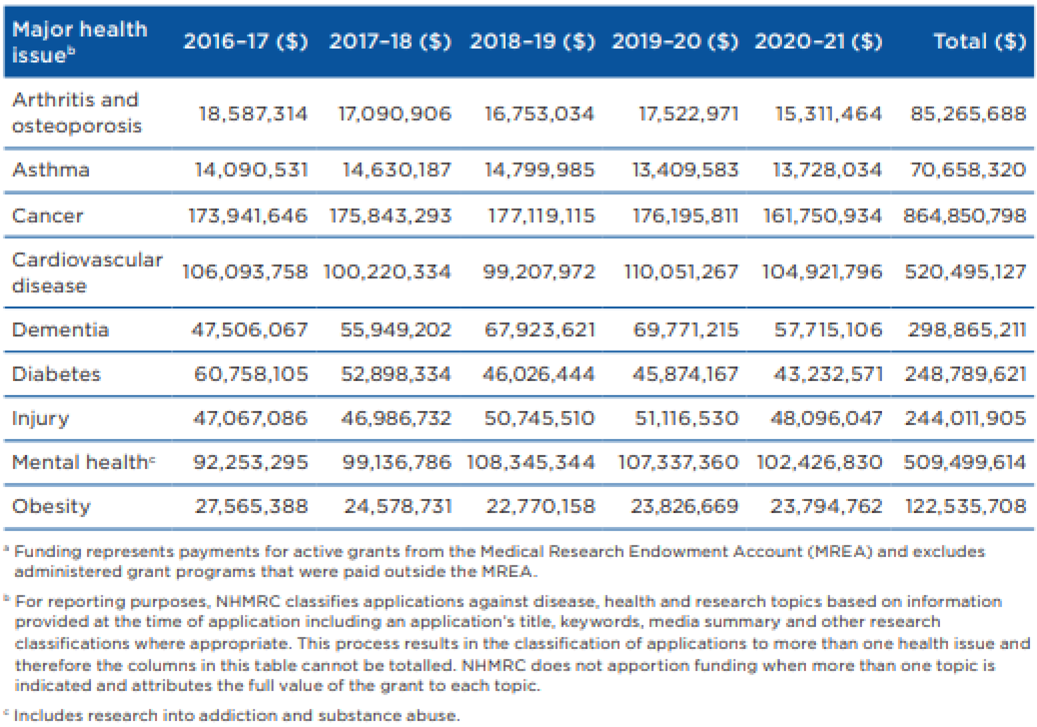
[2] See, for example, La Trobe University – the Olga Tennison Autism Research Centre (OTARC), *Submission 55*, p. 22; Australian Medical Association (AMA), *Submission 40*, p. 2; Northern Territory Office of the Public Guardian, *Submission 20*, [p. 8]; Family Planning NSW, *Submission 28*, p. 6; BioAutism Ltd, *Submission 93*, p. 6; Name withheld, *Submission 38*, [p. 1].

[3] CliniKids, *Submission 15*, [p. 9]; Cooperative Research Centre for Living with Autism (Autism CRC), *Submission 46*, p. 24; Australian Autism Alliance, *Submission 52*, p. 47.

NHMRC over the same period.[4] Similarly, Assistance Dogs Australia pointed to a 'significant gap' in NHMRC funding for research into intellectual/cognitive health issues compared to the funding provided for physical health issues.[5]

8.6 This appears to be supported by data provided by the departments. At the time of their submission, the departments noted that the NHMRC had provided around $33.8 million in funding towards autism research since 2010.[6] However, data from the latest NHMRC Annual Report suggests that this amount is dwarfed by expenditure on the nine identified major health issues (see Figure 8.1).[7] Over the last ten years, autism received less than half the funding that asthma (the major health issue with the lowest funding) received in the last five.

Figure 8.1 NHMRC expenditure on major health issues, 2016–17 to 2020–21



Major health issue[b]	2016-17 ($)	2017-18 ($)	2018-19 ($)	2019-20 ($)	2020-21 ($)	Total ($)
Arthritis and osteoporosis	18,587,314	17,090,906	16,753,034	17,522,971	15,311,464	85,265,688
Asthma	14,090,531	14,630,187	14,799,985	13,409,583	13,728,034	70,658,320
Cancer	173,941,646	175,843,293	177,119,115	176,195,811	161,750,934	864,850,798
Cardiovascular disease	106,093,758	100,220,334	99,207,972	110,051,267	104,921,796	520,495,127
Dementia	47,506,067	55,949,202	67,923,621	69,771,215	57,715,106	298,865,211
Diabetes	60,758,105	52,898,334	46,026,444	45,874,167	43,232,571	248,789,621
Injury	47,067,086	46,986,732	50,745,510	51,116,530	48,096,047	244,011,905
Mental health[c]	92,253,295	99,136,786	108,345,344	107,337,360	102,426,830	509,499,614
Obesity	27,565,388	24,578,731	22,770,158	23,826,669	23,794,762	122,535,708

[a] Funding represents payments for active grants from the Medical Research Endowment Account (MREA) and excludes administered grant programs that were paid outside the MREA.

[b] For reporting purposes, NHMRC classifies applications against disease, health and research topics based on information provided at the time of application including an application's title, keywords, media summary and other research classifications where appropriate. This process results in the classification of applications to more than one health issue and therefore the columns in this table cannot be totalled. NHMRC does not apportion funding when more than one topic is indicated and attributes the full value of the grant to each topic.

[c] Includes research into addiction and substance abuse.

Source: National Health and Medical Research Council, Annual Report 2020-21, p. 5.

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[4] CliniKids, *Submission 15*, [pp. 9-10].

[5] Assistance Dogs Australia, *Submission 43*, p. 7.

[6] Department of Social Services, Department of Education, Skills and Employment, Department of Health, *Submission 53*, p. 26.

[7] National Health and Medical Research Council, *Annual Report 2020–21*, p. 5. The nine priority health issues are based on the former National Health Priority Areas, which sought to focus public attention and health policy on areas that contribute significantly to the burden of disease in Australia.

Existing research gaps

8.7 There was significant stakeholder consensus around the need for more research into autism.[8] This seems to be supported by the findings of a recent mapping of disability research in Australia conducted under the auspices of the National Disability Research Partnership (NDRP). The NDRP mapping appears to show that autism research makes up a disproportionately small proportion of all disability research in Australia. For example, while autistic people with autism make up 33 per cent of NDIS participants, autism was the subject of only 13.1 per cent of identified research papers and 12.2 per cent of identified research reports.[9] This appears to be the biggest discrepancy among all comparable disability types represented in both the NDIS and the NDRP mapping (see Table 8.1).[10]

Table 8.1 Proportion of NDIS disability types versus proportion of NDRP identified research

Disability type	% NDIS participants	% NDRP identified research papers	% NDRP identified research reports
Autism	33	13.1	12.2
Intellectual disability	19	17	8.4
Acquired brain injury	3	3.2	0.9
Hearing impairment	5	2.8	0.5
Visual impairment	2	1.4	3.8

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[8] See, for example, Queensland Law Society, *Submission 124*, p. 2; Australian Psychological Society, *Submission 110*, p. 8; Northern Territory Office of the Public Guardian, *Submission* 20, [p. 8]; Commissioner for Children and Young People Western Australia, *Submission 42, Attachment 1*, p. 3; Name withheld, *Submission 155*, p. 22; Autism Advisory and Support Service, *Submission 21*, p. 7.

[9] National Disability Research Partnership, *Mapping disability research in Australia*, www.ndrp.org.au/mapping-research (accessed 18 November 2021). The mapping did not include papers that were basic science or clinical research whose primary focus was related to treatment or diagnosis. The mapping found a total of 1646 individual pieces of Australian disability research over the 2018–2020 period, comprising 1421 peer-reviewed journal articles or book chapters (research papers) and 225 research reports. The majority had a general focus on disability (33.7 per cent of identified research papers and 52.5 per cent of research reports).

[10] While the NDIS disability types and the NDRP research categories do not align perfectly, there are substantial similarities. The NDIS category of 'Intellectual disability' has been compared with the NDRP research category of ' Intellectual/cognitive disability'. The NDIS category of 'Acquired brain injury' has been compared with the NDPR research category of 'Brain injury'. The NDIS category of 'Hearing impairment' has been compared with the NDPR research category of 'Hearing loss impairment, deaf'. The NDIS category of Visual impairment' has been compared with the NDPR research category of 'Visual impairment, visual loss, blind'.

Spinal cord injury	1	2.1	0.5

Source: National Disability Insurance Agency, NDIS Quarterly Report to disability ministers, September 2021, p. 590; National Disability Research Partnership, Mapping disability research in Australia, www.ndrp.org.au/mapping-research *(accessed 18 November 2021).*

8.8 Against this backdrop of a general deficiency in autism research, stakeholders also identified issues and gaps in relation to:

- specific research topics;
- the type of research required;
- the approach to research; and
- the translation of research into practice.

8.9 Stakeholders also raised concerns about the future of the Autism CRC and what will happen to funding for autism research after that time.[11]

Research topics

8.10 Some stakeholders, such as Autism Spectrum Australia (Aspect), noted that, until relatively recently, most funding for autism research was allocated to biological research. However, this began to change in 2013 with the establishment of the Autism CRC which has an investment portfolio that prioritises 'research across the lifespan rather than health and medical research.[12]

8.11 According to the Autism CRC, one study found that between 2008-2012, almost half of the total autism research funding of $14 million 'was allocated to biological research, with no identifiable funding allocated to lifespan issues, infrastructure or surveillance'. Between 2013–2017, the total funding increased to $44 million and included a significant allocation to lifespan issues, infrastructure and surveillance (see Figure 8.2).[13]

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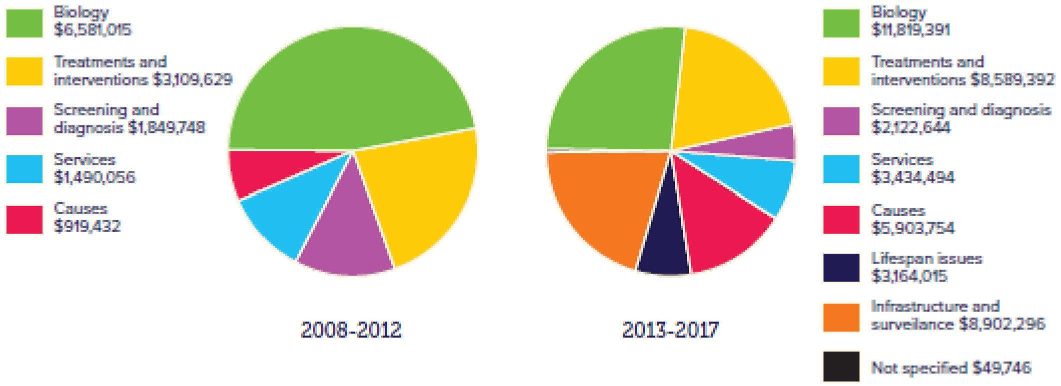
[11] Name withheld, *Submission 126*, p. 23.

[12] Autism Spectrum Australia (Aspect), *Submission 64*, p. 21.

[13] Autism CRC, *Submission 46*, p. 24.

Figure 8.2 Distribution of Australian autism research funding in 2008–2012 and 2013–2017



Source: Cooperative Research Centre for Living with Autism (Autism CRC), Submission 46, p. 24.

8.12 While this change in focus has been welcomed, stakeholders have identified a number of specific areas where there is a need for further research. These include:

- research to enhance screening and diagnostic tools (particularly in relation to the diagnosis of autistic females) and to develop tools for assessing functioning and support needs;[14]
- research to build the evidence-base around specific interventions, including the relative efficacy of different interventions (including early interventions), methods for identifying which intervention is most appropriate for which individual (and when), and the potential of very early interventions beginning in infancy;[15]
- research into vulnerable and disadvantaged cohorts and their experiences of autism, including First Nations communities, culturally and linguistically diverse communities, autistic people that identify as LGBTQIA, and those in the justice system;[16]

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[14] See, for example, Autism CRC, *Submission 46*, pp. 11 and 12; Department of Developmental Disability Neuropsychiatry, University of New South Wales (UNSW 3DN), *Submission 95*, p. 5; Australian Psychological Society, *Submission 110*, p. 9; Queensland Law Society, *Submission 124*, p. 3; Name withheld, *Submission 126*, p. 25.

[15] See, for example, CliniKids, *Submission 15*, [p. 2]; Autism CRC, *Submission 46*, p. 4; ND Australia, *Submission 97*, [p. 1]; Queensland Law Society, *Submission 124*, p. 4; AMA, *Submission 40*, p. 2; Monash University, *Submission 94*, p. 23; Ethnic Disability Advocacy Centre, *Submission 75*, p. 10.

[16] See, for example, National Aboriginal Community Controlled Health Organisation (NACCHO), *Submission 104*, [p. 9]; The Royal Australasian College of Physicians, *Submission 29*, p. 4; Royal Australian and New Zealand College of Psychiatrists, *Submission 17*, [p. 1]; Queensland Family and Child Commission, *Submission 36*, p. 4; Commissioner for Children and Young People Western Australia, *Submission 42*, p. 7; Australian Psychological Society, *Submission 110*, pp. 8 and 9; Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 3]; Family Planning NSW, *Submission 28*, p. 6; Ethnic Disability Advocacy Centre, *Submission 75*, p. 10; The

- research into effective education environments and supports, as well as educational transitions;[17]
- research into post-school options, transitions and employment;[18]
- research into the needs of autistic adults and effectiveness of services and supports;[19]
- research into autism and co-occurring mental health issues and related supports;[20]
- research into neurodiverse relationships, sexuality, sexuality support and access to reproductive and sexual healthcare services;[21] and
- research into complex needs (including co-occurring intellectual disability) and severe behaviours.[22]

Research types

8.13 In addition to specific research topics, stakeholders identified the importance of supporting particular types of research. For example, La Trobe University's Olga Tennison Autism Research Centre (OTARC) pointed to a lack of large-scale longitudinal studies which are:

> …important in assisting us to predict pivotal outcomes for autistic adults and the impact of co-occurring conditions, accessibility to services and adequacy of supports.[23]

Autistic Realm Australia (TARA), *Submission 86*, p. 9; Speech Pathology Australia, *Submission 87*, p. 21; Name withheld, *Submission 126*, p. 25; Name withheld, *Submission 155*, p. 23.

[17] See, for example, PEERS Australia, *Submission 108*, p. 5; The Sycamore School, *Submission 118*, p. 9; Name withheld, *Submission 120*, [p. 5]; Disability Discrimination Legal Service, *Submission 153*, p. 10; Commissioner for Children and Young People Western Australia, *Submission 42*, p. 6; Aspect, *Submission 64*, p. 22.

[18] See, for example, Autism Advisory and Support Service, *Submission 21*, p. 7; Aspect, *Submission 64*, p. 9; Scope-University of Melbourne Partnership, *Submission 83*, p. 10.

[19] See, for example, OTARC, *Submission 55*, p. 22; UNSW 3DN, *Submission 95*, p. 19; Autism Advisory and Support Service, *Submission 21*, p. 7; Assistance Dogs Australia, *Submission 43*, p. 7; St Vincent's Health Australia, *Submission 72*, p. 3; Scope-University of Melbourne Partnership, *Submission 83*, p. 6; Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 7]; Aspect, *Submission 64*, p. 9; Name withheld, *Submission 9*, p. 2; Mr David Staples, *Submission 143*, [p. 19].

[20] See, for example, Marymead Autism Centre, *Submission 128*, p. 11; Aspect, *Submission 64*, p. 22; St Vincent's Health Australia, *Submission 72*, p. 3; Scope-University of Melbourne Partnership, *Submission 83*, p. 29; Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 7]; Name withheld, *Submission 155*, pp. 6, 7, and 13.

[21] Family Planning NSW, *Submission 28*, p. 2; Name withheld, *Submission 12*, [p. 4].

[22] See, for example, Irabina Autism Services, *Submission 130*, p. 3; Speech Pathology Australia, *Submission 87*, p. 21; Name withheld, *Submission 61*, [p. 2]; UNSW 3DN, *Submission 95*, p. 20.

[23] OTARC, *Submission 55*, p. 22.

8.14 This view was supported by other contributors, such as The Sycamore School[24] and CliniKids, which noted that an understanding of long-term impacts was also vital to making an economic argument for the provision of early intervention services.[25]

8.15 The need to establish the long-term financial impact of different supports was also raised by Irabina Autism Services as a particular issue in relation to autistic individuals with complex needs and behaviours:

> …longitudinal studies are required to ascertain the long-term financial impact of … 'treatment as usual' experienced by most individuals with autism presenting with severe behaviours of concern, including but not limited to hospital visits, intensive respite, relinquishment and care by secretary orders. These longitudinal studies should seek to compare … costs of inadequate 'treatment as usual' to those [costs] incurred by individuals who have received recommended intensive behavioural interventions and support aimed at achieving sustained positive changes in their behavioural presentation.[26]

8.16 The Autism CRC also reflected that long-term funding certainty has also been critical to the ability to invest in 'quality research projects' that bring a range of parties together over multiple years to address significant national needs. It argued that 'without such time and resources, the National Guideline for the Assessment and Diagnosis of Autism and the inclusionED education practices platform could not have been delivered'.[27]

Approach to research

8.17 Numerous stakeholders advocated for the use of participatory approaches to autism research that include autistic people as partners in the design and implementation of autism research.[28]

8.18 For example, the Autism CRC argued that co-production leads to better research design and 'more trustworthy conclusions', as well as 'the potential to generate more relevant and appropriate research that is responsive to the needs of people on the spectrum'. In addition, it stated that 'research findings and interventions are more likely to be accessible, useful and sustainable, and more widely disseminated'. To this end, the Autism CRC noted the role of its Sylvia Rodger

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[24] The Sycamore School, *Submission 118*, p. 9.

[25] CliniKids, *Submission 15*, [p. 7].

[26] Irabina Autism Services, *Submission 130*, p. 13.

[27] See, for example, Autism CRC, *Submission 46*, p. 25.

[28] See, for example, Autism CRC, *Submission 46*, p. 4; Scope-University of Melbourne Partnership, *Submission 83*, p. 23; ND Australia, *Submission 97*, [p. 1]; Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 8]; TARA, *Submission 86*, pp. 3 and 25; Name withheld, *Submission 120*, [p. 9]; Name withheld, *Submission 155*, p. 22.

Academy in developing the capacity of research and autistic adults 'to work as peers in research'.[29]

8.19 Both the Autism CRC and OTARC observed that participatory approaches to research can also contribute to increasing the social inclusion, agency and self-esteem of autistic people and communities.[30]

Translating research into practice

8.20 Both CliniKids and the Scope-University of Melbourne Partnership (Scope-UoM) identified a gap in relation to translating research into clinical practice.[31] For example, the Scope-UoM described the 'systemic uptake of research findings and integration of research evidence into clinical practice' as 'an ongoing challenge in Australia'.[32]

8.21 As a result, CliniKids suggested that, in addition to building an evidence base, the development of 'an independent, authoritative and accessible framework' for the collation and dissemination of knowledge would be beneficial to the research and autism communities.[33]

The Autism CRC

8.22 According to the Autism Alliance, the Autism CRC is:

> …essential to linking what could otherwise be a disconnected suite of research projects, adding value to each and ensuring that the knowledge attained through each project is understood and applied nationally.[34]

8.23 As such, some submitters raised concerns about the end of Commonwealth funding for the Autism CRC. For example, Aspect expressed its fear that 'research into services, supports and interventions that have practical and meaningful benefits to autistic people will once again be minimised'.[35] Similarly, the Autism Alliance cautioned that the gains made in understanding autism and autistic people's needs could 'backslide'.[36]

8.24 The Department of Developmental Disability Neuropsychiatry, University of New South Wales (UNSW 3DN) pointed out that that this may make it difficult for researchers to access recurrent funding. This could, in turn, leave them more reliant on short-term funding from state governments, where funding

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[29] Autism CRC, *Submission 46*, pp. 25 and 29.

[30] Autism CRC, *Submission 46*, p. 29; OTARC, *Submission 55*, p. 23.

[31] CliniKids, *Submission 15*, [p. 7]; Scope-University of Melbourne Partnership, *Submission 83*, p. 32.

[32] Scope-University of Melbourne Partnership, *Submission 83*, p. 32.

[33] CliniKids, *Submission 15*, [p. 7].

[34] Australian Autism Alliance, *Submission 52*, p. 47.

[35] Aspect, *Submission 64*, p. 21.

[36] Australian Autism Alliance, *Submission 52*, p. 47.

responsibilities are often split between disability and health services. Accordingly, UNSW 3DN suggested that there was a need to 'consider the best ways to support and sustain research in this area,' such as exploring the potential use of the Medical Research Future Fund.[37]

A National Autism Register

8.25 Various stakeholders highlighted the lack of accurate data on autistic people in Australia as a challenge to doing better research. For example, the Commissioner for Children and Young People Western Australia and the Autism CRC both underscored the role inadequate data play in preventing better understanding of the prevalence of autism in Australia.[38] ND Australia shared this view:

> Even the 2018 [Australian Bureau of Statistics] snapshot of Autism in Australia was based on an estimation and it acknowledged there were errors in the sampling and that some of the estimates needed to be used with caution.[39]

8.26 According to CliniKids, understanding the prevalence of autism, as well as trends in prevalence over time, 'is critical for planning both broad and targeted policies and services that are effective and responsive to community needs'.[40]

8.27 Accordingly, the Queensland Law Society suggested enhancing the utility of current data collections (such as those held by the NDIS and Centrelink).[41]

8.28 Others proposed that a National Autism Register be developed to better understand the prevalence of autism, as well as to enable research and inform policy development.[42] Both CliniKids and ND Australia suggested that a National Autism Register could be modelled on the Autism Register currently operating in Western Australia (see Box 8.1).[43]

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[37] UNSW 3DN, *Submission 95*, p. 20.

[38] See, for example, Commissioner for Children and Young People Western Australia, *Submission 42, Attachment 1*, p. 4; Autism CRC, *Submission 46*, p. 10. Dr John Wright, New South Wales Chief Psychiatrist, Ministry of Health, New South Wales, *Proof Committee Hansard*, 28 July 2020 p. 55.

[39] ND Australia, *Submission 97*, [p. 7].

[40] CliniKids, *Submission 15*, [p. 4].

[41] Queensland Law Society, *Submission 124*, pp. 2-3.

[42] Autism CRC, *Submission 46*, p. 4; Autism Awareness Australia, *Submission 47*, p. 4; ND Australia, *Submission 97*, [p. 7]; Commissioner for Children and Young People South Australia, *Submission 88*, p. 6; Ethnic Disability Advocacy Centre, *Submission 75*, p. 4; BioAutism, *Submission 93*, p. 5 and 6.

[43] See, for example, CliniKids, *Submission 15*, [p. 2]; ND Australia, *Submission 97*, [p. 7]; Commissioner for Children and Young People South Australia, *Submission 88*, p. 6.

8.29 While Autism Awareness Australia highlighted the need to protect individuals' privacy[44] and one submitter opposed the creation of a national register,[45] the Queensland Law Society noted that:

> Researchers in the disability and health sectors have access to well-documented protocols for pseudonymisation and anonymisation of individuals' sensitive information for privacy protection.[46]

Box 8.1 The Western Australian Autism Register (WA Autism Register)

The WA Autism Register is administered by the Telethon Kids Institute. It is the first register of its kind in Australia and has collected information on newly diagnosed cases of autism spectrum conditions in WA since 1999. Some of the uses of the WA Autism Register include:

- research (using its own data, and for linking interested families with current projects);
- understanding characteristics that are shared across everyone with a diagnosis; and
- help in planning for appropriate services, including health, education and disability.

The WA Autism Register has formed the basis of important research advances and provided key data to the first autism prevalence estimate in Australia, which was published in 2008. The WA Autism Register collects simple demographic and diagnostic data for each person receiving a new diagnosis, including:

- date of birth, gender, primary language at home;
- diagnostic criteria used;
- diagnostic methods;
- IQ (verbal and non-verbal) and/or developmental abilities;
- other cognitive assessments;
- comorbidity (the presence of other conditions);
- language assessments; and
- adaptive behaviour.

The data is entered into a web portal by diagnosticians and are stored in encrypted form, with confidentiality and data-security procedures informed by an ethics committee. The information kept on the register is strictly confidential and is only used for the purposes for which it was intended. Any person or organisation requesting information from the WA Autism Register must approach the Advisory Committee. Identifying information, such as names, are not released without consent from a parent or the individual with autism.

Source: Telethon Kids Institute, The Autism Register, www.telethonkids.org.au/autismregister/ *(accessed 19 November 2021); CliniKids, Submission 15, [p. 4].*

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[44] Autism Awareness Australia, *Submission 47*, p. 4.

[45] Name withheld, *Submission 32*, [p. 2].

[46] Queensland Law Society, *Submission 124*, p. 3.

8.30 As noted by CliniKids, the WA Autism Register 'has formed the basis of many important research advances'. It also 'provided key data to the first autism prevalence estimate in Australia, published in 2008'. According to CliniKids, prevalence studies since that time have been reliant on broader research or administrative datasets, such as those related to the Longitudinal Study of Australian Children and the Helping Children with Autism program, which are 'suboptimal' for the purpose.[47]

8.31 The Autism CRC emphasised the need to establish links between a National Autism Register and other national datasets, such as those administered by the Australian Institute of Health and Welfare (AIHW), the health system and the NDIS.[48]

8.32 To this end, the AIHW reported that the Commonwealth and governments of New South Wales, Queensland, South Australia, and Victoria are working together to develop a National Disability Data Asset (NDDA) that incorporates datasets from different levels of government. According to the AIHW, the NDDA aims to:

> …improve outcomes for people with disability, their families and carers, by sharing de-identified data to better understand the life experiences and outcomes of people with disability in Australia.[49]

8.33 The NDDA is currently in a pilot phase designed to demonstrate the potential of using data to support improved policy development, program design and service delivery for people with disability. The test cases focus on early childhood, justice, education to employment, mental health, and how linked administrative data can support an outcomes framework under the new National Disability Strategy.[50] The value of the NDAA was shared by Professor Julian Trollor, from the University of New South Wales:

> This is a rich resource bringing together multi linkages, including people with all sorts of disability types and linking it to other sources of information that would help us understand the health and wellbeing outcomes and other outcomes for those with disabilities. …If we were able to promote that resource and ensure that it is actually developed, that would be a really great help for the autistic community and shine light on gaps and strategies that we may be able to use [51]

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[47] CliniKids, *Submission 15*, [p. 4].

[48] Autism CRC, *Submission 46*, p. 10.

[49] Australian Institute of Health and Welfare (AIHW), *Submission 74*, [p. 4].

[50] AIHW, *Submission 74*, [p. 4].

[51] Professor Julian Trollor, Chair, Intellectual Disability Mental Health; and Head, Department of Development Disability Neuropsychiatry, School of Psychiatry, UNSW Sydney, *Proof Committee Hansard*, 15 April 2021, p. 42.

8.34 The potential long-term benefits of the NDAA for different users are described in Table 8.2.

Table 8.2 Potential long-term benefits of the National Disability Data Asset for different users

People with disability, family members and carers	Access better information to understand what supports and services may be right for their needs and situation. Over time, benefit from supports and services that have been designed for their needs and situation because service providers have access to better evidence about what works. Use the better supports, services and information to live and work with greater inclusion and opportunity.
Organisations that serve people with disability	Access information to help them deliver better and more suitable supports and services. Move into areas of unmet demand and growing demand to better serve people with disability. Access evidence to support positive social and economic changes for people with disability.
Researchers	Access better, more complete data from system-wide and person-centred perspectives. Access data in in a safe, timely and simple manner – including protecting privacy. Collaborate with government, the disability community and industry to improve outcomes for people with disability.
Governments	Understand the outcomes of people with disability. Understand how to better reach and serve vulnerable and less-often-reached groups in the community. Understand how different supports and services contribute to outcomes for people with disability.

Source: National Disability Data Asset, The NDAA for different users, www.ndda.gov.au/about/the-ndda-for-different-users/ *(accessed 17 November 2021).*

A National Autism Research Framework

8.35 Various stakeholders argued for a nationally coordinated approach to autism research[52] and proposed that the National Autism Strategy be used to define a National Autism Research Framework.[53] For example, the Samaritans suggested that:

> A research framework should be clearly defined in the National Autism Strategy. It should identify priority areas for research, establish overarching principles and guidelines for all research projects and provide coordination for the distribution of funding.[54]

8.36 In addition, more than one submitter suggested using the work of the Australian Autism Research Council (AARC) as a starting point.[55] The AARC was established under the Autism CRC to determine national priorities for autism research (see Figure 8.3).[56] It includes representatives of the autistic and broader autism communities, as well as service providers, health and education professionals, government program managers and policy makers, and researchers.[57]

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[52] See, for example, Australian Autism Alliance, *Submission 52*, p. 6; Autism CRC, *Submission 46*, p. 26; St Vincent's Health Australia, *Submission 72*, p. 3.

[53] See, for example, Australian Autism Alliance, *Submission 52*, p. 47; Samaritans, *Submission 99*, p. 8; Commissioner for Children and Young People South Australia, *Submission 88*, p. 5.

[54] Samaritans, *Submission 99*, p. 8.

[55] CliniKids, *Submission 15*, [p. 10]; Australian Autism Alliance, *Submission 52*, p. 47.

[56] Australian Autism Alliance, *Submission 52*, p. 47.

[57] Autism CRC, *Australian Autism Research Council*, www.autismcrc.com.au/aarc (accessed 17 November 2021).

Figure 8.3 Australian Autism Research Council priorities

Australian Autism Research Council:
2019 Research Priorities

Gender, diversity and inclusion
How do we ensure equity for autistic individuals regardless of gender, intersectional identity or cultural background?

Built environment
How can built environments be made more accessible to the autistic community?

Education
How can we transition to an inclusive education system that meets the needs of students on the autism spectrum?

Health and disability services delivery
How is the physical and mental health of autistic Australians affected by the availability and accessibility of health, disability and education services?

Choice in living and housing
How do we ensure that autistic people have choice and control over where they live and who they live with?

Employment
How can Australia transition to an inclusive workforce that provides opportunities for meaningful employment to all autistic people?

Health and wellbeing
How do we ensure optimal physical and mental health for all autistic Australians?

Communication
How can we best support the communication skills of autistic Australians?

Family and carer support
How can we best support families and carers of people on the spectrum?

Justice
What measures can be taken to prevent discrimination, exploitation, violence and abuse of autistic Australians, and ensure equity in accessing justice?

Source: Australian Autism Research Council, Australian Autism Research Council: 2020–21 research priority update, April 2021, p. 7.

8.37 In addition, the Autism Alliance observed that a National Autism Research Framework should complement the National Disability Research Agenda being developed as part of the National Disability Research Partnership.[58]

Committee view

8.38 In the committee's view, funding for autism research appears disproportionately low compared to the prevalence of autism in the community. It is particularly puzzling that autism does not feature more prominently in National Health and Medical Research Council funding given that it is in the top 20 leading causes of non-fatal burden of disease in Australia,[59] as well as being the most common (and fastest growing) disability type in the National Disability Insurance Scheme (NDIS).

8.39 However, the committee realises there will always be constraints on the amount of funding available for research. Therefore, the committee believes a National Autism Research Framework is needed to guide autism research in Australia and maximise the impact of limited funding. The national framework should

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[58] Australian Autism Alliance, *Submission 52*, p. 47.

[59] AIHW, *Australian Burden of Disease Study: impact and causes of illness and death in Australia 2018*, pp. 31–36 and 89–90. In 2018, autism ranked as the 16th leading cause of non-fatal burden of disease (up from 25th in 2003). Autism ranked 11th for males overall, 6th for males under 5 years, 3rd for males aged 5–14 years, 8th for males aged 15–24 years and 9th for males aged 25–54. It was ranked 10th for females aged 5–14 years.

establish priority research topics, as well as guide an appropriate mix basic and applied research, as well as longitudinal and cross-sectional studies.

8.40 To this end, the committee notes the significant work done by the Australian Autism Research Council to determine national priorities for autism research in Australia. This work, along with the recommendations in this report, should form the basis of the new research framework. The committee also endorses co-production of research with the autistic community as a core principle of the framework.

8.41 However, the committee is mindful that the new autism research framework would not exist in a vacuum. There is significant work underway at a national level on general disability research. The National Disability Research Partnership and the National Disability Data Asset pilot are promising initiatives, with the potential to help improve outcomes for people with disability. Consideration should be given to establishing a National Autism Register to allow data linkage across states and between levels of government (including as part of any future implementation of the National Disability Data Asset).

8.42 Efforts should be made to ensure the new National Autism Research Framework aligns with these broader national research initiatives. Conversely, these national research initiatives should also consider establishing autism as a key priority area for research. For example, given concerns about the sustainability of NDIS, governments should consider whether autism should be given greater priority in national research agendas. This could be done by creating autism specific funding streams within existing grants programs.

Recommendation 26

8.43 The committee recommends that a National Autism Research Framework be agreed under the auspices of the National Autism Strategy. This framework should be:

- **based, as a starting point, on the research priorities agreed by the Australian Autism Research Council;**
- **informed by the recommendations in this report; and**
- **compatible with the National Disability Research Agenda being developed by the National Disability Research Partnership.**

Recommendation 27

8.44 The committee recommends that the taskforce established to develop the National Autism Strategy investigate options for improving the collection of data about autistic people to better inform research, policy and practice in relation to improving life outcomes for autistic people. This should include:

- **exploring the feasibility of establishing a National Autism Register;**

- **engaging with the Disability Advisory Council to ensure any proposed activities build on (or are compatible with) the results of the National Disability Data Asset pilots;**
- **engaging with the Disability Advisory Council to ensure that data needs in relation to autistic people are adequately represented in any future National Disability Data Asset; and**
- **identifying any gaps in data collection that will not be met by the National Disability Data Asset.**

Recommendation 28

8.45 The committee recommends that the Australian Government prioritise autism research as part of the National Disability Research Agenda and National Disability Data Asset, given that autism represents the most prevalent (and fastest growing) primary disability type in the NDIS. This should include the creation of separate autism-specific funding streams within existing research grant programs.

Chapter 9
Advocacy

9.1 This chapter provides an overview of the current state of disability advocacy in Australia, as well as a discussion of identified challenges in relation to autism advocacy. These include:

- unmet demand and lack of funding for advocacy services;
- the lack of autism-specific advocacy services; and
- challenges arising from the breadth of the autism spectrum.

Overview

9.2 The Department of Social Services defines disability advocacy as 'acting, speaking or writing to promote, protect and defend the human rights of people with disability'.[1] Advocacy can be either systemic or individual.[2]

9.3 Stakeholders highlighted the importance of advocacy to people with autism, as well as those with disability more broadly.[3] For example, the Tasmanian Government stated that advocacy services are 'critical in helping ensure people with disability can enjoy the same rights and access the same services as others'.[4] Likewise, the Marymead Autism Centre described advocacy as 'a vital safeguard for autistic people across an array of different rights and areas of life'.[5] Another submitter pointed to the effectiveness of funding advocacy services, noting that 'every dollar used by Australia's independent disability advocacy agencies delivers $3.50 in benefits'.[6]

9.4 In 2019–20, Australian Government funding for disability advocacy was 'close to $46 million'. This included $20.8 million for the National Disability Advocacy Program (NDAP) which awards grant funding to providers to deliver disability

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[1] Department of Social Services, *Disability Advocacy Fact Sheet*, 5 December 2018, [p. 1].

[2] Department of Social Services, *National Disability Advocacy Framework*, 1 August 2012, p. 2. Systemic advocacy seeks to introduce and influence longer term changes to ensure the rights of people with disability are attained and upheld to positively affect the quality of their lives. Individual advocacy supports people with disability to exercise their rights, through either one-to-one support, or by supporting people to advocate for themselves individually, through a third party or on a group basis.

[3] See, for example, The Sycamore School, *Submission 118*, p. 7; Autism Advisory and Support Service, *Submission 21*, pp. 5-6; Coalition of Autistic Women, *Submission 125*, [p. 15]; Marymead Autism Centre, *Submission 128*, p. 9; Name withheld, *Submission 126*, p. 24.

[4] Tasmanian Government, *Submission 19*, p. 9.

[5] Marymead Autism Centre, *Submission 128*, p. 9.

[6] Name withheld, *Submission 126*, p. 24.

advocacy support.[7] Advocacy support provided under the NDAP aims to promote 'the social inclusion and participation of people with disability within the economy and community'.[8]

9.5 It is not clear how many autistic people currently access advocacy support via the NDAP. Since 2017-18, autism has been captured within a broad 'psychiatric' category that includes a number of other conditions. In 2018-19, that category represented 22.9 per cent of clients accessing disability advocacy services. Prior to that time, in 2016-17, autistic people represented 12.4 per cent of people accessing services funded through the NDAP.[9]

9.6 The Australian Government also funds advocacy support through the National Disability Insurance Scheme (NDIS) Appeals Program. This program provides support to people seeking reviews of decisions of the National Disability Insurance Agency (NDIA) in the Administrative Appeals Tribunal. Support is provided through access to a disability advocate who acts as a support person, as well as access to funding for legal services in some cases. In 2019-20 the program funding was $10.7 million.[10]

9.7 According to the Department of Social Services, Department of Education, Skills and Employment, and Department of Health (the departments), all state governments—except South Australia—also have programs to fund disability advocacy services.[11]

9.8 Evidence presented to the inquiry suggests that the primary issues identified in relation to advocacy relate to:

- unmet demand and lack of funding for advocacy services;
- the lack of autism-specific advocacy services; and
- challenges arising from the breadth of the autism spectrum.

Demand and funding for advocacy services

9.9 The need for autism advocacy support was underlined by the findings of an Australian Autism Alliance (the Autism Alliance) survey which asked about

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[7] Department of Social Services, Department of Education, Skills and Employment, and Department of Health, *Submission 53*, p. 56; Department of Social Services, *Operational Guidelines for the National Disability Advocacy Program*, January 2021, pp. 5 and 6.

[8] Department of Social Services, Department of Education, Skills and Employment, and Department of Health, *Submission 53*, p. 56.

[9] Department of Social Services, Department of Education, Skills and Employment, and Department of Health, *Submission 53*, p. 56.

[10] Department of Social Services, Department of Education, Skills and Employment, and Department of Health, *Submission 53*, p. 57.

[11] Department of Social Services, Department of Education, Skills and Employment, and Department of Health, *Submission 53*, p. 56. See also, Australian Autism Alliance, *Submission 52*, p. 51.

people's 'confidence and understanding' in relation to self-advocacy. The survey found that:

- more than 22 per cent of autistic adults reported that they did not know where to get help if they were experiencing violence, abuse or neglect;
- 45 per cent did not know where to get help if they were experiencing discrimination or exclusive practices (such as a lack of opportunities to access education, accommodation, recreation and leisure); and
- 39 per cent did not know where to get help with the law, tenancy, Centrelink or with having enough money to meet their needs, or to speak up for themselves and self-advocate in general.[12]

9.10 The Autism Advisory and Support Service noted that this may be a particular issue for disadvantaged cohorts whose vulnerability in the absence of an advocate may result in a failure 'to access crucial supports'.[13] Mrs Grace Fava, Chief Executive Officer of the Autism Advisory and Support Service explained further:

> We work in south-western Sydney. We have one of the largest [culturally and linguistically diverse] communities, one of the lowest socio-economic communities… There is a lack of funding for advocacy and a lack of funding for family support, yet, if you want a good outcome for an individual, you need to support the whole family.[14]

9.11 While there appears to be a lack of data on the utilisation of advocacy services,[15] some stakeholders also indicated that demand is exceeding supply.[16]

9.12 Evidence provided by Autism Aspergers Advocacy Australia (A4) appeared to support the notion of a shortage of advocacy services, with reports that funded services were referring growing numbers of autistic clients to charities and volunteer organisations such as A4. Likewise, another submitter described disability advocacy services as 'understaffed, overburdened and overwhelmed'.[17] This sentiment was also evident in the experience of one autistic submitter who contended that existing services were being overwhelmed by demand:

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[12] Australian Autism Alliance, *Submission 52*, pp. 51-52.

[13] Autism Advisory and Support Service, *Submission 21*, pp. 5-6. In this context, disadvantaged cohorts include those from diverse cultural, linguistic and socio-economic backgrounds, those with other co-occurring conditions and mental health difficulties, and carers with disabilities.

[14] Mrs Grace Fava OAM, Chief Executive Officer, Autism Advisory and Support Service, *Proof Committee Hansard*, 28 July 2021, p. 46.

[15] Australian Autism Alliance, *Submission 52*, p. 51; Autism Aspergers Advocacy Australia (A4), *Submission 54*, p. 27.

[16] See, for example, Marymead Autism Centre, Submission 128, p. 9; Autism Advisory and Support Service, *Submission 21*, p. 8; Name withheld, *Submission 126*, p. 24.

[17] Name withheld, *Submission 155*, p. 23.

> Oh, and please fund disability advocates—they are scarce and overwhelmed. The notion that they would help me with an appeal of my NDIS rejection was illusory. They just didn't have the staff to cover it. I get the feeling that disability advocacy partly still exists to salve the consciences of people who never expect to need a disability advocate.[18]

9.13 The committee heard that the NDIS was a key factor behind the increase in demand.[19] For example, the Autism Alliance indicated that, following the introduction of the NDIS, there was a 70 per cent increase in the number of people requesting advocacy related to disability services and the NDIS.[20]

9.14 At the same time, the Autism Alliance suggested that this was compounded by the absence of an 'ongoing and consistent funding model', as well a lack of clarity about the roles of the Commonwealth, state and territory governments in relation to advocacy funding.[21] The Autism Alliance also suggested that funding for advocacy services was not keeping up with the increased demand. It also observed that the United Nations' Committee on the Rights of Persons with Disabilities had 'expressed concern about the unsustainability and inadequacy of resources for continuous, individual and independent advocacy programmes in Australia'.[22]

9.15 Accordingly, stakeholders such as the Autism Alliance and the Commissioner for Children and Young People South Australia, called for the development of a nationally consistent approach to disability advocacy that clearly defined responsibilities for all levels of government.[23]

Autism-specific advocacy services

9.16 Evidence presented to the committee suggests there is the need to improve dedicated advocacy services for autistic people. This includes:

- less reliance on general disability advocacy services;
- support for autistic-led advocacy services;
- support for systemic advocacy; and
- a focus on building autistic people's self-advocacy skills.

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[18] Name withheld, *Submission 112*, [p. 16].

[19] Name withheld, *Submission 126*, p. 24.

[20] Australian Autism Alliance, *Submission 52*, p. 51.

[21] Australian Autism Alliance, *Submission 52*, pp. 6 and 51.

[22] Australian Autism Alliance, *Submission 52*, p. 51. See also, Name withheld, *Submission 126*, p. 24.

[23] Australian Autism Alliance, *Submission 52*, p. 6; Commissioner for Children and Young People South Australia, *Submission 88*, p. 11.

General disability advocacy services

9.17 Despite autism being the largest single cohort in the NDIS, the committee heard that the NDAP does not support autism-specific advocacy services and that many of the general advocacy organisations just assume that 'supports designed for other disabilities will suit autistic people'.[24]

9.18 However, as noted by Different Journeys, such assumptions can often set autistic people up for failure, rather than success.[25] A4 gave the example of generic services focusing on social inclusion rather than access to behaviour support that would help an autistic person prepare for a transition to increased social inclusion. According to A4:

> The advocates simply do not recognise and understand – they have no experience with – the risks due to unsupported social submersion and how social skills might or might not emerge for an autistic person.[26]

9.19 This was supported by multiple stakeholders, who expressed the view that general disability advocacy groups are not equipped to meet the needs of autistic people.[27] For example, A4 considered 'generic' advocates—or those with specialisations other than autism—to be 'quite poor in their advocacy for autistic clients'. As a result, this means that autistic people have:

> …very little experience of appropriate supports and few good models to emulate so their self-advocacy is often limited by their lack of experience of appropriate services and service models.[28]

9.20 Different Journey concurred and argued that the unique nature of autism requires autism-specific advocacy that can model 'different ways to communicate, behave, and question to ensure that their voices are heard'.[29]

9.21 However, the committee heard that this issue is not peculiar to Australia. The Autism Alliance referred to a United Kingdom survey of advocacy organisations which found that 62 per cent 'experienced significant difficulty working with autistic people and had little confidence in the ability to advocate effectively for this population', while 32 per cent would not provide services to autistic people. The concerns of advocacy organisations generally centred on

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[24] A4, *Submission 54*, pp. 27 and 28.

[25] Different Journeys, *Submission 30*, p. 22.

[26] A4, *Submission 54*, p. 28.

[27] See, for example, Australian Autism Alliance, *Submission 52*, p. 52; Different Journeys, *Submission 30*, p. 21; Name withheld, *Submission 126*, p. 24.

[28] A4, *Submission 54*, p. 24.

[29] Different Journeys, *Submission 30*, p. 21.

'their understanding of autism or concerns about advocating for people with communication difficulties'.[30]

9.22 In response, at least one submitter advocated for training to help 'disability advocacy organisations to build their autism capacity in leadership and governance'.[31]

Autistic-led advocacy services

9.23 The committee heard that 'while autism training is necessary',[32] it is not sufficient on its own to improve advocacy services for autistic people. For example, Ms Geraldine Robertson explained that:

> …the complexity of autism means that it is unlikely that most people will understand the subtleties required to understand the motives, motivators and challenges experienced by this population. Even parents, with all their love and dedication to their children, often do not have those perspectives.[33]

9.24 The importance of lived experience of autism was also highlighted by Different Journeys:

> Our role is simple compared to those that are funded for advocacy—we have lived experience, we understand, we can show [autistic people] advocacy in a way that empowers them to eventually be able to do it for themselves…[34]

9.25 Accordingly, there was support for increasing the role autistic-led organisations play in advocating for autistic people.[35] For example, the Autism Alliance argued that autistic people need advocacy that is 'user led' and has 'a thorough understanding of the issues faced by autistic people'.[36]

9.26 The Autism Alliance and other submitters also highlighted the potential for autistic-led advocacy organisations to work with mainstream services and general advocacy groups to build their understanding of autism.[37]

9.27 This view was supported by Ms Geraldine Robertson who also noted that the 'very deep understanding of autism' acquired by many autistic people is

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[30] Australian Autism Alliance, *Submission 52*, p. 52.

[31] Name withheld, *Submission 126*, p. 24.

[32] Ms Geraldine Robertson, *Submission 165*, [p. 4].

[33] Ms Geraldine Robertson, *Submission 165*, [p. 4].

[34] Different Journeys, *Submission 30*, p. 21.

[35] See, for example, Australian Autism Alliance, *Submission 52*, p. 6; Scope-University of Melbourne Partnership, *Submission 83*, p. 7; Name withheld, *Submission 126*, p. 24; Yellow Ladybugs, *Submission 49*, p. 2; Autism Advisory and Support Service, *Submission 21*, p. 8.

[36] Australian Autism Alliance, *Submission 52*, p. 52.

[37] Australian Autism Alliance, *Submission 52*, p. 52. See also, Different Journeys, *Submission 30*, p. 21; Name withheld, *Submission 126*, p. 24.

proving to be a valuable resource to 'many organisations with autistic advisory boards and autistic employees who provide a conduit between organisations and systems and the autistic users'.[38]

Systemic advocacy

9.28 A number of stakeholders raised the need to better support autism-related systemic advocacy.[39] The Autism Alliance pointed to the role systemic advocacy plays in aligning 'government policy and program design with the needs and expectations of autistic people'.[40]

9.29 Accordingly, there were multiple calls for governments to establish and fund a national peak body for autism organisations—or a national autism advisory panel—that could provide advice to government and 'apply an autism lens to policy proposals, legislation and regulations beyond those that specifically target people with autism'.[41] Mrs Donna Blanchard of Autism Tasmania shared this view:

> We know that our community here is very vulnerable. They don't have the sophistication that's required to have their voice at a table such as this. We do need to invest in systemic advocacy at state and federal level.[42]

9.30 Both the Cooperative Research Centre for Living with Autism (Autism CRC) and The Autistic Realm Australia (TARA) also raised the importance of autistic representation on boards (and in other influential positions) in order to influence policy and practice.[43] To this end, the Autism CRC acknowledged recent progress in this regard and highlighted the work of its Sylvia Rodger Academy which delivers programs in governance, leadership and advocacy. At the time of submitting, the Autism CRC noted that 14 autistic adults were in the process of completing the Governance Program, while 45 autistic adults had participated in the Future Leaders programs since 2018.[44]

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[38] Ms Geraldine Robertson, *Submission 165*, [p. 4].

[39] Australian Autism Alliance, *Submission 52*, p. 53; Scope-University of Melbourne Partnership, *Submission 83*, p. 7; A4, *Submission 54*, p. 28; Different Journeys, *Submission 30*, p. 21; Mr David Staples, *Submission 143*, [p. 20].

[40] Australian Autism Alliance, *Submission 52*, p. 53.

[41] Commissioner for Children and Young People South Australia, *Submission 88*, p. 5. See also, Australian Autism Alliance, *Submission 52*, p. 53; A4, *Submission 54*, p. 28; The Autistic Realm Australia (TARA), *Submission 86*, p. 26.

[42] Mrs Donna Blanchard, Chief Executive Officer, Autism Tasmania Incorporated, *Proof Committee Hansard*, 29 April 2021, p. 5.

[43] Cooperative Research Centre for Living with Autism (Autism CRC), *Submission 46*, p. 29; TARA, *Submission 86*, p. 2. See also, Mrs Natasha Staheli, Strategic Relationships and Policy Adviser, Yellow Ladybugs, *Proof Committee Hansard*, 11 February 2021, p. 38.

[44] Autism CRC, *Submission 46*, p. 29. Recent progress in relation to autistic representation includes:

Building self-advocacy skills

9.31 The committee heard multiple calls for action to build the self-advocacy skills of autistic individuals.[45] For example, A4 highlighted the 'enormous scope to develop autistic self-advocacy and self-determination'. It observed that increasing the ability of autistic people to advocate for themselves will, in turn, help to increase their independence as they experience success in their advocacy attempts. However, it also pointed to the need for services and communities to be 'receptive and responsive' to autistic self-advocacy.[46]

9.32 Both Amaze and Different Journeys suggested that peer networks could play an important role in building the capacity of autistic people to advocate for themselves and other autistic individuals.[47] As an example, Amaze pointed to the role its statewide peer-led support groups play in engaging and empowering autistic people and parents of autistic children:

> Built on foundations of self-reliance and self-advocacy, this network provides autistic people with information, empowerment, and control over how they engage with the autism community and essential service providers, such as the NDIS. Importantly, these groups help their members to self-manage a range of decisions, challenges and opportunities in their engagement with mainstream services and in their daily lives.[48]

9.33 However, Different Journeys stressed that additional funding would be needed to expand peer-led supports. It explained that high burnout rates and an overreliance on goodwill and volunteer staff mean that current arrangements are unsustainable.[49]

9.34 The committee also heard evidence that capacity building could start much earlier in life. For example, the Commissioner for Children and Young People Western Australia argued there was a need for 'mechanisms to support children

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- the appointment of autistic individuals to Board and management positions with a number of autism service providers;
- the appointment of an autistic co-chair at the Australian Autism Alliance, in addition to a number of other autistic members;
- the appointment of an autistic co-chair to the Australian Autism Research Council, in addition to a number of other autistic members; and
- the appointment of two autistic members to the National Disability Insurance Agency (NDIA) Autism Advisory Group.

[45] See, for example, Government of Western Australia, *Submission 103*, p. 8; Autism Advisory and Support Service, *Submission 21*, p. 8; Yellow Ladybugs, *Submission 49*, p. 10; The Sycamore School, *Submission 118*, p. 9; PEERS Australia, *Submission 108*, p. 7; Spectrum Labor, *Submission 1*, [p. 20].

[46] A4, *Submission 54*, p. 27.

[47] Amaze, *Submission 154*, [p. 2]; Different Journeys, *Submission 30*, p. 21.

[48] Amaze, *Submission 154*, [p. 2].

[49] Different Journeys, *Submission 30*, p. 21.

and young people with autism to have a say in decision making and the design of services and supports'.[50]

9.35 Some stakeholders pointed to the role schools could play in building self-advocacy skills for autistic people. For example, The Sycamore School explained how self-advocacy and self-determination skills are instilled in students at the school:

> …and just as we expect they will be able to engage with the NDIS in this way into the future, we similarly involve them in goal setting and planning for their educational and developmental progress. By empowering students to describe their wants, needs and challenges, our teaching teams are able to develop meaningful and effective teaching and learning strategies … The impact of this approach has been extremely positive, resulting in students taking ownership of the goals they set, and responsibility for their effort and progress.[51]

9.36 Similarly, the Scope-University of Melbourne Partnership suggested schools could be supported to provide advocacy training that is 'designed by, or at least in consultation with, autistic individuals'.[52]

9.37 Some stakeholders, such as the Government of Western Australia, advocated for the NDIS to play a greater role in funding individual capacity building activities.[53]

The breadth of the autism spectrum

9.38 Evidence provided to the committee suggests that some of the challenges in relation to autism advocacy arise from the breadth of the spectrum itself. As one submitter noted, the diagnostic term Autism Spectrum Disorder 'covers people in very different "worlds", with vastly diverse experiences and conflicting worldviews regarding autism'.[54] Similarly, A4 noted that:

> The issue of what autism actually is, in the eyes of the autism community, is a primary issue. Autism is defined in manuals of 'disorder' … However, many articulate autistics say autism is not a 'disorder', instead they describe it as a 'condition' or 'difference'. Some use the term 'neurodivergent'.[55]

9.39 This diversity means that while some autistic people are very capable of self-advocacy, many others are not. A4 pointed out that, in 2018, almost 70 per cent of autistic Australians were 'severely or profoundly affected by their autism'. This means:

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[50] Commissioner for Children and Young People Western Australia, *Submission 42*, p. 9.

[51] The Sycamore School, *Submission 118*, p. 7.

[52] Scope-University of Melbourne Partnership, *Submission 83*, p. 7.

[53] Government of Western Australia, *Submission 103*, p. 8.

[54] Name withheld, *Submission 31*, p. 3.

[55] A4, *Submission 54*, p. 27.

> They are not good communicators. They do not articulate clearly their long-term goals. They need support with strategy, communication, organisation, activation and with achieving their goals and aspirations.[56]

9.40 Communication Rights Australia also noted that some autistic people are affected to the point of having little or no speech.[57]

9.41 More than one submitter contended that the variation in the spectrum was 'unfortunately a source of discord between autism advocates'.[58] This seemed to be a particular issue in relation to autistic people with more complex presentations, who may be non-verbal and therefore reliant on parent or carer advocacy.[59]

9.42 While the importance of parental advocacy was recognised by a number of submitters,[60] A4 asserted that 'non-autistic advocates often do not respect the views and experience of autistic people'.[61] Other submitters emphasised the need to prioritise the autistic voice over non-autistic parents and carers.[62] For example, TARA argued that while parents and health professionals have an important advocacy role, 'those voices must not be prioritised over those of the autistic community':

> Listen to us. People talk over autistic people all the time. Governments and society need to actively seek out autistic people to hear what we have to say. Non-autistic parents of autistic children are not representative of our community. We need people to listen to us and take action based on what we say – Joanna, 48.
>
> The voices and lived experience of adult autistic people need to be prioritised over parents of autistic children. We were those children. Those children will grow up to be us. While any parent knows their child best, autistics know autism best. We could be such valuable assets and allies if we were listened to – Anna, 56.[63]

9.43 However, the committee also heard concerns that this approach prioritises the voices of articulate autistic people who are capable of self-advocacy and is not

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[56] A4, *Submission 54*, p. 28.

[57] Communication Rights Australia, *Submission 151*, p. 10.

[58] Name withheld, *Submission 31*, p. 3. See also, A4, *Submission 54*, p. 27; Aspergers Victoria, *Submission 90*, [p. 9].

[59] Name withheld, *Submission 2*, p. 2.

[60] La Trobe University – the Olga Tennison Autism Research Centre (OTARC), *Submission 55*, p. 25; Australian Autism Alliance, *Submission 52*, p. 52; Name withheld, *Submission 122*, [p. 1].

[61] A4, *Submission 54*, p. 27.

[62] See, for example, Scope-University of Melbourne Partnership, *Submission 83*, p. 7; Spectrum Labor, *Submission 1*, [pp. 17 and 20].

[63] TARA, *Submission 86*, pp. 25 and 26.

inclusive of people with more complex presentations, including those with concurrent intellectual disability, as well as multiple co-occurring conditions.[64]

9.44 For example, one submission described the experience of Alex, a 12-year-old boy in the Complex Needs NDIS stream, who is diagnosed as Autism Spectrum Disorder Level 3 with 'severe intellectual disability, severe communication disorder, severe sensory processing difficulties and generalised anxiety disorder', as well as physical health issues that cause significant digestive pain. Alex also displays 'high frequency, high intensity behaviours that present significant risks to himself and others on several days each week'. While Alex's parents explained they are 'genuinely glad' for autistic people who are able to contribute productively to society and can celebrate their autism as neurodiversity, they argued that:

> …the neurodiversity perspective cannot be considered an appropriate representation for Alex and others with severe/profound [intellectual disabilities] and debilitating co-morbidities. That would put them at very high risk of being misunderstood, left behind, in some cases worse off and inevitably hidden.[65]

9.45 In relation to autistic behaviours, A4 noted that less verbal autistic people will sometimes 'express their needs and preferences through their behaviour' and that people do not recognise this until it escalates to a point where it cannot be ignored and is called 'unwanted' or 'challenging'. According to A4, 'people rarely recognise and respect expression-through-behaviours as 'self-advocacy' or 'self-determination'.[66]

9.46 While recognising Alex's behaviours as expressions of distress, Alex's parents explained that these behaviours are triggered significantly by the combination of both his physical health issues, which cause extended periods of distress and pain, and his neurodevelopmental conditions. They explained that these behaviours continue to present daily, 'despite support from highly skilled staff in all settings, an environment which is fully adapted to meet his needs and attentive, devoted parents and carers'. Accordingly, Alex's parents argued that there was a need for:

> …much greater understanding of those severely impacted with autism, severe/profound [intellectual disabilities] and complex behaviours … so that appropriate advocacy can be established. This is a small, highly vulnerable group of individuals, largely misunderstood, whose existence and heart-breaking realities are often treated, in our view, even by leading autism advocacy groups, as 'myths' to be dispelled or stereotypes to be avoided.[67]

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[64] Name withheld, *Submission 38*, [p. 3].

[65] Name withheld, *Submission 31*, pp. 1 and 3–4.

[66] A4, *Submission 54*, p. 29.

[67] Name withheld, *Submission 31*, pp.1 and 3.

9.47 Likewise, Communication Rights Australia emphasised the need for specialised advocacy services to ensure the need, concerns and wishes of autistic people with high communication support needs.[68]

9.48 Despite these diverging views, the committee heard from other stakeholders who hoped to bridge this divide. For example, one submitter noted that while her experience of autism may not resonate with the parents of autistic children with severe challenges, she hoped that 'as both a mother and an autistic, I can contribute to some common understanding between the two groups'. She also suggested connecting self-advocates with families of children with multiple disability so that parents and self-advocates could learn from each other by walking 'a mile in each other's shoes'.[69]

9.49 In addition to the tension between parents and self-advocates, the committee also heard that there were polarised views within the autistic community itself. For example, A4 stated that 'some autistic advocates do not respect other autistics with views that vary from their own'.[70] A similar view was shared by Aspergers Victoria which reflected that 'sometimes the loud voices of a few advocates who are capable of gaining voice shout down the voices of others on the spectrum'. It argued that:

> This needs to be considered—that an influential advocate doesn't speak for everyone. The autism community includes our autistics, parents/families, allies and professional supporters—and they all need a voice. We need a balance of voices to be heard at government levels.[71]

9.50 Given the heterogeneity of the autism spectrum, and the relative recency of the consolidated Autism Spectrum Disorder diagnostic label, Aspergers Victoria suggested pursuing a federated model of representation, which is an approach sometimes used in health advocacy.[72]

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[68] Communication Rights Australia, *Submission 151*, p. 10.

[69] Name withheld, *Submission 2*, p. 2.

[70] A4, *Submission 54*, p. 27.

[71] Aspergers Victoria, *Submission 90*, [p. 9].

[72] Aspergers Victoria, *Submission 90*, [p. 10]. The DSM-5 was released in 2013. Federated representation involved representatives of particular subgroups speaking on behalf of their smaller constituency when addressing certain issues but coming together with other representatives (either under the auspices of an umbrella organisation or as part of an ad hoc coalition) to speak as one about issues affecting a broader group of people.

Committee view

9.51 The committee heard that there is significant unmet demand for advocacy services, particularly in the wake of the introduction of the National Disability Insurance Scheme (NDIS). However, a lack of data means it is difficult to gain an accurate understanding of the utilisation and effectiveness of existing advocacy services.

9.52 The committee also heard that the current advocacy landscape lacks clarity in relation to its funding, roles and responsibilities, with the Commonwealth, state and territory governments all playing a role in funding advocacy services for people with disability.

9.53 The committee is also aware that a National Disability Advocacy Framework (NDAF) was agreed by all disability ministers in 2008. While its aims are laudable, the status of the document is unclear. As it appears to lack performance measures and timeframes, it is also not clear how much progress has been made toward delivering on its stated objectives.

9.54 Given the increase in demand for advocacy services, as well as the amount of time that has passed since the NDAF was released, the committee sees merit in a renewed commitment to a national approach to disability advocacy. This should include a review of the NDAF, as well as the inclusion of performance measures to allow monitoring of progress against agreed commitments.

9.55 Within this broader national framework, an autism-specific advocacy plan should be developed to guide actions in relation to improving advocacy for autistic people.

Recommendation 29

9.56 The committee recommends that the Commonwealth, state and territory governments re-commit to a national approach to disability advocacy. This should include:

- **reviewing the effectiveness of the National Disability Advocacy Framework, including the current status of its outputs and reform and policy directions; and**
- **updating the National Disability Advocacy Framework to include performance measures and reporting requirements for each of the outputs and reform and policy directions.**

Recommendation 30

9.57 The committee recommends that a National Autism Advocacy Plan be developed under the auspices of the National Autism Strategy. The National Autism Advocacy Plan should:

- **align with the National Disability Advocacy Framework; and**

- **identify actions to:**
  - **improve data collection and reporting on the utilisation and effectiveness of advocacy services for autistic people;**
  - **encourage the growth of autism-specific advocacy services, including autistic-led services;**
  - **increase the numbers of autistic people appointed to key positions in all organisations, including autism and disability-related organisations;**
  - **ensure better understanding of, and advocacy for, the needs of autistic people with complex presentations; and**
  - **bring together the diverse views and perspectives of the autistic community to improve advocacy for all autistic people.**

9.58 The committee is sensitive to the fact that there are range of views, capabilities and experiences among the autistic community. This reflects the diversity of the spectrum itself and can be a source of tension within the community.

9.59 For example, the committee heard from people who are able to embrace and celebrate their autism from a neurodiversity perspective. It also heard from parents and carers who fear that this view prioritises autistic people who are capable of self-advocacy and excludes those with complex presentations, as well as those with multiple disabilities.

9.60 During the course of the inquiry, the committee heard evidence that some autistic people thought they knew autism best, while some parents and carers felt they knew their children best. As one stakeholder suggested to the committee, perhaps more could be achieved if these groups walked a mile in each other's shoes[73] and built on what they have in common.

9.61 However, the committee also notes that tensions also exist within the autistic community itself. Therefore, the committee cautions against an approach to advocacy that sees any one group claiming to represent all autistic people or an approach that focuses only on the loudest voices at the table. The committee believes that, while there is a need to centre autistic voices, other voices must be heard as well, particularly when they speak for autistic individuals who are not able to advocate for themselves.

Recommendation 31

9.62 The committee recommends that the proposed National Autism Advocacy Plan reflects the need for differentiated advocacy services to support the range of presentations across the spectrum and the stage of life for those autistic people requiring advocacy.

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[73] Name withheld, *Submission 2*, p. 2.

9.63 As with disability services in general, generic advocacy approaches are not delivering for autistic people. The committee heard that these services lack the autism-specific skills and understanding to be effective advocates. Evidence presented to the committee suggests that uninformed advocacy can be ineffective, and in some cases, harmful.

9.64 Given that autism is the biggest single disability cohort in the NDIS and the NDIS is a significant driver of increased demand for advocacy service, the committee finds it incomprehensible that the major national advocacy program—the National Disability Advocacy Program—does not appear to fund autism-specific advocacy services. In the committee's view, there is an urgent need to ensure that all government-funded disability advocacy programs support at least one specialist autism advocacy service.

9.65 At the same time, governments should identify ways to improve the capacity of general advocacy services to support autistic people. This should include utilising the knowledge and skills of autism-specific advocacy groups.

Recommendation 32

9.66 The committee recommends that the Australian Government ensure that the National Disability Advocacy Program and other Commonwealth-funded disability advocacy programs fund at least one autism-specific advocacy service in each state and territory.

Recommendation 33

9.67 The committee recommends that state and territory governments commit to funding autism-specific advocacy services under their funded disability advocacy programs. Progress toward implementation could be monitored through the National Federation Reform Council.

Recommendation 34

9.68 The committee recommends that the Australian Government, through the Department of Social Services' Information Linkages and Capacity Building program, fund autism-specific advocacy groups to build the capacity of general disability advocacy organisations to support autistic people.

9.69 Alongside more targeted and responsive advocacy services, there is also a need to build the self-advocacy skills of autistic people. Not only does this improve access to services and supports but it builds confidence and independence—all of which have an impact on overall life outcomes.

9.70 The committee heard that peer support is one key way of building self-advocacy skills. Likewise, schools could also play a role in developing self-advocacy skills via the 'Personal and Social Capability' general capability within the Australian Curriculum. The potential for the NDIS to play a greater role in supporting participants' advocacy skills should also be explored.

Recommendation 35

9.71 **The committee recommends that the Australian Government, through the Department of Social Services' Information Linkages and Capacity Building program, fund autism-specific advocacy groups to build the self-advocacy and self-determination skills of autistic people (and their families), including through peer support programs.**

Recommendation 36

9.72 **The committee recommends that the Department of Education, Skills and Employment work with state and territory education authorities, the Australian Curriculum, Assessment and Reporting Authority, Education Services Australia and other relevant stakeholders to provide guidance and resources to help schools teach self-advocacy skills. While applicable to all school children, there should be a particular focus on making this content accessible to students with autism.**

Recommendation 37

9.73 **The committee recommends, as part of the inquiry into the National Disability Insurance Scheme proposed in Recommendation 6, that consideration be given to whether the National Disability Insurance Scheme could play a greater role in supporting the development of self-advocacy skills (as part of a participant's Capacity Building budget).**

Chapter 10
Diagnosis

10.1 This chapter briefly outlines the process of obtaining an autism diagnosis. It then goes on to discuss the importance of early diagnosis, as well as identified challenges in relation to consistent, timely and best practice autism diagnoses.

Overview

10.2 As described in Chapter 2, diagnosis of autism is made on the basis of developmental assessments and behavioural observations against the American Psychiatric Association's *Diagnostic and statistical manual of mental* disorders (5th edition)—commonly referred to as the DSM-5.

10.3 Autism can be diagnosed by either a single health professional or a multidisciplinary team of health professionals. A multidisciplinary team may be necessary where the symptoms are less clear or there are co-occurring conditions that make diagnosis more difficult.[1] Multidisciplinary approaches to assessments are also recommended as best practice.[2]

10.4 Autism diagnoses can be made in either the public or private health system. The process of obtaining a diagnosis usually begins with a referral from a general practitioner to a health professional who is qualified to make the diagnosis—for example, a psychologist, psychiatrist or paediatrician. Referrals can also be made directly to publicly funded assessment services in some cases.[3]

10.5 Publicly funded assessment services are generally free and usually consist of multi-disciplinary teams (or individual clinicians) based in hospitals or other publicly funded health services.[4]

10.6 Private assessments are offered on a fee-for-service basis. For children under 13 years of age, there are Medicare rebates that help cover the cost of an assessment by a paediatrician or child psychiatrist, as well as assessments by up to four

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[1] Autism Awareness Australia, *Who can diagnose autism?*, www.autismawareness.com.au/diagnosis/children/getting-a-diagnosis (accessed 20 November 2021).

[2] National Disability Insurance Agency (NDIA), *Submission 56*, p. 9.

[3] Autism What Next, *First steps to diagnosis*, www.autismwhatnext.com.au/pathway/children/road-to-diagnosis/first-steps-to-diagnosis (accessed 20 November 2021).

[4] Autism What Next, *First steps to diagnosis*, www.autismwhatnext.com.au/pathway/children/road-to-diagnosis/first-steps-to-diagnosis (accessed 20 November 2021).

allied health professionals (including psychologists, speech pathologists, occupational therapists, audiologists, optometrists and physiotherapists).[5]

The importance of early diagnosis

10.7 Currently, the average age of diagnosis in children in Australia is about 3-4 years of age,[6] with the most frequent age for diagnosis being 5.9 years.[7] This is despite research showing that diagnosis is possible as early as 18-24 months of age and that early diagnosis leads to better educational, social and economic outcomes for autistic people.[8]

10.8 For example, studies by La Trobe University's Olga Tennison Autism Research Centre (OTARC) have shown that children diagnosed before the age of two are less likely to receive a secondary diagnosis of intellectual disability and more likely to be in a mainstream school than children diagnosed later (see Table 10.1). Early diagnosis also reduces (by 30 per cent) the ongoing support required by school age children,[9] as well as lowering overall support costs for families and the wider community.[10]

Table 10.1 Effects of early diagnosis (* = IQ <70 at school age)

Diagnosis by 24 months	Diagnosis between 3–5 years
8 per cent have an intellectual disability*	24 per cent have an intellectual disability*
77 per cent in mainstream schools	57 per cent in mainstream schools

Source: La Trobe University – the Olga Tennison Autism Research Centre (OTARC), Submission 55, p. 4.

10.9 Despite this, OTARC revealed that in Australia:

- less than three per cent of children are diagnosed by two years of age; and
- less than 20 per cent of children are diagnosed by three years of age.[11]

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[5] Autism Awareness Australia, *Medicare and other funding*, www.autismawareness.com.au/funding/children/medicare (accessed 20 November 2021).

[6] La Trobe University – the Olga Tennison Autism Research Centre (OTARC), *Submission 55*, p. 4.

[7] Australian Medical Association (AMA), *Submission 40*, p. 1. Based on an analysis of Medicare data.

[8] See, for example, OTARC, *Submission 55*, pp. 4–5; Speech Pathology Australia, *Submission 87*, p. 8; Positive Youth Incorporated, *Submission 85*, p. 3; Office of the Public Advocate Victoria, *Submission 80*, p. 10; Aspect, *Submission 64*, p. 3; Australian Autism Alliance, *Submission 52*, p. 9.

[9] OTARC, *Submission 55*, p. 4.

[10] AMA, *Submission 40*, p. 1.

[11] OTARC, *Submission 55*, p. 4.

10.10 According to Autism Spectrum Australia (Aspect), diagnosis is likely to occur even later for 'females, milder presentations, those living in regional areas, and those who also have other conditions or developmental concerns'.[12]

10.11 While emphasising the importance of early diagnosis, the Australian Autism Alliance (the Autism Alliance) observed that diagnosis at any age provides benefits.[13] As a result, access to diagnosis remains important right across the lifespan. For example, without diagnosis, older children and adults may be unable to access appropriate supports, including via the National Disability Insurance Scheme (NDIS).[14] Diagnosis at an older age can also be important for autistic people's health and wellbeing. Professor Sandra Jones, Australian Catholic University, pointed out that for adults:

> …diagnosis is important to mental and physical health, as well as social and economic outcomes as it helps adults understand their needs and explain them to others, as well as dealing with being 'different' or feeling inadequate.[15]

10.12 The Autistic Realm Australia (TARA) concurred and observed that struggling 'with a sense of our difference, but without any understanding of why' can adversely an individual's ability to 'build meaningful and satisfying lives'.[16]

Challenges to obtaining a consistent, timely and best-practice diagnosis

10.13 Multiple stakeholders observed significant delays in obtaining an autism diagnosis.[17] For example, Speech Pathology Australia (SPA) noted that while best practice guidelines recommend a waiting period of no longer than three months, the median wait time for an assessment in the public system is 16 weeks (within a range of 2-108 weeks).[18]

10.14 Other submitters suggested that waiting periods could be even longer. For instance, Monash University contended that children wait a minimum of six months—but typically longer—for a formal assessment.[19] In addition, the

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[12] Autism Spectrum Australia (Aspect), *Submission 64*, p. 3.

[13] Australian Autism Alliance, *Submission 52*, p. 14.

[14] Aspect, *Submission 64*, p. 8; People with Disability Australia, *Submission 102*, p. 10.

[15] Professor Sandra Jones, Pro Vice-Chancellor, Engagement, Australian Catholic University, *Proof Committee Hansard*, 28 July 2020, pp. 13–14.

[16] The Autistic Realm Australia (TARA), *Submission 86*, p. 13.

[17] See, for example, AMA, *Submission 40*, p. 1; Department of Developmental Disability Neuropsychiatry, University of New South Wales (UNSW 3DN), *Submission 95*, p. 4; Early Start Australia, *Submission 76*, p. 2; Australian Autism Alliance, *Submission 52*, p. 8.

[18] Speech Pathology Australia, *Submission 87*, p. 8.

[19] Monash University, *Submission 94*, p. 15.

Australian Medical Association (AMA) reported that a survey of parents and carers revealed that 34 per cent waited over a year for a diagnosis, and almost 20 per cent waited for more than two years.[20]

10.15 For those in regional and remote areas, limited access to diagnostic services can further exacerbate these waiting periods.[21]

10.16 In response, stakeholders highlighted the role that a National Autism Strategy could play to set out actions to improve access to diagnosis and reduce waiting times.[22] Some, such as the Autism Alliance, advocated for a waiting period target of three months, as well as regular reporting to monitor progress.[23]

10.17 Overall, the committee heard that consistent, timely and best-practice diagnosis is hampered by a combination of factors, including:

- the complexity of diagnosis;
- inconsistent approaches to diagnosis;
- the availability of diagnostic services;
- the cost of diagnostic services; and
- a lack of autism awareness and understanding.

Complexity of diagnosis

10.18 Various stakeholders highlighted the complexity involved in providing an autism diagnosis and the heavy reliance on the expertise and experience of the professionals involved.[24]

10.19 For example, Autism Aspergers Advocacy Australia (A4) noted that in the absence of a biological marker, diagnosis relies on a 'subjective interpretation of a person's behaviour'.[25] Likewise, CliniKids observed that diagnosing autism is 'a "best estimate" clinical judgement based on the behavioural presentation of the individual'. While CliniKids argued that diagnostic manuals provide 'clear behavioural criteria for diagnoses', the breadth of autism symptoms and their overlap with other developmental disorders means that 'the appraisal of

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[20] AMA, *Submission 40*, p. 1.

[21] Australian Autism Alliance, *Submission 52*, p. 15; BioAutism, *Submission 93*, p. 12; Speech Pathology Australia, *Submission 87*, p. 8.

[22] See, for example, Aspect, *Submission 64*, p. 1; Early Start Australia, *Submission 76*, p. 4; Name withheld, *Submission 7*, [p. 2].

[23] Australian Autism Alliance, *Submission 52*, p. 4. See also, Ms Kay Turner, Chief Executive Officer, SDN Children's Services, *Proof Committee Hansard*, 28 July 2020, p. 40.

[24] See, for example, Royal Australasian College of Physicians, *Submission 29*, p. 5; Aspect, *Submission 64*, p. 2; Monash University, *Submission 94*, p. 17; Autism Awareness Australia, *Submission 47*, p. 2.

[25] Autism Aspergers Advocacy Australia (A4), *Submission 54*, p. 6.

individual behaviours is an inherently subjective task that relies heavily on clinician experience and skill'.[26]

10.20 Monash University also emphasised the importance of 'professional judgement and clinical experience', particularly as assessment tools are not reliable enough to form the sole basis of an autism diagnosis.[27]

10.21 Other stakeholders, such as SPA, also pointed to lack of precision in diagnosis when someone may have autism and co-occurring mental health conditions.[28]

Inconsistent approaches to diagnosis

10.22 According to the Royal Australasian College of Physicians (RACP), the task of providing accurate autism diagnoses in Australia is further complicated by significant variability between states and territories in relation to who can diagnose autism. It noted that:

> While some states require an [autism] diagnosis to be made through consensus of an experienced multidisciplinary assessment team of a paediatrician/psychiatrist, psychologist and speech pathologists, other states have less stringent criteria.[29]

10.23 SPA highlighted the importance of multidisciplinary diagnostic teams by explaining the role that speech pathologists play:

> An important role of a speech pathologist … is the differential diagnosis of autism and other communication related conditions … In addition, the speech pathologist will assist the multidisciplinary team to decide if the person's communication profile is more consistent with a description of intellectual disability, trauma, anxiety, or attention deficit disorder, or autism in conjunction with one or more of these other conditions.[30]

10.24 In addition to variability across state borders, differences can even occur within individual states and territories. For example, Mrs Mitzi Polacsek, Marymead Autism Centre, asserted that while the Australian Capital Territory Child

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[26] CliniKids, *Submission 15*, p. 3.

[27] Monash University, *Submission 94*, p. 17. This submission referred to a systematic review of studies exploring the diagnostic accuracy of existing tools. The study showed that even the best tools led to false positive and false negative diagnoses for children with autism. The study of the accuracy of the Autism Diagnostic Observation Schedule (ADOS) showed that out of 1000 preschool children, ADOS indicated autism was present in 725 cases and not present in 275 cases. The actual diagnosis showed that this included 58 false positives and 43 false negatives, with implications for additional strain on resources, as well as missed opportunities for early intervention.

[28] Speech Pathology Australia, *Submission 87*, pp. 12–13.

[29] Royal Australasian College of Physicians, *Submission 29*, p. 5.

[30] Speech Pathology Australia, *Submission 87*, p. 7. Other communication related conditions include specific language impairment, social (pragmatic) communication disorder, language disorder, speech sound disorder (such as childhood apraxia of speech), and specific learning disorders (such as dyslexia).

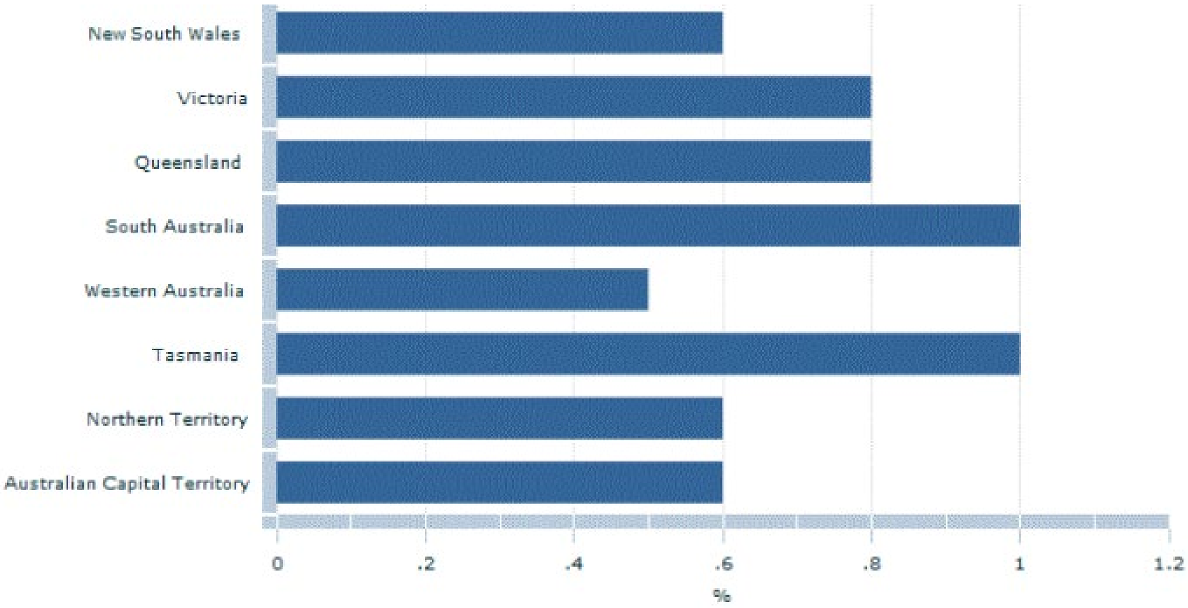
Development Service follows the recommended multidisciplinary approach, this is not necessarily the case in the private sector:

> The way the Child Development Service do diagnoses is the recommended approach. They use a multidisciplinary approach. However, since many parents don't want to wait that long, they go through the private system with a private psychologist, and that's just the one psychologist. That's not the best way, but it can get them the diagnosis that they need for support.[31]

10.25 According to Early Start Australia (ESA), the differences in practice also extend to the type of assessments administered as part of the diagnostic process.[32]

10.26 The inconsistency in process appears to be reflected in the varying proportions of autistic people across states and territories (see Figure 10.1).

Figure 10.1 Proportion of autistic people by state or territory of usual residence (2015)



Source: Australian Bureau of Statistics, Survey of Disability, Ageing and Carers: Summary of Findings – 2015.

10.27 Stakeholders such as the Cooperative Research Centre for Living with Autism (Autism CRC) and the National Disability Insurance Agency (NDIA) also noted that the variability in diagnostic approach means that some fall short of best practice.[33]

10.28 According to the Autism CRC, these inconsistencies cause 'much confusion, time and resource wastage, frustration, and entrenchment of disability'.[34]

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[31] Mrs Mitzi Polacsek, Team Leader, Marymead Autism Centre, *Proof Committee Hansard*, 27 July 2021, p. 4.

[32] Early Start Australia, *Submission 76*. p. 2.

[33] NDIA, *Submission 56*, p. 9; Cooperative Research Centre for Living with Autism (Autism CRC), *Submission 46*, p. 6.

[34] Autism CRC, *Submission 46*, p. 6.

This view was echoed by the Autism Alliance which asserted that inconsistent practices create 'inequities, inefficiencies, confusion and distress among those seeking assessment and diagnosis'.[35] This was reflected in the experience of one parent who described the pathway to diagnosis as 'complex and opaque' and advocated for action to make diagnosis easier.[36] This was supported by St Vincent's Health Australia which called for clear and well-publicised pathways to diagnosis.[37]

10.29 In addition, Aspect noted that these differences can result in the need for 'unnecessary repeat assessments'. For example, this may occur when a diagnosis made in one state is not accepted in another state, or a diagnosis made in the health system is not recognised in the education system.[38]

10.30 In response to the aforementioned issues, the Autism CRC, in collaboration with the NDIA, developed the *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorder in Australia* (the National Guideline). The National Guideline was released in 2018 after 24 months of development and aims to provide a standardised and consistent clinical process for the assessment and diagnosis of autism in Australia.[39]

10.31 According to CliniKids, the National Guideline provides a 'clear, evidence-based process for diagnosing autism in a manner that is accurate, timely and acceptable to families'. It is also able to be integrated into exiting health, education, and disability systems at both the Commonwealth and state levels.[40]

10.32 However, uptake of the National Guideline has been uneven. For example, while Professor Andrew Whitehouse, Research Strategy Director of the Autism CRC, described the National Guideline as 'amongst the first things of great substance that the whole sector unanimously agrees upon',[41] Aspect noted that it had 'not been adopted broadly at this stage, particularly in the private sector'.[42] Likewise, while the Autism CRC observed adoption of the National Guideline at the 'grass roots level', it recognised that the benefits of the new approach will

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[35] Australian Autism Alliance, *Submission 52*, p. 15.

[36] Name withheld, *Submission 81*, [p. 3].

[37] St Vincent's Health Australia, *Submission 72*, p. 2.

[38] Aspect, *Submission 64*, p. 2.

[39] CliniKids, *Submission 15*, [p. 3].

[40] CliniKids, *Submission 15*, [p. 3].

[41] Professor Andrew Whitehouse, Research Strategy Director, Autism CRC, *Proof Committee Hansard*, 3 March 2021, p. 2.

[42] Aspect, *Submission 64*, p. 2.

only be realised through 'consistent, national implementation' in practice across the health, disability and education sectors.[43]

10.33 Accordingly, a number of stakeholders called for a focus on implementing the National Guideline.[44] This included the Autism Alliance which proposed that use of the National Guideline should be mandatory.[45]

10.34 Other submitters advocated for a funded strategy to implement the National Guideline.[46] For example, the RACP proposed that the development of a 'robust, fully funded strategy' for implementation, supported by a clinical reference group with experience in diagnosing autism, would:

> …ensure that all Australians can receive the best evidenced diagnostic practices, regardless of their age or location, and make informed decisions about next steps.[47]

10.35 The Autism Alliance also observed that consistent implementation of the National Guideline could also play a role in reducing waiting times by freeing up diagnostic capacity in the system:

> …the guidelines will deliver cost savings by rationalising assessment requirements and funding mechanisms across service systems – including health, disability and education. This will reduce duplication and the frustrating need for multiple assessments across systems.[48]

10.36 In response, the Department of Social Services, Department of Education, Skills and Employment, and Department of Health (the departments) noted that they had been working with the NDIA to drive uptake of the National Guideline. While recognising that implementation would take time, the departments indicated that, as an initial step, $194 000 had been provided to the Autism CRC to develop 'educational resources targeted at clinicians, service providers, people with autism and their families and carers'.[49]

10.37 While funded education activities were seen as important, more than one stakeholder argued that the most important driver of uptake would be reform of the Medicare Benefits Schedule (MBS) items related to autism diagnosis.[50] For

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[43] Autism CRC, *Submission 46*, p. 7.

[44] Commissioner for Children and Young People South Australia, *Submission 88*, p. 6; Early Start Australia, *Submission 76*, p. 3.

[45] Australian Autism Alliance, *Submission 52*, p. 4.

[46] Royal Australasian College of Physicians, *Submission 29*, p. 4; ND Australia, *Submission 97*, [p. 7].

[47] Royal Australasian College of Physicians, *Submission 29*, p. 4.

[48] Australian Autism Alliance, *Submission 52*, p. 16.

[49] Department of Social Services, Department of Education, Skills and Employment, and Department of Health, *Submission 53*, p. 25.

[50] ND Australia, *Submission 97*, [p. 7]; Professor Andrew Whitehouse, Research Strategy Director, Autism CRC, *Proof Committee Hansard*, 3 March 2021, pp. 2-3.

example, CliniKids explained that widespread use of the National Guideline is unlikely until there are appropriate funding mechanisms to support its use:

> Currently, there are only a few items on the Medicare Benefit Scheme relevant to autism diagnosis, and these have limited funding to support a rigorous diagnostic procedure. This limited funding can promote sub-optimal clinical practices, which has an impact on the quality of care that families receive, and can leave families in excess of $1000 out of pocket…[51]

10.38 Professor Andrew Whitehouse, Autism CRC, concurred and noted that the Commonwealth government's 'significant efforts' to build capacity within the medical profession would hit a roadblock without funding to support changes in clinical practice:

> We can build all the capacity we want, but if there is no funding—Medicare funding or other funding mechanisms—that supports the clinical activities then people on the ground will take shortcuts. That's the reality of a hand-to-mouth existence of disability service provision.[52]

Availability of diagnostic services

10.39 A lack of available services was cited as another key reason for delayed diagnosis, with stakeholders noting the long wait time for a diagnosis in the public sector.[53] As one submitter noted, the delay often occurs at time when early intervention could make the greatest difference to a child's outcomes:

> The public waitlist is often up to a two year wait, which for any child is an extremely long time, but for a child under seven years old in the prime early intervention years, two years can mean the difference between accessing early intervention therapy and not.[54]

10.40 While wait times were generally much shorter in the private sector, some stakeholders noted that this varied by location. For example, ESA noted that parents in the Northern Territory were waiting three to six months for private and not-for-profit services.[55] Similarly, there were reports of diagnosis in the private system taking more than 11 months due to long waitlists for professionals in certain locations.[56]

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[51] CliniKids, *Submission 15*, p. 6.

[52] Professor Andrew Whitehouse, Research Strategy Director, Autism CRC, *Proof Committee Hansard*, 3 March 2021, pp. 2–3.

[53] See, for example, Monash University, *Submission 94*, p. 15; St Vincent's Health Australia, *Submission 72*, p. 2; A4, *Submission 54*, p. 7; Samaritans, *Submission 99*, p. 4; Name withheld, *Submission 116*, [p. 2].

[54] Name withheld, *Submission 116*, [p. 2].

[55] Early Start Australia, *Submission 76*, p. 2.

[56] Name withheld, *Submission 81*, [p. 1].

10.41 The committee heard that the lack of available services related largely to workforce shortages,[57] including a limited number of paediatricians, psychiatrists, and clinical psychologists who specialise in autism.[58]

10.42 Stakeholders also noted a shortage of services for adult diagnosis (with most services focused on children),[59] as well as a lack of easily accessible avenues for assessment. For instance, Professor Adam Guastella, Chief Clinical Adviser and Founder of ND Australia, noted that many adults don't know where to get a diagnosis. He also argued there should be a greater focus on building assessment opportunities into existing service offerings:

> It has to be something that's easy for people to go in and out of, in terms of the assessment process. Who delivers it? Where is it delivered? There's a role for … maternal clinics but also for early childcare settings. … sometimes it comes down to simple things like not being able to access the clinic, so it really is about trying to integrate it into services that families currently access.[60]

10.43 More than one submitter pointed out that issues of service availability were exacerbated for those living in regional and remote locations.[61]

10.44 In response, a number of stakeholders called for action to increase the numbers of clinicians and other professionals working in the field of autism diagnosis.[62] To this end, the AMA recommended that governments work with medical colleges and professional bodies to ensure that the supply of relevant health professionals is able to meet the demand for timely diagnosis.[63]

10.45 Other submitters suggested expanding the range of health professionals who can undertake Medicare-rebated autism assessments to include nurse practitioners and allied health professionals.[64]

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[57] See, for example, Tasmanian Government, *Submission 19*, p. 5; Name withheld, *Submission 111*, [p. 3]; Name withheld, *Submission 116*, [p. 2].

[58] See, for example, AMA, *Submission 40*, p. 1; Name withheld, *Submission 62*, p. 2; Name withheld, *Submission 120*, [p. 3].

[59] See, for example, Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 4]; Government of Western Australia, *Submission 103*, p. 4; Name withheld, *Submission 9*, p. 3.

[60] *Proof Committee Hansard*, 15 April 2021, p. 3.

[61] See, for example, National Aboriginal Community Controlled Health Organisation (NACCHO), *Submission 104*, [p. 4]; Queensland Law Society, *Submission 124*, p. 5; Name withheld, *Submission 122*, [p. 1]; Name withheld, *Submission 126*, p. 8.

[62] See, for example, AMA, *Submission 40*, p. 5; Name withheld, *Submission 62*, p. 1; Name withheld, *Submission 111*, [p. 3]; Name withheld, *Submission 116*, [p. 2].

[63] AMA, *Submission 40*, p. 2.

[64] St Vincent's Health Australia, *Submission 72*, p. 3; Australian College of Nurse Practitioners, *Submission 127*, [p. 2].

10.46 Stakeholders also raised the need for a specific focus on improving the accessibility of diagnosis services adults and those in regional and remote areas.[65] This could include actions such as expanding telehealth services, providing assessment clinics in regional areas,[66] and providing clear pathways to diagnosis for adults seeking an autism diagnosis.[67]

Cost of diagnostic services

10.47 Cost was identified by stakeholders as another significant impediment to timely diagnosis.[68] According to the results of an Autism Alliance survey, two-thirds of autistic adults and over one third of parents and carers identified cost as a barrier to seeking diagnosis. In terms of costs, 40 per cent reported paying over $1000, with out-of-pocket costs reaching as high as $3000.[69]

10.48 This appeared to align with evidence provided by SPA that suggested the cost of private assessments could be as high as $2750, while the total Medicare rebate for those assessments could be as low as $340.[70] See Box 10.1 for further information on relevant MBS items.

Box 10.1 Autism diagnosis: Medicare Benefits Schedule (MBS) items

There are currently two Medicare items that subsidise consultant paediatricians (item 135) or psychiatrists (item 289) to provide diagnosis of autism for children under 13 years of age (on referral from another medical practitioner). The applicable Medicare Schedule Fee for these items is $278.75, while the benefit amounts are $209.10 (75 per cent benefit) and $236.95 (85 per cent benefit).

These items are for assessment, diagnosis and creation of a treatment and management plan. This can include patient referral for MBS subsidised allied health assessment services (items 82000–82030). A maximum of 4 allied health assessment services are subsidised in total. The applicable Medicare Schedule Fees and benefits for these items are:

- 82000 (psychology) – $103.80 (fee), $88.25 (85 per cent benefit);
- 82005 (speech pathology) – $91.50 (fee), $77.80 (85 per cent benefit);

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[65] Early Start Australia, *Submission 76*, p. 4; Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 4].

[66] Aspect, *Submission 64*, p. 4; Name withheld, *Submission 79*, p. 1.

[67] Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 4].

[68] See, for example, Samaritans, *Submission 99*, p. 4; UNSW 3DN, *Submission 95*, p. 4; Australian Autism Alliance, *Submission 52*, p. 14; BioAutism *Submission 93*, pp. 20–21; TARA, *Submission 86*, p. 10; A4, *Submission 54*, p. 8; Australian Autism Alliance, *Submission 52*, p. 14; Name withheld, *Submission 9*, p. 3.

[69] Australian Autism Alliance, *Submission 52*, p. 15.

[70] Speech Pathology Australia, *Submission 87*, p. 8.

- 82010 (occupational therapy) – $91.50 (fee), $77.80 (85 per cent benefit); and
- 82030 (audiology, optometry, orthoptic or physiotherapy) – $91.50 (fee), $77.80 (85 per cent benefit).

The Medicare rebates cover a portion of the fee for the service, although providers may choose to bulk bill.

Source: Joint Submission from the Department of Social Services, Department of Education, Skills and Employment, and Department of Health, Submission 53, p. 11; Australian Government Department of Health, MBS Online, www9.health.gov.au/mbs/search.cfm *(accessed 22 November 2021).*

10.49 Multiple stakeholders observed that the high cost of diagnosis has a disproportionate effect on lower socioeconomic households.[71] Mrs Grace Fava OAM explained the impact on clients of Autism Advisory and Support Services:

> Because of the low socioeconomic capacity of a lot of our families they have to go through the health system in order to access a diagnosis. You're looking at a six to 12 month wait for a diagnostic assessment. For a lot of children who have fallen under the radar that is a little bit late. They're at school or are much older.[72]

10.50 As noted by the Autism Alliance, this creates 'a divide between those who can afford timely private assessments and diagnoses, and those who are forced to wait in the log-jammed public system'.[73] This divide was recognised by many families:

> We were fortunate; we could afford to pay over $1000 for a private assessment and had an appointment and diagnosis within three months. With the diagnosis reports we were able to access NDIS and early intervention. I know other families who can't afford to pay this kind of money, who have been waiting literally a year or more for an appointment … It's totally unfair that your ability to access a timely diagnosis depends on your ability to pay. – Rachel, 41.[74]

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[71] See, for example, Positive Youth Incorporated, *Submission 85*, p. 3; Speech Pathology Australia, *Submission 87*, p. 8; Australian Autism Alliance, *Submission 52*, p. 8; Marymead Autism Centre, Monash University, *Submission 94*, pp. 16-17; *Submission 128*, p. 7; Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, pp. 4-5; Name withheld, *Submission 126*, p. 8.

[72] Mrs Grace Fava OAM, Chief Executive Officer, Autism Advisory and Support Services, *Proof Committee Hansard*, 28 July 2020, p. 46.

[73] Australian Autism Alliance, *Submission 52*, p. 8.

[74] TARA, *Submission 86*, p. 10.

10.51 Submitters also noted the additional costs involved in seeking a diagnosis for older children or adults given the Medicare rebates for diagnosis are only available for children under the age of 13.[75]

10.52 In line with these concerns, stakeholders called for action to reduce the cost of diagnosis.[76] For example, the Office of the Public Advocate Victoria advocated for free access to diagnostic professionals,[77] while others such as the Autism Alliance suggested extending Medicare rebates to cover the full cost of diagnosis,[78] including adult diagnosis.[79]

10.53 In response, the relevant Commonwealth departments pointed to the work of the MBS Review Taskforce which—at the time of its submission—was considering a number of draft recommendations by the Allied Health Reference Group (AHRG) to improve access to complex allied health assessments and encourage multidisciplinary planning under the MBS.[80]

10.54 In June 2020, the MBS Review Taskforce endorsed a number of the draft AHRG recommendations, including:

- lifting the age limit on autism related items from 13 to 25 years;
- increasing the number of allied health assessment appointments from four per lifetime to eight per lifetime (with a review by the referring practitioner after the first four assessments);
- allowing up to two allied health assessment items to be used for case conferencing for children with a potential autism diagnosis; and
- allowing inter-disciplinary referral between allied health professionals during the assessment phase (in consultation and agreement with, but without a physical attendance by, the original referring practitioner).[81]

10.55 To date, it appears that only one of the above recommendations has been implemented. In November 2021, three new MBS items were introduced to

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[75] See, for example, A4, *Submission 54*, p. 9; Australian Autism Alliance, *Submission 52*, p. 14; Name withheld, *Submission 126*, p. 9.

[76] See, for example Speech Pathology Australia, *Submission 87*, p. 25; UNSW 3DN, *Submission 95*, p. 5; Name withheld, *Submission 81*, [p. 3]; Name withheld, *Submission 112*, [p. 6].

[77] Office of the Public Advocate Victoria, *Submission 80*, p. 10.

[78] Australian Autism Alliance, *Submission 52*, p. 4.

[79] Australian Autism Alliance, *Submission 52*, p. 4. See also, Aspergers Victoria, *Submission 90*, p. 10; Aspect, *Submission 64*, p. 4; Name withheld, *Submission 126*, p. 9.

[80] Department of Social Services, Department of Education, Skills and Employment, and Department of Health, *Submission 53*, p. 15.

[81] Medicare Benefits Schedule Review Taskforce, *Report on Primary Care*, June 2020, pp. 122, 123, 125 127 and 128–129. Case conferencing involves the referring practitioner and other members of the multidisciplinary team assessing a child. The parent may also be present.

enable allied health practitioners to participate in multidisciplinary case conferencing for children with, or suspected of having, autism.[82]

10.56 In relation to the recommendation to lift the age limit on autism-related items, Ms Fiona Sharkie, Autism Alliance, suggested that raising the age limit to 25 years was 'nonsensical' and should instead be removed altogether:

> Really there should be no age cap. That goes to the earlier comments about autistic adults who are being discriminated against by the lack of access to diagnosis in their different situations of life. We do think it's an urgent matter.[83]

10.57 In addition, both ESA and the RACP argued there was a need for a more comprehensive review of MBS items in relation to autism diagnosis.[84] The RACP suggested this should include investigation of:

- a new MBS item to allow an annual hour-long review of patient goals and needs;
- a standalone MBS item for transition to adult services; and
- the application of certain MBS items for people with intellectual disability to those with autism.[85]

Autism awareness and understanding

10.58 As with other services, stakeholders identified a lack of autism awareness and understanding among parents, health professionals and educators as a significant obstacle to accurate and timely diagnosis. This was seen as a particular issue in relation to the late diagnosis of females.

Parents

10.59 Many parents lack awareness of the early signs of autism. As one parent explained, it was not until her son was diagnosed at age five that she realised many of the signs of her son's autism had been apparent from a very early age (around 4 months).[86]

10.60 Positive Youth Incorporated pointed out that for many parents, information about child development comes via contact with health services.[87] This includes child health and development screening programs that operate in most states and involve a series of developmental checks from birth until four

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[82] Department of Health, *Fact Sheet/FAQ Allied Health Services*, 16 September 2021, p. 2.

[83] Ms Fiona Sharkie, Member, Australian Autism Alliance, *Proof Committee Hansard*, 28 July 2020, p. 13.

[84] Early Start Australia, *Submission 76*, p. 4; Royal Australasian College of Physicians, *Submission 29*, pp. 3–4.

[85] Royal Australasian College of Physicians, *Submission 29*, pp. 3–4.

[86] Name withheld, *Submission 113*, [p. 2].

[87] Positive Youth Incorporated, *Submission 85*, p. 3.

years of age.[88] For example, in New South Wales (NSW), these checks are carried out either by a child and family health nurse or by a general practitioner and are listed in the 'Blue Book' provided to each child born in NSW. The Blue Book also contains the *Learn the Signs. Act Early* developmental checklist to help parents identify whether or not their child is meeting developmental milestones.[89]

10.61 However, the committee also heard concerns that these processes did not provide enough information for parents. For example, one mother observed that the development milestones in South Australia's Blue Book relate primarily to physical, rather than social, development. Unfortunately, this provided false reassurance that her daughter was progressing normally:

> …on paper, my daughter was mostly meeting her milestones and nobody thought there was anything of concern about her. This 'tick box' exercise gave me false comfort that my daughter was doing fine when in fact we should have seen a specialist much sooner.[90]

10.62 As with other services, it was noted that the effectiveness of child development checks relies on the knowledge of those carrying out the assessments.[91] In some cases, this works very well. For example, one mother observed that after having her concerns dismissed by doctors and specialists, her local child health nurse was 'the only person who took my concerns seriously'.[92]

10.63 Given the well-established and widespread nature of child screening and development programs, both OTARC and the Autism Alliance called for a national rollout of OTARC's training program for maternal and child health nurses to improve early identification of autism (see Box 10.2).[93]

Box 10.2 OTARC training for maternal and child health nurses

In 2018, the Victorian Government announced $1.1 million for OTARC to train all Victorian Maternal and Child Health nurses in the early identification of autism for children under three years.

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[88] Examples include South Australian Child and Family Health Service, *Health and Development Checks*, www.cafhs.sa.gov.au/services/health-checks (accessed 21 November 2021); Western Australia Department of Health, *Community Child Health Program*, www.healthywa.wa.gov.au/Articles/A_E/Community-Child-Health-Program (accessed 21 November 2021).

[89] NSW Government, *Submission 65*, p. 5.

[90] Name withheld, *Submission 62*, p. 5.

[91] NSW Government, *Submission 65*, p. 5.

[92] Name withheld, *Submission 111*, [p. 2].

[93] OTARC, *Submission 55*, p. 2; Australian Autism Alliance, *Submission 52*, p. 17. See also, Name withheld, *Submission 126*, p. 7.

The training aimed to give maternal and child health nurses confidence in identifying the early signs of autism in infants, creating referral pathways, and raising concerns with parents in an empathetic and supportive way.

The program also aimed to empower parents as well as nurses in order to narrow the gap between parents' first concerns and receiving a definitive diagnosis.

The professional development package was offered to all maternal and child health nurses in Victoria and included both online and face-to-face training.

At the time of the announcement, training had already been rolled out across Tasmania and parts of New South Wales, with over 98 per cent of nurses reporting confidence in identifying early signs and deciding which referral paths to follow.

Source: La Trobe University, Life-changing autism training funded, 5 September 2018, www.latrobe.edu.au/news/articles/2018/release/life-changing-autism-training-funded *(accessed 23 November 2021).*

10.64 The Autism Alliance also called for further development and use of autism detection apps such as OTARC's ASDetect which is available in English Mandarin and Spanish. ASDetect guides parents through a series of activities for children aged 11–30 months which test social attention and communication behaviours. It then provides an assessment of the likelihood of autism. According to the Autism Alliance, research underpinning the app shows it has an accuracy rate of between 81–83 per cent, with the remaining percentage going on to be formally diagnosed with other developmental delays.[94]

10.65 Other suggestions included the use of existing information channels to target information to parents, including the Blue Book equivalent in each state and territory.[95]

Health professionals

10.66 When able to find 'skilled and supportive' professionals with an understanding of autism, the committee heard that the process of assessment and diagnosis can be 'overwhelmingly positive and affirming'.[96]

10.67 However, in addition to the limited number of medical professionals specialising in autism,[97] stakeholders also reported a general lack of autism knowledge among the broader health workforce—including GPs, psychologists and psychiatrists.[98] As noted by one parent, the path to diagnosis is:

> …highly dependent on finding and being able to access a knowledgeable clinician. Many GPs, paediatricians, allied health practitioners and

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[94] Australian Autism Alliance, *Submission 52*, p. 17.

[95] Name withheld, *Submission 62*, p. 6.

[96] TARA, *Submission 86*, p. 11.

[97] AMA, *Submission 40*, p. 2.

[98] See, for example, Australian Autism Alliance, *Submission 52*, p. 21; UNSW 3DN, *Submission 95*, p. 13; TARA, *Submission 86*, p. 10; Name withheld, *Submission 81*, [p. 3]; A4, *Submission 54*, p. 5.

> psychologists do not have an adequate modern understanding of autism, and cannot adequately identify it…[99]

10.68 According to BioAutism, this lack of understanding was reflected in the results of an unpublished survey of over 200 parents which found that a lack of professional knowledge accounts for just under 70 per cent of delays in diagnosis.[100]

10.69 Poor autism understanding can also result in inaccurate and delayed diagnoses. For example, the results of an Autism Alliance survey revealed that over half of autistic adults were 'misdiagnosed with another condition before being diagnosed as autistic'. In addition, '31 per cent of parents and carers reported the same experience for children in their care'.[101]

10.70 The committee heard numerous accounts of parents' concerns being ignored by medical professionals. In one case, a parent described how they had raised concerns with multiple health professionals for more than a year:

> We were adamant there was more to [redacted]'s speech delay and behaviour but were frequently told by different GPs and health specialists that boys are developmentally slower than girls, or everyone will talk at their own pace, and my favourite: even Albert Einstein didn't talk until he was five. It's also our experience that first time parents' concerns are disregarded until a developmental delay is blindingly obvious.[102]

10.71 Even parents who are well-educated about autism face difficulties. One mother described having her concerns 'repeatedly dismissed' despite having studied psychology and worked with autistic children for two years, before becoming a mother:

> I identified that my son exhibited many red flags for autism from 12 months of age, including not pointing, restricted interest in toys, limited eye contact, no vocalising and not making or responding to my gestures. Despite my background, my concerns were repeatedly dismissed by doctors, specialists and paediatricians. … After two years of taking my son to appointments with my concerns, he was eventually diagnosed with Autism Spectrum Disorder Level 2, at three years of age.[103]

10.72 Some stakeholders also identified instances where a lack of knowledge was accompanied by harmful and outdated views about autism. For example, A4 advised that some clinicians still believe autism is an 'attachment disorder' or

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[99] Name withheld, *Submission 81*, [p. 3].

[100] BioAutism, *Submission 93*, p. 12. The survey found that the main reason (just under 50 per cent) for delays in diagnosis was reassurances from health professionals that 'the delay is normal and nothing to worry about', while nearly 20 per cent were told their child was too young. Approximately 20 per cent of delays in diagnosis related to access to diagnostic services.

[101] Australian Autism Alliance, *Submission 52*, p. 15.

[102] Name withheld, *Submission 116*, [p. 2].

[103] Name withheld, *Submission 111*, [p. 2].

associated with 'refrigerator mothers'—despite this theory being 'thoroughly discredited decades ago'.[104]

10.73 These views played a role in one submitter's eight-year journey to obtain a diagnosis for her son. After first trying to get a diagnosis when her son was three, she tried again at age five before finally getting a private diagnosis at 10 years old. The mother described the comments of the professionals she saw—none of whom had an adequate understanding of autism—as 'very damaging':

> I was told such things as 'it is a cry for attention because he comes from a broken home', 'it is trauma because his parents are separated', 'he doesn't look autistic', 'try a parenting class', 'it is an attachment issue—he wouldn't act this way if you were a full time stay at home mother', 'he will grow out of it if you discipline him more', we are all a bit autistic', there is no money for help even if he does get a diagnosis', and 'you don't want to burden him with an unnecessary label'.[105]

10.74 Stakeholders also reported that health professionals, particularly those working outside the disability sector, often promoted a 'wait and see approach' to diagnosis.[106] For example, one mother explained that her daughter had been diagnosed with sensory processing disorder at two and a half. After asking for a more complete diagnosis when her daughter was three, she was told to wait until her daughter was seven. When her daughter was seven, she was then told that assessments were not required and that she should focus on her daughter's handwriting via occupational therapy. In the end, a diagnostic assessment was not triggered until her daughter was 10 years old and had experienced a six-month period of debilitating symptoms including insomnia, extreme anxiety, behaviours of concern, social difficulties, panic attacks, and obsessive-compulsive traits.[107]

10.75 While much of the evidence provided to the committee in relation to autism understanding focused on children, some stakeholders also highlighted the need for health professionals to have a better understanding about how autism presents in adults.[108] For example, one submitter reported that in response to a

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[104] A4, *Submission 54*, p. 9.

[105] Name withheld, *Submission 81*, [p. 1].

[106] See, for example, Early Start Australia, *Submission 76*, p. 3; Autism Awareness Australia, *Submission 47*, p. 2; A4, *Submission 54*, pp. 7 and 10; Name withheld, *Submission 62*, p. 6; Name withheld, *Submission 111*, [p. 3]; Name withheld, *Submission 116*, [p. 2].

[107] Name withheld, *Submission 78*, p. 5.

[108] Professor Andrew Whitehouse, Research Strategy Director, Autism CRC, *Proof Committee Hansard*, 3 March 2021, p. 4; Professor Adam Guastella, Chief Clinical Adviser and Founder, ND Australia, *Proof Committee Hansard*, Thursday 15 April 2021, p. 3; Mr Bob Buckley, Convener, Autism Aspergers Advocacy Australia, *Proof Committee Hansard*, 27 July 2020, p. 19.

survey of 78 healthcare professionals, 80 per cent wanted further training in autism in adulthood.[109]

10.76 Ms Nicole Rogerson, Chief Executive Officer, Autism Awareness Australia, noted that similar delays in diagnosis wouldn't be accepted in relation to other health conditions:

> The one thing that's really common is that the medical professions can be where we get stopped. It can be a GP who doesn't know enough. It can be a paediatrician who says, 'come back in six months'. We just wouldn't do this in any other area of health.[110]

10.77 In response to these issues, numerous stakeholders identified the need for better autism education for health professionals—as part of both initial training and ongoing professional development.[111] According to the Department of Developmental Disability Neuropsychiatry, University of New South Wales (UNSW 3DN), this should include a focus on the heterogenic presentations of autism.[112]

10.78 More than one submitter also suggested providing more clinical guidance for GPs in relation to the identification of autism. For example, the AMA advocated for clinical guidelines for GPs,[113] while Professor Julian Trollor, UNSW 3DN, suggested using clinical pathways for autism embedded into software used by GPs, such as HealthPathways. A similar strategy has been used successfully to address health needs in people with intellectual disability.[114]

Early childhood educators and teachers

10.79 Stakeholders observed that the signs of autism in children can often be missed until the child comes into contact with the education system.[115] This can be the result of a lack of parental awareness about the signs of autism but can also occur in situations where parents' concerns have been dismissed by medical practitioners.

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[109] Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 2].

[110] Ms Nicole Rogerson, Chief Executive Officer, Autism Awareness Australia *Proof Committee Hansard*, 28 July 2020, p. 3.

[111] See, for example, Australian Autism Alliance, *Submission 52*, p. 4; AMA, *Submission 40*, p. 2; TARA, *Submission 86*, p. 19; Name withheld, *Submission 81*, [p. 3]; Name withheld, *Submission 79*, p. 1; Aspect, *Submission 64*, p. 4; A4, *Submission 54*, p. 11.

[112] UNSW 3DN, *Submission 95*, p. 5.

[113] AMA, *Submission 40*, p. 2.

[114] Professor Julian Trollor, Chair, Intellectual Disability Mental Health; and Head, Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW, *Proof Committee Hansard*, Thursday 15 April 2021, p. 43.

[115] Name withheld, *Submission 126*, p. 6; Name withheld, *Submission 148*, p. 4 and 5.

10.80 However, the committee heard that autism awareness also varies within the early childhood and education sectors, with at least one submitter reporting that their concerns about their child were dismissed by professionals, including early childhood educators and teachers.[116]

10.81 Despite early childhood educators and teachers being well-placed to identify early signs of autism, many do not feel well-equipped to engage with parents about their concerns. Ms Tamika Hicks, Manager of the Cardinia Lakes Early Learning Centre, described the challenges that face educators:

> Educators are ill equipped with a 'toolbox' for answering questions, advising on pathways and providing assistance to children who need inclusion support in services. Conversations are difficult and are quite emotional, stressful and at times distressing for both the family and educators. Many conversations are met with push back and denial which can leave families distressed and educators quite frustrated knowing how important early intervention is.[117]

10.82 This was reflected in evidence provided by one mother whose son was diagnosed with autism 12 months after early childhood educators at his preschool raised concerns. While 'initially offended' by the suggestion that her son's behaviours needed further assessment, she stated that she was 'now grateful that the preschool staff spoke up'.[118]

10.83 As with healthcare professionals, stakeholders identified the need to embed autism understanding within both initial education courses and ongoing professional development for educators.[119] For those in early childhood settings, Ms Tamika Hicks suggested this could include the option for a qualification such as a Diploma of Inclusion Support.[120]

10.84 Some stakeholders also suggested that screening programs could be established in early childhood settings and schools.[121]

10.85 To promote better engagement with parents, Ms Tamika Hicks suggested connecting Maternal Health Care Nurses with early childhood and child care

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[116] Name withheld, *Submission 62*, p. 7.

[117] Ms Tamika Hicks, *Submission 14*, [pp. 1-2].

[118] Name withheld, *Submission 113*, [p. 1].

[119] See, for example, A4, *Submission 54*, p. 11; Mr Shawn Stevenson, *Submission 115*, [p. 3]; Mansfield Autism Statewide Services, *Submission 117*, [p. 1]; Autism Queensland Limited, *Submission 129*, p. 11; Autism Advisory and Support Service, *Submission 21*, p. 7.

[120] Ms Tamika Hicks, *Submission 14*, [p. 2].

[121] See, for example, Office of the Public Advocate Victoria, *Submission 80*, p. 4; Name withheld, *Submission 62*, p. 7.

services to support teachers and families, and to run family-friendly sessions on autism.[122]

Gender bias

10.86 Many stakeholders raised the issue of a gender bias in relation to autism diagnosis and noted that that the existing diagnostic criteria are based on a typical male presentation.[123] According to the Autism Alliance, this also applies to diagnostic tools like the Autism Diagnostic Observation Schedule and the Autism Diagnostic Interview-Revised, meaning they may 'lack the sensitivity and specificity required to identify autistic characteristics in women and girls.'[124]

10.87 This has a particular impact on females who may not present with 'typical' autistic behaviours.[125] For example, OTARC argued that 'female "special interests" may not stand out as being unusual (e.g., toy animals, Disney)' and may be considered 'gender typical'.[126] This view was echoed by the Coalition of Autistic Women:

> …when girls are lining up Barbie dolls on a shelf or grouping clothing in her wardrobe, rather than observing a restricted and repetitive behaviour, girls are likely to be praised for neatness, traditionally highly desirable in girls.[127]

10.88 The committee heard that cultural stereotypes can also lead to dismissive attitudes toward some parents' concerns. One mother explained that she felt her concerns about her daughter weren't taken seriously in part because of the 'misconception that Asian little girls are often shy'.[128]

10.89 In addition, females are also known to be better at camouflaging or masking their autism through social imitation.[129]

10.90 As a result, females are likely to be diagnosed later than males. The Autism Alliance reported that 65.9 per cent of female respondents to the Study of Australian School Leavers with Autism were diagnosed at age nine or older, compared with 37.7 per cent of males.

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[122] Ms Tamika Hicks, *Submission 14*, [p. 2].

[123] See, for example, Samaritans, *Submission 99*, p. 5; UNSW 3DN, *Submission 95*, p. 5; Australian Association of Social Workers, *Submission 96*, p. 7.

[124] Australian Autism Alliance, *Submission 52*, p. 18.

[125] See, for example, TARA, *Submission 86*, p. 10.

[126] OTARC, *Submission 55*, p. 9.

[127] Coalition of Autistic Women, *Submission 125*, p. 6.

[128] Name withheld, *Submission 62*, p. 7.

[129] See, for example, Australian Association of Social Workers, *Submission 96*, p. 7; National Disability Insurance Agency, *Submission 56*, p. 8; Yellow Ladybugs, *Submission 49*, p. 7; Name withheld, *Submission 167*, [p. 3].

10.91 Late diagnosis was also a common theme among submissions to the inquiry. For example, one submitter told the committee that her daughter was diagnosed at age 11, despite being engaged with health professionals over the previous decade in relation to her behaviours of concern.[130]

10.92 The under-recognition of non-typical autistic behaviours also leads to misdiagnosis of autistic females. According to the Autism Alliance, females are 'more likely to receive a primary diagnosis of a mental health condition rather than autism'.[131] Similarly, TARA revealed that respondents to its survey had been 'misdiagnosed with bipolar disorder, borderline personality disorder and psychosis, before receiving a correct diagnosis of autism'.[132]

10.93 TARA also stressed that while mental health conditions can co-occur with autism, this is different from misdiagnosis, which—in addition to not facilitating appropriate supports—can also lead to autistic people being inappropriately medicated, with potentially serious consequences.[133] Similarly, the Australian Association of Social Workers cautioned that autism in females can be 'overshadowed' by a mental health diagnosis (or misdiagnosis).[134]

10.94 The complexity of autism diagnosis for females, including the interaction of autism with mental health conditions, was described by one autistic submitter who was initially misdiagnosed and subsequently went on a convoluted journey to eventually receive an autism diagnosis (see Box 10.3).

Box 10.3 The complexity of autism diagnosis for females with co-occurring mental health conditions

Like most females diagnosed as autistic, I was diagnosed by accident.

After changing doctors because I was dissatisfied with the treatment I was receiving, my new GP after reviewing my file took me off all medication and weened me off a 20-year opioid addiction (I was taking up to eight codeine-based pills a day).

Once the opioids were out of my system, he quickly realised I suffered crippling social anxiety, suicidal depressive episodes, chronic insomnia and severe mood instability, the symptoms of which had been suppressed by my daily opioid use.

Through a friend who works in the mental healthcare industry I found a really good local psychiatrist who my GP was happy to refer me to for diagnosis and treatment for suspected bipolar mood disorder.

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[130] Name withheld, *Submission 78*, p. 3.

[131] Australian Autism Alliance, *Submission 52*, p. 18.

[132] TARA, *Submission 86*, p. 12.

[133] TARA, *Submission 86*, p. 13.

[134] Australian Association of Social Workers, *Submission 96*, p. 7.

> It only took two visits for my psychiatrist to work out I was NOT bipolar and medicating me for that condition would have had seriously detrimental effects on my health.
>
> Like most female adult autistics, I'm incredibly adapted at appearing 'NORMAL' for short periods of time, so it took a little while for my psychiatrist to twig that I was effectively playing the part of a NORMAL person and tell me to stop doing it. Realising I wasn't going to get correctly diagnosed, I stopped pretending to be NORMAL and acted as I would in a safe place like at home and my psychiatrist had the 'ah ha' moment.
>
> Just to ensure he had as much information as possible he, with my permission, interviewed my mum and dad, got information from my sisters and others, as well as read his way through the plethora of paperwork my mum had kept, everything from my first K1 school report onward.
>
> It took six months of testing, interviews, information gathering and a second opinion to confirm my official diagnosis of Autism Spectrum Disorder (Level 2) with co-morbid ADHD and other associated mental health issues.

Source: Name withheld, Submission 9, p. 5.

10.95 Multiple stakeholders also highlighted the need for better education for parents, health professionals and others on different presentations in women and girls.[135]

10.96 There were also a number of calls for the development of screening tools that will better identify autism in women, as well as other autistic people with less typical presentations.[136]

Committee view

10.97 Current waiting times for an autism diagnosis are simply unacceptable—especially given the importance of early intervention to future life outcomes. The committee finds it particularly troubling that access to timely diagnosis appears so heavily reliant on having the ability pay for a private diagnosis and living in close proximity to a metropolitan centre.

10.98 While the committee acknowledges that the lack of biological markers for autism makes the diagnostic process more complex, no child should have to wait years for a diagnosis. The committee believes that a maximum timeframe for diagnosis must be established nationally and reported on at least annually. Ideally, this should be based on the best practice target of three months.

10.99 Although some of the current delay relates to the supply of diagnostic services, the committee heard that a significant proportion also arises from ignorance

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[135] See, for example, UNSW 3DN, *Submission 95*, p. 5; Name withheld, *Submission 78*, p. 6; Name withheld, *Submission 62*, p. 7; A4, *Submission 54*, p. 11; Name withheld, *Submission 78*, p. 6.

[136] See, for example, Autism CRC, *Submission 46*, p. 12; Australian Autism Alliance, *Submission 52*, p. 4; Australian Psychological Society, *Submission 110*, p. 9; Name withheld, *Submission 78*, p. 6; Name withheld, *Submission 126*, p. 25.

about autism. Addressing the delay in diagnosis will require action to both increase the supply of health care professionals who can diagnose autism, as well as improve the knowledge and skills of the existing workforce.

10.100 No child should have to wait eight years for a diagnosis because no one will take their parents' concerns seriously. As the committee heard, it is hard to imagine another condition or illness where these kinds of delays would be tolerated as a matter of course.

10.101 While the committee does not expect all health care professionals to be experts in autism, evidence provided to this inquiry suggests that some lack even the most basic understanding of autism, particularly in relation to the heterogenic nature of its presentation. The committee heard disturbing accounts of health care professionals who dismissed the concerns of parents, actively perpetuated misinformation and harmful stereotypes, and promoted a 'wait and see' approach to diagnosis. In more than one case, this resulted in an eight year wait for a diagnosis. As the committee heard, it is hard to imagine another condition or illness where these kinds of delays would be accepted.

10.102 As well as improving the supply of, and training for, professionals involved in diagnosis, there is also a need to expand the available pathways to early diagnosis. This should include options such as:

- co-locating autism screening services with other early childhood services;
- national implementation of the OTARC training program for maternal and child health nurses;
- supporting collaboration between trained maternal health nurses and early childhood educators;
- promoting use of the ASDectect app by parents, health practitioners and educators;
- making better use of telehealth options to support regional and remote diagnosis; and
- ensuring that existing child health and development programs maximise detection of the early signs of autism.

10.103 In addition, a lack of consistency in the approach to diagnosis is confusing for individuals and families. It also leads to variable quality of diagnosis. The committee heard that this variation persists despite the release of the *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorder in Australia* (the National Guideline) in 2018.

10.104 While the committee agrees that education and training are important to support broader uptake of the National Guideline, it is simply not enough. Indeed, it is apparent to the committee that there will be no significant change until the MBS items related to autism diagnosis align with the process set out in the National Guideline. The committee is disappointed that the recent MBS

Review did not explicitly address this issue—despite its stated goal of better aligning MBS items with 'contemporary clinical evidence and practice'.[137]

10.105 The committee is also concerned that many of the recommendations that were supported by the MBS Review Taskforce have not yet been implemented. While the committee supports the Taskforce's recommendations in relation to diagnosis, complex allied health assessments, and multidisciplinary planning, it does not support the proposal to lift the age limit for diagnosis-related MBS items from 12 years to 25 years. Given the lifelong nature of autism, the committee believes the proposed age cap is arbitrary and should be removed altogether.

Recommendation 38

10.106 The committee recommends that, as a matter of priority, the National Autism Strategy identify actions to improve access to autism diagnosis. This should include:

- **establishing, and publicly reporting on progress against, an agreed target for a maximum waiting time for diagnosis that reflects best practice;**
- **improving information for families and adults about autism and the pathways to diagnosis;**
- **identifying opportunities to co-locate autism screening and assessment services within existing services, such as maternal health clinics, early childhood and child care services, and school education settings;**
- **a national rollout of the Olga Tennison Autism Research Centre’s training program for maternal and child health nurses to improve early identification of autism;**
- **identifying opportunities for collaboration between maternal health care nurses and early childhood educators to support identification of, and communication about, autism in early childhood and child care settings;**
- **promoting use of the ASDectect app by parents, health practitioners and educators**
- **developing diagnostic tools that are more sensitive to the heterogenic presentation of autism, particularly in women and girls;**
- **working with medical colleges and professional bodies to improve the supply of healthcare professionals with expertise in autism diagnosis;**
- **embedding autism within initial education courses for healthcare professionals and educators, including training in the heterogenic presentation of autism;**
- **promoting use of the Autism HealthPathways platform to aid clinical decision-making in relation to autism assessments; and**

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[137] Australian Government Department of Health, *Medicare Benefits Schedule (MBS) Review*, 6 October 2021, www.health.gov.au/initiatives-and-programs/mbs-review (accessed 22 March 2022).

- **identifying ways to improve access to diagnostic services for people in regional and remote areas, including telehealth options.**

Recommendation 39

10.107 The committee recommends that state and territory governments review their child health and development screening programs to identify opportunities to improve early identification of autism.

Recommendation 40

10.108 The committee recommends that the Australian Government task the Medicare Benefits Schedule (MBS) Review Advisory Committee with an immediate review of MBS items related to diagnosis of autism. The aim of the review should be to align current MBS items with the diagnostic process established in the *National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorder in Australia*, as well as recommend new items required for the same purpose.

Recommendation 41

10.109 The committee recommends that the Department of Health prioritise implementation of the remaining recommendations of the Medicare Benefits Schedule Review Taskforce (the Taskforce) in relation to the diagnosis of autism, complex allied health assessments and multidisciplinary planning (as set out in the Taskforce's June 2020 *Report on Primary Care*).

Recommendation 42

10.110 The committee recommends the removal of the current age limit on Medicare Benefits Schedule items related to the diagnosis of autism.

Chapter 11
Early intervention and support

11.1 This chapter examines the importance of evidence-based early intervention and support for autistic children, including through the Early Childhood Approach. It also provides a snapshot of some of the barriers identified by stakeholders, including delayed access to timely diagnosis and services, as well as confusion about the availability and appropriateness of early intervention.

11.2 The chapter is not intended to provide a comprehensive overview or assessment of the different approaches to early intervention but looks at the need to provide the best life outcomes for autistic children and young people.

Early intervention and support services

11.3 There are a variety of non-pharmacological interventions for autistic children and young people. These interventions are normally a collection of therapies that are applied to support an autistic person's development and participation in the community. Indeed, the Cooperative Research Centre for Living with Autism (Autism CRC) states that evidence-based early intervention 'is considered important, providing significant opportunities to support early development and reduce longer-term disability'.[1]

11.4 Some intervention practices are designed to target one aspect of child development or family wellbeing, whereas others may target multiple areas at once. As such, intervention practices can be delivered on their own, or in combination, depending on the support needs and preferences of individuals. Figure 11.1 summarises many of the categories of intervention that have been designed for autistic children.

11.5 The Autism CRC has noted that a wide range of early intervention approaches are currently offered by providers, and they are often divided into the following broad categories:

- behavioural;
- developmental;
- naturalistic developmental behavioural interventions;
- sensory-based interventions; and
- technology-based interventions.[2]

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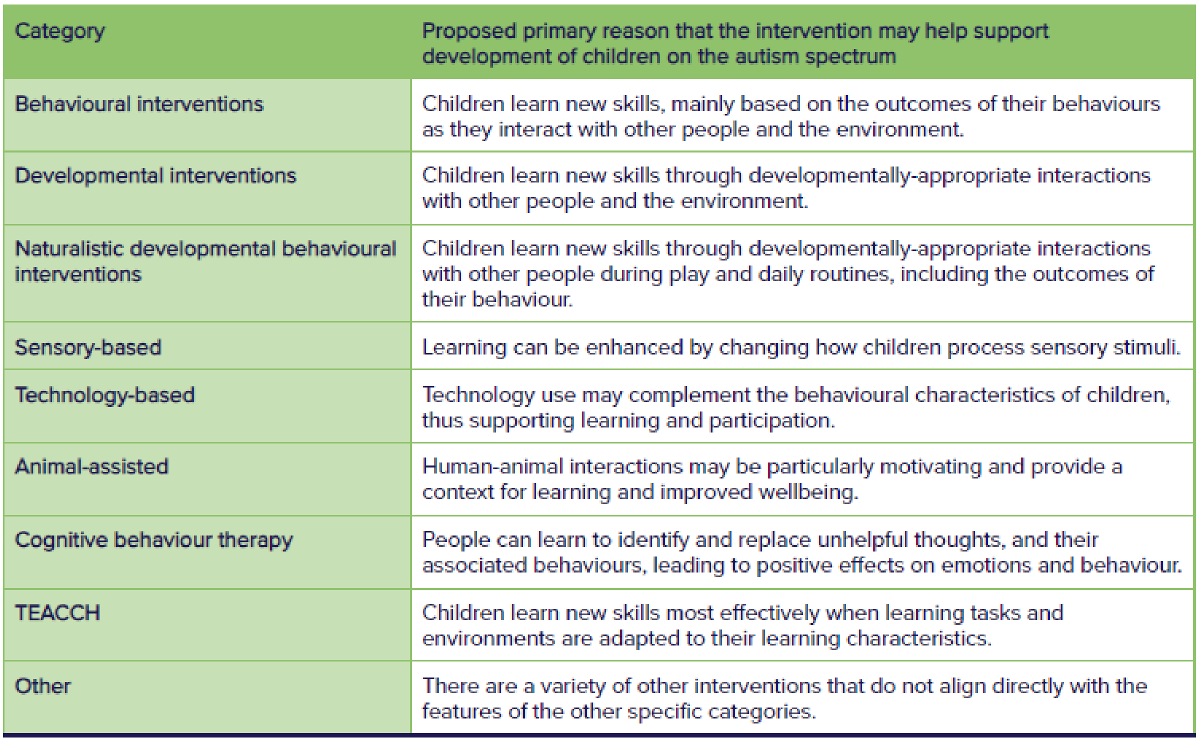
[1] Cooperative Research Centre for Living with Autism (Autism CRC), *Submission 46*, p. 13.

[2] Autism CRC, *Submission 46*, p. 13.

Figure 11.1 Overview of intervention categories



Category	Proposed primary reason that the intervention may help support development of children on the autism spectrum
Behavioural interventions	Children learn new skills, mainly based on the outcomes of their behaviours as they interact with other people and the environment.
Developmental interventions	Children learn new skills through developmentally-appropriate interactions with other people and the environment.
Naturalistic developmental behavioural interventions	Children learn new skills through developmentally-appropriate interactions with other people during play and daily routines, including the outcomes of their behaviour.
Sensory-based	Learning can be enhanced by changing how children process sensory stimuli.
Technology-based	Technology use may complement the behavioural characteristics of children, thus supporting learning and participation.
Animal-assisted	Human-animal interactions may be particularly motivating and provide a context for learning and improved wellbeing.
Cognitive behaviour therapy	People can learn to identify and replace unhelpful thoughts, and their associated behaviours, leading to positive effects on emotions and behaviour.
TEACCH	Children learn new skills most effectively when learning tasks and environments are adapted to their learning characteristics.
Other	There are a variety of other interventions that do not align directly with the features of the other specific categories.

Source: Autism CRC, Interventions for children on the autism spectrum: A synthesis of research evidence, November 2020 (Narrative review summary), p. 3.

Evidence-based therapies

11.6 The need for early intervention approaches to be supported by sound evidence was emphasised by many stakeholders. For example, the Autism CRC argued:

> Given the importance of early intervention, with its impact upon neurodevelopmental pathways, it is critical that the efficacy; optimal characteristics of the individual child and the mode of delivery; and safety of intervention approaches are supported by the highest level of clinical evidence. We do not accept less for pharmacological therapeutics or other therapies used in clinical practice for other conditions – and should not in the case of autism.[3]

11.7 Indeed, Early Start Australia (ESA) noted that there were several 'non-evidence-based and occasionally potentially harmful therapy approaches that are routinely promoted within Australia (e.g., diet restrictions, complementary and alternative medicine, restrictive practices including punishment)'. ESA argued:

> …there is currently little oversight or restriction regarding less evidence-based or potentially harmful practices within Australia for children with [Autism Spectrum Disorder] and some clinicians and complementary medicine practitioners continue to promote and use these practices. As a result, parents may not realise they are accessing a less effective treatment

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[3] Autism CRC, *Submission 46*, p. 13.

> approach for their child and miss the opportunity for the key early intervention period.[4]

11.8 The importance of building the evidence base for early intervention therapies was acknowledged by the National Disability Insurance Agency (NDIA), which engaged the Autism CRC to undertake an independent review of the best available evidence about early intervention approaches for autistic children.[5]

11.9 The Autism CRC's report, *Interventions for children on the autism spectrum: A synthesis of research evidence* (Autism Interventions Evidence Report) provided a comprehensive evaluation of the current evidence about non-pharmacological interventions for autistic children aged up to 12 years.[6]

11.10 The Autism Interventions Evidence Report found, among other things, that:

- no single 'one size fits all' approach to intervention works for all autistic children;
- there was no one intervention that improves all developmental outcomes for all children;
- there was no consistent evidence to suggest that more intervention necessarily leads to better outcomes; and
- it was important for families to be part of the support autistic children receive.[7]

11.11 The NDIA subsequently released its *Consultation Paper: Interventions for children on the autism spectrum*.[8] This consultation paper called for input and feedback from participants, their families, and caregivers, as well as providers and the disability sector to assist in developing clearer advice on National Disability Insurance Scheme (NDIS) funding of early intervention services for autistic children.[9] In response, the NDIA received more than 450 submissions and is

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[4] Early Start Australia, *Submission 76*, p. 4 (citation omitted).

[5] National Disability Insurance Agency (NDIA), 'NDIA welcomes release of Autism CRC report on early intervention', *Media Release*, 9 November 2020, https://www.ndis.gov.au/news/5587-ndia-welcomes-release-autism-crc-report-early-intervention (accessed 20 December 2021).

[6] Autism CRC, *Interventions for children on the autism spectrum: A synthesis of research evidence*, November 2020, p. 9.

[7] Autism CRC, *Interventions for children on the autism spectrum: A synthesis of research evidence*, November 2020, p. 9.

[8] NDIA, *National Disability Insurance Scheme, Consultation paper: Interventions for children on the autism spectrum*, March 2021.

[9] NDIA, 'NDIA releases consultation paper on best practice early intervention autism supports', *Media Release*, 30 March 2021, https://www.ndis.gov.au/news/6199-ndia-releases-consultation-paper-best-practice-early-intervention-autism-supports

currently 'considering the feedback and continues to engage with the sector to deliver better outcomes for [autistic children] and their families'.[10]

11.12 Work is also underway on the development of a national guideline for supporting the development and participation of autistic children and their families (Supporting Children National Guideline).[11] The guideline will build on the findings of the Autism Interventions Evidence Report and be developed according to the National Health and Medical Research Council's (NHMRC's) recommended process. It will also include a community consultation process, which will begin in early 2022.[12]

11.13 However, several stakeholders have argued that more research and funding is needed to develop the existing evidence base. For example, CliniKids highlighted the large gaps in research knowledge that still exists in relation to the effectiveness of early interventions:

> While our scientific understanding of the efficacy of early interventions has grown over the past two decades, there are still large gaps in our research knowledge. A particularly critical research goal is to obtain an understanding of which intervention is most effective for which individual, and at which period of their life? Currently, these clinical decisions are often made on a 'trial and error' basis, which creates the potential for patient harm, and wastage of limited financial resources.[13]

11.14 Similarly, the Northern Territory Office of the Public Guardian argued:

> It is widely accepted that with appropriate and adequate early intervention and supports the health, educational and employment outcomes for people with autism are significantly increased. This warrants increased funding for research to ensure the best practice diagnosis, intervention and support for people with autism across Australia.[14]

Importance of early intervention

11.15 It was widely acknowledged by stakeholders that early intervention for autistic children was a crucial factor in producing the best long-term outcomes,

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[10] NDIA, *Annual Report 2020–21*, p. 40. See also, NDIA, *Autism Advisory Group June 2021 communique*, https://www.ndis.gov.au/about-us/reference-group-updates/autism-advisory-group/autism-advisory-group-june-2021-communique (accessed 21 December 2021).

[11] Autism CRC, *New national practice guideline for supporting the development and participation of children on the autism spectrum and their families*, New national practice guideline for supporting the development and participation of children on the autism spectrum and their families | Autism CRC (accessed 17 December 2021).

[12] Autism CRC, *New national practice guideline for supporting the development and participation of children on the autism spectrum and their families*, New national practice guideline for supporting the development and participation of children on the autism spectrum and their families | Autism CRC (accessed 17 December 2021).

[13] CliniKids, *Submission 15*, [p. 7].

[14] Northern Territory Office of the Public Guardian, *Submission 20*, p. 8.

particularly in relation to individuals with less complex needs who may gain employment with the right supports. For example, the Royal Australasian College of Physicians (RACP) noted:

> Research shows that early intervention is particularly important for children with [Autism Spectrum Disorder] as it may lead to improvements in language abilities and overall more positive outcomes in development. It is important that those children who do not have official diagnosis are able to access NDIS.[15]

11.16 Likewise, the Queensland Family and Child Commission (QFCC) stressed the importance of diagnosis at the earliest opportunity, advising that the 'age at which intervention begins has been associated with improved outcomes, with younger children showing greater gains from intensive early intervention'.[16]

11.17 The challenges to obtaining a consistent, timely and best practice diagnosis is discussed in Chapter 10 of this report.

Pre-emptive intervention

11.18 CliniKids, which is based at the Telethon Kids Institute in Perth, emphasised that while 'autism interventions traditionally commence at the point of diagnosis (typically older than two years of age), there is reason to believe that commencing intervention prior to this period may be particularly effective in reducing long-term disability'.[17] Indeed, CliniKids argued:

> The infancy period (<18 months of age) is a particularly sensitive time for brain development, providing an optimal period for a child to benefit from therapeutic intervention. We recently tested a developmental intervention for infants (aged 12 months of age) showing early behavioural signs of autism. We found that, while the intervention did not reduce autistic symptoms, the children receiving the intervention had better parent-reported communication and social skills compared to a control group when assessed 6 months later. This is a very promising area of research that may lead to significant improvements to the way that we provide early intervention for young children.[18]

11.19 The research by the Telethon Kids Institute, recently published in JAMA Pediatrics, found that intervention commencing at the very earliest point in infancy (so called pre-emptive intervention) had significant long-term

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[15] Royal Australasian College of Physicians, *Submission 29*, p. 10.

[16] Queensland Family and Child Commission, *Submission 36*, p. 4 (citation omitted). See also, Autism Spectrum Australia (Aspect), *Submission 64*, pp. 2–3; Australian Autism Alliance, *Submission 52*, pp. 8–9.

[17] CliniKids, *Submission 15*, p. 7.

[18] CliniKids, *Submission 15*, p. 7, (citation omitted).

improvements on development, and reduced the likelihood that children meet criteria for autism in later childhood.[19]

11.20 The findings from this research have been used to inform the implementation of pre-emptive family focused interventions within the National Health Service (NHS) in England.[20]

Early Childhood Approach (formerly the Early Childhood Early Intervention pathway)

11.21 In 2016, the NDIA implemented a nationally consistent approach to supporting children with disability known as the Early Childhood Early Intervention (ECEI) pathway. The ECEI pathway supports children aged 0–6 years who have a developmental delay or disability and provides families and carers with access to individualised early childhood intervention support for their child.

11.22 Under the NDIS, eligible children can access ECEI supports using existing referral pathways, including maternal child health services, paediatricians, and general practitioners. Parents and carers with children aged 0–6 years can also self-refer to their local ECEI provider or through the NDIS directly.

11.23 The Autism CRC has argued that the core principle of the ECEI pathway is the:

> Provision of swift, appropriate early intervention following the earliest clinical indications of developmental delay, whether or not a diagnosis has yet been attained, promotes longer-term, positive functional outcomes for individuals on the autism spectrum.[21]

11.24 The Autism CRC went on to explain that:

> Delayed receipt of intervention does not capitalise on the highly 'plastic' [i.e. neuroplasticity] elements of neurodevelopment within the early years of life. There is now a wealth of scientific evidence for a range of 'behavioural markers' identifiable during the first two years of life that indicate a significant likelihood that an infant might subsequently be diagnosed as being on the autism spectrum. Providing intervention to these young children once the 'behavioural markers' have been identified is highly likely

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[19] Whitehouse AJO, Varcin KJ, Pillar S, et al. 'Effect of Pre-emptive Intervention on Developmental Outcomes Among Infants Showing Early Signs of Autism: A Randomized Clinical Trial of Outcomes to Diagnosis', *JAMA Pediatrics*, vol. 175, no. 11, 2021, e213298. doi:10.1001/jamapediatrics.2021.3298, https://jamanetwork.com/journals/jamapediatrics/fullarticle/2784066 (accessed 14 December).

[20] Jonathan Green, Kathy Leadbitter, et al. 'A New Early Care Pathway for Autism – Children and Families, Proven and sustained support from day one', NHSE Working Paper, https://www.pacttraining.co.uk/wp-content/uploads/2021/09/Green-et-al-NHSE-WORKING-PAPER-on-a-new-Autism-Care-Pathway1.pdf (accessed 17 December 2021).

[21] Autism CRC, *Submission 46*, p. 21.

> to deliver better outcomes in reducing long-term disability compared to waiting until diagnostic behaviours emerge in later years.[22]

11.25 Several stakeholders raised concerns around the suitability of the ECEI pathway for autistic children. For example, the Australian Autism Alliance (the Autism Alliance) asserted that the ECEI pathway was 'not a good fit' for autistic children:

> There is significant concern that participation in ECEI can delay access to diagnosis. Further, the light touch and short-term approach used in ECEI can postpone autistic children accessing the intensity of supports that evidence shows makes a real difference to their trajectory. Providing autistic children with access to an individually funded plan at the earliest opportunity will provide the best return on investment for the NDIS.[23]

11.26 Regarding the operation of the ECEI pathway, the Autism CRC commented:

> It is generally recognised that the initial implementation of the ECEI arrangements has not adequately delivered the desired benefits of early childhood intervention, including family capacity building. The Tune Review [2019 Review of the *National Disability Insurance Scheme Act 2013*] of the NDIS legislation found that more flexibility is needed in the pathway to maximise the benefits of early intervention in supports for children with disability.[24]

11.27 Similarly, La Trobe University's Olga Tennison Autism Research Centre (OTARC) indicated that the ECEI pathway was not providing the best outcomes for autistic children:

> With regards to the ECEI pathway, the delays to access and the level of service provided is insufficient to meet the needs of young autistic children. Our current understanding on the importance of early and intensive behavioural supports for autistic children to impact developmental progress means that the ECEI pathway will be less effective. While this cannot be properly ascertained without data collection on children's outcomes, from the reports received to date, utility is low.[25]

11.28 Some stakeholders argued that parents are not aware that they can access NDIS funding for their children who are undergoing ECEI programs, and this funding is often inadequate. For example, Autism Awareness Australia noted:

> Problems with the [ECEI] program has resulted in many families not understanding that they can receive some funding and support from the NDIS whilst they are waiting on the formal diagnosis.[26]

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[22] Autism CRC, *Submission 46*, p. 21.

[23] Australian Autism Alliance, *Submission 52*, p. 10.

[24] Autism CRC, *Submission 46*, p. 21.

[25] La Trobe University Olga Tennison Autism Research Centre (OTARC), *Submission 55*, p. 20.

[26] Autism Awareness Australia, *Submission 47*, p. 3. See also, Name withheld, *Submission 126*, p. 15 and 28.

11.29 AEIOU Foundation (AEIOU) submitted that there was a lack of appreciation of autism and the potential of early treatment and perhaps an impetus to cut costs and delay access. As a result, it argued that families need to resort to persistent advocacy to ensure access to intensive supports. AEIOU recommended that all ECEI planners be required to have better training on the autism spectrum, the reintroduction of autism advisers to assist families, and action to streamline the pathway to minimise delayed access.[27]

11.30 AEIOU highlighted the paucity of information and support provided through the ECEI approach and the NDIS more generally:

> It is apparent the rules, operational guidelines and legislation have been created with adult participants in mind, with ECEI failing to properly consider the needs of children and families. Parents with very young autistic children simply do not have the knowledge and understanding of both the needs of the child and the kinds of support likely to gain positive outcomes. Subsequent review processes are poorly equipped to be able to react to the changing needs of the child in a timely manner. As a result, it is virtually impossible for a parent to get an appropriate support plan for an autistic child within that critical early intervention window without delay or need for review.[28]

11.31 As a result, AEIOU recommended that NDIS phase out the ECEI pathway and introduce a simpler, fairer system for scheme participants.[29]

11.32 Some stakeholders also drew attention to the need to understand the individual impact of each case of autism, rather than rely on broad levels defined in the American Psychiatric Association's fifth edition of the *Diagnostic and Statistical Manual* (DSM-5). For example, Autism Spectrum Australia argued that the DSM-5, typically used by diagnosticians, leads to variable standards. It argued:

> The timely and accurate diagnosis of autism is important, as it allows individuals to access appropriate early intervention services. Children who receive early interventions demonstrate improved cognitive, developmental, and adaptive functioning, enhanced language and social skills, as well as a decrease in symptom severity, cognitive impairment, and maladaptive behaviours as compared to children who are treated later.[30]

11.33 The NDIA has undertaken a review of the ECEI pathway to identify what is working well and the problem points, gaps and issues in the implementation of this approach. The review involved extensive consultation with stakeholders with the aim to:

> Create a distinct ECEI implementation model, differentiated from the general Scheme, which enables the right young children to receive the right

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[27] AEIOU Foundation, *Submission 50*, pp. 4–5.

[28] AEIOU Foundation, *Submission 50*, p. 6.

[29] AEIOU Foundation, *Submission 50*, pp. 3 and 7.

[30] Aspect, *Submission 64*, p. 3.

> level and mix of support for the right period of time (including more pre-access assistance and transition support) through a family centred approach aligned with best practice.[31]

11.34 The initial project consultation report set out 23 recommendations designed to reset the ECEI pathway approach. These recommendations comprised of overarching recommendations and enablers as well as recommendations along the three main stages of the ECEI approach—early support (including access to the NDIS), planning and implementation, transition.[32]

11.35 Through extensive consultations, stakeholders were generally supportive of the new approach and the proposed recommendations to implement it.[33]

11.36 Following further consultation with stakeholders and the decision not to proceed with independent assessments, the NDIA released a progress update of the proposed implementation timeline for the recommendations in October 2021 (see Appendix 3.E).[34]

Post-diagnosis support

11.37 The importance of post-diagnosis support was highlighted by stakeholders as crucial to the success of early intervention. For example, QFCC argued that '[a]ccessing timely post-diagnostic support is important for autistic children, as they need a range of supports and these can alter over time'. QFCC noted

> …autism is often linked with other physical, developmental, or mental health conditions such as intellectual disability, epilepsy, gastro-intestinal issues, attention deficit hyperactivity disorder, dyspraxia, anxiety, or depression. These co-occurring conditions can further complicate an autism diagnosis, including exacerbating features of autism. It can be challenging to provide supports and holistic therapeutic interventions to meet all the needs of an autistic child where comorbidities exist.[35]

11.38 The QFCC also pointed out that '[p]ost-diagnosis support is a difficult journey to navigate, and parents can feel they do not have enough information on the

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[31] National Disability Insurance Scheme (NDIS), *You said, we heard: supporting young children and their families early, to reach their full potential*, March 2020, p. 3.

[32] NDIS, *Early Childhood Early Intervention (ECEI) Implementation Reset: Project Consultation Report*, November 2020, p. 14.

[33] NDIS, *You said, we heard: Post-consultation reports*, 22 July 2021, https://www.ndis.gov.au/community/we-listened/you-said-we-heard-post-consultation-reports (accessed 16 December 2021).

[34] NDIS, *ECEI reset recommendations update*, 11 October 2021, https://www.ndis.gov.au/community/we-listened/you-said-we-heard-post-consultation-reports/supporting-young-children-and-their-families-early-reach-their-full-potential/how-were-improving-way-we-support-young-children-and-their-families/ecei-reset-recommendations-update (accessed 16 December 2021).

[35] Queensland Family and Child Commission, *Submission 36*, p. 5 (citation omitted).

different options for therapeutic interventions, with the expectation that it is up to families to contact therapists to determine appropriate courses of action'.[36]

11.39 Indeed, feedback provided to SDN Children's Services from families of children with an autism diagnosis highlighted the lack of follow-up support:

> Once my eldest was diagnosed we were not directed to any services, other than the paediatrician, to assist us with what the diagnosis meant and what services we can access. 2 years down the track I am still learning about what services are available to my son and our family.[37]

11.40 Another family noted that there 'is no hand holding after an autism diagnosis, nor are there government-funded support groups available. I rely heavily on other parents. Not enough autism services/professionals'.[38]

11.41 RCAP also highlighted evidence that showed First Nations families 'often receive little or confusing advice about post-diagnostic support, and experience long waiting lists for early intervention, high cost and limited availability of therapies, particularly in regional and remote Australia'.[39] RCAP noted:

> The experiences of racism in mainstream services can make people extremely wary of seeking help from such services. Poverty and marginalisation can also impede access to services: even for free services, difficulties getting to such services can be a disincentive and insufficient or confusing post-diagnostic advice and support.[40]

11.42 The Royal Australian and New Zealand College of Psychiatrists observed that '[s]evere behavioural problems in children that prohibit school placement are a significant concern, not only for parents but for our entire mental health system'. It noted that:

> Early intervention for these children and their families is inconsistent. The lack of centre-based, disability-focused school holiday programs for these children is being increasingly recognised as problematic in terms of family/carer burnout.[41]

Barriers to effective early intervention

11.43 Stakeholders identified several barriers to effective early intervention. These included delays in diagnosis and the lack of availability of clinicians with appropriate expertise, as well as access to appropriate services and supports.

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[36] Queensland Family and Child Commission, *Submission 36*, p. 5

[37] SDN Children's Services, *Submission 44*, p. 12.

[38] SDN Children's Services, *Submission 44*, p. 14.

[39] Royal Australasian College of Physicians, *Submission 29*, p. 6. See also, Ethnic Disability Advocacy Centre, *Submission 75*, p. 5.

[40] Royal Australasian College of Physicians, *Submission 29*, p. 7. See also, The Autistic Realm Australia (TARA), *Submission 86*, p. 9.

[41] Royal Australian and New Zealand College of Psychiatrists, *Submission 17*, [p. 2].

Together, these barriers often lead to inconsistencies in experiences and outcomes for many autistic children and young people.

11.44 The committee notes that these were common barriers experienced by autistic individuals and their families, as outlined in other chapters of this report.

11.45 Stakeholders have reported significant delays in obtaining an autism diagnosis. In turn this often undermines opportunities for many children to benefit from appropriate early intervention. For example, a group from Monash University noted:

> Wait times for most Australian autism assessment clinics have increased by six months due to COVID-19, extending waiting times to over one year. These waits occur at a critical time in a child's development where interventions may have their most significant impact. Importantly, parents are already aware of the specific problems their child is experiencing and the types of supports they require, yet such periods are wasted because planning for services and interventions are put on hold.[42]

11.46 Similarly, Spectrum Labor noted that waiting lists for early intervention services can see 'many autistic children miss out on early intervention during the most important formative years and are not as school ready or do not get adequate support at school'.[43]

11.47 Irabina Autism Services advocated for the funding of specialist diagnostic clinics to address the growing demand for diagnostic assessments and facilitate access to early intervention.[44]

11.48 Even with an appropriate diagnosis of autism, stakeholders argued that many children and young people often had difficulty accessing early intervention services. For example, Mindful informed the committee of problems of 'inequity of access to services, with significantly longer waiting lists in areas of lower socio-economic disadvantage and in rural areas'.[45]

11.49 The availability of clinicians and staff with appropriate expertise was identified by stakeholders as a potential barrier for autistic children and young people to access early intervention and other support services. For example, ESA argued that while 'there is training available to clinicians for specific intervention strategies (for example, many ESA therapists have some additional certification or training, such as Hanen, ESDM [Early Start Denver Model] or ABA [Applied Behaviour Analysis)':

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[42] Monash University, *Submission 94*, p. 15.

[43] Spectrum Labor, *Submission 1*, p. 4. See also, Autism Advisory and Support Services, *Submission 21.1*, pp. 4–5.

[44] Irabina Autism Services, *Submission 130*, p. 5.

[45] Mindful, *Submission 162*, p. 4.

> …it is not currently a requirement that therapists providing NDIS services to individuals with autism have any training beyond their foundational qualification e.g. Occupational Therapist or Psychologist. This means that there is currently little accountability for service providers, and autism service quality is largely unregulated. Participants often have little understanding of the difference between interventions or their possible harms and risks. Considering the complexity of the condition and the likelihood of vastly differing outcomes and need for tailoring of service delivery, we support the inclusion of additional training expectations for health professionals/clinicians providing therapy.[46]

11.50 The Autism Behavioural Intervention Association (ABIA) highlighted the 'significant shortage of qualified and experienced professionals able to deliver the services that are needed across the life-span of an individual with autism'. As evidence of this, ABIA pointed to the number of [their] providers sourcing staff internationally' as well as the 'long wait-lists with ABA Service Providers'.[47] ABIA also noted:

> Behaviour Therapists are highly sought after in the wider disability sector (not just families choosing ABA services). This is because of the evidence base and rigour inherent in EPB [Evidence-Based Practices]. Its' also because behaviour analytics is a scientific methodology and an accredited discipline. This demand for therapists has resulted in the current situation where families wanting ABA services for their child are now competing with general disability service providers who are sending ABA trained people out as carers.[48]

11.51 AEIOU drew the committee's attention to the increased costs for the health system and community services due to delays in access to early intervention:

> Children already experience significant delays to access a diagnosis and granting access to life-changing intervention is time sensitive – this will ensure children have the best opportunity to overcome the disabling aspects of autism within the appropriate windows of early intervention. By delaying access, the futures of these children are compromised, and financial and emotional wellbeing of families is compromised.[49]

11.52 The Australian National Audit Office (ANAO) performance audit of early intervention services for children with disability in 2015–16 found:

> Access to, and the utilisation of services, has remained reliant on the proximity to [Department of Social Services] registered service providers, with claims and expenditure for eligible children living in regional and remote areas being disproportionately low when compared to claims by

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[46] Early Start Australia, *Submission 76*, p. 6.

[47] Autism Behavioural Intervention Association (ABIA), *Submission 70*, p. 6.

[48] ABIA, *Submission 70*, p. 7.

[49] AEIOU Foundation, *Submission 50*, p. 6. See also, Spectrum Labor, *Submission 1*, p. 15. The AEIOU Foundation's submission argued that the NDIS requires more funding in this area to achieve the goals of successful early intervention.

> children living in urban areas. This is despite additional funding being made available to children in these areas to assist with the cost of accessing services.[50]

11.53 Indeed, international evidence suggests that access to early intervention is correlated to affluence. For example, among a United States paediatric population with autism, neighbourhood affluence was linked to greater access to early intensive behavioural intervention. Indeed, the University of New South Wales Department of Developmental Disability Neuropsychiatry called for specific strategies and additional supports to be provided to ensure health care access for autistic people living in poverty.[51]

Committee view

11.54 The committee recognises the importance of early supports to the life outcomes of autistic children and young people, as well as the need for better information about, and support for, evidence-based early intervention. Specifically, the committee notes that current information and evidence on best practice in pre-emptive and early intervention should be more widely available to the autism community and service providers, as well as to government agencies, including the National Disability Insurance Agency (NDIA).

11.55 The committee is particularly mindful that autistic children have characteristics which manifest in highly individual ways, that diagnosis is complex, and that there is no 'one size fits all' approach. Indeed, the committee recognises the need to continue to build on the existing research into evidence-based early intervention. Therefore, the committee recommends that the Australian Government commit further funding to quality research addressing gaps in the evidence for early intervention approaches.

11.56 The committee is also concerned by evidence from stakeholders that there continue to be barriers to effective early intervention, which often contribute to delays in children and young people receiving appropriate assessments and access to support services. The committee heard from several stakeholders that these barriers particularly affected populations with existing disadvantages, such as those imposed by gender, poverty, remoteness, or culturally and linguistically diverse backgrounds.

11.57 As such, the committee believes that there needs to be clearer identification and coordination of post-diagnostic service supports and interventions to help families with autistic children to better navigate all available options. In particular, the committee recognises the need to help families to navigate the pathway from diagnosis into therapy. To this end, the committee recommends

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[50] Australian National Audit Office, *Submission 13*, p. 2.

[51] Department of Developmental Disability Neuropsychiatry, University of New South Wales (UNSW 3DN), *Submission 95*, p. 11.

that the government investigate options to improve post-diagnosis support, including a one-stop shop for directing individuals to the most appropriate support services.

11.58 In addition, the committee is cognisant that there needs to be improved education and training for those providing early intervention services, particularly among National Disability Insurance Scheme (NDIS) planners and educators. The committee recommends that all NDIS planners and educators associated with the new Early Childhood Approach be required to undergo training in understanding autism and best evidence-based approaches to early intervention.

11.59 The committee is also encouraged by the work currently underway to create a national practice guideline (Supporting Children National Guideline) for supporting the development and participation of children on the autism spectrum. The committee looks forward to the Supporting Children National Guideline assisting planners and educators to more effectively deliver early intervention services based on the specific needs and circumstances of individuals and their families.

Recommendation 43

11.60 The committee recommends that the Australian Government commit funding to quality research to continue addressing gaps in the evidence for early intervention approaches.

Recommendation 44

11.61 The committee recommends that the Australian Government investigate options to improve post-diagnosis support, including a one-stop shop for directing individuals to the most appropriate support services.

11.62 The one-stop shop should be accessible via a range of platforms, including more traditional mediums such as print and phone support services.

Recommendation 45

11.63 The committee recommends that all National Disability Insurance Scheme planners and educators associated with the new Early Childhood Approach undergo training in understanding autism and best evidence-based approaches to intervention.

Chapter 12
Education

12.1 This chapter provides an overview the primary legislation underpinning equality of access to education in both school and higher education settings. It then discusses common challenges to improving education outcomes for autistic students, as well as ways to improve the transition from education to employment.

12.2 Although the education system also encompasses early childhood education and child care, this chapter focuses solely on school and higher education. This reflects the balance of the evidence provided to the committee. It also reflects the fact that early childhood education and child care settings have a strong focus on early intervention, which is discussed in greater detail in Chapter 11.

Overview

12.3 As outlined in Chapter 3, school educational outcomes for autistic people are far worse than those of the general population. In terms of post-school education, autistic people's outcomes are also worse than those of people with other forms of disability.

12.4 In addition, actions taken to date, such as the introduction of the *National Disability Strategy 2010–2020* (the *National Disability Strategy*), appear to have made little difference. For instance, The Sycamore School noted that in the decade since its introduction, there have been no improvements in 'educational attainment levels for autistic students, and the numbers of students whose developmental and academic needs are unmet also remains unchanged'.[1]

12.5 Stakeholders were also critical of the Disability Standards for Education (DSE)[2] which set out both the rights of students with disability, as well as the obligations of all education and training providers, under the *Disability Discrimination Act 1992* (Disability Discrimination Act). All jurisdictions, education sectors and providers are required to comply with the DSE (see Box 12.1).[3]

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[1] The Sycamore School, *Submission 118*, p. 8.

[2] See, for example, Australian Autism Alliance, *Submission 52*, p. 32; Disability Discrimination Legal Service, *Submission 153*, p. 22; Ms Julie Phillips, *Submission 152*, p. 8.

[3] Department of Social Services, Department of Education, Skills and Employment, Department of Health, *Submission 53*, p. 15. In addition to the *Disability Discrimination Act 1992*, each state and territory has legislation that makes discrimination of the basis of disability unlawful in areas such as employment, education, access, and the provision of goods and services.

Box 12.1 Disability Standards for Education 2005 (DSE)

The DSE aim to ensure students with disability can access and participate in education on the same basis as other students. Students with disability must have comparable opportunities and choices in relation to:

- admission and enrolment;
- participation in courses or programs; and
- use of facilities and services.

Accordingly, the DSE cover enrolment, participation, curriculum development, accreditation and delivery, student support services and elimination of harassment and victimisation. Education providers have three main types of obligations under the DSE. These are to consult, make reasonable adjustments, and eliminate harassment and victimisation.

This means education providers must:

- **consult** to understand the impact of a student's disability and to determine whether any adjustments are needed to help the student;
- make **reasonable adjustments** to help a student with disability participate in education on the same basis as other students. An adjustment is reasonable if it does this while accounting for the student's learning needs and balancing the interests of all parties affected (including those of the student with disability, the education provider, staff and other students); and
- develop and implement strategies to prevent **harassment and victimisation** of people with disability.

The DSE apply to preschools, kindergartens, public and private schools, public and private education and training places and tertiary institutions including TAFEs and universities. It is unlawful to breach the DSE.

The DSE do not currently apply to child care providers, although they are subject to the *Disability Discrimination Act 1992*. It is proposed the DSE will be amended to include the early childhood education and child care sector from 2023.

Source: Department of Education, Skills and Employment, Fact Sheet 2: Disability Standards for Education 2005, 1 October 2015, www.dese.gov.au/swd/resources/fact-sheet-2-disability-standards-education-2005 *(accessed 25 November 2005); Department of Education, Skills and Employment, Final Report of the 2020 Review of the Disability Standards for Education 2005, 2020, p. ix.*

12.6 Despite the requirement for the DSE to be reviewed every five years, the Australian Autism Alliance (the Autism Alliance) indicated that its shortcomings remain unaddressed and key inclusion indicators are 'going backwards'. According to the Autism Alliance, there is a need to substantially overhaul the DSE in order to:

> …positively reframe inclusive education as a right, strengthen protections and create accountabilities in the education system for progressively

improving outcomes (e.g., improved school attainment, reduced suspensions and expulsions, elimination of restrictive practices).[4]

12.7 Other stakeholders, such as the Disability Discrimination Legal Service (DDLS), recommended rescinding the DSE altogether, as well as making a number of amendments to the Disability Discrimination Act. If not rescinded, the DDLS advocated reforming the DSE to:

- ensure the term 'reasonable adjustment' is commensurate with the definition in the Disability Discrimination Act;
- ensure it includes examples of the sorts of actions that may help students with cognitive disabilities such as autism;
- ensure the definition of 'consultation' is consistent with the Convention on the Rights of Persons with Disabilities in relation to the participation of people with disabilities in decision-making;
- more adequately recognise the obligation on providers to protect students from bullying, including strengthening the test for compliance; and
- emphasise the primacy of expert knowledge of disability in relation to decision-making for reasonable adjustments, and reduce the discretion given to education providers.[5]

12.8 The most recent review of the DSE took place in 2020, with the *Final Report of the 2020 Review of the Disability Standards for Education 2005* (the DSE Review Report) released in March 2021.[6]

12.9 Evidence provided to the committee suggests that many of the concerns raised by stakeholders in relation to school and higher education settings were also reflected in the DSE Review Report and its recommendations.[7] Overall, the DSE Review Report made 13 recommendations, with implementation progress to be reported annually. A summary of key actions is shown at Table 12.1.[8]

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[4] Australian Autism Alliance, *Submission 52*, p. 32.

[5] Disability Discrimination Legal Service, *Submission 153*, pp. 8–9.

[6] Department of Education, Skills and Employment, *2020 Review of the Disability Standards for Education 2005*, 12 March 2021, www.dese.gov.au/disability-standards-education-2005/2020-review-disability-standards-education-2005 (accessed 10 December 2021).

[7] The need for greater accountability, including compliance audits, was raised in the 2020 Review of the Disability Standards for Education 2005 (see Table 12. 1). This issue was also raised in a number of submissions. See, for example, Name withheld, *Submission 126*, p. 19; Disability Discrimination Legal Service, *Submission 153*, p. 9.

[8] Department of Education, Skills and Employment, *2020 Review of the Disability Standards for Education 2005*, 12 March 2021, www.dese.gov.au/disability-standards-education-2005/2020-review-disability-standards-education-2005 (accessed 10 December 2021).

Table 12.1 Disability Standards for Education: areas for reform

Empowering and supporting students with disability and their families	
Information for students and their families	Develop information products that explain students' rights and provide information to students and families at relevant points
Clearer rules on consulting with students and families and handling issues and complaints	Change the DSE to explain how education providers should consult with students and their families about supports and adjustments and handle issues and complaints
Sharing information when students change schools	Look at how to transfer relevant information about students' needs when they change schools or move to training or higher education
Strengthening the knowledge and capability of educators and providers	
Information for education providers	Develop information products that explain provider responsibilities and provide examples of good practice
Training school teachers and leaders	Ask state and territory governments to ensure teachers and school leaders receive training on the DSE and supporting students with disability
Including the DSE in higher education policies	Make sure the DSE are included in the policies and practices of higher education providers.
More accountability for the Standards throughout education	
Making sure education policies match the DSE	Work with state and territory governments to make sure that rules and policies that apply to education providers align with the DSE
Improving vocational education and training	Work with state and territory governments to strengthen delivery of vocational education and training for students with disability
Public information on how schools support students with disability	Require school education authorities to explain the services and supports their schools provide for students with disability on their websites
Data and reporting	Work with states and territories on principles for data collection and reporting on how students take part in school education
Checking how well the DSE are followed	Ask state and territory governments to conduct an audit to see how well the DSE are followed.

Source: Department of Education, Skills and Employment, Summary of the 2020 Review of the Disability Standards for Education 2005, 12 March 2021, pp. 1-2.

12.10 While the committee heard that many of the challenges faced by autistic people in school and higher education settings have the same genesis—such as a lack of understanding of autism or discriminatory practices—it also understands that these challenges can manifest differently for students in each setting. In addition, the length of time spent in school and its compulsory nature mean that the bulk of evidence provided to the committee about education relates to school education. For this reason, the remainder of this chapter deals separately with school and higher education. The exception to this is the section on the transition from education to work, which covers both school and higher education settings.

School education

Mainstream versus special education settings

12.11 Information about where autistic students are being educated is not clear as data on autistic student enrolment types appear to vary. For example, the Australian Bureau of Statistics (ABS) *Disability, Ageing and Carers, Australia: Summary of Findings* reported that 40.8 per cent of autistic children in 2018 attended a special class in a mainstream school or a special school.[9] By contrast, the Autism Alliance survey found that:

- 72.2 per cent of autistic students attended a mainstream school;
- 10.9 per cent of autistic students attended a special school;
- 9 per cent of autistic students attended a dual (mainstream and special) school;
- 3.3 per cent of autistic students were home-schooled; and
- 2.2 per cent of autistic students undertook distance education.[10]

12.12 However, various stakeholders also noted that there has been a shift in enrolments away from mainstream schools and into special schools.[11] For instance, Children and Young People with Disability Australia (CYDA) stated that enrolment rates in Victorian special schools have increased by 53 per cent since 2010.[12]

12.13 According to the Cooperative Research Centre for Living with Autism (Autism CRC), the increased numbers of students in segregated education

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[9] Australian Bureau of Statistics (ABS), *Disability, Ageing and Carers, Australia: Summary of Findings*, 24 October 2019, www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#autism-in-australia (accessed 11 December 2021).

[10] Australian Autism Alliance, *Submission 52.2*, p. 7.

[11] See, for example, Cooperative Research Centre for Living with Autism (Autism CRC), *Submission 46*, p. 14; Australian Autism Alliance, *Submission 52*, p. 32; People with Disability Australia, *Submission 102*, p. 23; Children and Young People with Disability Australia, *Submission 109*, p. 4.

[12] Children and Young People with Disability Australia, *Submission 109*, p. 4.

settings may be the result of 'concerning inconsistencies in the access and implementation of inclusive practices throughout Australia' identified in multiple commissioned reviews over the last five years. The Autism CRC also noted an increase in the number of children being home schooled, with 'special learning needs' being provided as a rationale for 25 per cent of home-schooled students in NSW in 2018 (compared with 20 per cent in 2016).[13]

12.14 The Autism Alliance concurred and argued that both the rise in segregated enrolments and the increase in home schooling 'speaks volumes about a system that ignores the needs and rights of autistic people'.[14] People with Disability Australia (PWDA) also suggested that while some parents may view special schools as necessary, 'this is because there is currently no real choice between special schools and mainstream inclusive education'.[15]

12.15 For some stakeholders, such as PWDA, the reported increase in special school placements raises concerns that Australia is moving toward a segregated education system.[16] Accordingly, some submitters advocated for the phasing out of segregated education in Australia.[17] This reflected a view that segregated education does not meet Australia's obligations under the *Convention on the Rights of Persons with Disabilities* (CRPD),[18] as well as evidence showing better educational and social outcomes for students who are integrated into inclusive mainstream education environments.[19] However, in relation to the CRPD, the DDLS noted that 'while the CRPD indicates that inclusive education for students with disability in mainstream environments should be the norm, there may be exceptions'.[20]

12.16 To create inclusive education environments, stakeholders, such as the Autism CRC and the Scope-University of Melbourne Partnership (Scope-UoM), proposed the adoption of a Universal Design for Learning (UDL) approach.

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[13] Autism CRC, *Submission 46*, pp. 14 and 15.

[14] Australian Autism Alliance, *Submission 52*, p. 32.

[15] People with Disability Australia, *Submission 102*, p. 24.

[16] People with Disability Australia, *Submission 102*, p. 23.

[17] See, for example, Children and Young People with Disability Australia, *Submission 109*, p. 3; People with Disability Australia, *Submission 102*, p. 24; Ms Julie Phillips, *Submission 152*, p. 8.

[18] See, for example, Children and Young People with Disability Australia, *Submission 109*, p. 3; People with Disability Australia, *Submission 102*, p. 24; Ms Julie Phillips, *Submission 152*, p. 8.

[19] See, for example, Autism CRC, *Submission 46*, p. 15; People with Disability Australia, *Submission 102*, p. 23; Children and Young People with Disability Australia, *Submission 109*, p. 3; Dr Bruce Baer Arnold, *Submission 39*, p. 9.

[20] Disability Discrimination Legal Service (DDLS), *Submission 153*, p. 13. This exception is based upon the language needs for some students with disability. The DDLS submitted that this is an appropriate interpretation. While it accepted there will be exceptions to the general rule of inclusive education, it does not believe the Australian education system currently reflects this.

According to Scope UoM, UDL seeks to identify universal supports that will help most students and then makes individual accommodations where needed for individual students. The Autism CRC also noted that UDL is able to incorporate various evidence-based teaching strategies to accommodate students with diverse abilities and backgrounds.[21]

12.17 However, the committee also heard conflicting evidence about the increase in special school enrolments. For example, Autism Aspergers Advocacy Australia (A4) questioned some of the figures that have appeared in education journals and the media that claim to reflect ABS data. Instead, A4 argued that the most recent ABS data showed an increase in mainstream enrolments and a decrease in special class and special school placements (see Table 12.2).[22]

Table 12.2 School enrolment types 2009–2018

Year	Cannot attend (per cent)	Special class (per cent)	Special school (per cent)	Mainstream (per cent)
2009	3.3	24.2	22.8	49.7
2012	6.8	24.9	26.1	42.2
2015	2.0	21.7	27.5	48.8
2018	4.3	19.9	20.0	55.8

Source: Autism Aspergers Advocacy Australia (A4), Submission 54, Attachment 1, p. 12.

12.18 Aside from a lack of definitive data on autistic school enrolments, other stakeholders suggested there is also a need for a more nuanced approach to the debate about mainstream and segregated education. For example, specialist education provider Autism Spectrum Australia (Aspect) advocated for a model that accounts for individual student needs and recognises the role that specialist autism schools can play in helping autistic students transition into mainstream schools. Under this model, special schools are just one part of a 'specialised, comprehensive, multifaceted approach':

> The approach to education for students on the autism spectrum needs to be flexible, align to the student's specific autistic learning styles and needs, and involve a continuum of special education services that is inclusive of their strengths and abilities.
>
> This continuum includes autism-specific special school placement, small support or satellite classes staffed by autism-specialist teachers in mainstream schools, autism-specific itinerant teacher services to support

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[21] Autism CRC, *Submission 46*, p. 15; Scope-University of Melbourne Partnership, *Submission 83*, p. 8.

[22] Autism Aspergers Advocacy Australia (A4), *Submission 54, Attachment 1*, pp. 11-12.

> students who are included in mainstream classes and full mainstream school placement…[23]

12.19 The role of specialist autism schools was also highlighted by The Sycamore School which submitted that the 'distinct challenges' faced by autistic students necessitated 'specialist and focused strategies' and meaningful supports to achieve good outcomes. In line with this, The Sycamore School advised that it provides access to speech therapy, occupational therapy, wellbeing and independent living skills, social work and mental health supports. In addition, it delivers the Australian Curriculum 'in a meaningful and adjusted way, paralleled with an autism-specific curriculum that supports the developmental needs of each student'. In contrast to advocates of UDL approaches, The Sycamore School cited research showing that 'best practice' includes the use of 'an autism-specific curriculum aimed at addressing the developmental needs of autistic students'. It considered the success of its approach to be evident in:

> …the educational progress our students make, the levels of engagement with learning we experience in our classrooms, as well as the developmental gains many of our students have made. Our students take responsibility for their goal setting, and using the self-advocacy skills we teach, are learning to take control around their independence.[24]

12.20 In addition, while not believing that 'segregation should be the norm', the DDLS suggested that disability-specific schools will be required in response to the language needs of particular students or for 'some students with cognitive disabilities or disabilities that manifest with challenging behaviour'. However, the DDLS considered that, in this situation, a school would 'provide targeted and intensive evidence-based support with the objective of facilitating the student moving/returning to a mainstream education setting'.[25]

12.21 According to an Autism Queensland survey, a mixed model also appears to be supported by parents, with most respondents preferring mainstream schools but with notable levels of support identified for combined options, as well as autism-specific classes in mainstream schools and autism-specific schools. While the least preferred options were home schooling/distance education and general special schools, the most significant gap between current placements and parents' preferences were in relation to wanting autism-specific classrooms

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[23] Autism Spectrum Australia (Aspect), *Submission 64*, pp. 14-15. Aspect schools work on a 'transitional model' that aims to provide students, from primary school through to high school, with the skills they need to move into a mainstream education or other specialist environment. Classes are small with a high teacher to student ratio and a teachers' aide appointed to each class. Aspect aims to help students develop the skills to become as independent as possible and to enable them to succeed in the wider community. A large number of students transition through Aspect educational services and schools, into mainstream schools each year.

[24] The Sycamore School, *Submission 118*, p. 4.

[25] Disability Discrimination Legal Service, *Submission 153*, p. 13.

and schools—as opposed to special classes and schools that are not autism-specific (see Table 12.3).[26]

Table 12.3 Autism Queensland survey: current and preferred school placement types

Placement type	Primary school		Secondary school	
	Current (per cent)	**Preferred** (per cent)	**Current** (per cent)	**Preferred** (per cent)
Mainstream classroom	61.5	50.9	48.9	42.9
Combination of part-time options	17.8	12.9	20.1	21.1
Special class in mainstream school	7.2	5.7	17.8	9.1
Autism-specific class in mainstream school	0	13.9	0	10.9
Special school	5.3	2.5	9.2	1.1
Autism-specific special school	2.5	8.4	1.1	9.1
Home school/distance education	4.8	3	2.3	4.6

Source: Autism Queensland, Submission 129, pp. 8-9.

12.22 However, the committee also heard some evidence that the quality of special schools can be variable.[27] Some submitters, such as Communication Rights Australia, also raised concerns that special schools have been the subject of allegations about the use of violence against students.[28]

12.23 While not a commonly preferred option, other stakeholders such as the Ethnic Disability Advocacy Centre called for home schooling to be supported as an alternative for autistic children 'that do not fit in mainstream and special schools'.[29]

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[26] Autism Queensland, *Submission 129*, pp. 8–9. Parents described preferences for many combinations of part-time options including: (a) regular mainstream classroom and a special education classroom, (b) home school/distance education and special education classroom, (c) home school/distance education and an autism specific school, and (d) regular mainstream classroom and an autism specific school.

[27] Disability Discrimination Legal Service, *Submission 153*, p. 13; Name withheld, *Submission 126*, p. 19.

[28] Communication Rights Australia, *Submission 151*, p. 6.

[29] Ethnic Disability Advocacy Centre, *Submission 75*, p. 8.

12.24 Similarly, Yellow Ladybugs highlighted the benefits of remote and flexible learning for autistic girls. These include reduced anxiety, less sensory overwhelm, less pressure on executive functioning skills, a lack of bullying, and more one-on-one support. This was reflected in the experience of one student who, prior to remote learning, had been experiencing disengagement, self-harm, mental health concerns, bullying and school refusal:

> The shift to remote learning has been a positive experience for her, and an eye-opener for me … Learning from home has allowed K to relax. She has less anxiety and is more physically comfortable without sensory overload. She is able to learn without needing to wear her 'mask' and is more engaged as a result. I've seen her learn and do more work in the past four weeks than she did in the past four years! ... This experience has proved that we need to rethink how we deliver education for those autistic girls for whom neither physical school attendance, nor traditional home schooling, meet their particular needs.[30]

12.25 Overall, while there was significant support for improving inclusive education practices in mainstream schools,[31] the committee also heard that a range of school placement options may be required to meet the specific and varied needs of autistic students.[32]

Challenges to school education access and outcomes

12.26 Broadly, the committee heard that the main challenges faced by autistic people in relation to school education access and outcomes relate to:

- discrimination, bullying and low expectations;
- a lack of adequate supports and adjustments;
- insufficient autism knowledge and understanding; and
- inadequate resources to implement adjustments.

Discrimination, bullying and low expectations

12.27 Multiple stakeholders reported experiences of discrimination and bullying in schools.[33] For example, according to the Autism Alliance, over one third of survey respondents felt their child 'had been discriminated against in school or

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[30] Yellow Ladybugs, *Submission 49*, pp. 25 and 26.

[31] See, for example, Children and Young People with Disability Australia, *Submission 109*, p. 6; People with Disability Australia, *Submission 102*, p. 24; Scope-University of Melbourne Partnership, *Submission 83*, pp. 8-9; The Autistic Realm Australia (TARA), *Submission 86*, p. 3; Name withheld, *Submission 120*, [p. 9].

[32] Autism Queensland, *Submission 129*, p. 11; Aspect, *Submission 64*, p. 15.

[33] See, for example, Australian Autism Alliance, *Submission 52*, p. 32; Name withheld, *Submission 2*, p. 1; Name withheld, *Submission 4*, p. 3; Name withheld, *Submission 6*, [p. 1]; Name withheld, *Submission 82*, [p. 1]; Name withheld, *Submission 112*, [p. 7]; Name withheld, *Submission 120*, [p. 1]; Name withheld, *Submission 148*, p. 10.

when seeking to access an education'.[34] In relation to bullying, a survey by Autism Queensland found that it was the second most common reason for autistic children changing schools.[35]

12.28 For many parents, discrimination began before their child was enrolled at school, with gatekeeping practices often reported.[36] A4 stated that these practices occur at both primary and secondary school levels and that 'private schools rarely enrol autistic students'.[37] Examples of gatekeeping provided to the committee include a student being refused enrolment by a private school due to his autism diagnosis[38] and a student being refused enrolment by a government primary school until the school was sure the child would secure disability program funding.[39]

12.29 In response, one submitter advocated for wider application of the approach they claimed is used in Queensland, whereby the Queensland Department of Education contacts schools directly if it is notified about a refusal to enrol a student.[40]

12.30 The committee heard that discrimination and exclusionary practices can continue even after a student is enrolled, with some schools only allowing partial attendance, excluding autistic students from school activities, or suspending or expelling students.[41] This aligned with the findings of CYDA's 2019 National Education Survey which found that 12.5 per cent of respondents with disability had been refused school enrolment, with another 16.6 per cent not attending school full-time and 14 per cent having been suspended.[42]

12.31 In addition, some submitters noted that discrimination can take the form of low expectations about the ability of autistic people to achieve academically,[43] which

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[34] Australian Autism Alliance, *Submission 52*, p. 32.

[35] Autism Queensland, *Submission 129*, p. 7.

[36] See, for example, Autism Awareness Australia, *Submission 47*, p. 7; Scope-University of Melbourne Partnership, *Submission 83*, p. 8; Disability Discrimination Legal Service, *Submission 153*, p. 28; Name withheld, *Submission 148*, p. 2.

[37] A4, *Submission 54, Attachment 1*, p. 27.

[38] Name withheld, *Submission 16*, [p. 1].

[39] Name withheld, *Submission 120*, [p. 1].

[40] Name withheld, *Submission 126*, p. 19.

[41] See, for example, Autism Awareness Australia, *Submission 47*, p. 8; Yellow Ladybugs, *Submission 49*, p. 28; Australian Autism Alliance, *Submission 52*, p. 30; Commissioner for Children and Young People South Australia, *Submission 88*, p. 7; A4, *Submission 54, Attachment 1*, pp. 27-28; Scope-University of Melbourne Partnership, *Submission 83*, p. 8.

[42] Children and Young People with Disability Australia, *Submission 109*, p. 4.

[43] See, for example, A4, *Submission 54, Attachment 1*, p. 35; Disability Discrimination Legal Service, *Submission 153*, p. 7; Name withheld, *Submission 126*, p. 19.

the Autism Alliance described as the 'soft bigotry of low expectations'.[44] While not specific to autistic students, CYDA reported that about 70 per cent of students with disability responding to its survey stated that they 'were not encouraged to complete or to choose subjects to lead a good ATAR score for higher education'.[45]

12.32 The Autism Alliance also observed that once in school, autistic students are 'significantly more likely than their non-autistic peers to be targets of bullying and suffer depression and anxiety'.[46] This was reflected in research by La Trobe University's Olga Tennison Autism Research Centre (OTARC) which found that 59 per cent of autistic students were bullied at school, versus 45 per cent of non-autistic students.[47] Scope UoM explained that differences in communication and social interaction, which affect how autistic students understand social norms and the use of social skills in particular contexts, can leave them more susceptible to bullying.[48]

12.33 According to one submitter, the level of bullying and ostracism experienced by autistic children is 'horrific', leading to challenging behaviours, suspensions and exclusions, as well as severe school avoidance.[49] The Coalition of Autistic Women also highlighted school refusal as a common occurrence when children 'can no longer bear daily bullying, harassment and abuse by students and sometimes, staff'.[50]

12.34 One 11-year-old submitter described being 'hit, threatened, sworn at, and excluded from playing' because they are different. In addition, they had belongings stolen and put in the toilet, and were not invited to parties like the rest of their classmates. As they told the committee:

> This makes me feel very, very sad and lonely. It makes me feel like I'm not welcome at school. It makes me feel less than other people.
>
> That's not fair.[51]

12.35 Yellow Ladybugs relayed the experience of one student who went from being an academic high achiever to not completing Year 10 after suffering severe bullying and mental health issues:

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[44] Australian Autism Alliance, *Submission 52*, p. 28.

[45] Children and Young People with Disability Australia, *Submission 109*, p. 5.

[46] Australian Autism Alliance, *Submission 52*, p. 30.

[47] La Trobe University – Olga Tennison Autism Research Centre (OTARC), *Submission 55*, p. 23.

[48] Scope-University of Melbourne Partnership, *Submission 83*, p. 11.

[49] Name withheld, *Submission 81*, [p. 4].

[50] Coalition of Autistic Women, *Submission 125*, pp. 17-18.

[51] Name withheld, *Submission 82*, [p. 1].

> After experiencing severe bullying in Year 7 my daughter transferred to a different secondary school (for Year 8) but due to her increasing mental health issues found it difficult to make social connections. She therefore withdrew from mainstream schooling and commenced distance education. Prior to doing distance education my daughter was one of the smartest students at school, her NAPLAN results were in the top triangles, she received distinctions in the UNSW competitive exams and often received academic awards (her abbreviated IQ is also in the gifted range). So an intelligent student, who was once a top student, isn't even completing Year 10 because of so many barriers.

12.36 As noted by the Department of Social Services, Department of Education, Skills and Employment and Department of Health (the departments), coping with bullying and teasing was a 'top ten issue' for autistic students.[52] Despite this, the Autism Alliance survey found 'an absence of support for the social and emotional wellbeing of autistic students.[53]

12.37 In addition, some submitters recommended strengthening anti-bullying education programs to ensure the safety of autistic students at school.[54] Autism Queensland suggested that this should include:

- greater accountability and responsibility for bullying, including the family and parents of the perpetrators; and
- supervised lunchtime programs for students who are vulnerable to bullying.[55]

12.38 Scope-UoM also highlighted the importance of providing supported opportunities for social engagement, as well as whole school approaches to positive behaviour support via the use of frameworks such as School Wide Positive Behaviour Interventions and Support.[56] The importance of supported

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[52] Department of Social Services, Department of Education, Skills and Employment and Department of Health, *Submission 53*, p. 18.

[53] Australian Autism Alliance, *Submission 52*, p. 30.

[54] See, for example, Spectrum Labor, *Submission 1*, [p. 10]; Disability Discrimination Legal Service, *Submission 153*, p. 33; Name withheld, *Submission 81*, [p. 4].

[55] Autism Queensland, *Submission 129*, p. 11.

[56] Scope-University of Melbourne Partnership, *Submission 83*, pp. 12 and 13. School Wide Positive Behaviour Interventions and Support (SWPBIS) builds on the well-established principles and practices of Positive Behaviour Support, which has been repeatedly demonstrated over the past 40+ years to be the intervention of choice to address behaviours that impede a person with disabilities' engagement and integration in society and to improve their quality of life. Where possible, Scope-UoM strongly endorses an inclusive SWPBIS model that first looks to transform the school environment, rather than changing behaviours that may not be understood by others. A clear example of this is the acceptance of 'stimming' behaviours. However, Scope-UoM also recognises that there are limits to this approach and some behaviours cannot be accommodated and need to be changed.

opportunities for social engagement was also emphasised by a mother whose autistic son has been bullied at his local primary school:

> He is bullied in the playground and has never been invited on a playdate. His social needs have not been supported at school. He has been punched in the playground several times and been unable locate a teacher on duty. While he has an [education assistant – EA] in class, there is rarely an EA in the playground and the teachers on duty rove around the school. … The playground environment is the perfect place for autistic children to learn important social skills such as turn taking, conflict resolution and flexibility with play. However, without guidance, this will not happen naturally. This is an opportunity to teach life skills that could significantly improve the quality of life for people with autism.

12.39 Scope UoM also pointed to other initiatives, such as gaming clubs, where students come together to play video games with staff support. This allows autistic students to 'use their established knowledge as a basis for engaging with their neurotypical peers' which 'positions autistic students as relative experts often providing much needed confidence'.[57]

12.40 However, other stakeholders, including the 11-year-old submitter referred to previously, also noted the broader need to improve understanding of autism within schools:

> We need a national education program for schools to better include and accept neuro-diverse kids. This should target kids, parents, teachers and schools.
>
> Understanding autism better will make other kids stop bullying kids who are a bit different and help them be kinder. It will also help teachers teach neuro-diverse kids better.[58]

Adequate supports and adjustments

12.41 The committee heard that school environments can pose multiple challenges for autistic students.[59] As described by Aspect, they can include:

> …large physical settings that can be noisy and chaotic, large class sizes that restrict individualised support, and an increased emphasis on unspoken social rules and academic progress as a student progresses through the upper primary stages of learning and into secondary education.[60]

12.42 In addition to environmental and social factors, Aspect noted that the unique learning styles of autistic students can also create barriers to autistic students

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[57] Scope-University of Melbourne Partnership, *Submission 83*, pp. 13 and 14.

[58] Name withheld, *Submission 82*, [p. 1].

[59] See, for example, Australian Autism Alliance, *Submission 52*, p. 28-30; Scope-University of Melbourne Partnership, *Submission 83*, pp. 9–11; Positive Youth Incorporated, *Submission 85*, p. 5

[60] Aspect, *Submission 64*, p. 14.

accessing the curriculum.[61] Aspect noted parents particular concerns about access to what it described as the 'hidden curriculum'. That is, social and general life skills which may not be taught directly 'but are nevertheless critical to the progress of young autistic people who may not acquire them in the usual ways'. These skills include self-care, self-regulation and speech and language skills.[62]

12.43 The challenges faced by autistic students were reflected in the ABS *Disability, Ageing and Carers, Australia: Summary of Findings*, which reported that autistic students 'may need a high level of support to participate in their education'. It found that in 2018, 40.4 per cent of autistic students needed special tuition and 32 per cent needed help from a counsellor or disability support person. In addition, almost half 'indicated that they needed more support or assistance at school than they were receiving'.[63]

12.44 The committee heard that specialist autism education providers such as The Sycamore School, Mansfield Statewide Autism Services and Aspect are generally well-equipped to provide a tailored and inclusive educational experience for autistic students, supported by qualified and experienced educators, support staff and allied health professionals (see Box 12.2).[64]

Box 12.2 The Aspect Comprehensive Approach

The Aspect Comprehensive Approach (ACA) is a framework that offers positive behaviour support through environmental accommodations, structured supports, transition planning, transdisciplinary expertise, family involvement and professional learning for staff.

The ACA is underpinned by five principles:

- it is applicable to all people on the autism spectrum;
- interventions support all areas of a person's development and are based on an assessment of individual strengths and needs;
- the approach is a positive and supportive model rather than a deficit approach;
- the approach involves collaboration between people on the spectrum, parents/carers and professionals; and
- the approach is based on ongoing reference to research, evaluation and continuous review.

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[61] Aspect, *Submission 64*, p. 14.

[62] Aspect, *Submission 64*, p. 14.

[63] ABS, *Disability, Ageing and Carers, Australia: Summary of Findings*, 24 October 2019, www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release#autism-in-australia (accessed 12 December 2021).

[64] The Sycamore School, *Submission 118*, p. 4; Mansfield Statewide Autism Services, *Submission 117*, [p. 3]; Aspect, *Submission 64*, p. 9.

In addition, Aspect curriculum programs include detail of accommodations required by students, which are individualised to meet students' cognitive abilities as well as their autism areas of difference.

Source: Autism Spectrum Australia (Aspect), Submission 64, p. 9; Autism Spectrum Australia, Aspect Comprehensive Approach, www.autismspectrum.org.au/about-aspect/who-we-are/aspect-comprehensive-approach *(accessed 11 December 2021).*

12.45 However, the committee heard that the experience of students in mainstream schools is much more inconsistent and is heavily reliant on the knowledge and skill of individual teachers and school leaders, rather than the more systemic approach found in specialist autism schools.[65] One mother, who chose a dual placement for her son, explained:

> Enrolling him in specialist school was streamlined, the staff knew exactly what to do, what plans to make, and their expertise, organisation and approach to educational guidelines and policy has been exemplary. There have been no barriers to my son's participation in any aspect of his schooling at his specialist school; assembly and perceptual motor program days were adjusted so my son could be present and participate. His mainstream school however needed reminding of their obligations to my son, reminding of Department of Education policy, and prompting to treat him with the dignity and respect he deserved.[66]

12.46 Another parent described how their son's experience fluctuated in response to changes in teaching staff:

> From year to year we were always hopeful for our son at school, but progressively things got worse for him until his Grade 4 teacher. Her classroom provided an inclusive environment and teaching for all students. Our son was wearing his uniform each day and more positive about school. His attendance increased and we started thinking differently about his future, the opportunities for secondary school that he may be able to attend widened. However, this was short lived and the following year our son's experience of mainstream education was at its worst.[67]

12.47 For parents, the lack of a systemic approach in mainstream schools creates significant anxiety about changes in school leadership or in teaching staff. This was reflected in the experience of one autistic mother whose autistic son currently has 'an amazing teacher and supports'. However, she explained that she is 'already depressed knowing he won't have his current teacher forever, or

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[65] See, for example, Autism Awareness Australia, *Submission 47*, p. 9; Name withheld, *Submission 113*, [p. 4]; Name withheld, *Submission 148*, p. 9; Name withheld, *Submission 120*, pp. [1-2]; Name withheld, *Submission 141*, p. 5; Name withheld, *Submission 16*, [p. 1].

[66] Name withheld, *Submission 148*, p. 9. The dual placement involved concurrent enrolment in a specialist school (that had the training and qualifications to teach the curriculum), as well as a mainstream school (to maintain local community connections).

[67] Name withheld, *Submission 120*, pp. [1–2].

the same education assistants in the future, and I have panic over what that will look like'.[68]

12.48 The committee heard numerous reports of failures to make adjustments and provide appropriate supports for autistic students. Even where adjustments are made, the Autism Alliance survey found they are often inadequate:

> Less than half of parents with schools aged children responding to our survey reported that adjustments made at school were mostly or completely adequate. Just over a third indicated that adjustments were partly or not at all adequate.[69]

12.49 According to the Autism Alliance survey, the most commonly made adjustments were 'having a key point of contact at the school to discuss their child's needs and progress; modifications to curriculum, assessment and exam conditions; and access to an education aide'.[70]

12.50 Autism Queensland pointed to the frequency of movement between schools as evidence of the failure of mainstream schools to meet the needs of autistic students. In response to its survey, Autism Queensland found that 34 per cent of autistic primary school students and 53 per cent of autistic secondary school students had changed schools because the school was 'not a good fit'. Of those who had changed schools, 30 per cent had changed more than once. In addition, the most frequent reason for changing schools was a lack of appropriate support.[71] As one parent reported to Autism Queensland:

> We have tried several schools that said they could support my son, but they could do very little for him and he could not continue attending. He could not cope with the social environment of school and was not able to perform his calming rituals and behaviours. We left four schools in three years, not staying longer than one term in each. He was bullied more than enough at each school. The social pressures caused severe depression. Home education worked for a short time, but his symptoms were debilitating, and we had to find a school that could take him on. We moved the family to the city to find a school fit.[72]

12.51 However, the committee also heard of mainstream schools, such as Adelaide's Springbank Secondary College (Springbank), that have successfully implemented systemic, inclusive approaches to education (see Box 12.3). Springbank's success was also highlighted by the Commissioner for Children and Young People South Australia, who relayed students' reflections about the inclusive nature of their school:

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[68] Name withheld, *Submission 119*, pp. 9 and 10.

[69] Australian Autism Alliance, *Submission 52*, p. 30.

[70] Australian Autism Alliance, *Submission 52*, p. 30.

[71] Autism Queensland, *Submission 129*, pp. 5, 6, 7 and 11.

[72] Autism Queensland, *Submission 129*, p. 7.

> The [disability] unit was never merged with mainstream and now they are merged and people treat them like normal and you won't get that at a different school (Year 10-12 group).
>
> This school allows everybody to be themselves ... A myriad of schools squeeze students into a tiny little box, they want every individual student to act the same, dress the same, and function the same and if you go against that you're ridiculed for it. This school allows students to be individuals and take their own direction in life. (Year 10-12 group).
>
> There is no bullying happening since I've been here like my old school, no one has name called me. (Year 8-9 group).[73]

12.52 In addition to general adjustments and supports, the committee also heard that particular supports may be required for the transition from primary school to secondary school, as well as for students transitioning through puberty.[74]

Box 12.3 Springbank Secondary College, Adelaide

The committee visited Springbank Secondary College (Springbank) in Adelaide on 16 November 2020. Springbank is one of 15 South Australian schools participating in the Inclusive School Communities project, which aims to build the capacity of schools to create inclusive school communities.

While Springbank has had a disability unit since 2006, the deteriorating condition of the building that housed the unit led the school to rethink its segregated approach to disability education. As a result, Springbank committed to becoming a fully inclusive school by 2025. To date, this has involved reducing segregation and creating opportunities for true inclusion, including:

- moving the Year 8 cohort out of the disability unit and into mainstream classes, supported by co-teaching arrangements (from 2021 this is expected to extend to the current Year 9 cohort, with the aim of disbanding all separate disability unit classes by 2025);
- providing the option for senior disability unit students to join some mainstream classes, if desired;
- removing labelling of classrooms as either 'unit' or 'mainstream' and changing the language used to describe student cohorts in the school; and
- establishing a professional learning community to support the development of inclusive practices, including understanding and supporting students with autism.

The committee heard that the co-teaching model had helped break down barriers between disability unit teachers and other teaching staff. It has also gained in popularity since its introduction, with 12 out of 22 teachers applying to be co-teachers for the 2021 school year.

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[73] Commissioner for Children and Young People South Australia, *Submission 88*, pp. 8 and 9.

[74] See, for example, Spectrum Labor, *Submission 1*, [p. 8]; Family Planning NSW, *Submission 28*, p. 3; Positive Youth Incorporated, *Submission 85*, p. 6; Scope-University of Melbourne Partnership, *Submission 83*, pp. 17-18.

Key challenges for Springbank include having enough teachers to implement co-teaching arrangements, helping new teachers adjust to the school culture and approach, building community awareness of inclusive education, and increasing enrolments from cohorts other than students with disability (for example, 'stretch' cohorts).

Transition to secondary school

12.53 As outlined in Chapter 4, the characteristics of autism can make school transitions difficult for autistic students. Various stakeholders identified the transition from primary school to high school as an especially challenging time for autistic students[75] due to the new routines and people, increased academic and social pressures, and a more complex learning environment.[76]

12.54 The committee heard evidence of inconsistent and ineffective approaches to transition support. For example, one mother described her daughter's transition into high school as 'marked by failure on the school's part to deliver inclusion processes as stated by the Department of Education'. In response to questions about the support available for her daughter, the school psychologist told both her and her daughter:

> We can do nothing for you. This is high school and you need to learn that you will be one of 800 girls here and you do not get everything you want in life. We have a very good transition program and we transition all our girls the same, they don't need anything other than what we offer.[77]

12.55 As a result of experiences like this, at least one stakeholder called for schools to fund specialised support for key school transitions.[78]

12.56 In addition, Scope-UoM advocated for a nationally-consistent approach to supporting transitions from primary to secondary school settings. It suggested this could include:

- visits to the new school prior to starting;
- visual supports where appropriate, such as a school map and photos of the school and teachers;
- developmentally appropriate transition tools such as checklists, schedules, transition songs and visual cues;

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[75] See, for example, National Disability Insurance Agency (NDIA), *Submission 56*, p. 12; Positive Youth Incorporated, *Submission 85*, p. 6; Spectrum Labor, *Submission 1*, [p. 8].

[76] See, for example, Early Start Australia, *Submission 76*, p. 12; Dr Peter Walker, *Proof Committee Hansard*, 16 November 2020, p. 18; Heather Joy Nuske, Elizabeth McGhee Hassrick, Briana Bronstein, Lindsay Hauptman, Courtney Aponte, Lynne Levato, Aubyn Stahmer, David S Mandell, Peter Mundy, Connie Kasari and Tristram Smith, 'Broken bridges—new school transitions for students with autism spectrum disorder: A systematic review on difficulties and strategies for success', *Autism*, vol. 23, no. 1, February 2018, pp. 1 and 3, https://doi.org/10.1177/1362361318754529.

[77] Name withheld, *Submission 78*, p. 8.

[78] Name withheld, *Submission 126*, p. 19.

- the use of a peer buddy system, supported recess and lunch breaks, and communication methods that suit student needs; and
- developmentally appropriate self-regulation tools developed in conjunction with a student's allied health professionals.[79]

12.57 The Commissioner for Children and Young People South Australia also identified a need for more information about the services available to support school transitions.[80]

Transition through puberty

12.58 In relation to support for students transitioning through puberty, submitters identified the need to improve the availability and quality of sexuality and relationship education for autistic students.[81]

12.59 As explained by Family Planning NSW, comprehensive sexuality education is 'crucial to help people with autism to adjust to the physical, social and psychological changes associated with puberty'.[82] Stakeholders noted that appropriate education and support would help:

- support the development of healthy and respectful relationships;[83]
- decrease the vulnerability of autistic people to abuse and exploitation;[84] and
- support autistic people to engage in healthy, safe and socially acceptable sexual behaviours (see Box 12.4).[85]

Box 12.4 The need for improved sexuality and relationship support

People with autism experience increased vulnerability to poor reproductive and sexual health outcomes, including STIs, abuse and sexual exploitation. Sexuality and relationship support is important for people with autism to develop positive relationships and lead healthy lives, reducing the risk of violence, abuse and exploitation.

Without proactive sexuality and relationship support and education, adolescents with autism may have difficulty expressing their feelings in a socially appropriate manner and understanding emotions expressed by others.

People with autism may also have fewer social opportunities, have more significant anxiety about finding a life partner and worry that others misinterpret

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[79] Scope-University of Melbourne Partnership, *Submission 83*, pp. 17–18.

[80] Commissioner for Children and Young People South Australia, *Submission 88*, p. 11.

[81] See, for example, Family Planning NSW, *Submission 28*, p. 3; A4, *Submission 54*, pp. 14–15.

[82] Family Planning NSW, *Submission 28*, p. 3.

[83] Family Planning NSW, *Submission 28*, p. 2.

[84] See, for example, People with Disability Australia, *Submission 102*, p. 11; Family Planning NSW, *Submission 28*, p. 5.

[85] See, for example, Family Planning NSW, *Submission 28*, p. 3; Australian Association of Social Workers, *Submission 96*, p. 8.

their behaviour. Misunderstandings and misconceptions about people with autism can lead to experiences of social exclusion.

Adolescents with autism are more likely to engage in inappropriate sexual behaviours, including non-consensual touching and sexual behaviour in public than their neurotypical peers. Due to a combination of the lack of social understanding and the perseverative nature of some individuals with autism, behaviours may evolve into a determined pursuit, harassment, or intimidation.

However, there may be a range of reasons behind the behaviour (for example, sexual behaviours viewed as 'inappropriate' may be a sign of possible underlying health issues, a need for education on consent and privacy, or experiences of violence or abuse). The behaviours may also be normal, healthy and consensual, but are perceived as inappropriate.

Source: Family Planning NSW, Submission 28, pp. 4-5.

12.60 However, as noted by A4, existing sexuality education is 'often limited and not designed for an autistic communication style'. In addition, the opportunity to learn from peers can be hampered by 'social isolation and negative peer experiences'.[86] Family Planning NSW also observed that teachers currently lack the skills and confidence to deliver comprehensive sexuality education that is inclusive and accessible for people with disability.[87]

Impact of inadequate supports and adjustments

12.61 The committee heard that a failure to provide adequate supports and adjustments can have serious consequences for autistic students, particularly for those who demonstrate challenging behaviours. In the worst cases, this can include a reliance on restrictive practices as a behavioural management strategy.

12.62 The impact of a lack of support for these students appears to be reflected in the results of CYDA's 2019 National Educational Survey which found that one in four respondents had been subject to restraint or seclusion.[88] Similarly, the Autism Alliance described the use of restrictive practices in schools as a 'live issue', with no agreed or consistent approach in place regarding positive behaviour management.[89]

12.63 As noted by the DDLS, a lack of appropriate support can mean autistic students are caught in a 'Catch 22' situation:

> …without appropriate evidence-based supports and adjustments, autistic students very well may develop behaviours of concern due to the inappropriate environment, and maintain those behaviours when credentialled behavioural experts are not engaged. Thus, the situation

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[86] A4, *Submission 54*, p. 14.

[87] Family Planning NSW, *Submission 28*, p. 3.

[88] Children and Young People with Disability Australia, *Submission 109*, p. 4.

[89] Australian Autism Alliance, *Submission 52*, p. 30.

> spirals out of control, an unhappy situation for all involved. This should not be considered to be the fault of the autistic student but rather the inadequacy of the system that is supposed to support them.[90]

12.64 More than one submitter highlighted the effectiveness of positive behaviour support in preventing the need for restrictive practices[91] but also stressed the need for it to be implemented by trained behaviour therapists.[92] The need for qualified practitioners was also highlighted by the DDLS which argued that Australia currently has 'no regulation for those that claim to be "behaviour analysts", "behaviour therapists" or those who use other similar nomenclatures'. As an example, it pointed to the use by some state governments of people with backgrounds in martial arts.[93]

12.65 In response, a number of stakeholders advocated for all restrictive practices to be removed,[94] while some, such as the Queensland Law Society, also proposed they should be replaced with 'evidence-based behaviour management strategies, behaviour-support plans, functional behaviour assessments and safeguards'.[95] The DDLS expressed a similar view and proposed that this should include mandatory assessments—such as functional behaviour assessments—to determine autistic students' needs and help develop 'an evidence-based positive behaviour support plan/program'.[96]

Autism knowledge and understanding

12.66 As with other service sectors, inadequate support in schools is often a function of a lack of autism understanding,[97] particularly in mainstream schools.[98] For example, the Autism Alliance reported that teachers are unsure of how best to support autistic students, with respondents to its survey identifying a lack of capacity in mainstream school settings. The Autism Alliance relayed the views of one teacher who had taught in both mainstream and special school settings:

> As a teacher, I do not think that enough training is provided to mainstream teachers and support staff to understand autism well enough. I taught in

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[90] Disability Discrimination Legal Service, *Submission 153*, p. 28.

[91] Disability Discrimination Legal Service, *Submission 153*, p. 40; Name withheld, *Submission 126*, pp. 15–16.

[92] Name withheld, *Submission 126*, pp. 15-16.

[93] Disability Discrimination Legal Service, *Submission 153*, p. 40.

[94] See, for example, Australian Autism Alliance, *Submission 52*, p. 32

[95] Queensland Law Society, *Submission 124*, p. 6. See also, Autism Family Support Association, *Submission 22, Attachment 1*, [p. 1].

[96] Disability Discrimination Legal Service, *Submission 153*, p. 40.

[97] See, for example, Commissioner for Children and Young People South Australia, *Submission 88*, p. 7; Name withheld, *Submission 120*, pp. 1 and 2; Name withheld, *Submission 167*, p. 6.

[98] Australian Autism Alliance, *Submission 52*, p. 29.

> mainstream schools, but now in a special school, and I know that mainstream schools are nowhere near well enough equipped with the knowledge, strategies or resources to successfully integrate children with more complex autism.[99]

12.67 The connection between improved autism understanding and some of the issues described in this chapter was summarised by the DDLS:

> If teachers have received a meaningful education in inclusive education principles and strategies, there is less of a need for a segregated education system. If education providers have a stronger grounding in disability education, the discretion they hold in determining reasonable adjustments … may be more justifiable. If teachers have a stronger understanding of inclusive education and disability education there might be less of a need to rely on restrictive practices rather than proactive processes.[100]

12.68 As a result, multiple stakeholders identified a need to improve initial teacher education and professional development for teachers, school leaders and support staff.[101] There was also support for embedding autism training in teacher standards and registration processes.[102]

12.69 Scope-UoM pointed to the Queensland University of Technology's initial teacher education program as a potential model for teacher training. Under this model, every teaching student completes a minimum of two subjects focused on inclusive education. Within this model, Scope-UoM suggested that teachers learn about:

- legal rights of students with disabilities and neurological differences under Australian and international law;
- types of functional challenges experienced by students with disabilities and differences; and
- practical evidence-based strategies for supporting these learners within their classrooms.[103]

12.70 In terms of ongoing capacity building, submitters noted the importance of the federally funded Positive Partnerships program,[104] which aims to build partnerships between schools and families to improve the educational outcomes

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[99] Australian Autism Alliance, *Submission 52*, p. 29.

[100] Disability Discrimination Legal Service, *Submission 153*, p. 47.

[101] See, for example, Scope-University of Melbourne Partnership, *Submission 83*, p. 18; Australian Autism Alliance, *Submission 52*, p. 34; Spectrum Labor, *Submission 1*, [p. 9]; Mr Shawn Stevenson, *Submission 115*, [p. 3]; Name withheld, *Submission 81*, [p. 4].

[102] Australian Autism Alliance, *Submission 52*, p. 34.

[103] Scope-University of Melbourne Partnership, *Submission 83*, p. 19.

[104] See, for example, Marymead Autism Centre, *Submission 128*, p. 13; Name Withheld, *Submission 81*, [p. 4].

of students with autism.[105] However, the Autism Alliance observed that the scale of the program is 'has limited reach and high demand means sessions are often over-subscribed'.[106]

12.71 The Autism Alliance also suggested that Queensland's Autism Hub (see Box 12.5) was a 'standout example' that could be replicated around the country to help schools better support autistic students.[107]

Box 12.5 Queensland's Autism Hub

Introduced in 2015 as part of the Queensland Department of Education's 'Advancing education, an action plan for education in Queensland', the Autism Hub is designed to build the capacity of school leaders, teachers and parents, and support the inclusion of autistic students.

Autism coaches are located in 7 regions across Queensland. They provide schools with advice on how to best support autistic students in an inclusive environment and improve their educational outcomes.

A website provides autism specific resources including:

- a Guided Functional Behaviour Assessment Tool which helps teachers and parents understand, respond to and prevent frequent minor behaviours; and
- the Queensland School Autism Reflection Tool which helps school leaders to plan, implement and review processes that support autistic students.

Australian Autism Alliance, Submission 52, p. 29; Queensland Government, Autism Hub, https://autismhub.education.qld.gov.au/ *(accessed 11 December 2021).*

12.72 However, the DDLS also suggested that relying solely on teachers as disability experts is problematic given that their knowledge and experience is not comparable to that of an expert medical practitioner. As an example, it pointed to a Victorian initiative where teachers are trained to 'identify and implement their own positive behaviour support programs'. While the DDLS acknowledged the importance of upskilling teachers, it also argued that it was

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[105] Department of Social Service, Department of Education, Skills and Employment and Department of Health, *Submission 53*, p. 12. Positive Partnerships program activities include professional development for teachers, principals and other school staff to build their understanding, skills and expertise in working with school-age students with autism; workshops and information sessions for parents and carers of school-age students with autism; and a website providing online learning modules and other resources, including resources for parents and carers from culturally and linguistically diverse backgrounds, as well as resources developed in consultation with First Nations communities. The program has continued to be re-funded on the back of external evaluations in 2011 and 2015, with a further external evaluation in 2019 recommending the program be re-funded for a fourth phase.

[106] Australian Autism Alliance, *Submission 52*, p. 29.

[107] Australian Autism Alliance, *Submission 52*, p. 29.

'unrealistic to expect them to learn the skills of another profession that requires years of learning and practice to master'.[108] For similar reasons, Autism Awareness Australia also described the education system's heavy reliance on 'minimally trained teachers' aides' as flawed.[109]

12.73 In response, Autism Awareness Australia suggested the following actions to improve autism knowledge and understanding within schools:

- specialist mobile inclusion and behaviour teams that can be sent into schools to design individualised programs for students (thereby helping teachers' skill development and enabling autistic children to engage with learning;
- specialist face-to-face help for rural and regional schools to train staff members, as well as remote access to specialists for ongoing management of the situation; and
- specialist inclusion and behaviour support workers to replace the systemic use of teachers' aides by state education departments.[110]

12.74 However, Spectrum Labor suggested that the issue with teachers' aides is that their roles are 'underpaid and undervalued as stereotypically female occupations'.[111] Accordingly, stakeholders such as Spectrum Labor reflected that transforming teachers' aides into a skilled occupation with ongoing training, higher pay and job security could help 'ensure autistic children get the best quality assistance including the stability that is related to the autistic need for routine'.[112]

12.75 A similar view was expressed by Learning for Life Autism Centre (L4L) which argued that the potential value of education support staff was overlooked, with some viewing them as 'just an extra set of hands to play with and supervise' autistic students. L4L argued that with appropriate training, these staff could 'play a crucial role in supporting these autistic students to learn to engage in more prosocial behaviours'.[113]

12.76 In addition, Spectrum Labor proposed employing autistic teachers and teachers' aides to 'help promote understanding and acceptance of autistic students and provide positive role models'.[114]

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[108] Disability Discrimination Legal Service, *Submission 153*, p. 47.

[109] Autism Awareness Australia, *Submission 47*, p. 8.

[110] Autism Awareness Australia, *Submission 47*, p. 8.

[111] Spectrum Labor, *Submission 1*, [p. 9].

[112] Spectrum Labor, *Submission 1*, [pp. 9–10]. See also, Name withheld, *Submission 2*, p. 4.

[113] Learning for Life Autism Centre, *Submission 144*, p. 10.

[114] Spectrum Labor, *Submission 1*, [p. 10].

Resources to implement adequate adjustments

12.77 The committee also heard that a lack of resources also affects the ability of schools to implement adequate adjustments.[115] This includes concerns about inadequate school funding, issues around student eligibility for state and territory disability funding programs, and problems with the interface between school funding and the National Disability Insurance Scheme (NDIS).

School funding

12.78 Some submitters noted the increased cost of delivering the model of education required to support autistic students.[116] The committee heard that much of this additional cost is attributable to the increased staffing required to implement more inclusive models of education. This can include staffing related to smaller class sizes, co-teaching models and the provision of teachers' aides or specialist support, such as speech or occupational therapy.[117] Other additional costs relate to equipment as well as specialist programs and staff development activities.[118]

12.79 As noted by the DDLS, financial constraints 'severely limit' the ability of schools to provide adequate supports and adjustments. It noted the results of an Australian Education Union State of our Schools survey which found that:

> …81 per cent of principals believed they had insufficient resources to properly educate students with disability and 88 per cent stated they had to redirect funds from other areas of the school budget to help cater for students with disability.[119]

12.80 According to the DDLS, this creates 'an environment where schools, looking for the lowest-cost alternative, provide cheaper supports and adjustments that fail to meet the needs of the child'.[120]

12.81 As explained by the departments, the additional cost associated with educating students with disability in schools is recognised in the form of a school funding loading for students with disability. This loading is based on the level of educational adjustments reported by schools under the Nationally Consistent

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[115] See, for example, Disability Discrimination Legal Service, *Submission 153*, p. 27; Learning for Life Autism Centre, *Submission 144*, p. 4; Dr Martina Waring, *Submission 23*, p. 1; Name withheld, *Submission 81*, [p. 4]; Name withheld, *Submission 119*, p. 10.

[116] See, for example, Disability Discrimination Legal Service, *Submission 153*, p. 28; The Sycamore School, *Submission 118*, p. 10.

[117] See, for example, The Sycamore School, *Submission 118*, p. 10; Name withheld, *Submission 81*, [p. 4]; Name withheld, *Submission 2*, p. 4.

[118] The Sycamore School, *Submission 118*, p. 10.

[119] Disability Discrimination Legal Service, *Submission 153*, p. 28.

[120] Disability Discrimination Legal Service, *Submission 153*, p. 28.

Collection of Data on Schools Students with Disability (NCCD – see Box 12.6).[121]

Box 12.6 School funding for students with disability

Recurrent funding for schooling is based on the framework of the Schooling Resources Standard (SRS). The SRS is an estimate of the funding a school requires to meet the educational needs of its students. The SRS is comprised of a base funding amount and six loadings to address different types of disadvantage. This includes a loading for students with disability (SWD loading).

The Australian Government and state and territory governments contribute to meeting the total SRS funding amount. By 2023, the Australian Government will fund at least 20 per cent of the total SRS for government school systems and at least 80 per cent of the total SRS for non-government schools and systems. State and territory governments make a greater contribution to the government school sector.

In 2018, the SWD loading was the second largest SRS loading. In 2019 it accounted for 9.3 per cent ($1.85 billion) of the Australian Government's total recurrent school funding of $19.9 billion. Funding for the SWD loading is estimated to grow, on average, by 5.1 per cent per year between 2018–2029.

The SWD loading is based on the Nationally Consistent Collection of Data on Schools Students with Disability (NCCD). The NCCD is a record of all the reasonable educational adjustments made by schools—across four levels of adjustment—to support students with disability. Three levels of adjustment attract funding under the SWD loading. These are 'supplementary', 'substantial' and 'extensive' adjustments. Adjustments recorded as 'quality differentiated teaching practice' do not attract additional funding.

The use of the NCCD to determine funding represented a shift away from the previous model, where funding was provided through targeted programs, National Partnership funding, or a flat-rate loading based on medical diagnosis (rather than the adjustments actually provided by schools).

In 2018, the majority of students included in the NCCD were in the government sector (67 per cent). This aligns with the government sector's share of overall student enrolments (66 per cent). The government sector also supported the majority of students at each NCCD level of adjustment.

National School Resourcing Board, Review of the loading for students with disability: Final Report, December 2019, pp. v, 5, 7, 9, 10, 13 and 15.

12.82 However, as noted by at least one submitter, a 2019 review of the loading for students with disability, undertaken by the National School Resourcing Board, stated that there was 'insufficient evidence to determine the adequacy of current loading values for students with disability' and recommended that further work

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[121] Department of Social Service, Department of Education, Skills and Employment and Department of Health, *Submission 53*, p. 17.

be done to improve the evidence base for the loading and inform a refined costing model for use from 2023.[122]

12.83 The use of the NCCD to determine the loading for students with disability was raised as a particular concern for independent special schools. For example, The Sycamore School noted that prior to the NCCD, independent special schools received a flat loading of 223 per cent of the base funding amount per student, irrespective of the level of need of the student. According to The Sycamore School, the NCCD-based funding model has led to a considerable reduction in funding that no longer covers school-wide supports. While agreeing with the principle of aligning funding with individual student needs, The Sycamore School argued that independent special schools required additional support 'given the nature of the setting, in that all students who attend are diagnosed with a disability'.[123]

12.84 In its submission to the National School Resourcing Board review, the Department of Education, Skills and Employment agreed that the NCCD model may not be meeting the needs of special schools:

> The administrative burden on staff at special and special assistance schools is greater than in mainstream schools. Related is the comparative difficulty in quantifying adjustments made for students in an environment that caters specifically to high need students. Research indicates that special schools tend to under-report students in the NCCD, despite provision of adjustments for the vast majority of their students.
>
> Meeting the NCCD evidentiary requirements and assurance processes can be challenging for these schools.[124]

Eligibility for state and territory disability funding programs

12.85 While school funding for students with disability is calculated on a per school basis, the principle of subsidiarity means that it is not necessarily distributed in the same way. This principle recognises that individual school systems have more detailed knowledge of their students and schools than the Australian Government and enables school systems to distribute funding in a way that addresses 'needs as they see them'.[125]

12.86 This means that many state and territory governments use a mix of targeted programs and equity-based programs to distribute student with disability funding to schools. The purpose and eligibility criteria for state and territory

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[122] National School Resourcing Board, *Review of the loading for students with disability: Final report*, December 2019, pp. ix and 35. See also, Name withheld, *Submission 126*, p. 16.

[123] The Sycamore School, *Submission 118*, p. 10.

[124] Department of Education, Skills and Employment, *Submission to the review of the loading for students with disability 2019*, p. 5.

[125] National School Resourcing Board, *Review of the loading for students with disability: Final report*, December 2019, p. 7.

targeted programs vary, reflecting individual state and territory circumstances and the needs of their students. Accordingly, there is no direct correlation between a student's assessed NCCD level and the funding they may attract under a state-based targeted funding program.[126]

12.87 However, the committee heard that the eligibility criteria of some targeted funding programs do not accommodate the complex needs of autistic students. For example, the committee heard that the autism category within one state's targeted funding program excludes children without a severe language deficit. One parent reported her distress at feeling forced to apply for funding under the severe behaviour disorder category to enable her son to remain in his specialist setting during secondary school:

> Despite being a parent who constantly tells her son to be proud of who he is, it was **me** that was forced to state that my son was just a 'naughty boy', and that his behaviours had nothing to do with his autism, as it is a requirement that the severe behaviour issues are not related to autism, if you are to be successful in attracting support funding under this category. I still cry when I think that I was forced to do this.[127]

12.88 Similarly, a survey by Yellow Ladybugs found that 34 per cent of respondents felt their child needed access to a teachers' aide but did not meet the funding requirements. As one parent explained to Yellow Ladybugs:

> My daughter has strong language skills, so missed out on funding. She didn't get funding for behaviour because she is not outwardly disruptive to other students, but she is imploding internally, not performing to her potential and I am concerned the real impact will not be seen until her teens and adult life.[128]

12.89 At least one submitter observed that this means children who are diagnosed as Autism Spectrum Disorder Level 1 and attend mainstream schools can find it 'almost impossible to get *any* support at school' despite the fact that they 'struggle enormously in school'.[129] As noted by L4L, without support to address the social difficulties experienced by these autistic students, they can end up at greater risk of escalating behaviours and exclusion from school.[130]

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[126] National School Resourcing Board, *Review of the loading for students with disability: Final report*, December 2019, pp. 28 and 29. Generally, targeted programs provide resources to support a subset of students with a specific form of disability and moderate to high needs, while equity-based programs use a formula to distribute funding for students with lower levels of need. It should be noted that targeted programs do not represent the totality of state and territory spending on students with disability.

[127] Name withheld, *Submission 11*, [p. 8].

[128] Yellow Ladybugs, *Submission 49*, p. 8.

[129] Name withheld, *Submission 81*, [p. 4]. See also, Spectrum Labor, *Submission 1*, p. 9.

[130] Learning for Life Autism Centre, *Submission 144*, p. 1.

12.90 As a result, some submitters, such as DDLS, advocated for increased funding for state and territory targeted disability programs, as well as changes to eligibility criteria to support all students with an identified need.[131]

12.91 As an alternative to making it easier to access program funding, L4L suggested that an 'emergency funding' category could be built into state and territory targeted funding programs to support autistic students who don't meet the eligibility criteria. According to L4L, its 'evidence demonstrates that with really targeted supports for a period of about a year, many of these autistic students can make significant gains'.[132]

12.92 At a more global level, the DDLS proposed tying Commonwealth funding to evidence that 'each school has sufficient funds to cater for reasonable adjustments required for all students with disability'.[133] It indicated that this approach had been taken under the North American *Individuals with Disabilities Education Act* and had been 'proven effective'.[134]

Interaction with the NDIS

12.93 A number of submitters highlighted difficulties with the interaction between school funding and the NDIS.[135] For example, more than one stakeholder noted the frustration caused by inconsistencies between eligibility criteria for the NDIS and state-based targeted funding programs. As argued by one submitter:

> I would contend that any child that is given access to the NDIS should also receive school funding. It is a logical assessment that any child that has barriers to everyday life will also have barriers in learning.[136]

12.94 There was also confusion and dissatisfaction with the delineation of responsibilities between schools and the NDIS for supports provided to autistic students. For example, L4L stated that the NDIS guidelines on the intersection of NDIS and school funding are 'not clear cut'. As a result, L4L found that both schools and NDIS planners often interpret the guidelines to mean it is inappropriate to provide behaviour support within school settings. According to L4L:

> This represents a significant barrier for this group of autistic students because best practice guidelines indicate that consistency across environments is a key element to successful support … But this consistency

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[131] Disability Discrimination Legal Service, *Submission 153*, pp. 28-29.

[132] Learning for Life Autism Centre, *Submission 144*, p. 11.

[133] Disability Discrimination Legal Service, *Submission 153*, p. 8.

[134] Disability Discrimination Legal Service, *Submission 153*, p. 29.

[135] See, for example, Learning for Life Autism Centre, *Submission 144*, pp. 6–7; The Sycamore School, *Submission 118*, p. 7; Name withheld, *Submission 113*, [p. 4].

[136] Name withheld, *Submission 126*, p. 16.

> is not able to be achieved if a behaviour specialist is unable to work across both the home and school environments.[137]

12.95 In a similar vein, Early Start Australia (ESA) underscored the lack of a coordinated, consistent approach for service providers who work within the NDIS or disability sectors.[138] ESA explained that since the introduction of the NDIS there had been a proliferation of NDIS providers seeking access to schools. While this 'rightly' led schools to step in and control access, it also increased pressure to deliver services in 'limited out of school time slots'. At the same time, ESA noted that the NDIS had delineated personal and education-based goals, referring the latter to state and territory departments of education. However, as ESA observed:

> There has not been a corresponding increase in therapy support or funding in education that we are aware of and as a result many of our clients do not have the support needed to ensure educational success.[139]

12.96 Some schools, such as The Sycamore School, employ a range of school-wide supports themselves in order to provide a holistic approach to education. However, it explained that although these supports align with the provisions of the NDIS, they are not funded by the NDIS:

> These include supports such as speech therapy, occupational therapy, wellbeing and independent living skills, social work and mental health supports. Clearly, these supports fit with the service provisions under the NDIS yet, our families are not able to build these school supports into their packages, nor can the school receive any financial support for these unique school-based services from the NDIS.[140]

12.97 As a result of these difficulties, stakeholders, such as the Queensland Law Society, called for strategies to improve the relationship between the NDIS and the school system.[141] According to ESA, this should include the development of guidelines around providing supports in schools, including information about who can provide services.[142]

12.98 In addition, The Sycamore School argued that NDIS funds should be made available for school-provided supports that are covered by the NDIS, such as psychology, speech therapy and occupational therapy. Similarly, L4L suggested

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[137] Learning for Life Autism Centre, *Submission 144*, p. 7.

[138] Early Start Australia, *Submission 76*, p. 7.

[139] Early Start Australia, *Submission 76*, p. 7.

[140] The Sycamore School, *Submission 118*, p. 7.

[141] Queensland Law Society, *Submission 124*, p. 6.

[142] Early Start Australia, *Submission 76*, pp. 7-8.

building a caveat into NDIS funding guidelines that would allow some funding to be used for behaviour-based interventions within school settings.[143]

12.99 In response, the National Disability Insurance Agency (NDIA) recognised the importance of better 'integration and collaboration' between service systems and noted that:

> …there remain some areas at the NDIS and education interface that require further work, and [the NDIA] will continue to collaborate with Disability Ministers and state and territory governments to resolve these issues.[144]

Higher education

12.100 Improving pathways and accessibility to further education and training for people with disability is identified as a policy priority under *Australia's Disability Strategy 2021–2031*.[145] According to the Mentoring Autism Community of Practice (Mentoring Autism), evidence from both Australia and overseas suggests there are increasing numbers of autistic students entering the higher education sector. However, many are likely to 'either fall short of their potential or not achieve success in their academic pursuits'. As noted by Mentoring Autism, this is particularly concerning given autistic people possess great attention to detail, a tendency toward hyper focus on areas of interest, and a range of 'outstanding cognitive skills and talents'.[146]

12.101 The committee heard that the primary challenges faced by autistic people in relation to higher education access and outcomes include:

- fears about discrimination, isolation and low expectations;
- a lack of transition support; and
- inadequate supports and adjustments.

Fear of discrimination, isolation and low expectations

12.102 Similar to the challenges surrounding school education, autistic higher education students also have concerns about discrimination, isolation and low expectations. For example, Scope-UoM observed that autistic adults in both the vocational education and training (VET) and university sectors report 'similar experiences of isolation and at times exclusion where their learning needs are not understood and reasonable adjustments to the curriculum delivery and assessment are not made'.[147]

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[143] Learning for Life Autism Centre, *Submission 144*, p. 11.

[144] NDIA, *Submission 56*, p. 12.

[145] Department of Social Services, *Australia's Disability Strategy 2021-2031*, p. 24.

[146] Mentoring Autism Community of Practice (Mentoring Autism), *Submission 73*, [p. 1].

[147] Scope-University of Melbourne Partnership, *Submission 83*, p. 8.

12.103 However, the situation in higher education settings is additionally complex as poor school experiences can make many autistic people reluctant to disclose their diagnosis, which may lead to insufficient support. While there are no definitive statistics regarding disclosure of diagnoses, Untapped Holdings Pty Ltd (Untapped Holdings) estimated that only 'one in four or five' students disclose their autism to their university.[148] However, an Autism Alliance survey suggested that the proportion may be higher—with 51.3 per cent of adult respondents reporting they had disclosed their diagnosis.[149]

12.104 According to Untapped Holdings, without support these students will often leave university, or only ask for help once a crisis point has been reached:

> The stigma they have experienced at high school is a burden that weighs on them and they naturally avoid this and try to get by on their own. … So, it is often the case that towards the end of the first year, when assignments are due and exams are looming, they either drop out or only then seek assistance – when it is likely too late.[150]

12.105 The Autism Alliance also reported fears that revealing a diagnosis would lead to bullying and discrimination. It relayed one parent's views about the impact of this fear on their son:

> His life at university has been impacted by his refusal to tell the university that he is autistic, he feels that it would single him out and expose him to the same bullying he experienced at high school.[151]

12.106 Fears about discrimination and isolation also drive students to mask their autism in order to 'fit in', which can have devastating impacts on students' mental health. The desire to fit in was described by one autistic submitter:

> I desperately wanted to fit in though. So I masked. Masking is exactly what it sounds like. It’s basically pretending. Acting. Camouflaging. Masking is when autistic people hide their autism and try to appear neurotypical in order to fit in. For me, it means I copy the behaviours of those around me and try to suppress my own traits that make me stand out. It means I wear a smile and say all the right things (at least, I hope so) and I make sure not to do anything that makes people stare. Don't flap. Don't rock. Don't run. Don't wear headphones. Don't hide under the desk. Don't have a meltdown or a panic attack in front of anyone.[152]

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[148] Untapped Holdings, *Submission 92*, [pp. 1–2].

[149] Australian Autism Alliance, *Submission 52.2*, p. 9.

[150] Untapped Holdings Pty Ltd, *Submission 92*, [pp. 1–2].

[151] Australian Autism Alliance, *Submission 52*, p. 30.

[152] Name withheld, *Submission 167*, [p. 3].

12.107 For those who do disclose their diagnosis, the 'soft bigotry of low expectations'[153] can affect how they are treated. For example, JFA Purple Orange described the experience of Sarah, an autistic student who was advised to change her enrolment to part-time purely on the basis of her autism. Low expectations also appeared to play a role in Sarah's treatment by one of her lecturers following a group presentation:

> …on the day of their presentation one of the other group members arrived unprepared and Sarah's group had to present without them. At the end of the presentation the lecturer, who was aware Sarah was autistic, told Sarah in front of the class that she should be really proud to have continued on with the presentation and that she should go home and tell her mum about it.
>
> None of the other group members were addressed in this way, making Sarah feel uncomfortable and questioning why she was singled out by the lecturer.[154]

Transition support

12.108 As noted by OTARC, a supported transition from school to further education is critical to its success.[155] To this end, the department highlighted the existence of the National Disability Coordination Officer Program, which provides around $4.4 million each year to 'assist people with disability transition from school to tertiary education and subsequent employment'.[156]

12.109 Despite this, Untapped Holding suggested that the transition from school to further education is neither well understood, nor well supported. As a result, it contended that 'parents and carers don't have confidence in the safety of the transition and the autistic individuals don’t feel empowered to take that step'.[157]

12.110 Similarly, Scope UoM pointed out that, unlike transitions between levels of schooling, there is no file transfer or handover process that occurs when students move into higher education. Unfortunately, this lack of support occurs just when students are experiencing increased expectations about their self-sufficiency:

> Tasks such as enrolments, fee management, communication with lecturers/tutors are all required to be done by students themselves, as opposed to secondary school where students are given support ... The requirement to be so self-sufficient, while also managing a new and extremely large environment, increasing academic requirements and an

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[153] Australian Autism Alliance, *Submission 52*, p. 28.

[154] JFA Purple Orange, *Submission 84*, pp. 12–13.

[155] OTARC, *Submission 55*, p. 11.

[156] Department of Social Service, Department of Education, Skills and Employment and Department of Health, *Submission 53*, p. 19.

[157] Untapped Holdings Pty Ltd, *Submission 92*, [p. 1].

> entirely new social landscape almost places greater strain on autistic students than what they've ever previously experienced, and yet most or all supports are taken away.[158]

12.111 OTARC also noted research confirming stakeholder concerns about the level of support provided for the transition to higher education. For example, one study showed that while 77 per cent of transition aged autistic people would have liked support, only 28 per cent received support. According to OTARC, 'this indicates a high demand for support and inadequate access to existing support'.[159]

12.112 The importance of better support for this transition was highlighted by the experience of one autistic submitter who masked her autism in order to fit in at university:

> But I had no one to show me what else to do. There was no autistic mentor program and very limited support for autistic students. I needed, but couldn't find, an older autistic student to look up to. I had no one to show me that autistic students can succeed at university by being themselves. I had no one to tell me which cafes were quiet at which times. No one to tell me which lecture seats were good for a quick exit. No one to help me navigate the social situations which differ greatly from the ones in high school. This left me feeling isolated, anxious and lonely.[160]

12.113 Peer mentoring programs were identified as one mechanism institutions could use to better support the transition into higher education (as well as supporting ongoing participation).[161] According to Mentoring Autism, these programs are already used at a number of institutions such as Curtin University, the Australian National University, the University of Newcastle and the University of Tasmania.[162] In addition, peer mentoring is also a feature of the Australian Catholic University's Autism Inclusion Program.[163]

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[158] Scope-University of Melbourne Partnership, *Submission 83*, p. 17.

[159] OTARC, *Submission 55*, p. 11.

[160] Name withheld, *Submission 167*, [p. 3].

[161] Mentoring Autism Community of Practice, *Submission 73*, [pp. 2–3]. Feedback from program coordinators—based on both internal evaluations and grounded observations—indicates that specialist mentoring programs can make a significant positive difference to the education experiences and outcomes of autistic students. See, also, Scope-University of Melbourne Partnership, *Submission 83*, p. 18; Autism Queensland, *Submission 129*, p. 24; Name withheld, *Submission 167*, [p. 4].

[162] Mentoring Autism Community of Practice, *Submission 73*, [pp. 2-3]. In addition, the Queensland University of Technology and the University of Southern Queensland have peer facilitated skills programs. Some peer mentoring programs utilise resources developed by Curtin University and provided by the Autism CRC to support universities across Australia to implement their own peer mentoring program.

[163] Australian Autism Alliance, *Submission 52*, pp. 33–34.

12.114 However, Mentoring Autism raised concerns that the ability to plan for the future and leverage off successful peer mentoring programs is limited by ongoing funding uncertainty.[164] Accordingly, it advocated for the Australian Government to establish a dedicated funding stream for good practice support programs, such as peer mentoring.[165]

12.115 Mentoring Autism also suggested that there would be value in a review of specialist mentoring programs across the higher education sector, which could help 'establish benchmarks for good practice' and help autistic people 'make more information choices about university selection'.[166]

12.116 Other suggestions to improve the transition of autistic students from school to higher education included:

- training for students to support the transition processes;[167]
- sharing of information about students between schools and higher education providers;[168]
- the development of autism-friendly information packs for enrolling students;[169] and
- the use of in-person and recorded lectures by autistic students to explain the differences between school and university, as well as how they coped, which parts of the campus are busy or quiet at which times, how to make friends, and what autistic students might find good or hard.[170]

12.117 In addition, the Autism Alliance advocated for implementation of the recommendation from *Looking to the Future – Report of the review of senior secondary pathways into work, further education and training* that all senior secondary students with disability have access to work experience and have an individual post-school transition plan in place prior to leaving school.[171]

Adequate supports and adjustments

12.118 As with school education, the committee heard that tertiary education environments can pose multiple challenges for autistic students. As observed by Mentoring Autism, these can include navigating the built environment, adjusting to different teaching formats, adopting helpful study and

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[164] Mentoring Autism Community of Practice, *Submission 73*, [p. 3].

[165] Mentoring Autism Community of Practice, *Submission 73*, [p. 4].

[166] Mentoring Autism Community of Practice, *Submission 73*, [p. 4].

[167] Scope-University of Melbourne Partnership, *Submission 83*, p. 18.

[168] Scope-University of Melbourne Partnership, *Submission 83*, p. 18.

[169] Scope-University of Melbourne Partnership, *Submission 83*, p. 18.

[170] Name withheld, *Submission 167*, [p. 4].

[171] Australian Autism Alliance, *Submission 52*, p. 34.

organisational techniques, and having limited access to social supports. Autistic students can also have difficulties 'managing everyday routines, coping with anxiety and social engagement'.[172]

12.119 In recognition of these challenges, the Australian Government funds the Higher Education Disability Support Program which helps students with disability to access higher education (see Box 12.7)[173]

Box 12.7 Higher Education Disability Support Program (HEDSP)

The HEDSP consists of two components—the Disability Support Fund (DSF) and the Australian Disability Clearinghouse on Education and Training (ADCET). Total funding for the HEDSP in 2020 was $7.78 million.

The DSF provides supplementary funding to providers to help them attract domestic students with disability to participate in higher education, and deliver appropriate support for them to succeed.

DSF funding is based on enrolment numbers of domestic students with disability at eligible higher education providers. A smaller funding component reimburses providers for equipment and educational supports for students with disability with high-cost needs.

DSF funding can be used for staff training, to support students with disability, and to modify course content, teaching materials and delivery methods to better meet the needs of students with disability.

The ADCET is an online resource hosted by the University of Tasmania that provides information, advice and resources to disability practitioners, teachers and students with disability, on inclusive practices within the post-secondary education sector.

Source: Other Grants Guidelines (Education) 2012, paras 1.90, 1.95.1 and 1.100.1; Department of Education, Skills and Employment, Higher Education Disability Support Program, 26 November 2020, www.dese.gov.au/higher-education-disability-support-program *(accessed 25 November 2021).*

12.120 In addition, the departments noted that the National Centre for Vocational Education Research has developed a *Good Practice Guide: Supporting tertiary students with a disability or mental illness*, which is designed to help higher education teaching and disability services staff to provide 'individualised or institution level adjustments in teaching, learning and assessment methods to support students with disability or ongoing ill health'.[174]

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[172] Mentoring Autism Community of Practice, *Submission 73*, [pp. 1–2].

[173] Department of Social Service, Department of Education, Skills and Employment and Department of Health, *Submission 53*, p. 19.

[174] Department of Social Service, Department of Education, Skills and Employment and Department of Health, *Submission 53*, p. 19. See also the Department of Education, Skills and Employment, *Looking to the Future – Report of the review of senior secondary pathways into work, further education and training*, 2020, p. 22.

12.121 Despite this, the committee heard that the rate of adjustments for autistic students in both VET and university settings remains low. For example, in response to an Autism Alliance survey, 48 per cent of adults who disclosed their diagnosis reported that 'no adjustments were made by the institution'. One survey respondent described this experience to the Autism Alliance:

> It's been horrible, I don't feel like I am listened to at all in the [student] support services, and the teaching has been so inconsistent. Half the lecturers straight up refuse to record lectures, disability service did not advocate for my need despite having an auditory processing disorder, they just said that was it and they can't change it. It has taken me eight years to get to do my last semester of my degree. The whole experience has been depressing.[175]

12.122 This experience appears to be reflected in the results of an Autism Queensland survey which found that the most common reasons for autistic people withdrawing from tertiary education courses were anxiety and stress (23 per cent) and a lack of support (20 per cent).[176]

12.123 According to the Autism Alliance, for those students who did receive adjustments, the most commonly provided were:

- modified assessment/exam procedures;
- provision of a disability support person;
- a quiet room/area; and
- being able to leave the classroom without explanation for a break.[177]

12.124 However, the committee heard that, in some cases, the support offered does not necessarily match the needs of autistic students. For example, the CoAW reported the experience of one autistic student who was only offered generic supports, such as help in the library (which was not wanted) and access to a quiet room. As explained by the student:

> It is up to lecturers to decide what accommodations they will give. They did not want to compromise their courses by giving additional help. I needed to be able to talk about assignment briefs to be sure I understood.[178]

12.125 Inadequate supports and adjustments at university can also compound existing anxieties resulting from poor experiences at school. This situation was described by one autistic student who, already burnt out by a lack of appropriate support during school, struggled to manage the 'sensory and social demands' of university without support. She described being driven home by her parents

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[175] Australian Autism Alliance, *Submission 52*, pp. 11 and 30.

[176] Autism Queensland, *Submission 129*, p. 21.

[177] Australian Autism Alliance, *Submission 52*, p. 30.

[178] Coalition of Autistic Women, *Submission 125*, [p. 18].

halfway through lectures, after which she would be 'unable to speak or eat for the rest of the day'. In the end, she withdrew from university altogether:

> Despite being among the top ATAR students in my school, I am now unable to work and have withdrawn from university twice, as I simply couldn't manage. It's been two years since I graduated and I am still suffering from the intense anxiety that I developed in school.[179]

12.126 As with school education, the lack of support and adjustments in higher education settings is driven partly by a lack of autism knowledge and understanding. For example, one autistic student told the CoAW that they failed an exam due to their sensitivity to smell and the strong perfume of a nearby student. The student's request to change seats was 'denied as ridiculous'. Similarly, another female student described being given a support plan 'more suited to a male expression of autism'.[180]

12.127 Even when appropriate adjustments are made, a lack of autism understanding among the student cohort can also create challenges for autistic students. As one student reported to the CoAW:

> The lecturer was excellent and gave me a dedicated workstation, so I did not have to compete for equipment because being bumped and general noise aggravated my sensory difficulties. Other students were angry that I had special treatment and said I played the 'autism card' so I dropped out because I was too ashamed to face the comments every day.[181]

12.128 In response, stakeholders such as Scope-UoM called for better training for all academic and administrative staff in VET and university education settings.[182] Other suggestions included:

- encouraging higher education institutions to develop neurodiversity plans to help tailor adjustments (including in administrative services) to student needs;[183]
- adding a flag to student records to help minimise misunderstandings when autistic individuals contact student services;[184] and
- encouraging Universities Australia to establish policies and promote practices that support the inclusion of autistic students.[185]

12.129 In addition, the Autism Alliance noted 'some promising examples of inclusive practices' in higher education settings, including the Australian Catholic

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[179] Name withheld, *Submission 167*, [p. 3].

[180] Coalition of Autistic Women, *Submission 125*, [p. 19].

[181] Coalition of Autistic Women, *Submission 125*, [pp. 18–19].

[182] Scope-University of Melbourne Partnership, *Submission 83*, p. 18.

[183] Name withheld, *Submission 155*, p. 15.

[184] Name withheld, *Submission 155*, p. 15.

[185] Scope-University of Melbourne Partnership, *Submission 83*, p. 20.

University's Autism Inclusion Program which it described as a 'stand out' example of how to support autistic students (see Box 12.8).[186]

Box 12.8 Australian Catholic University – Autism Inclusion Program

The Australian Catholic University (ACU) launched the Autism Inclusion Program at its Melbourne and Ballarat campuses in 2020. The program was rolled out across all campuses in 2021. The program provides individual students with academic, social and wellbeing supports, while also addressing structural barriers to inclusion.

The program is designed to be embedded in the activities of the university, with strong cross-unit collaboration. Core elements include:

- access to comprehensive information for prospective students;
- working with schools to support transition;
- peer mentoring program, including ongoing professional development for mentors;
- academic skills workshops;
- Education Inclusion Plans;
- professional development for teaching and administrative staff;
- a resource library;
- environmental audits and adjustments;
- a low-sensory room on campus;
- sensory maps;
- social events; and
- a webpage and student portal page:

Program development and implementation is being led by autistic staff and students. The program Steering Committee includes representatives of key ACU portfolios. An Advisory Group includes current and former autistic students and academics from ACU and other universities.

Source: Australian Autism Alliance, Submission 52, p. 33-34.

Transition from education to work

12.130 While challenges relating to employment services for autistic people are covered in Chapter 13, a number of stakeholders also raised the need to better support the transition between education settings and work.[187]

12.131 This concern is driven by research such as that cited by the Autism CRC showing autistic students are more likely than non-autistic students to struggle with the transition from school.[188] In addition to challenges arising from

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[186] Australian Autism Alliance, *Submission 52*, p. 33.

[187] See, for example, Autism Awareness Australia, *Submission 47*, p. 9; Autism CRC, *Submission 46*, p. 19.

[188] Autism CRC, *Submission 46*, p. 27.

characteristics of autism, the Autism CRC observed that autistic students also experience:

> …anxiety about life after school, difficulties imagining their life after high school, and limited opportunities to engage in real-life experiences that help them develop important skills and successfully transition to work and independent living.[189]

12.132 However, the committee heard that instead of attracting additional support at this time, the transition from education coincides with the service 'cliff' described in Chapters 4 and 6.[190] Accordingly, it is common for autistic students to experience a lack of support for the transition from school to further education or work.[191]

12.133 In addition, Specialisterne Australia (Specialisterne) noted that some existing supports, such as the NDIS School Leavers Employment Support (SLES) program, are only available to a limited cohort of NDIS participants. Specialisterne also commented that—with a few exceptions such as the Autism Association of WA and Aspect—the SLES program is generally delivered by Disability Employment Service providers who lack the 'specific skill and expertise to work with autistic students and jobseekers'.[192] The Autism Alliance also remarked on the restricted eligibility criteria and argued that the program starts 'too late in a student's school life' and lacks aspiration in relation to student 'potential and prospects'.[193]

12.134 As a result, stakeholders like Scope-UoM advocated for governments to fund transition support programs to help autistic students transfer between education and employment settings.[194]

12.135 Similarly, the Autism CRC pointed to the need for a 'clear and coordinated transition planning approach'—that starts well before the end of school—to improve the likelihood of successful transitions:

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[189] Autism CRC, *Submission 46*, p. 19.

[190] See, for example, PEERS Australia, *Submission 108, Attachment 1 – Select Committee on Autism 2020-21*, [p. 32]; Scope-University of Melbourne Partnership, *Submission 83*, p. 17.

[191] See, for example, Australian Autism Alliance, *Submission 52*, p. 31; Scope-University of Melbourne Partnership, *Submission 83*, p. 17.

[192] Specialisterne Australia, *Submission 67*, p. 8. Specialisterne Australia stated that the program is only accessible to autistic individuals who are deemed to have an 'extreme' enough impairment to require funded supports. This generally excludes most individuals who are diagnosed at Level 1 (and in some cases, Level 2). This can be extremely challenging for autistic people as quite often their impairments are related to social, communicative and emotional interactions. Therefore, their challenges are harder to articulate and quantify than others who may have an obvious physical, behavioural or intellectual impairment.

[193] Australian Autism Alliance, *Submission 52*, p. 31.

[194] Scope-University of Melbourne Partnership, *Submission 83*, pp. 22–23.

> Providing young autistic people with early support using a tailored career planning program can set them up for future success with employment. … starting career planning and goal setting early, preferably in Year 9 of high school, ensures adequate time and opportunities to identify career interests, develop life skills including independent community mobility, and participate in work experiences.[195]

12.136 National Disability Services also underscored the importance of starting employment preparation programs while students are still at school. It also stressed that this should involve 'collaboration between schools and agencies preparing people with disability for the world of work', as seen in its Ticket to Work program (see Box 12.9).[196]

Box 12.9 Ticket to Work

Ticket to Work is an initiative of National Disability Services (NDS) that aims to improve school to work pathways for young people with significant disability. It was established in response to poor and falling school to work transition rates for young Australians with disability.

Ticket to Work's connected approach consists of 34 local networks, 205 schools and 145 local organisations. It has delivered 1621 jobs for young people mainly with significant disability. Approximately 38 per cent were students with autism.

Ticket to Work prepares young people for work through a combination of vocational/career development and early contact with work environments. Ticket to Work:

- brings together disability-specific and mainstream representatives from a variety of sectors to work strategically and collaboratively;
- supports young people to gain access to early experiences that positively influence their views of themselves as workers;
- prepares young people for the workplace and gives them an employment pathway that is typical of other young adults; and
- meets the needs of employers, providing enhanced retention and profitability.

Evaluations of the Ticket to Work model have shown that participants are substantially more likely than a similar comparison group to work in open employment, complete Year 12, participate in the labour force, and be involved in the community.

Source: National Disability Services, Submission 98.1, pp. 1, 2 and 3.

12.137 CYDA also argued that low expectations of young people with disability mean that 'they receive little tailored information or assistance around career planning and early employment'.[197]

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[195] Autism CRC, *Submission 46*, p. 19.

[196] National Disability Services, *Submission 98.1*, pp. 4–5.

[197] Children and Young People with Disability Australia, *Submission 109*, p. 3.

12.138 More broadly, evidence provided to the committee suggests that transition planning models should include a focus on the following three elements:

- career planning;
- work experience; and
- skills development.

Career planning

12.139 As noted by PEERS Australia, a lack of targeted services that 'help individuals research, apply to, and prepare for potential job opportunities' may be contributing to poor employment outcomes.[198] Accordingly, it argued for the implementation of strategies that can be used by practitioners to improve employment outcomes, including:

> …checklists (to identify skills and prioritise the goals of young adults), ecological assessments (to assess both students and environments where students spend time specifically in employment settings) and person-centred planning (team meeting approach where the young adult is the focus and plays a major role in decision making and goal development).[199]

12.140 In a similar vein, Aspect argued for the development of programs that 'understand and assess an autistic individual based on their strengths and motivate them to be successful in navigating and accessing suitable employment opportunities'.[200]

12.141 PEERS Australia also suggested that educators may require training in evidence-based practices in order to help them implement processes that will help secondary school students achieve strong transitions.[201]

12.142 In addition, the Autism CRC suggested integrating evidence-based transition planning resources into high school-based transition planning, the Australian Curriculum Work Studies for Years 9–10, and the NDIS SLES program.[202] According to the Autism CRC, one such resource, is the Better OutcOmes and Successful Transitions for Autism (BOOST-A) transition planning tool, which has been incorporated into the *myWAY Employability* web platform (see Box 12.10).

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[198] PEERS Australia, *Submission 108, Attachment 1 – Select Committee on Autism 2020-21*, [p. 33].

[199] PEERS Australia, *Submission 108*, p. 7.

[200] Aspect, *Submission 64*, p. 13.

[201] PEERS Australia, *Submission 108*, p. 7.

[202] Autism CRC, *Submission 46*, p. 20.

Box 12.10 BOOST-A and *myWay Employability*

BOOST-A was developed as an accessible and appropriate transition planning tool for young autistic people and the adults in their lives who assist with them in planning for their working life.

In a nationwide randomised control trial, students reported higher levels of self-determination to achieve their goals for further study or training and employment, than students who used the existing generic school-based transition planning processes.

BOOST-A has been incorporated into the *myWAY Employability* web platform.

myWAY Employability is designed specifically to help young autistic people plan and prepare for their working life. *myWAY Employability*:

- guides young people though a series of questions to help them identify their strengths, interests, and learning and environmental preferences;
- undertakes matching to relevant potential careers and employment pathways; and
- provides scaffolded goal-setting to track progress towards employment.

It also contains a variety of articles co-produced with the autistic community, covering topics such as Preparing for Work Experience, Getting Around, Creating a Job Application, Pathways to University, TAFE, or College, and Disclosure in the Workplace.

An educator's guide to using *myWAY Employability* is also available on the *incluionED* practice platform.

Source: Cooperative Research Centre for Living with Autism (Autism CRC), Submission 46, p, 19; Autism CRC, Better OutcOmes and Successful Transitions for Autism (BOOST-A), August 2020, www.autismcrc.com.au/knowledge-centre/reports/better-outcomes-and-successful-transitions-autism-boost *(accessed 14 December 2021).*

12.143 In addition to transition planning tools, some stakeholders, such as the I CAN Network (I CAN), suggested that the Australian Government run or fund events that bring young autistic people together with universities and employers so that autistic people are able to 'see their future possibilities'.[203]

12.144 As an indication of the value of these events, I CAN pointed to its annual autistic career expos which it runs in partnership with ANZ Bank in multiple locations across Victoria:

> Each expo is entitled 'AWETISM Expo' because it showcases and celebrates the unique talents and strengths of autistic young people and adults. We bring together autistic students from our face-to-face programs to run presentations and exhibits which express their talents and interests to not only other students but also the media and the community. We also assemble universities and companies who set up stands to expose autistic young people and adults to meaningful career pathways. The Expo has been

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[203] I CAN Network, *Submission 107*, p. 21.

> positively received … with 88 per cent of attendees enjoying 2019's AWETISM Expo (Melbourne).[204]

12.145 PEERS Australia also indicated its intention to host the *PEERS® for Careers* training in Australia once program research has been completed. The *PEERS® for Careers* program provides skills development for autistic undergraduate and graduate students to help them obtain and maintain a job. It also provides an internship experience that offers autistic students a chance to implement learned skills.[205]

12.146 In addition, there may be opportunities to implement aptitude testing tools, used by recruitment companies such as WithYouWithMe, in schools. WithYouWithMe's testing tool has been developed in conjunction with the University of Sydney and includes:

- Aptitude Assessment – what is an individual's ability and likelihood of learning a new technology-based skill?
- Psychometric Assessment – what type of technology-based role will they be most comfortable with?
- Learning Style Assessment – how will they best learn technology-based skills?
- Culture Fit Assessment – in what type of technology company or team will they thrive?[206]

Work experience

12.147 As noted by OTARC, limited work history and lack of access to work experience and training opportunities create a challenge for autistic people wanting to transition into the workforce.[207] In a similar vein, the Autism CRC highlighted the importance of work experience to school students as:

> ...an enabler of post-school employment, developing employability, increasing awareness of career options and employment, and increasing self-understanding and confidence.[208]

12.148 The Autism Alliance highlighted the Ticket to Work program as including opportunities for work experience. Despite demonstrating 'significant improvements in employment opportunities and outcomes for young people with disability', the Autism Alliance also noted that Ticket to Work 'has limited reach and long-term sustainability issues'.[209]

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[204] I CAN Network, *Submission 107*, p. 20.

[205] PEERS Australia, *Submission 108, Attachment 1 – Select Committee on Autism 2020-21*, [p. 7].

[206] WithYouWithMe, *Submission 158*, p. 5.

[207] OTARC, *Submission 55*, p. 18.

[208] Autism CRC, *Submission 46*, p. 20.

[209] Australian Autism Alliance, *Submission 52*, p, 31.

12.149 As a result, stakeholders such as the Autism CRC, recommended that work experience programs be developed for autistic school students, with governments to support their implementation via capacity building incentives. The Autism CRC suggested this could potentially leverage the growing number of companies with neurodiversity employment programs—including government agencies.[210]

Skills development

12.150 As part of the broader lack of transition support, ESA also noted that there were particular problems in relation to social skill development, which is a 'significant barrier to successful participation in training and employment'.[211]

12.151 The importance of extra support to develop social skills was emphasised by one submitter who suggested that autistic students may need to be given an extra two to four years of support:

> …as a bridge past the yawning chasm of depression and unemployment that lies in their path at the end of high school. For so many, this will be the difference between an autistic kid being an ineffective manual labourer or retail assistant who can't keep a job, and a kid going on to successfully fill a role that they have true aptitude for.[212]

12.152 To this end, another submitter recommended the development of locally based clubs to encourage 'social and employability skills'. They also advocated for government funding for social skill development and support programs such as 'Be Confident Belong for adolescents, the ICAN Network in schools, The Lab computer skills for autistic children and Aspergers Victoria Adult Support Group'.[213]

12.153 Different Journeys also highlighted the importance of life skills to supporting independence and employment outcomes. For example, it noted that:

> Many of our autistic community are expected to simply go and get a job but people assume these individuals have everyday life skills and do not even consider some could have barriers. Barriers include, but are not limited to, walking out of the house, utilising video chats, having a bank account, using an ATM card to name a few.[214]

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[210] Autism CRC, *Submission 46*, p. 20.

[211] Early Start Australia, *Submission 76*, p. 5.

[212] Name withheld, *Submission 112*, [p. 11].

[213] Name withheld, *Submission 2*, p. 5.

[214] Different Journeys, *Submission 30*, p. 23.

Committee view

12.154 The committee is deeply troubled by the experience of autistic people inside Australia's education system. Despite pockets of good practice and dedicated teachers and school leaders, a multitude of reviews and inquiries have heard evidence of gatekeeping practices in schools, inadequate consultation with students and parents, a lack of adjustments within education settings, high rates of bullying in schools, and the use of restrictive practices in place of proper behavioural support strategies. This points to the absolute failure to date of the Disability Standards for Education 2005 (DSE) to improve educational experiences for autistic people.

12.155 The committee welcomes the recommendations that have emerged from the 2020 review of the DSE and notes that they address some of the key areas of concern raised by stakeholders during this inquiry, including the need to:

- provide more clarity about the requirement to consult with students and families;
- build the capability of teachers and schools to support students with disability;
- provide more information about the services schools provide students with disability; and
- strengthen accountability in relation to meeting the DSE.

12.156 While the committee supports prompt implementation of the DSE review recommendations, it acknowledges the scepticism of stakeholders who argue that previous reviews of the DSE have failed to generate meaningful change. This must not be allowed to happen again. To this end, the committee is pleased to see that implementation will be accompanied by public progress reports.

12.157 However, the committee is still concerned that changes to the DSE will not be enough to make a difference for autistic students, whose needs are complex, unique and often invisible. Therefore, if the DSE review recommendations are going to make a difference for autistic students, governments will need to apply an 'autism lens' to their implementation. This needs to include collaboration with autistic people and their support networks.

12.158 Bullying was identified as a particular area where schools are failing autistic students. While social and communication challenges make autistic students especially vulnerable to bullying, it appears this is not well-understood or accounted for in many anti-bullying strategies. The committee contends that urgent action is required by education authorities to reduce bullying of autistic students in schools.

Recommendation 46

12.159 The committee supports implementation of the recommendations of the *2020 Review of the Disability Standards for Education 2005* and recommends that

the Department of Education, Skills and Employment and state and territory education authorities:

- **work with the taskforce established to develop the National Autism Strategy to apply an 'autism lens' to the implementation of the Disability Standards for Education review recommendations; and**
- **include specific actions to ensure the Disability Standards for Education meet the needs of autistic students.**

Recommendation 47

12.160 The committee recommends that the Australian Government coordinate with all government and non-government education authorities to ensure that policies on bullying include specific measures to address bullying of autistic students, including the use of:

- **frameworks for positive behaviour interventions and support; and**
- **opportunities for supported social engagement.**

12.161 The committee is concerned that, despite the significant funding attached to the loading for students with disability, there appears to be no concerted effort by governments to measure whether this funding is actually making a difference to outcomes. This also makes it difficult to determine what models and approaches are working for autistic students and whether they can be scaled up or shared.

12.162 While acknowledging that there are attribution issues in relation to determining the impact of particular measures on education outcomes, it is the committee's view that it is long overdue. This work should be guided by an agreed framework developed in consultation with the autism community.

12.163 In addition, as a first step toward greater transparency of funding for students with disability, the committee also supports the National School Resourcing Board's recommendation in relation to the publication of school-level Nationally Consistent Collection of Data on Schools Students with Disability student numbers on the My School website.

Recommendation 48

12.164 The committee recommends that the Education Ministers Meeting develop and implement a framework for regularly monitoring and publicly reporting on education outcomes for students with disability from 2023. This should include monitoring and reporting on outcomes for autistic students as a separate cohort and should be informed by consultation with the taskforce established to develop the National Autism Strategy.

12.165 The committee heard support for a mix of schooling options from fully inclusive mainstream settings to autism-specific schools and home-schooling options. It is clear to the committee that one size does not fit all in education and that different approaches work best for different students and families. The concept of choice in schooling remains important to families.

12.166 In addition, while some stakeholders called for an end to special schools and classes, others recognised there will always be a need for these options to cater for some students who do not cope in mainstream settings, no matter how inclusive they may be. This specialist support may be for a short period of time, or for longer, or it may be part of a 'dual enrolment' arrangement.

12.167 Overall, the committee also supports parents' rights to choose. However, in order to make informed choices, parents and carers need more information about the options available to them and the support that is on offer.

12.168 While supportive of choice, the committee also believes that all mainstream schools should work toward becoming inclusive schools, modelled on universal design principles. At Springbank Secondary College the committee saw firsthand the results that can be achieved when schools commit to becoming fully inclusive. The committee notes that building system capacity to deliver inclusive education is also a policy priority under *Australia's Disability Strategy 2021-2031*.[215]

12.169 However, the committee recognises that inclusive models of schooling come at an additional financial cost—one that many mainstream schools simply aren't resourced to meet at present. In addition, most teachers and school leaders are already time-poor and overburdened. This explains, in part, why autistic student experiences are so reliant on the skills and experience of individual teachers.

12.170 Accordingly, teachers, school leaders and support staff in mainstream schools need better training and support, including in the use of evidence-based adjustments to assist autistic students. As such, the committee believes autism awareness should be embedded in initial teacher education and ongoing professional development requirements, including those related to teacher registration.

12.171 However, the committee also recognises that teachers cannot be expected to meet the often complex needs of autistic students without specialist support. To this end, additional specialist support should be made available to all mainstream schools to help teachers meet the needs of autistic students. Queensland's Autism Hub is one model that might have wider applicability.

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[215] Department of Social Services, *Australia's Disability Strategy 2021-2031*, p. 23.

12.172 In terms of school funding, the committee notes that the loading for students with disability is the second largest loading overall, as well as the fastest growing overall in terms of the dollars allocated per student.[216] Despite this, there are concerns that the funding provided to support students with disabilities in schools is insufficient. These concerns relate to the calculation of the loading itself, as well as concerns about how education authorities distribute the funding, with many autistic students missing out on vital support.

12.173 Accordingly, the committee supports revisiting the students with disability loading as recommended by the National School Resourcing Board. However, education authorities also need to review the way they distribute disability funding to ensure schools are receiving sufficient funding to meet the needs of autistic students.

Recommendation 49

12.174 The committee supports the 2019 recommendation of the National School Resourcing Board in relation to refining the costing model for the students with disability loading to inform the loading settings from 2023. Accordingly, the committee recommends that implementation of the new costing model be accompanied by stronger accountability measures requiring government and non-government education authorities to demonstrate that schools are receiving adequate funds to meet the needs of students with disability—including autistic students.

Recommendation 50

12.175 The committee recommends that, where state and territory education authorities use targeted programs to distribute funding for students with disability, eligibility for these programs be reviewed and adjusted to better meet the needs of autistic students.

Recommendation 51

12.176 The committee recommends that the Australian Government work with state and territory education authorities and relevant stakeholders to identify and implement measures to build the capacity of teachers, school leaders and parents to support the inclusion of autistic students in schools. This should include the provision of additional specialist support in schools.

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[216] National School Resourcing Board, *Review of the loading for students with disability: Final report*, December 2019, p. v.

Recommendation 52

12.177 The committee recommends that the Australian Institute of Teaching and School Leadership work with state and territory teacher regulatory authorities to:

- **ensure all initial teacher education courses include at least two units on inclusive education, with a focus on the functional challenges experienced by autistic students, as well as evidence-based strategies for supporting autistic students in classrooms; and**
- **incorporate autism understanding into professional development requirements tied to teacher registration.**

Recommendation 53

12.178 The committee recommends that the Australian Institute of Teaching and School Leadership work with relevant stakeholders create additional autism-related Illustrations of Practice—across all domains of teaching and for all career stages—to help teachers better support autistic students in classrooms and schools.

Recommendation 54

12.179 The committee recommends that the Department of Education, Skills and Employment works with state and territory governments and the non-government school sector to develop clear guidance on the schooling options available for autistic students so that parents and carers can make more informed choices. This should include information about the role of—and interaction between—mainstream, special schools, autism-specific schools and home-schooling options within the education ecosystem.

12.180 The intersection between the National Disability Insurance Scheme (NDIS) and in-school supports remains problematic despite being raised as an issue in both the 2015 and 2020 reviews of the Disability Standards for Education.

12.181 For years, stakeholders have heard the same refrain—that the National Disability Insurance Agency is working with disability ministers and state and territory governments to resolve these issues. All the while, autistic students continue to fall through the cracks in the system, poorly supported in school, with many failing to complete their education.

12.182 After eight years of the NDIS, the committee can only conclude that the lack of progress arises from a lack of genuine resolve to do anything to fix this issue. This must now be addressed as a matter of urgency.

Recommendation 55

12.183 The committee recommends that the Australian Government coordinate the National Disability Insurance Agency, the Department of Education, Skills and Employment, and state and territory education authorities to:

- **resolve, as a matter of urgency, any outstanding issues in relationship to the intersection of school funding and the NDIS; and**
- **develop clear guidance in relation to the intersection of school funding and the NDIS, including in relation to the provision of NDIS supports within schools.**

12.184 During the course of the inquiry, the committee noted with interest that one of Universities Australia's strategic priorities for 2017-2021 was 'encouraging policies and programs that enable and support any person with the ability to obtain a high-quality university education to do so, and support diversity within universities'.[217] Yet this aim does not appear to be reflected well on the ground. While enrolments of undergraduate students with disability have increased by 123 per cent since 2008,[218] completion rates for autistic students are low.

12.185 The committee heard that higher education settings are generally not well-adapted to the needs of autistic students. Significant numbers of students do not disclose their diagnosis out of a fear of being discriminated against. This can potentially leave them without support, exhausted from trying to mask their autism, and vulnerable to not completing their studies, as well as suffering mental health impacts that can be long lasting.

12.186 Autistic student transitions into higher education need to be better supported. As the committee learned, only a very small percentage receive adequate transition support. Peer mentoring programs have been identified as one very important source of support but they need to be used more widely.

12.187 The committee also heard about low rates of adjustments to meet the needs of autistic students. This may, in part, reflect the lack of pedagogical knowledge and skills among teaching staff, especially in relation to students with disability, including those with autism. As university teaching staff do not require teaching qualifications, autism understanding should form part of their ongoing professional development. This should also apply to staff working in administration and student support roles.

12.188 As with school education, the committee also heard examples of good practice. For example, the committee is heartened by the development of the Autism Inclusion Program which has been implemented by the

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[217] Universities Australia, *Strategic Plan 2017–2021*, p. 4.

[218] Universities Australia, The Demand Driven System, www.universitiesaustralia.edu.au/policy-submissions/diversity-equity/the-demand-driven-system/ (accessed 16 December 2021).

Australian Catholic University. The committee believes such programs should become the norm at all Australian universities.

12.189 In addition, the committee notes that there are plans to develop a Student Equity in Higher Education Roadmap. The needs of autistic students should be a high priority for this roadmap.

Recommendation 56

12.190 The committee recommends that the Equity in Higher Education Panel include a specific focus on the needs of autistic students as part of its work to develop a Student Equity in Higher Education Roadmap. This should include consultation with the taskforce established to develop the National Autism Strategy, as well as a focus on:

- **increasing autism understanding among all teaching and administrative staff;**
- **creating autism-friendly information for current and prospective students;**
- **creating autism-friendly campus environments and services; and**
- **widespread adoption of autism inclusion and peer mentoring programs.**

12.191 The transition from education settings to work is one of the most critical for autistic students but also appears to be one of the most poorly supported, as it often occurs at the same time as the 'services cliff' experienced by autistic school leavers. Therefore, the committee supports calls for a coordinated approach to transition planning that begins well before the end of secondary school. This will align with the policy priority identified in *Australia's Disability Strategy 2021–2031* in relation to improving the transition of young people with disability from education to employment.[219]

Recommendation 57

12.192 The committee recommends that a Transition to Work Roadmap be developed under the auspices of the National Autism Strategy and as part of the National Autism Employment Framework proposed at Recommendation 58. This should provide a nationally agreed and coordinated approach to transition planning across school and higher education settings and should identify actions to:

- **improve students' social and employability skills;**
- **embed the use of evidence-based transition planning resources, such as Better OutcOmes and Successful Transitions for Autism (BOOST-A) and the *MyWAY Employability* web platform in schools and work preparation programs (including the NDIS School Leaver Employment Supports);**

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[219] Department of Social Services, *Australia's Disability Strategy 2021–2031*, p. 8.

- **improve the autism understanding of NDIS School Leaver Employment Supports providers;**
- **expand the reach of the Ticket to Work program; and**
- **establish stronger links between schools, universities and employers to facilitate autism-aware work experience opportunities.**

Chapter 13
Employment

13.1 This chapter provides an overview of the key challenges raised by stakeholders in relation to employment rates for autistic Australians and explores options to improve employment outcomes.

13.2 This chapter does not address pathways from school to further education and work. These are covered in Chapter 12.

Overview

13.3 As described in Chapter 3, autistic people's employment outcomes remain far worse than those of the general population. They are also below those of people with disability more broadly. Overall, autistic people experience high rates of unemployment and underemployment—both in terms of hours worked and skills utilised. For example, Specialisterne Australia (Specialisterne) noted that autistic people are 'often over-educated and underemployed for roles, with an over-representation in casual employment'.[1] Similarly, the Australian Autism Alliance (the Autism Alliance) reported that a third of autistic people with bachelor's degrees are unemployed.[2] The experience of underemployment was described by one autistic individual who works as a supermarket cashier, despite having two degrees:

> I have two degrees, yet I have worked in jobs (and I am still working) that do not use the fields of study in my degrees. I have had periods of unemployment, which has been very depressing. I have been, and still am, underemployed. This has been soul destroying for me.[3]

13.4 As noted by Reframing Autism, 'the impact of unemployment and underemployment for the Autistic population is difficult to overestimate', with around 45 per cent of autistic people living in, or close to, poverty as a result of being unemployed.[4]

13.5 Submitters also highlighted the link between unemployment and poorer mental health,[5] with a lack of support in either area likely to exacerbate problems in the other. For example, Specialisterne reflected that isolation and long-term

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[1] Specialisterne Australia, *Submission 67*, p. 3.

[2] Australian Autism Alliance, *Submission 52*, p. 36.

[3] Name withheld, *Submission 114*, [p. 3].

[4] Reframing Autism, *Submission 24*, [p. 10].

[5] See, for example, Specialisterne Australia, *Submission 67*, p. 7; Reframing Autism, *Submission 24*, [p. 10]; PEERS Australia, *Submission 108, Attachment 1 - Select Committee on Autism 2020-21*, [p. 35]; Mr Cameron Boyd, *Submission 157*, [pp. 10-11].

exclusion from the workforce leads to autistic individuals being diagnosed with secondary mental health conditions.[6] Conversely, Reframing Autism noted that an inability to afford mental health services can limit employment opportunities. This, in turn, can lead to worse mental health outcomes and further exclusion from the workforce and the community more broadly:

> Autistic Australians often cannot afford the psychological and psychiatric support they need to provide them with the confidence and scaffolding to participate in the community. Many autistic adults then have decreased feelings of self-efficacy and self-worth because of their under- or unemployment, which exacerbates their mental health complications, which in turn limits their opportunities and expectations to participate in the community.[7]

13.6 However, the committee heard that high rates of unemployment and underemployment among autistic people do not reflect a lack of desire to work or a lack of skill and capacity. Indeed, as noted by various stakeholders, the autistic community remains a significant reserve of untapped potential for employers.[8] For example, while noting that each autistic person is different, Services Australia asserted that many have 'exceptional skills' (over and above those of non-autistic people) which have a broad application across a range of jobs. These skills include:

- being task focused and being able to work independently;
- strong problem solving and critical thinking skills;
- a high aptitude for analysis, in particular, pattern recognition and spatial processing;
- a high tolerance for repetitive tasks;
- high and sustained concentration ability; and
- being honest, reliable and ethical.[9]

13.7 This view was supported by other stakeholders, including one autistic submitter, who added that autistic employees have good attention to detail, an excellent work ethic and are loyal, resulting in low absenteeism and low staff turnover.[10] In addition, Specialisterne observed that autistic employees have

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[6] Specialisterne Australia, *Submission 67*, p. 7.

[7] Reframing Autism, *Submission 24*, [p. 10].

[8] See, for example, Australian Autism Alliance, *Submission 52*, p. 9; Northern Territory Office of the Public Guardian, *Submission 20*, [p. 5]; Mr Rhett Ellis, *Submission 45*, [pp. 1 and 2]; Name withheld, *Submission 155.2*, [p. 1].

[9] Services Australia, *Submission 66*, p. 3.

[10] Name withheld, *Submission 114*, [p. 2]. See also, Auticon, *Submission 160*, [p. 2]; Coalition of Autistic Women, *Submission 125*, [p. 19]; Name withheld, *Submission 3*, p. 1.

been shown to be 'more productive and more efficient than their non-autistic colleagues'.[11]

13.8 This means that employers—and society more broadly—are currently missing out on the benefits of this underutilised talent. For example, the Autism Alliance highlighted the competitive advantages offered by a neurodiverse workforce, including 'productivity gains, quality improvement, boosts in innovative capabilities, increases in employee engagement and reputational enhancement'.[12] Likewise, La Trobe University's Olga Tennison Autism Research Centre (OTARC) pointed out that in addition to improving life outcomes and 'empowering autistic adults to become more engaged and active within their communities', increasing autistic employment rates would also contribute to the community and economy more broadly.[13] In a similar vein, the Scope-University of Melbourne Partnership estimated that autistic unemployment costs the economy $381 million per annum in lost taxation revenue.[14]

13.9 Despite the significant benefits that would accrue from improving autistic employment outcomes, significant challenges remain. These include:

- inflexible recruitment processes;
- a lack of adjustments and support in the workplace;
- discrimination and a lack of autism understanding in the workplace; and
- the need for more specialised disability employment services, as well as targeted employment programs and incentives.

Recruitment processes

13.10 Numerous stakeholders identified traditional recruitment processes as an impediment to autistic employment.[15] For example, the Autism Alliance reported on the results of its survey which found that difficulties with job

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[11] Specialisterne Australia, *Submission 67*, pp. 3 and 10. Specialisterne referred to the statement by James Mahoney, Global Head of Autism at Work, JPMorgan Chase, that 'employees on the autism spectrum were as much as 140 percent more productive than their peers'.

[12] Australian Autism Alliance, *Submission 52*, p. 9.

[13] La Trobe University – the Olga Tennison Research Centre (OTARC), *Submission 55*, p. 17.

[14] Scope-University of Melbourne Partnership, *Submission 83*, p. 20.

[15] See, for example, OTARC, *Submission 55*, p. 18; Department of Defence, *Submission 106*, [p. 3]; Specialisterne Australia, *Submission 67*, p. 4; Australian Autism Alliance, *Submission 52*, p. 37; Autism Queensland, *Submission 129*, p. 24; Commissioner for Children and Young People Western Australia, *Submission 42*, p. 6; PEERS Australia, *Submission 108, Attachment 1 - Select Committee on Autism 2020-21*, [p. 32]; Mr Cameron Boyd, *Submission 157*, [pp. 9–10]; Name withheld, *Submission 79*, p. 4; Name withheld, *Submission 9*, pp. 8–9; Ms Kirsty Richards, Program Lead, Autism and Agriculture, SunPork Farms, *Proof Committee Hansard*, 3 March 2021, p. 15.

application processes and interviews were common for autistic people seeking employment.[16]

13.11 Specialisterne expanded on this notion and explained that normal recruitment systems have an inherent bias toward 'desirable behaviours, characteristics and responses that recruiters and employers feel comfortable and familiar with'. According to Specialisterne, this works against autistic people who can have different ways of thinking and processing information, as well as non-conventional presentation and interpersonal skills. Specific problems with traditional recruitment processes include:

- the use of jargon, acronyms and vague or general terms in job advertisements and position descriptions;
- a lack of clarity and clear instruction about the application process;
- interview processes built around a person's ability to talk, sell themselves and build rapport quickly with strangers (as opposed to a process designed to draw out and practically assess a person's aptitude, technical skills and abilities to undertake a specific role);
- interview environments that fail to consider the sensory or processing challenges that many autistic people experience; and
- interviewer bias against autistic people presenting with non-conventional social and communication styles.[17]

13.12 The experience of undertaking a traditional recruitment process was described in detail by one autistic individual (see Box 13.1), who found it 'harrowing', despite having 'three university degrees, defence security clearance and the ability to see patterns in data even computers struggle to find'.[18]

Box 13.1 Case study – a 'harrowing' recruitment process

Well to start with there is the responses to selection criteria, as it turns out employers don't actually ask questions they want the answer to but you're expected to just know when they say 'list your hobbies' that they actually want to know how many 'teams and groups' you belong to not what your actual hobbies are.

If I make it to interview things get worse because I'm suddenly expected to talk to people I have never met before and I suffer crippling social anxiety as part of my autism. Communication in person is so very difficult for me because I can't read facial expressions, I don't hear tone change in voice which would indicate someone asked a question but said it like a statement of fact, and I answer the questions you ask me so I miss the subtext that you actually want to know something totally

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[16] Australian Autism Alliance, *Submission 52*, p. 37.

[17] Specialisterne Australia, *Submission 67*, p. 4.

[18] Name withheld, *Submission 9*, p. 8.

> different to what you asked. Oh, and if you present me with questions where the answer can be yes or no then more than likely you'll get a yes or no as the answer.
>
> Now they have me sitting in front of them and I'm probably not dressed correctly for a job interview, I'm so tense you can see it because every muscle in my body is rigid and I can't look at anyone directly without visible flinching as it makes my brain hurt.
>
> Then they start asking questions and expect to get similar responses to what the previous 10 candidates have given and they don't… The person who doesn't ask direct questions is met with total silence and then asks 'are you going to answer my question' to be told 'you haven't asked me a question you made a statement of fact', which trust me is the wrong thing to say to the CEO or an Army General.
>
> Harder still for the interviewers is the fact that…I do not have variation of pitch or tone in my voice and I have zero facial expressions not even micro expressions. I also don't move my hands or body when in job interviews because someone long ago told me not to fidget when talking to people as it gives a bad impression.
>
> So the interviewers have none of the normal verbal cues unconsciously used by normal people to tell if I'm stressed, happy, sad, worried, thinking about how to respond, lying or just plain board out of my brain.
>
> Since I lack the ability to know when to stop talking if the interviewers ask me a question I can answer in detail, they'll either have to spend 45 minutes listening to a mini lecture on the topic or tell me to stop talking, neither option goes well in an interview.

Source: Name withheld, Submission 9, pp. 8-9.

13.13 In response, submitters suggested that the use of alternative or relaxed recruitment methods should be encouraged,[19] with some using the examples of the approaches used by the Aurora[20] and RISE[21] programs (see Box 13.2).

13.14 In addition, OTARC suggested that a national industrial relations guideline could be developed 'to guarantee equitable accessibility of recruitment practices for autistic people'.[22]

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[19] See, for example, OTARC, *Submission 55*, p 19; Australian Autism Alliance, *Submission 52*, p. 38; Marymead Autism Centre, *Submission 128*, p. 10; Spectrum Labor, *Submission 1*, [p. 11]; Mr Cameron Boyd, *Submission 157*, [p. 9]; Name withheld, *Submission 2*, p. 5.

[20] Services Australia, *Submission 66*, p. 4.

[21] Australian Autism Alliance, *Submission 52*, p. 39.

[22] OTARC, *Submission 55*, p. 3.

Box 13.2 Alternative recruitment methods

The Aurora Program was established in 2019 by Services Australia in collaboration with Specialisterne Australia. The program aims to recruit autistic employees into non-ICT roles.

The Aurora Program uses pre-selection exercises and a four-week assessment centre to identify and match the right candidate for available roles. Each candidate is assessed and evaluated against targeted activities developed by Specialisterne and Services Australia. This allows assessors to observe individual skills in a range of scenarios.

In 2019-20, nine people were engaged in specialist fraud and compliance roles within Services Australia through the Aurora program.

The RISE program was launched by the Victorian Department of Health and Human Services in 2017 to create career opportunities for autistic people in records management.

Initially designed with Specialisterne, the RISE program does not involve an interview process. Instead, it allows participants to demonstrate their strengths and role-related capabilities over an extended period of time.

This involves 'discovery days' and a paid two-week internship. For those that find the work a good fit, a four-week paid assessment period follows before a formal offer of employment.

The program has recruited 20 autistic people over successive intakes.

Source: Services Australia, Submission 66, p. 4; Services Australia, Annual Report 2019-20, p. 184; Australian Autism Alliance, Submission 52, p. 39.

Adjustments and supports in the workplace

13.15 Stakeholders reported that, once employed, the unique characteristics of autism can affect an individual's success in the workplace if not supported adequately. These characteristics may include:

- difficulties with social communication, including the ability to understand social norms and unspoken workplace protocols;
- sensory seeking or avoidance behaviours;
- organisation and executive functioning challenges;
- the need for clarity around roles and expectations, as well as structure, routine, or predictability in work tasks and instructions;
- difficulties matching strengths and weaknesses to job-specific tasks;
- low frustration tolerance; and
- interference from common comorbid medical conditions such as epilepsy.[23]

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[23] See, for example, Cooperative Research Centre for Living with Autism (Autism CRC), *Submission 46*, p. 19; Autism Queensland, *Submission 129*, p. 24; Auticon, *Submission 160,* [p. 2]; Marymead Autism Centre, *Submission 128*, p. 10; PEERS Australia, *Submission 108, Attachment 1 - Select Committee on Autism 2020-21*, [p. 32]; Name withheld, *Submission 62*, pp. 10 and 11.

13.16 As one autistic individual told the Autism Alliance:

> All kinds of 'normal' stuff is MUCH harder when you have sensory processing issues, for me an open plan office with fluro lights is like trying to work in a disco. A desk that is also near the lunchroom has actually brought me to panicky tears just from the noise. 'Team building' activities often directly make you feel more isolated and different and are often even more anxiety producing.[24]

13.17 Stakeholders also pointed to the tendency for employers to make use of standardised induction programs and 'on the job training that does not take into account the varied and different learning and processing styles of autistic people'.[25]

13.18 Autistic people may also face challenges outside the work environment, such as not having a bank account or being unfamiliar with using ATMs, as well as experiencing anxiety related to leaving the house, driving or public transport.[26]

13.19 Despite these challenges, Mr Cameron Boyd noted that autistic people are very capable of succeeding in employment when appropriate support and adjustments are provided. For example, as a result of the support and opportunities offered by his employer, Mr Boyd stated that he has been able to make significant achievements, including buying his own house. He described his success as 'an excellent example of how someone on the autism spectrum can succeed in employment given a supportive environment and a few basic accommodations'.[27]

13.20 While population-based figures are not available, the 2020 *Employment outcomes for NDIS participants* report indicated that only 53.7 per cent of autistic National Disability Insurance Scheme (NDIS) participants aged 25 and over and 66.2 per cent of those aged 15–24 years (working outside Australian Disability Enterprises [ADEs]) felt supported to do their jobs. For participants working in ADEs, the percentages that felt supported to do their jobs were much higher—88.3 per cent of those aged 25 and over and 90.1 per cent of those aged 15-24 years. The report noted that the support provided in ADEs 'helped participants understand their work tasks and roles and provided reassurance'.[28]

13.21 In addition to benefits for individual employees, workplace adjustments can also have benefits for other employees and organisations as a whole. For

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[24] Australian Autism Alliance, *Submission 52*, p. 38.

[25] Specialisterne Australia, *Submission 67*, p. 4.

[26] See, for example, Marymead Autism Centre, *Submission 128*, p. 10; Different Journeys, *Submission 30*, p. 23; Commissioner for Children and Young People Western Australia, *Submission 42, Attachment 1 – Speaking Out About Autism*, pp. 12–13.

[27] Mr Cameron Boyd, *Submission 157*, [pp. 9 and 10].

[28] National Disability Insurance Scheme (NDIS), *Employment outcomes for NDIS participants*, 31 December 2020, p 65.

example, Dr Bruce Baer Arnold reflected that changing an office layout can reduce distractions caused by 'noise, poor lighting, movement and interruptions' for both autistic and non-autistic employees. Similarly, Dr Arnold noted that the COVID-19 pandemic had demonstrated that many organisations can 'function effectively with employees working from home' with 'no substantive loss of accountability' and reports of 'increased job satisfaction and productivity'.[29] As JFA Purple Orange reported, working from home has proved hugely beneficial for some autistic employees:

> Working from home has been great. I don't have to worry about what I look like to other people. I don't have to go through driving an hour to and from work and all the concentration that requires. It's meant I'm free to be creative and sit in solitude which I need to concentrate for long periods of time. I've been able to escape into hyper-concentration phases without being interrupted—I've at least doubled my productivity since working from home. COVID-19 has given me opportunities to participate in more things because they are being held online. I'm worried about 'returning back to normal' because this new normal has been better for me.[30]

13.22 The benefit of workplace supports and adjustments was also illustrated in a case study provided by autistic advocate, Ms Geraldine Robertson (see Box 13.3).

13.23 This was also the experience of SunPork Farms which described the wraparound approach it takes to supporting its ten permanent autistic employees and the benefits that this beings to its business, its employees and the communities it supports (see Box 13.4).[31]

13.24 However, the committee heard that not all workplaces make appropriate adjustments for their autistic employees.[32] According to an Autism Alliance survey, the most common response to the question of what adjustments had been made, was 'none' (31.8 per cent). The survey also found that:

> Less than one in ten reported that adjustments had been made to the sensory environment, and fewer still reported information had been provided to others in the workplace on how to support them at work. More common adjustments included flexible hours, providing a set work routine, avoiding changes and adapting communication methods to match preferences.[33]

13.25 An unwillingness to make workplace adjustments was reflected in the experience of one autistic speech pathologist whose employer of ten years

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[29] Dr Bruce Baer Arnold, *Submission 39*, pp. 6-7.

[30] JFA Purple Orange, *Submission 84*, p. 20.

[31] Ms Kirsty Richards, Program Lead, Autism and Agriculture, SunPork Farms, *Proof Committee Hansard*, 3 March 2021, p. 15.

[32] See, for example, Australian Autism Alliance, *Submission 52*, p. 38; Yellow Ladybugs, *Submission 49*, p. 9; Name withheld, *Submission 114*, [p. 2].

[33] Australian Autism Alliance, *Submission 52*, p. 38. This refers to the percentage of adult respondents who had disclosed their diagnosis to their employer.

refused her request to return from maternity leave one day per week. As she reported to Yellow Ladybugs, this followed previous refusals by the employer in relation to working flexible hours:

> I have also previously requested to alter the mix of my work duties—specifically to complete more non-clinical work for our team over face-to-face duties, as this may enable me to work more hours (due to less exhaustion from maintaining a client interface all day). Any variation to my work duties or role was refused. As a result, I will not be returning to the workforce for the foreseeable future. I know I have so much to offer my profession, but I just need flexibility from my workplace regarding working a reduced time fraction and structuring my days so that I see no more than 2–3 face-to-face clients a day.[34]

Box 13.3 Case study – 'H'

H. had a Bachelor of Science but was unable to find suitable employment. He obtained a position in a plant nursery but was about to be sacked for being lazy.

Like many autistics, H. had difficulties with spatial awareness and was slow to perform the task of stacking empty flowerpots on a shelf, ordered by size. As H. was so bright, his employer thought he was being lazy and stubborn, refusing to speed up after a second demonstration of what needed to be done.

His parents asked an autistic advocate for advice. The solution was to paint the colour coded outlines of the three sizes of pots on a bench top so that H. could rapidly match the pots and place them in the appropriate colour coded site on the shelf.

His work speed improved rapidly. In addition, other tasks were customised for H. and these changes also assisted other employees. During the time saved, H. began to manage the garden centre website, which gave him great job satisfaction.

Source: Ms Geraldine Robertson, Submission 165, [p. 2].

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[34] Yellow Ladybugs, *Submission 49*, p. 10.

Box 13.4 SunPork Farms

Our initiative is a world-first initiative, in collaboration with the Autism CRC, that employs autistic adults in animal care. We do this by recognising the barriers. We provide an open, flexible recruitment process and two weeks of competency-based training, and we focus on individual strengths for our new recruits. We allow people to show us what they can do rather than ask them to tell us or sell us what they can do.

Concurrently, we focus heavily on the understanding of autism within the workplace to promote acceptance and inclusion. Once in employment, we recognise the importance of tasking individuals to their strengths, of offering flexibility where they require it, providing mentors and buddies and providing support outside the workplace, including assistance for relocation, for independent living and for maintaining a healthy lifestyle.

Employment has been transformative for our autistic employees. It's given them independence, it's built confidence, it's supported them to establish friendships and it's provided the satisfaction and reward of meaningful work, a career path and a salary—things that most of us would take for granted. They really are a part of a team that values them for who they are.

Autism in agriculture has provided our neurotypical workforce with an opportunity to learn, to mentor, to support and to give back. To our wider business, it has demonstrated that shifting from the traditional recruitment paradigm and focusing on strengths, on inclusion and equity, and ultimately prioritising people over positions, over process and over systems, really can work.

We see the project as a tremendous investment in our business, our culture, our people, their families and the communities we support. For our employees, their families and their extended support networks, it's fair to say that their employment has been life changing.

Source: Ms Kirsty Richards, Program Lead, Autism and Agriculture, SunPork Farms, Proof Committee Hansard, 3 March 2021, p. 15.

13.26 The impact of a lack of appropriate adjustments was described by one autistic submitter who explained that the constant stress of going to work in an unsupportive environment is 'physically, mentally and emotionally draining':

> As a result my cluster migraines increase, I fail to eat properly because I get so stressed about going to work I vomit up breakfast and by the end of the day I'm too exhausted to cook ... I constantly stress that due to the constant interruptions I'll have forgotten to do something correctly so I don’t sleep well. I start going in early and staying late to get my job done without interruptions. Because I'm hyper-anxious about my job performance the only thing my brain focuses on is my job. As a consequence … my domestic life falls apart as I forget to pay bills, I forget to buy groceries until I run out of toilet paper or coffee and I avoid social situations because I'm just too

> tired to cope with more people. … the longer I'm in that job the more stressed I get to the point I will become physically ill and unable to work.[35]

13.27 While the reasons for the low rate of adjustments is unclear, it is likely that it is driven by a lack of understanding about autism and the needs of autistic employees. However, Krofne suggested some employers may also have fears 'both real and perceived' about additional supervision requirements and costs, as well as 'loss of productivity by incumbent staff, and the challenge of catering for the physical needs of the client employee'.[36]

13.28 As a result, various stakeholders called for greater training and resources to help employers better understand the reasonable adjustments that can be made to support better recruitment and onboarding processes.[37]

13.29 For example, Autism Awareness Australia suggested that the University of Sydney's 'Switched On' program—which has developed a toolkit for employers that could be scaled nationally—is 'a perfect example of what is needed'.[38] Likewise, following a successful trial with over 100 employers, the Cooperative Research Centre for Living with Autism (Autism CRC) has released An Integrated Employment Success Tool (IEST).[39] The IEST is a practical manual that aims to improve employer confidence, employee productivity, job retention, and the overall success of autistic employees in the workplace.[40]

13.30 Submitters also pointed to the annual Autism@Work employer forum as a way to increase awareness of autism employment programs and share resources and experiences about the challenges and benefits of hiring autistic employees.[41] Building on this forum, the Autism Alliance proposed that an employment summit be held to bring together a wide range of stakeholders and deliver 'practical change and tangible models for employers to have a successful experience of hiring autistic people'.[42]

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[35] Name withheld, *Submission 9*, p. 11.

[36] Krofne, *Submission 57*, [p. 2].

[37] See, for example, Autism CRC, *Submission 46*, p. 5; Autism Queensland, *Submission 129*, p. 25; Autism Advisory and Support Service, *Submission 21*, p. 8; JFA Purple Orange, *Submission 84*, p. 21; Queensland Law Society, *Submission 124*, p. 7; SDN Children's Services, *Submission 44*, p. 20; Name withheld, *Submission 63*, [p. 4]; Name withheld, *Submission 114*, [p. 3].

[38] Autism Awareness Australia, *Submission 47*, p. 10.

[39] Autism CRC, *Submission 46*, p. 27.

[40] Autism CRC, *Register to access the Integrated Employment Success Tool (IEST)*, www.autismcrc.com.au/access/user/register/iest (accessed 29 November 2021).

[41] Autism CRC, *Submission 46*, p. 27; DXC Technology, *Submission 68*, p. 2; Name withheld, *Submission 114*, [p. 3].

[42] Australian Autism Alliance, *Submission 52*, p. 40.

13.31 Other stakeholders called for specific adjustments and supports, such as providing dedicated mentors and advocates within workplaces,[43] or encouraging meaningful work from home opportunities—particularly for those who may not be able to work in a traditional workplace.[44] In addition, recruitment company WithYouWithMe advocated for the integration of allied health professionals into organisational human resource and employee management processes to ensure a greater focus on the needs of autistic employees and facilitate their long-term success.[45]

Autism understanding and workplace discrimination

13.32 While multiple stakeholders highlighted the importance of workplace adjustments to the success of autistic employees, some submitters noted that adjustments alone would not address the challenge of 'ingrained prejudice against difference'.[46] A number of stakeholders reported a lack of autism understanding,[47] as well as negative employer attitudes and experiences of discrimination in the workplace.[48] In addition, Children and Young People with Disability Australia (CYDA) also noted that employment-related complaints 'make up a significant proportion of all disability discrimination complaints made to Australian anti-discrimination agencies'.[49]

13.33 Poor understanding of, and responses to, autism were even reported in organisations that are otherwise proactive and supportive of diversity and other types of disability.[50]

13.34 JFA Purple Orange conveyed one autistic individual's frustrations in relation to the level of autism education and awareness in workplaces:

> You feel like you have to … prove yourself before anyone knows you have a disability so you're not automatically stereotyped. People don't know how to cope if I am having an escalation. They don't know how to support me but they don't have discussions about how to support me either. Workplaces don't have access and inclusion plans or mentors and there are few peer

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[43] Australian Autism Alliance, *Submission 52*, p. 38.

[44] See, for example, Marymead Autism Centre, *Submission 128*, p. 10; Ethnic Disability Advocacy Centre, *Submission 75*, p. 8; Name withheld, *Submission 11*, [p. 15]; Name withheld, *Submission 9*, p. 12.

[45] WithYouWithMe, *Submission 158*, p. 6.

[46] Name withheld, *Submission 63*, [pp. 3–4].

[47] See, for example, OTARC, *Submission 55*, p. 18; Autism CRC, *Submission 46*, p. 27; Name withheld, *Submission 114*, [p. 2].

[48] See, for example, Commissioner for Children and Young People Western Australia, *Submission 42*, p. 6; Mr Philip Gluyas, *Submission 8*, [p. 4]; Name withheld, *Submission 6*, [p. 2].

[49] Children and Young People with Disability Australia, *Submission 109*, p. 7.

[50] Name withheld, *Submission 63*, [p. 1].

> networks for autistics in paid employment. There's not much education for workplaces around autism. This has impacted my career aspirations.[51]

13.35 The committee heard that negative employer perceptions also act as a roadblock to autistic people gaining employment in the first place. For example, the Autism Alliance claimed that 'persistent misbeliefs … stymie the efforts of autistic job seekers', with many employers believing autistic people are either not capable, or that they will require expensive workplace adjustments. Such misconceptions affect autistic people early in their search for employment and can have long-lasting impacts:

> I am an intelligent, articulate, pedantic, passionate person. Yet, not a single employer would give me a chance. Not in my teens, not my 20s and not my 30s. I gave up. Taking a chance on any person who appears to have the drive and ability to do a job should be enough, despite their obstacles (and, if anything, the fact they are striving to overcome and deal with their obstacles and have been for decades, should demonstrate the gusto of the person, which is always overlooked).[52]

13.36 Another submitter, aware of the poor employment rates for autistic people, tried unsuccessfully to help her autistic son secure after-school work in order to build his resume:

> Two years! He applied for work for two years. Lodging online applications with fast food chains and large retail outlets. Not a single interview. He did resume drops at small local fast-food outlets. He received one trial. With no offer of work. I believe many make an immediate assumption of incompetency when faced with a person who is different or disabled.[53]

13.37 At the other end of the scale, autistic people can also suffer from unrealistic and stereotypical views of their abilities. As one submitter explained, people can assume that autistic people 'must understand computer code, computers on a level no-one else does'.[54]

13.38 A lack of understanding and fears about negative reactions means that autistic people are hesitant to disclose their autism to their employers or colleagues.[55] Adult respondents to an Autism Alliance survey indicated that only 30.4 per cent had disclosed their diagnosis to their employer. For most respondents, this was due to fears of being judged negatively and/or losing their job or having their hours reduced.[56] This fear was borne out by the experience of one young

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[51] JFA Purple Orange, *Submission 84*, p. 20.

[52] Australian Autism Alliance, *Submission 52*, p. 37.

[53] Name withheld, *Submission 4*, [p. 4].

[54] Name withheld, *Submission 6*, [p. 3].

[55] Commissioner for Children and Young People Western Australia, *Submission 42, Attachment 1 – Speaking Out About Autism*, p. 13.

[56] Australian Autism Alliance, *Submission 52*, p. 37.

kitchenhand who told the Commissioner for Children and Young People Western Australia that they were demoted 'on the spot' after disclosing their diagnosis.[57] Yellow Ladybugs referred to another submitter who was told that they would not be coming back to work after requesting a desk in a quiet corner, a $60 filter for the fluorescent light, and slightly adjusted working hours.[58]

13.39 Even when a disclosure does not lead to immediate consequences, a lack of autism understanding can still lead to inappropriate treatment. For example, one autistic individual told JFA Purple Orange that instead of 'freeing' her, revealing her diagnosis has put her in the spotlight:

> I get questioned a lot. If I talk about feeling anxious, that gets focused on by others. Colleagues advocate for me when I don't need it or want it. For example, they will contact my manager saying, 'we think Tina is stressed', when really they are the ones who are stressed about a situation. Revealing my autism has limited me in workplaces. I have not been given opportunities for higher roles. People treat you as though you are less capable or skilled. They won't invite you to social gatherings and it changes the way you are spoken to. I once told an interviewer about my diagnosis and you could feel the level of respect drop in the room.[59]

13.40 In response, stakeholders called for a commitment to inclusive employment practices[60] and better autism education for employers and neurotypical employees.[61] One submitter indicated that this could be done in connection with autism-specific organisations,[62] while another submitter suggested that it should include specific guidance and education about what discrimination against autistic employees looks like.[63]

13.41 Other suggestions included:

- a national advertising campaign to address discrimination and attitudes toward people with disability at work;[64] and

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[57] Commissioner for Children and Young People Western Australia, *Submission 42, Attachment 1 – Speaking Out About Autism*, p. 13.

[58] Yellow Ladybugs, *Submission 49*, p. 21.

[59] JFA Purple Orange, *Submission 84*, p. 19.

[60] Specialisterne Australia, *Submission 67*, p. 12.

[61] See, for example, OTARC, *Submission 55*, p 19; Australian Autism Alliance, *Submission 52*, p. 38; Queensland Law Society, *Submission 124*, p. 7; Autism Advisory and Support Service, *Submission 21*, p. 8; Commissioner for Children and Young People Western Australia, *Submission 42*, p. 6; Autism Spectrum Australia (Aspect), *Submission 64*, p. 12.

[62] Name withheld, *Submission 114*, [p. 3].

[63] Name withheld, *Submission 63*, [p, 4].

[64] People with Disability Australia, *Submission 102*, p. 26.

- expanding the Work Assist program (previously Jobs in Jeopardy) to help people who are at risk of losing their job because of their autism.[65]

Specialised employment services, targeted programs and incentives

13.42 The Australian Government provides a variety of specialist employment services to assist people with disabilities to find employment (see Box 13.5).

13.43 In addition, the National Disability Employment Strategy, *Employ My Ability*, (Developed in association with *Australia's Disability Strategy 2021-2031* [the National Disability Strategy]) aims to increase participation and improve employment outcomes by:

- lifting employer engagement, capability and demand;
- building employment skills, experience and confidence of young people with disability;
- improving systems and services for jobseekers and employers; and
- changing community attitudes.[66]

13.44 *Employ My Ability* is also supported by two targeted action plans that will 'apply an intensive focus over one to three years to achieve specific deliverables'. Reporting against the Disability Employment Strategy will include an annual progress report for the Employment Targeted Action Plan, as well as reporting against outcomes as part of the broader National Disability Strategy.[67]

13.45 Another national initiative is the National Disability Insurance Scheme's (NDIS) Participant Employment Strategy. This strategy aims to have 30 per cent of working-age participants in meaningful employment by 30 June 2023 and focuses on the following key areas:

- increasing participant aspiration and employment goals in NDIS plans;
- increasing participant choice and control over pathways to employment;
- increasing market innovations that improve the path to paid work;
- improving confidence of employers to employ NDIS participants; and
- leading by example as an employer.[68]

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[65] Name withheld, *Submission 114*, [p. 3].

[66] Department of Social Services, *Employ My Ability*, 3 December 2021, pp. 14, 18, 21 and 23. The four priority areas will provide employers with the tools and abilities to confidently hire, support and develop more people with disability; ensure young people with disability are supported to obtain meaningful work and careers of their choice; make it simpler for job seekers with disability and employers to navigate and utilise government services, and driving better performance from service providers; and change people's perception and expectation about the capability of people with disability in the workplace.

[67] Department of Social Services, *Employ My Ability*, 3 December 2021, p. 25.

[68] National Disability Insurance Agency (NDIA), *Submission 56*, p. 13; NDIA, *Participant Employment Strategy*, 26 November 2021, www.ndis.gov.au/about-us/strategies/participant-employment-strategy, (accessed 28 November 2021).

Box 13.5 Australian Government employment services for people with a disability

Responsibility for employment assistance programs rests with the Australian Government.[69] In addition to general job seeker supports, the Department of Social Services, Department of Education, Skills and Employment and Department of Health (the departments), outlined the additional support available for autistic jobseekers through initiatives such as:

- the Disability Employment Services (DES) program—which helps individuals with disability find and retain a job in the open market;
- the Disability Employment Continuity of Support (DECoS) program—which funds employment supports for people working in Australian Disability Enterprises (ADEs) and supported under the former Disability Employment Assistance (DEA) program;
- the Disability Support Pension (DSP)—which supports people unable to fully support themselves (but allows recipients to receive a part pension while engaging in less than 30 hours of paid employment per week);
- the Employee Assistance Fund—which provides funding for work related modifications and services;
- the National Disability Recruitment Coordinator—which works with employers to increase their knowledge of government supports, help them implement disability employment practices, and provide disability awareness training for staff; and
- funding of $1.5 million to expand the Dandelion Program in partnership with DXC Technology and $500 000 for initiatives to encourage employers to become 'autism-confident'.[70]

13.46 Despite these programs, the committee heard evidence that current employment services are not meeting the needs of autistic job seekers.[71] Accordingly, many stakeholders advocated for:

- improvements to the DES program;
- more targeted employment options for autistic people—including outside information and communications technology (ICT) fields and options for those with more complex needs or concurrent intellectual disability;
- more support for self-employment; and

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[69] Department of Social Services, Department of Education, Skills and Employment and Department of Health, *Submission 53*, p. 4.

[70] Department of Social Services, Department of Education, Skills and Employment and Department of Health, *Submission 53*, pp. 45, 46, 47 and 51. The Disability Employment Assistance (DEA) program ceased in March 2021 as funding for supported employment transitioned to the NDIS. The Disability Employment Continuity of Support (DECoS) program will support people with disability who are ineligible for the NDIS but currently receive job supports in Australian Disability Enterprises (ADEs) through the DEA program. The DECoS program will run until 30 June 2023.

[71] See, for example, Autism Awareness Australia, *Submission 47*, p. 9; Specialisterne Australia, *Submission 67*, p. 7; Coalition of Autistic Women, *Submission 125*, [p. 20]; OTARC, *Submission 55*, p. 14.

- additional government incentives and employment quotas.

Disability Employment Services program

13.47 The Disability Employment Services (DES) program supports job seekers with disability who have been assessed as needing the service. It provides support to build job seekers' confidence and capability to prepare for employment and find a job. It also provides ongoing support or services to maintain employment. Supported activities may include access to training and education at Certificate III level (and above) and developing resume writing or interview skills. It may also include working with employers to make reasonable adjustments and reduce the cost to employers. DES providers support participants in their first 52 weeks of employment and can continue to provide support if required.[72]

13.48 According to the 2020 *Employment outcomes for NDIS participants* report, 44 per cent of people aged 15-24 years and 29 per cent of those aged 25 and over thought 'more support from a DES provider' would be a key factor in helping them to secure employment. This was the most frequently mentioned factor for those aged 25 and over and the second most frequently mentioned for those aged 15-24 years.[73]

13.49 However, a number of submitters questioned the effectiveness of the assistance provided by DES providers. For example, the Autism Alliance asserted that DES providers achieve 'low rates of successful work placements for autistic job seekers'.[74] Similarly, OTARC indicated that 'few autistic job seekers receiving DES help are placed into work' and cited 2017 data showing that while autism accounted for 16 per cent of DES providers' caseloads, on average only 25 per cent of this cohort were placed into employment.[75] In addition, Specialisterne suggested that although 'placement rates for autistic jobseekers in the current DES system are encouraging', the last 12 months had seen a drop in placement activity and an increase in the number of job seekers who remain unplaced.[76]

13.50 Autistic job seekers' experiences of DES providers were also mixed. For example, Mr Cameron Boyd described his choice of the Personnel Group as the 'best split-second decision' he ever made. Mr Boyd stated that Personnel Group helped him to find employment and, when that did not work out, found him a role within their finance team—a role he has been in for over three years.[77]

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[72] Department of Social Services, *Inclusive. Accessible. Diverse. Shaping your new disability employment support program consultation paper*, November 2021, p. 5.

[73] NDIS, *Employment outcomes for NDIS participants*, 31 December 2020, p. 20.

[74] Australian Autism Alliance, *Submission 52*, p. 37.

[75] OTARC, *Submission 55*, p. 18.

[76] Specialisterne Australia, *Submission 67*, p. 7.

[77] Mr Cameron Boyd, *Submission 157*, [p. 4].

13.51 However, other autistic job seekers had less positive experiences with DES providers. Specialisterne relayed the experience of an autistic job seeker who had not been referred for many jobs, despite having been with DES providers for a number of years. In addition, the jobs he was referred to tended to be low-skilled—including one job washing caravans at minimum wage, which cost him more to attend than he was paid.[78] Specialisterne also reported one parent's view that 'any and all employment services' had been 'useless' for their son, despite him having a bachelor's degree in IT:

> He jumps through all of the hoops, has attended all of their tick-box meetings (where nothing ever gets done—it seems to be only for the benefit of the recruitment organisation—certainly not for his benefit as a job seeker) and so far has not even been offered an interview, or even a chance to get a job. His [autism] is obviously too much for them despite his qualifications. He has studied constantly since attaining his degree 18 months ago and has since learned many extra IT skills via online courses. He is an optimistic and positive young man but has become disillusioned and is less than hopeful of ever getting a job.[79]

13.52 Specialisterne also emphasised that some autistic job seekers' experiences had been so poor they ended up leaving the DES system completely. Specialisterne summarised the issues with DES providers as follows:

- a lack of specialist knowledge or qualifications among DES providers;
- the limited capacity of DES providers to recognise and identify autistic people's skills, strengths and employable attributes;
- a model that rewards fast placement of job seekers into employment, which incentivises job placement over job suitability;
- a focus on low-skilled or entry level roles, rather than roles that fit the technical skills and attributes of individuals;
- an over reliance on traditional job seeking methods, such as resume writing, which are not effective for autistic people; and
- poor perceptions of the DES and DES candidates in the mainstream employment and recruitment sector.[80]

13.53 This aligns with the findings of a mid-term review of the DES which found that despite some positive results, the program was not efficient or effective in meeting its objectives. In particular, it found that job placements for people with disability did not align with their skills or interests and offered limited career development and earning potential. In addition, both employers and job seekers

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[78] Specialisterne Australia, *Submission 67*, p. 7.

[79] Specialisterne Australia, *Submission 67*, p. 8.

[80] Specialisterne Australia, *Submission 67*, p. 7.

found the system hard to navigate, including the process of selecting a provider.[81]

13.54 The sense that DES providers were focused on the financial incentives for job placements, rather than the needs of clients, was emphasised by more than one submitter. For example, Autism Awareness Australia described the DES system as a 'design failure' in relation to autistic job seekers as it rewards DES providers for job placements without regard for 'the number of hours worked, the remuneration and conditions, and the longevity of the position'.[82] Another stakeholder stated that 'they're there to tick boxes, to rake in money for providing a service that truly does nothing'.[83] Indeed, one autistic submitter suggested that some DES providers even use 'trickery and coercion' to get job seekers to accept roles that do not suit them 'just so they can "tick off" their [key performance indicators] and get a bonus':

> I have … heard alarming stories … of providers pushing clients (I have reason to suspect autistic clients included) in to apply for unsuitable jobs .... In addition, more stories have piled up … of DES providers threating to cut off client's welfare payments breaching their rights and not informing clients of their rights when dealing with a DES provider.[84]

13.55 Concerns that the current DES funding model rewards 'speed to placement' were also raised in the *Inclusive. Accessible. Diverse. Shaping your new disability employment support program consultation paper* (the DES model consultation paper), which helped inform the new DES model. The paper noted that the current model can lead to unsuitable job placements, a focus on short-term placements, and poor outcomes for job seekers who are not seen as employable.[85]

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[81] Department of Social Services, *Inclusive. Accessible. Diverse. Shaping your new disability employment support program consultation paper*, November 2021, p. 5.

[82] Autism Awareness Australia, *Submission 47*, p. 9.

[83] See, for example, Name withheld, *Submission 6*, [p. 3].

[84] Name withheld, *Submission 155*, pp. 18-19.

[85] Department of Social Services, *Inclusive. Accessible. Diverse. Shaping your new disability employment support program consultation paper*, November 2021, p. 14.

13.56 Another common theme that emerged from evidence presented to the committee was the lack of autism knowledge and expertise among DES providers.[86] For instance, the Coalition of Autistic Women (CoAW) argued that very few DES providers 'understand or provide adequate assistance for autistic people and understanding of female presentation is rare'. The CoAW also submitted that few DES providers are proactive in engaging with potential employers about the challenges autistic people experience in traditional recruitment processes.[87] Likewise, the Autism Alliance observed that 'DES [providers] have no requirements for training their staff in autism'.[88]

13.57 In addition to a lack of understanding, the committee also heard that the DES system is primarily geared toward people with intellectual or physical disabilities.[89] For example, the Tasmanian Government observed that autistic people 'often have to "make do" with services designed for people with intellectual and cognitive disabilities, which are often not well aligned'.[90]

13.58 In addition, Specialisterne noted that there had been a shift away from DES providers partnering with specialist agencies to deliver targeted employment services. Instead, it argued that most DES providers operate as generalist services and expect that staff 'will be able to offer adequate and effective job search, coaching and employment support to jobseekers of all disability types'.[91]

13.59 The generalist nature of the DES system and providers' lack of capacity to support particular cohorts, including job seekers with autism, was also noted in the DES model consultation paper, which sought feedback on ways to lift workforce capability and whether specialist providers are needed to increase employment opportunities.[92]

13.60 Stakeholders also raised concerns about the lack of in-placement support offered by DES providers. For example, Ms Kirsty Richards, Program Lead, Autism and Agriculture at SunPork Farms, told the committee that SunPork was offered wage subsidies through the DES program but no in-work support:

> …we weren't looking for wage subsidies. What we were looking for was workplace support for our employees that went beyond the recruitment phase—so the idea that someone would be there six months or 12 months

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[86] See, for example, OTARC, *Submission 55*, p. 18; Specialisterne Australia, *Submission 67*, p. 7; Aspect, *Submission 64*, p. 12; Name withheld, *Submission 131.3*, p. 2.

[87] Coalition of Autistic Women, *Submission 125*, [p. 20].

[88] Australian Autism Alliance, *Submission 52*, p. 37.

[89] Coalition of Autistic Women, *Submission 125*, [p. 20].

[90] Tasmanian Government, *Submission 19*, p. 4.

[91] Specialisterne Australia, *Submission 67*, p. 7.

[92] Department of Social Services, *Inclusive. Accessible. Diverse. Shaping your new disability employment support program consultation paper*, November 2021, p. 15.

> down the track. Sometimes problems might appear two or three years later, and it's then that you need that trusted person who can come in and cast their eye over the situation, understanding the employer and the employee, and give you that little bit of advice and support. That doesn't exist in the DES context.
>
> They were very focused on the recruitment phase. We've worked out that we can do recruitment without any dramas at all. It's maintaining and providing that ongoing support in the workplace where the employer need really lies and understanding what that actually looks like.[93]

13.61 In a similar vein, the Department of Defence indicated that employment services 'often overlook the social support needs and on-the-job training required by employees with autism'.[94]

13.62 In recognition of the need to improve outcomes for people with disability, the Department of Social Services is designing a new Disability Employment Support Model (the new DES model) to replace the DES from 1 July 2023. The new DES model is being designed in collaboration with people with disability, employers and providers in order to make sure it supports both job seekers and employers to achieve sustained and successful employment. Six working groups have been established to consider employment reforms through the lens of specific cohorts and disabilities. This includes a working group on intellectual disability, autism and psychosocial disability.[95]

13.63 While the extent of the problem is not clear, the DES model consultation paper also noted the view that DES staff are largely unqualified to provide on-the-job support to help people with autism succeed in the workplace.[96]

13.64 In response, stakeholders made a number of suggestions to improve the effectiveness of the DES system for autistic job seekers. These included:

- auditing DES providers to assess their understanding of autism and the appropriateness of support provided to autistic job seekers;[97]

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[93] *Proof Committee Hansard*, 3 March 2021, p. 18.

[94] Department of Defence, *Submission 106*, [p. 3].

[95] Department of Social Services, *New Disability Employment Support Model*, 5 November 2021, www.dss.gov.au/new-disability-employment-support-model (accessed 1 December 2021). The other five working groups have a focus on young people; culturally and linguistically diverse and First Nations peoples; mature age; employment support providers, employers and recruiters; and system design, research and evaluation. The development of the New Model is also supported by the DES Reference Group, a series of workshops with people with disability and their carers, and a public consultation process that ran between 5 November 2021 and 4 January 2022.

[96] Department of Social Services, *Inclusive. Accessible. Diverse. Shaping your new disability employment support program consultation paper*, November 2021, p. 15.

[97] OTARC, *Submission 55*, p. 3.

- making it easier for autistic job seekers to identify DES providers with knowledge of autism;[98]
- providing autism education and training for all DES providers that work with autistic job seekers, including knowledge of the benefits of hiring autistic people, barriers to employment, and what works in terms of job placements;[99]
- introducing minimum qualification/experience requirements for DES staff;[100]
- building connections between DES providers and autism employment specialists to identify the skills and strengths of autistic job seekers and provide autism training to employing organisations;[101] and
- revising the DES performance framework to include qualitative measures and individual job seeker outcomes.[102]

13.65 Some these suggestions appear to be reflected in the stated aims of the new DES model which will aim to ensure:

- sustainable and cost-effective investment in employment services for people with disability;
- alignment with other Commonwealth-funded employment services programs;
- reduced duplication and overlap with other government investment in disability and related services, including the NDIS;
- delivery on the government's priorities for people with disability, including the Australian Disability Strategy and the new National Disability Employment Strategy;
- more genuine choice and control for job seekers around the employment services they receive;
- a tailored set of quality services and supports that meet the needs of job seekers and employers; and
- job seeker-centric design and delivery.[103]

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[98] Specialisterne Australia, *Submission 67*, p. 11.

[99] OTARC, *Submission 55*, p. 2; Australian Autism Alliance, *Submission 52*, p. 40; Aspect, *Submission 64*, p. 15; Specialisterne Australia, *Submission 67*, p. 11; Name withheld, *Submission 155*, p. 19.

[100] Specialisterne Australia, *Submission 67*, p. 11; Name withheld, *Submission 155*, p. 19.

[101] Specialisterne Australia, *Submission 67*, p. 11.

[102] Specialisterne Australia, *Submission 67*, p. 11.

[103] Department of Social Services, *New Disability Employment Support Model*, 5 November 2021, www.dss.gov.au/new-disability-employment-support-model (accessed 1 December 2021).

Targeted employment options

13.66 Specialisterne noted that autism employment programs have been gaining traction in both the government and the private sectors—not only as a diversity measure but also because of the skills that autistic employees can bring to an organisation.[104] For example, Services Australia indicated that it has provided autism-specific employment opportunities since 2015 via its Aurora and Dandelion (see Box 13.6) programs. It described the benefits of these programs as:

- providing meaningful and sustainable employment for people who may have otherwise struggled to find a job;
- building disability confidence within Services Australia and increasing awareness of the skills and talents of autistic people;
- building an inclusive workforce culture, which contributes to the provision of more effective government services; and
- attracting and developing new skills and capability in specialised areas of the organisation, including ICT, fraud and compliance.[105]

13.67 This view was shared by Dandelion program participants, trainee supervisors and parents. For example, one participant told Services Australia that the program had given them options and provided a career stepping stone, while a parent stated that the program was 'the best thing that's ever happened' to their son. In addition, a trainee supervisor reported that:

> The team is far surpassing our initial expectations with their desire to learn, their attention to detail and are embracing their roles of software test analysts in a new challenging environment. The commonly held beliefs and often negative stereotypes within society surrounding people with autism are being broken down as people get to know the employees in the Dandelion Team. They soon discover that they are awesome people who have so much to contribute.[106]

Box 13.6 The Dandelion program

The Dandelion program (the program) commenced in 2015 in collaboration with Services Australia, DXC Technology and Specialisterne. The program aims to provide autistic people with ongoing employment and long-term, sustainable careers.

The program's recruitment and induction processes enable applicants to demonstrate their strengths in a supportive environment, providing each person the opportunity to thrive in the workplace.

DXC Technology provided training, line management, performance management and related HR services as part of a fully managed service to build life skills and

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[104] Specialisterne Australia, *Submission 67*, p. 10.

[105] Services Australia, *Submission 66*, p. 3.

[106] Services Australia, *Submission 66*, p. 4.

self-advocacy for participants. Services Australia staff, including managers and colleagues of trainees, were trained to be autism aware and confident to support the trainees to perform at their best.

Since 2015, a total of 58 people have been engaged in ICT traineeship roles, including as business, systems and data analysts, technical and data engineers and web application developers. The roles have been located in the Adelaide, Brisbane and Canberra and are up to three years in duration.

The program has a retention rate of around 80 per cent and participants remain a valued part of the Services Australia's workforce. Two participants have since joined the Services Australia's science, technology, engineering and mathematics (STEM) graduate employment scheme. Another two participants have gained full-time roles in state government and private industry.

The program is also one of only two employment programs in the world to have been the subject of an independent research program, with Services Australia and the Department of Defence co-funding two three-year longitudinal studies. This research has been used to inform the program's evolution over a number of years.

The Dandelion program is estimated to have generated $26 million for Australia's GDP over five years.

Source: Services Australia, Submission 66, pp. 3–4; DXC Technology, Submission 68, p. 1; La Trobe University – the Olga Tennison Research Centre (OTARC), Submission 55, p. 18.

13.68 In addition to the growing interest in autistic employment, Specialisterne also noted a concurrent increase in the number of organisations focused on recruiting autistic employees into businesses.[107]

13.69 The committee heard that the primary difference between autism-focused programs and generalist employment services is the tailored approach taken to recruitment and workplace support. For example, Specialisterne advised that its approach involves:

- using practical and inclusive approaches to assess and source talent into businesses;
- building skills and inclusive practices across organisations, including the executive, human resources, team managers, supervisors and peers;
- helping autistic employees to transition into their new roles and identify any necessary workplace adjustments;
- mentoring and coaching autistic employees, including helping them to identify their own support networks;
- mentoring and coaching the employee's line manager, supervisors and peers; and

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[107] Specialisterne Australia, *Submission 67*, p. 5. This includes organisations such as Auticon, Employ for Ability, DXC Technology, Xceptional and Untapped.

- tracking and monitoring the career progress of all job seekers and employees that participate in its programs.[108]

13.70 However, while acknowledging the success of targeted initiatives such as the Dandelion Program and other initiatives run by specialist employment firms such as Xceptional and Specialisterne, stakeholders such as the Autism Alliance pointed out that they 'are of micro scale and are few and far between'.[109] The Autism CRC also noted the low numbers of individuals employed through these programs.[110]

13.71 The need to scale up successful targeted employment programs was also noted by WithYouWithMe (WYWM) which argued that just under 20 000 jobs would need to be created in order to meet the NDIS employment target of 30 per cent.[111]

13.72 Mr Rhett Ellis noted that the current cyber security skills shortage provides a potential solution to this problem. According to Mr Ellis, by 2026 there will be an estimated shortfall of 17 600 cyber security workers. At the same time, existing government initiatives only produce 500 new candidates per year, 'which does not even cover the interest let alone the backlog'. Mr Ellis indicated this gap could be filled by adjusting recruitment processes and office environments to suit autistic candidates:

> At the same time we have enough unemployed highly intelligent highly functional autistics that want to do that job and have an interest in IT to completely solve that skills shortage, the only missing puzzle piece is a supported on the job training program which tests them on merit instead of 30 year old unscientific interview techniques, it's very obvious to anyone who spends a few moments thinking about it that watching someone do the job is more effective than talking about doing the job, but for some reason we don't do that, and autistic people are unfairly written off despite being the best candidates for the job, we have demonstrated that with the JPMorgan study which saw long-term unemployed high school educated candidates being 140 per cent more effective than PhD educated experts.[112]

13.73 Both Mr Ellis and another submitter highlighted the success of Israel's unit 9900,[113] known as the Roim Rachok program, which recruits and trains autistic people in a range of professions. While the first Roim Rachok cohorts were trained to decipher aerial and satellite photographs, the program has since

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[108] Specialisterne Australia, *Submission 67*, p. 6.

[109] Australian Autism Alliance, *Submission 52*, p. 37.

[110] Autism CRC, *Submission 46*, p. 27. See also, OTARC, *Submission 55*, p. 18.

[111] WithYouWithMe, *Submission 158*, p. 2.

[112] Mr Rhett Ellis, *Submission 45*, [pp. 1–2].

[113] Mr Rhett Ellis, *Submission 45*, [p.1]; Name withheld, *Submission 155*, p. 19.

expanded to train candidates for civilian roles such as software quality assurance, information sorting, and electro-optics technicians.[114]

13.74 In addition, WYWM suggested that a 'bespoke neurodiversity hiring program' could be championed by a single agency such as the Digital Transformation Agency, in order to establish pathways for autistic job seekers to start technology-based careers with the Australian Government. The lessons from this program could then be applied across other Australian Government agencies.[115]

Options beyond ICT

13.75 In addition to the relatively low numbers of autistic people employed through existing employment programs, stakeholders observed that most of these programs are focused on technology-based roles.[116] According to one autistic submitter, these programs focus on an 'elite' group of autistic people and fail to cater for autistic job seekers whose skills and interests lie in different directions.[117] Another autistic individual told Yellow Ladybugs:

> I am so sick of getting asked to apply for computer programming jobs, because of the cliche and limited understanding of autism. I would love to get into teaching, beauty therapy or something with animals. We are not all engineers. Our interests are unique, but all existing services cater for male autistics.[118]

13.76 Accordingly, the committee heard calls to expand autism-specific employment programs to cater for a broader range of autistic job seekers.[119] For example, Autism Queensland cited a need for more programs that 'accommodate job seekers with a wide range of abilities and interests' including entry level jobs for those with no post-school qualifications, as well as highly-skilled professional positions for those with university qualifications.[120] Another submitter suggested expanding the technology-focused model to fields like 'health, government and policy, social sciences, education, business, finance and commerce'.[121]

13.77 To this end, Krofne indicated that its TEAM COACH program was seeking to change the dominant paradigm around autistic recruitment by focusing its

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[114] Roim Rachok, *Roim Rachok Program*, www.roim-rachok.org/english (accessed 1 December 2021).

[115] WithYouWithMe, *Submission 158*, p. 6.

[116] See, for example, The Sycamore School, *Submission 118*, p. 9; Reframing Autism, *Submission 24*, [p. 9]; Autism Queensland, *Submission 129*, p. 24.

[117] Name withheld, *Submission 155*, p. 20.

[118] Yellow Ladybugs, *Submission 49*, p. 9.

[119] See, for example, Autism CRC, *Submission 46*, p. 27; Name withheld, *Submission 38*, [p. 1].

[120] Autism Queensland, *Submission 129*, p. 24.

[121] Name withheld, *Submission 155*, p. 20.

training on 'foundational work-based skills modules' for job seekers, which are then directed to focus on industries that align with participants interests, skills and capabilities.[122]

13.78 The I CAN Network (I CAN) also called for greater support for autistic-led social enterprises that create jobs for autistic people:

> Giving trainee mentors a pathway to employment in I CAN Network provides them with fulfilling work in the short-term and transferable skills and experiences which will increase their employability in the long-term. This reduces their chances of unemployment and their reliance on government welfare payments and support. As at July 2020, I CAN Ltd has successfully developed 20 trainee mentors into paid I CAN mentor staff. [123]

13.79 However, I CAN stressed that additional funding would be required to allow it 'initiate more opportunities which create jobs for autistic people'. It suggested this kind of activity could be supported via funding from the Department of Social Services' Information, Linkages and Capacity Building program.[124]

Complex needs and concurrent intellectual disability

13.80 As noted by Autism Queensland, autistic people's abilities range 'from those who are academically gifted to those who experience learning and language comprehension challenges'.[125] However, Autism Awareness Australia suggested that current employment efforts focus too strongly on those with high-level skills and abilities:

> The recent focus on the benefits of people with autism in the workplace is excellent, however, there has been far too much focus on those on the spectrum with high IQs and high-level technical skills. Whilst this is a wonderful beginning, we cannot forget individuals with a different presentation of autism and different skill set. The rights of people with autism who want to and can work should be a priority.[126]

13.81 OTARC concurred and argued that many current programs are not inclusive of autistic people with co-occurring intellectual disability.[127]

13.82 The need to cater for the range of abilities across the autism spectrum appears to have been recognised by Krofne, which is using tiered training as part of its TEAM COACH program in recognition that some autistic people will be able to

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[122] Krofne, *Submission 57*, [p. 3].

[123] I CAN Network, *Submission 107*, p. 19.

[124] I CAN Network, *Submission 107*, p. 20.

[125] Autism Queensland, *Submission 129*, p. 24.

[126] Autism Awareness Australia, *Submission 47*, p. 9.

[127] OTARC, *Submission 55*, p. 14.

attend training independently, while others will need the assistance of a support worker to do so.[128]

13.83 In addition, more than one submitter noted the relatively high proportion of autistic people working in Australian Disability Enterprises (ADEs).[129] The Autism Alliance suggested that this represented an under-utilisation of autistic people's skills, while CYDA argued that 'segregated employment in Australian Disability Employment "sheltered workshops" constitutes a form of neglect of people's rights'.[130] To this end, People with Disability Australia (PWDA) recommended transitioning all workers with disability in ADEs into mainstream employment.[131]

13.84 However, one parent of an autistic man with intellectual disability highlighted the importance of supported employment options and activity centres for autistic people with more complex needs. They described how, in the absence of any suitable employment options within easy travelling distance, Arts Project Australia provides a very positive service for their son five days per week.[132]

13.85 Another autistic submitter stated that they did 'not condone the closure or slander of such facilities' and suggested instead that ADEs could be reformed to help upskill workers and prepare autistic job seekers for a transition into open employment.[133]

Self-employment

13.86 Some stakeholders suggested that self-employment could provide another pathway to employment for autistic people. For example, I CAN asserted that as '98 percent of Australian businesses are small businesses (sole traders or employing less than 20 people), starting up a business or social enterprise is a viable way for autistic people to be employed'.[134] Other stakeholders, such as The Autistic Realm Australia (TARA), also pointed out that self-employment can allow autistic people to better control their work environments.[135]

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[128] Krofne, *Submission 57*, [p. 3].

[129] See for example, Children and Young People with Disability Australia, *Submission 109*, p. 7; JFA Purple Orange, *Submission 84*, p. 19.

[130] Children and Young People with Disability Australia, *Submission 109*, p. 7.

[131] People with Disability Australia, *Submission 102*, p. 26.

[132] Name withheld, *Submission 38*, [pp. 2 and 4].

[133] Name withheld, *Submission 155*, p. 21.

[134] I CAN Network, *Submission 107*, p. 21.

[135] The Autistic Ream Australia (TARA), *Submission 86*, p. 21.

13.87 However, submitters recognised that additional support would be required to help autistic people start their own businesses.[136] This includes help to develop their business capabilities, as well as financial support.[137] As noted by I CAN, any support provided would need to 'consider the unique strengths and challenges autistic people possess such as their attention to detail and their fear of uncertainty, respectively'.[138]

13.88 The benefits and challenges of self-employment for autistic people were summarised by one parent who explained that while self-employment had been extremely positive for her son, it had also come at a cost:

> Running [redacted] business and watching his self-confidence soar to heights we could not envisage has been the very best thing I have done for him. It does involve a lot of work. I get burnt out. I worry about the longevity of his business. … No parent should have to work so hard on helping their child become employable. This is something I strongly believe. I am glad I do it. I wouldn't change a thing but I give up a lot for this to be possible. My daughter has less time with me. I still cannot pursue any form of employment (which I would dearly love). The ripple effect again can’t be measured. … But I know this: [redacted] will be a taxpayer. He will not be a welfare recipient. [redacted] spends money in his community. [redacted] hires kids from his high school.[139]

13.89 Accordingly, stakeholders made a range of suggestions to improve self-employment options for autistic job seekers. For example, I CAN proposed that a grants program be established to help autistic individuals set up (or expand) their businesses and improve their business skills and capabilities.[140]

13.90 In addition to small business grants, submitters also suggested that business mentoring programs should also be introduced to help guide autistic people through the process of establishing their own businesses.[141]

Government incentives and employment quotas

13.91 Multiple stakeholders identified a role for government in incentivising autistic employment,[142] and proposed the following mechanisms:

- establishing governments as model employers;

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[136] Scope-University of Melbourne Partnership, *Submission 83*, pp. 22–23.

[137] See, for example, Spectrum Labor, *Submission 1*, [p. 11]; Name withheld, *Submission 9*, p. 12.

[138] I CAN Network, *Submission 107*, p. 21.

[139] Name withheld, *Submission 4*, [pp. 4–5].

[140] I CAN Network, *Submission 107*, p. 21.

[141] Name withheld, *Submission 62*, p. 11; Name withheld, *Submission 11*, [p. 12].

[142] See, for example, Spectrum Labor, *Submission 1*, [p. 11]; Specialisterne Australia, *Submission 67*, p. 12; Autism Advisory and Support Service, *Submission 21*, p. 5; Name withheld, *Submission 126*, p. 21.

- introducing employment targets and quotas; and
- expanding social procurement approaches.

Governments as model employers

13.92 Some stakeholders, such as Specialisterne, pointed out that 'government leading the way in their own best practice will be key to driving change in the business sector'.[143]

13.93 Accordingly, a number of stakeholders suggested that governments at all levels commit to creating employment pathways into the public service for autistic people. This could include developing autism-specific streams within existing pathways such as graduate and trainee programs.[144]

13.94 The Autism CRC also suggested that the evidence-based benefits of, and practices for, neurodiversity in the workplace should be codified and promoted 'through major employer groups, such as the Business Council of Australia and the Australian Public Service'.[145]

Employment targets and quotas

13.95 Various stakeholders suggested that governments should set targets for autistic employment, including mandatory quotas.[146] One submitter pointed to evidence from Japan showing that, when enforced, quotas improved disability employment 'with little impact on businesses'.[147]

13.96 The Autism Alliance also noted the introduction of employment targets for people with disability more broadly, including a 6 per cent target in Victoria (rising to 12 per cent by 2021) and a 7 per cent target across the Australian Public Service by 2025.[148]

13.97 However, at least one stakeholder indicated that these figures were too low given the proportion of the population with a disability in Australia.[149] Indeed, PWDA suggested that the quota for the public sector should start at 15 per cent, with a quota of 51 per cent for the National Disability Insurance Agency (NDIA).[150]

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[143] Specialisterne Australian, *Submission 67*, p. 12.

[144] Specialisterne Australia, *Submission 67*, p. 12; Name withheld, *Submission 126*, p. 21

[145] Autism CRC, *Submission 46*, p. 5

[146] See, for example, Specialisterne Australian, *Submission 67*, p. 12; Marymead Autism Centre, *Submission 128*, p. 4; Coalition of Autistic Women, *Submission 125*, [p. 27]; Spectrum Labor, *Submission 1*, [pp. 10–11].

[147] Name withheld, *Submission 155*, [p. 1].

[148] Australian Autism Alliance, *Submission 52*, p. 39.

[149] Name withheld, *Submission 126*, p. 21.

[150] People with Disability Australia, *Submission 102*, p. 25.

13.98 In relation to autism more specifically, one submitter suggested that a target of 2.5 per cent should be set, reflecting the estimated prevalence of autism in Australia.[151] Another submitter suggested that tax incentives should be used to incentive businesses to meet employment targets.[152]

Social procurement approaches

13.99 Stakeholders highlighted the potential for governments to use their purchasing power to encourage or oblige vendors to increase the numbers of autistic people they employ.[153] For example, the Autism Alliance pointed out that some state governments have implemented social procurement initiatives that require contracted organisations to generate employment opportunities for marginalised job seekers. According to the Autism Alliance, this includes purchasing arrangements that preference social enterprises—including those hiring people with disability.[154]

13.100 However, the Autism Alliance noted a lack of social procurement measures at the Commonwealth level (other than the Indigenous Procurement Policy) and suggested that the Australian Government establish a social procurement framework that requires contracted organisations to provide 'training and employment opportunities for marginalised job seekers, including autistic people'.[155]

Committee view

13.101 The committee is alarmed by the poor employment statistics for autistic people. These statistics highlight the total failure of the Disability Employment Services (DES) system to support autistic people. This committee heard that this failure has reduced the quality of life of countless autistic people and has robbed Australian society of the skills and expertise that autistic people have to offer.

13.102 According to evidence provided to the inquiry, the effectiveness of the DES system is hampered by a lack of autism expertise and an overreliance on traditional job-seeking mechanisms. Perhaps most troubling were reports that the DES system actively rewards fast placement of job seekers into employment, rather than the appropriateness or sustainability of job placements. The committee is also concerned that, once a placement is made, DES providers appear not to be providing ongoing in-placement support—despite the DES system making provision for providers to support participants in their first year of employment (and longer if needed).

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[151] Name withheld, *Submission 2*, p. 5.

[152] Name withheld, *Submission 126*, p. 21.

[153] Specialisterne Australian, *Submission 67*, p. 12; Dr Bruce Baer Arnold, *Submission 39*, p. 7.

[154] Australian Autism Alliance, *Submission 52*, p. 40.

[155] Australian Autism Alliance, *Submission 52*, p. 40 and 41.

13.103 The committee is also disappointed to learn that general recruitment and induction processes remain largely inaccessible and ineffective for autistic people and that relatively few adjustments are made for autistic people within the work environment. The committee heard that fears about discrimination or inappropriate treatment also make autistic people reluctant to disclose their diagnosis. This suggests an urgent need to improve autism understanding among employers and employment service providers, including via the creation or promotion of resources to support the recruitment and onboarding process.

13.104 Although there are a handful of autism-specific employment programs that are achieving positive outcomes, they support relatively small numbers of autistic people. Without action to broaden the reach of these programs, they will always remain limited in what they can achieve. While recognising that ICT-focused programs are an important avenue for autistic employment, the committee also supports calls for these programs to be broadened beyond ICT in order to accommodate the wide range of interests and abilities found within the autistic community—including those individuals with more complex needs and/or co-occurring intellectual disability.

13.105 However, improving employment outcomes for autistic people cannot simply be the preserve of a few committed workplaces and specialised employment services providers. Governments and businesses need to work together to drive widespread, systemic change to hiring and induction processes, as well as developing workplace cultures and systems of supports that will help autistic individuals to maintain their employment. The committee notes that valuing the contribution people with disability make to the workforce and recognising the benefits of employing people with disability is also an identified policy priority under *Australia's Disability Strategy 2021-2031*.[156]

13.106 The committee believes that investing in greater support at start of an individual's employment journey will help to lower costs later on by reducing unnecessary reliance on government social security payments. According to some stakeholders, it also has broader economic benefits by increasing taxation revenue and gross domestic product (GDP). In particular, the committee notes evidence suggesting that a one-third reduction in the employment gap between people with disability and the broader population would increase GDP by $43 billion over ten years.[157]

13.107 The committee notes the release of the *Employ My Ability* strategy in December 2021. The *Employ My Ability* strategy contains admirable goals, including many that align with the evidence presented to this committee.

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[156] Department of Social Services, *Australia's Disability Strategy 2021-2031*, p. 31.

[157] Name withheld, *Submission 155.2*, [p. 1].

13.108 In addition, the Department of Social Services is developing a replacement for the DES system that will commence in 2023 and aims to further break down barriers to employment for people with disability. The committee is pleased to see that an autism-focused working group is contributing to the development of this new model.

13.109 The committee understands that it will take time to assess whether either of these measures will improve employment outcomes for autistic people. Accordingly, the committee urges the Department of Social Services to ensure that all monitoring and evaluation activities related to these measures allow for disaggregation by disability type, including autism.

13.110 However, the committee remains concerned that these measures may not be specific enough to meet the needs of autistic people. For this reason, the committee strongly believes that a national framework is required to coordinate and drive measures to improve autistic employment outcomes. Priorities for the framework should include actions related to:

- improving information for both autistic job seekers and employers;
- communicating the benefits of hiring autistic people;
- improving education and training for DES providers and employers;
- expanding ICT and non-ICT employment programs; and
- identifying ways to support self-employment, further establish governments as employers of choice, and incentivise private sector employment.

13.111 The committee also believes that the new DES model should build on the experience of, and evidence about, autism-specific programs in terms of what works to support autistic employment.

Recommendation 58

13.112 The committee recommends that a National Autism Employment Framework be agreed under the auspices of the National Autism Strategy. The framework should identify actions to:

- **promote the benefits of hiring autistic people to governments and business;**
- **further establish governments as employers of choice;**
- **incentivise private sector employment;**
- **encourage the expansion of both ICT and non-ICT autism-focused employment programs;**
- **support self-employment options for autistic people;**
- **improve information for autistic job seekers about available supports and DES providers with autism experience; and**

- **improve autism-related education, training and resources for DES providers and employers (building on existing resources where available).**

13.113 The framework should also be compatible with the *Employ My Ability* strategy and should help inform the new Disability Employment Support (DES) Model being developed by the Department of Social Services for implementation in 2023.

Recommendation 59

13.114 The committee recommends that the Department of Social Services ensure that all monitoring and evaluation activities related to the *Employ My Ability* strategy and the new Disability Employment Support Model allow for disaggregation by disability type, including autism.

Recommendation 60

13.115 The committee recommends that the Department of Social Services incorporate into the design of the new Disability Employment Support Model:

- **relevant elements of the National Autism Employment Framework; and**
- **lessons from autism-specific employment programs about what works in relation to achieving long-term employment outcomes for autistic people.**

Chapter 14
Health and mental health

14.1 This chapter provides an overview of health outcomes for autistic people, including the capacity of the current health care system to meet their needs. It then discusses the challenges autistic people face in relation to accessing adequate and appropriate health care services, with a particular focus on restrictive practices, maternal health care and mental health services.

14.2 While diagnosis and early intervention can fall within the broader category of health care, they are addressed separately in Chapters 10 and 11 respectively.

Overview

14.3 As described in Chapter 3, autistic people experience poor physical and mental health in comparison to the general population, with known—or probable—correlations between autism and certain medical conditions. These conditions include seizures, psychiatric illness, intellectual disability, attention deficit hyperactivity disorder, gastrointestinal disorders, sleep difficulties, problematic feeding behaviours, mobility restrictions, and frailty and premature ageing.[1] As described by the Department of Developmental Disability Neuropsychiatry, University of New South Wales (UNSW 3DN), the rate of co-occurring conditions 'suggests that this population group experiences one of the most significant health disadvantages of any population group in Australia'.[2]

14.4 The prevalence of co-occurring mental health conditions was highlighted as a particular issue for autistic people.[3] A number of stakeholders, including St Vincent's Health Australia (St Vincent's), noted that between 50-70 per cent of autistic individuals experience mental health conditions, with anxiety and depression being especially common, along with high rates of suicidal ideation.[4]

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[1] See, for example, Finale Doshi-Velez, Yaorong Ge and Isaac Kohane, 'Comorbidity Clusters in Autism Spectrum Disorders: An Electronic Health Record Time-Series Analysis', *Paediatrics*, January 2014, vol. 133, no. 1, p. 54. https://doi.org/10.1542/peds.2013-0819. See also, Department of Developmental Disability Neuropsychiatry, University of New South Wales (UNSW 3DN), *Submission 95*, pp. 7–9; La Trobe University – the Olga Tennison Autism Research Centre (OTARC), *Submission 55*, p. 14; BioAutism Ltd, *Submission 93*, p. 10.

[2] UNSW 3DN, *Submission 95*, p. 9.

[3] See, for example, OTARC, *Submission 55*, p. 14; Australian Autism Alliance, *Submission 52*, p. 9; NSW Government, *Submission 65*, p. 7; Royal Australian and New Zealand College of Psychiatrists, *Submission 17*, [p. 1]; Royal Australasian College of Physicians, *Submission 29*, p. 8; UNSW 3DN, *Submission 95*, p. 6; Mr Cameron Boyd, *Submission 157*, [p. 8].

[4] St Vincent's Health Australia, *Submission 72*, p. 4. See also, OTARC, *Submission 55*, p. 15; Scope-University of Melbourne Partnership, *Submission 83*, p. 28; UNSW 3DN, *Submission 95*, p. 6; Name withheld, *Submission 126*, p. 4; Name withheld, *Submission 162*, pp. 1–2.

This appears to align with the results of an Australian Autism Alliance (the Autism Alliance) survey which found that 75.2 per cent of adult respondents had a diagnosed mental health concern.[5] St Vincent's also pointed out that mental ill health is exacerbated by the 'poor physical health, socio-economic status and lack of social supports experienced by this population'.[6]

14.5 The intersection of autism and intellectual disability was also revealed to be another significant challenge. According to UNSW 3DN, just over one in every 1000 people is estimated to have both autism and an intellectual disability, with this dual diagnosis being 'linked to poorer health status and more complex health care needs across the lifespan'.[7] Likewise, St Vincent's noted that intellectual disability occurs in about half of people with autism. Given the high rates of mental health conditions found in both the autistic population and in people with intellectual disability, it surmised this would place the dually diagnosed population at even greater risk of mental ill health.[8]

14.6 Despite the general strength of Australia's health care system,[9] it appears that it does not meet the needs of autistic people. For example, UNSW 3DN described the health care landscape as 'one of lack of preparedness for the needs of autistic people'. According to UNSW 3DN, the problem is systemic and affects health care policy and practice at all levels of the health care system. It also contributes significantly to autistic people's poor physical and mental health outcomes:

> This lack of preparedness manifests on every level (practitioner, services, policy); in each health care compartment (primary, specialist and acute care settings); and in services across the life span (from childhood to later life). Such systemic lack of preparedness is a major contributor to the stark mental and physical health disadvantage experienced by people with developmental disabilities compared to the general Australian population.[10]

14.7 Monash University also argued that the health care system 'is known to fail those with complex problems requiring input from multiple professionals', with the negative impacts being 'amplified if care is provided by multiple agencies'.[11]

14.8 While there appears to be a lack of autism-specific statistics about use of—and satisfaction with—the health care system, available data suggest that autistic people have unusually high rates of hospital emergency department utilisation, which may indicate a failure of preventative and primary health care services.

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[5] Australian Autism Alliance, *Submission 52.2*, p. 17.

[6] St Vincent's Health Australia, *Submission 72*, p. 4.

[7] UNSW 3DN, *Submission 95*, p. 3.

[8] St Vincent's Health Australia, *Submission 72*, p. 4.

[9] Monash University, *Submission 94*, p. 13.

[10] UNSW 3DN, *Submission 95*, p. 18.

[11] Monash University, *Submission 94*, pp. 13–14.

For example, an Autism Alliance survey found that 35.1 per cent of autistic adults had attended a hospital emergency department in the previous 12 months. This compared to the Australian Bureau of Statistics' analysis of the general population which showed that only 12.7 per cent of people aged 25-64 years and 24.4 per cent of people aged 85 years and over presented at an emergency department at least once per year.[12]

14.9 The Autism Alliance also cited the Victorian Parliamentary Inquiry into Services for People with Autism Spectrum Disorder, which found that young autistic people are '10 times more likely to be admitted to hospital for medical illnesses and complaints'.[13] As noted by the Autism Alliance, this creates a 'dual burden' of higher health system costs associated with treatment in an acute setting, as well as 'the significant stress placed on patients when receiving care in a hospital'.[14] In response, UNSW 3DN advocated for the inclusion of autistic people's needs in all primary and preventative health care initiatives in order to 'address the high rate of potentially avoidable morbidity and hospitalisations'.[15]

14.10 Despite the poor outcomes of the autistic community and the failure of the health system to meet the needs of this cohort, multiple submitters noted the dearth of research aimed at improving their health trajectories.[16] For example, UNSW 3DN recommended that there should be routine analysis and reporting of 'population health outcomes for people with developmental disabilities and those on the autism spectrum, including health status, health service utilisation and health outcomes'. UNSW 3DN also recommended better tracking of mortality data for autistic data in order to inform health initiatives.[17] According to UNSW 3DN:

> Analysis and reporting of mortality data will detect gaps in care and care pathways, and direct future health care and social service spending and research initiatives towards areas of high need. Trends in mortality data over time are also crucial in tracking the impact of policy shifts and other changes in the health and social care landscape on the health of vulnerable populations.[18]

14.11 Other submitters identified the need to focus on better understanding co-occurring conditions and evaluating clinical interventions. For instance, the

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[12] Australian Autism Alliance, *Submission 52*, p. 20.

[13] Australian Autism Alliance, *Submission 52*, p. 20.

[14] Australian Autism Alliance, *Submission 52*, p. 20.

[15] UNSW 3DN, *Submission 95*, p. 13.

[16] See, for example, Scope-University of Melbourne Partnership, *Submission 83*, pp. 23–24; Family Planning NSW, *Submission 28*, p. 6; OTARC, *Submission 55*, p. 22; National Aboriginal Community Controlled Health Organisation (NACCHO), *Submission 104*, [p. 9].

[17] UNSW 3DN, *Submission 95*, p. 15.

[18] UNSW 3DN, *Submission 95*, p. 17.

Cooperative Research Centre for Living with Autism (Autism CRC) stressed the 'urgent need' to understand 'risk factors, causes and presentation of co-occurring conditions', as well as clinical interventions.[19]

14.12 Similarly, the Scope-University of Melbourne Partnership (Scope-UoM) contended that a lack of understanding about factors related to poor mental health means that 'we lack key data points for informing effective, individualised intervention and support approaches'.[20] Likewise, Monash University described as 'notably absent' the development and evaluation of appropriate interventions for autistic children with concurrent intellectual disability.[21]

Challenges in accessing health care

14.13 The committee noted that autistic people face a number of challenges when trying to access mainstream health care services. These include:

- difficulties navigating a complex service environment;
- a lack of autism knowledge and understanding;
- diagnostic overshadowing and co-occurring conditions; and
- a lack of autism-friendly health care environments.

Navigating a complex service environment

14.14 Australia's health care system is comprised of a complex mix of service providers and health professionals working in both government and non-government sectors across a range of settings, from large hospitals to small health clinics.[22]

14.15 This complexity is also reflected in the system's administration and funding arrangements. For example, responsibility for primary health services, other than general practitioners (GPs), lies with state and territory governments,[23] while responsibility for mental health supports and services are substantially shared across levels of government.[24] Similarly, funding for the National Disability Insurance Scheme (NDIS) is shared between all governments, while

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[19] Cooperative Research Centre for Living with Autism (Autism CRC), *Submission 46*, p. 18.

[20] Scope-University of Melbourne Partnership, *Submission 83*, p. 26.

[21] Monash University, *Submission 94*, p. 22.

[22] Australian Institute of Health and Welfare, *Health system overview*, 23 July 2020, www.aihw.gov.au/reports/australias-health/health-system-overview (accessed 6 December 2021).

[23] Department of Social Services, Department of Education, Skills and Employment, Department of Health, *Submission 53*, p. 4.

[24] Department of Social Services, *Australia's Disability Strategy 2021–2031*, p. 55.

the Commonwealth administers the *National Disability Insurance Scheme Act 2013* and exercises statutory powers with the agreement of states and territories.[25]

14.16 While issues related to poor service coordination are addressed in more detail in Chapter 6, stakeholders identified the complexity of the system as a barrier to accessing adequate health care services.[26]

14.17 For instance, the Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University (University of Queensland and RMIT) described how a lack of understanding about how the health system works, and how to access its different parts, can affect access to health care:

> For example, accessing allied health services can be confusing for reasons including the different pathways (e.g., privately and out-of-pocket, referral for bulk-billed appointments to private service using Medicare criteria for care plans or referral to public services, often with long wait times).[27]

14.18 This view was shared by the Australian Psychological Society which reported that its members' clients experience 'many difficulties navigating service provision, follow-up support and obtaining referrals'.[28]

14.19 UNSW 3DN explained that these difficulties can be exacerbated by the 'cognitive, communication based, and adaptive functioning challenges associated with intellectual disability and/or autism'. According to UNSW 3DN, these challenges mean that autistic people may have difficulty processing information, while those with concurrent intellectual disability may have poorer health knowledge and less ability to navigate complex systems or seek support services. UNSW 3DN also concluded that commonly used health resources, such as written brochures, may not be accessible for autistic people, further hampering their ability to participate in broader population health initiatives.[29]

14.20 However, challenges navigating the health care system were not limited to autistic people. Parents and carers of autistic people also reported difficulties.[30] For example, one submitter described the 'constant issue of deciphering which

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[25] National Disability Insurance Scheme (NDIS), *Governance*, 30 August 2021, www.ndis.gov.au/about-us/governance (accessed 6 December 2021).

[26] See, for example, Carers NSW, *Submission 71*, [p. 5]; NACCHO, *Submission 104*, [p. 7]; Children and Young People with Disability Australia, *Submission 109*, p. 22; Marymead Autism Centre, *Submission 128*, Attachment 1, p. 15; Australian Psychological Society, *Submission 110*, p. 7.

[27] Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 7].

[28] Australian Psychological Society, *Submission 110*, p. 7.

[29] UNSW 3DN, *Submission 95*, p. 10.

[30] See, for example, Name withheld, *Submission 59*, [p. 1]; Carers NSW, *Submission 71*, [p. 5]; Monash University, *Submission 94*, p. 12.

department or support system is responsible' for her son's supports—be it the NDIS, education, Medicare or the public health system. She also pointed to gaps in the system where her son's disability-related health and dental costs are not supported by either the NDIS or the public health system in a way that would improve outcomes for her son.[31]

14.21 The lack of a holistic approach to health care was also highlighted by other stakeholders.[32] According to some submitters, this has been exacerbated by changes to the Medicare Benefits Scheme that push 'patients to only discuss one issue or problem at a time with their GP'.[33] As a result, the committee heard calls for a more integrated approach to service delivery:

> To be frank the system needs to be clear, united and serve as a one-stop shop entry point for someone with autism to go and is well equipped to refer someone to another provider that can help if that cannot happen within the system.[34]

14.22 A similar sentiment was expressed by submitters who advocated for a single service interface, rather than having to deal with the NDIS for some supports and mainstream services for others.[35]

14.23 In response, multiple stakeholders, including La Trobe University's Olga Tennison Autism Research Centre (OTARC), highlighted the need for better care coordination and systemic change in order to better support autistic people.[36] For example, UNSW 3DN recommended that all mainstream health care services be required to develop 'clinical care pathways through each of their core service components', with information about the pathways made widely available to providers, consumers and carers.[37]

14.24 In addition, UNSW 3DN contended that the provision of health information should be underpinned by a minimum service standard that all information, including commonly used forms, are made available in an accessible format. It recommended that this be 'accompanied by training for health staff so that they know how to use them'.[38]

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[31] Name withheld, *Submission 148*, p. 3.

[32] See, for example, Different Journeys, *Submission 30*, p. 17; Marymead Autism Centre, *Submission 128*, Attachment 1, p. 19; Name withheld, *Submission 155*, p. 4.

[33] Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 6]. See also, Name withheld, *Submission 155*, p. 4.

[34] Name withheld, *Submission 155*, p. 4.

[35] See, for example, Name withheld, *Submission 11*, p. 14; Name withheld, *Submission 155*, p. 24.

[36] OTARC, *Submission 55*, p. 16.

[37] UNSW 3DN, *Submission 95*, p. 12.

[38] UNSW 3DN, *Submission 95*, p. 12.

14.25 UNSW 3DN also argued that states and territories should implement integrated models of care that target the health needs of autistic people. According to UNSW 3DN, this should include specialised and 'one-stop' health services for people with particularly complex needs, including autistic people with intellectual disability, such as those piloted in New South Wales (see Box 14.1). It argued that these services could provide timely and comprehensive assessment of care needs 'including oral health care and, if necessary, imaging, and other investigations and procedures under anaesthetic'. [39]

Box 14.1 New South Wales – support for complex presentations

There are a range of services that support people in health settings, including those with autism, when there is additional complexity.

Specialised Intellectual Disability Health Teams have been established for people who have complex health conditions, intellectual disability and:

- a current unresolved health problem;
- health care needs that cannot be met by usual care providers and pathways; and
- an existing primary treating clinician/team to implement care plan recommendations and follow through with care.

The teams and positions provide:

- comprehensive assessment of current needs;
- a health care plan with recommendations;
- referrals to health and other services; and
- advice, information and resources to the client's primary treating team (GP or other clinicians) who provide ongoing care and can implement the plan recommendations.

People with autism who have complex support needs may also be eligible for support through the Integrated Service Response (ISR) when their wellbeing is threatened by crisis that is unable to be resolved locally.

The ISR works with the NDIA, NSW Government agencies, non-government organisations, NDIS providers and the private sector to promote engagement, collaboration and innovation to effectively manage or resolve highly complex situations.

Source: NSW Government, Submission 65, p. 7.

14.26 In addition, the Autism Alliance advocated for the development of a 'national roadmap' to improve health services for autistic people. It suggested that, as with the *National Roadmap for Improving Health Services for People with Intellectual Disability*, there is 'great value in setting out the aims and goals for a specific cohort of people … and coordinating a response that includes input from the

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[39] UNSW 3DN, *Submission 95*, pp. 12 and 13.

community and healthcare providers'. As an example, it pointed to the United Kingdom National Health Service *Long Term Plan* which includes specific actions to address the causes of morbidity and preventable deaths for autistic people.[40]

14.27 Incorporating the needs of people with autism within health policy frameworks was also supported by UNSW 3DN, given 'their more frequent and complex health needs, as well as … their higher mortality rates associated with mental and physical health'.[41] This view was shared by the Royal Australian and New Zealand College of Psychiatrists which raised concerns that 'many key government policy documents do not acknowledge the increased vulnerability to mental health conditions and suicide experienced by people with [autism] who, in turn, may miss out on appropriate support'.[42]

14.28 Accordingly, the Autism Alliance advocated for the development of a National Plan on Autism in Mental Health to align with the 'the next iteration of the National Mental Health and Suicide Plan'.[43] Similarly, the New South Wales Government (NSW Government) recommended that the National Autism Strategy harmonise with 'national Mental Health and Suicide Prevention Plans and National Disability Strategies to ensure that suicide prevention approaches for people with [autism] are prioritised in policy with appropriate resources to create systemic change'.[44]

Autism knowledge and understanding

14.29 In line with stakeholder views on other service sectors, the adequacy of health care services is also affected by a lack of autism knowledge and understanding. For example, an Autism Alliance survey found that 86.7 per cent of autistic adults and 82.1 per cent of parents and carers 'reported challenges due to health professionals' lack of understanding about autism'. More specifically, only 22.5 per cent of respondents rated their GP's autism knowledge as good, while 32.6 per cent rated their GP's knowledge of autism as poor.[45]

14.30 This was also reflected in the experience of autistic submitters, as well as parents and carers of autistic individuals. For example, upon disclosing her diagnosis to a doctor at a medical clinic, one autistic woman was asked whether she had 'done the blood test for Aspergers' syndrome':

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[40] Australian Autism Alliance, *Submission 52*, p. 23.

[41] UNSW 3DN, *Submission 95*, p. 16.

[42] Royal Australian and New Zealand College of Psychiatrists, *Submission 17,* [p. 2].

[43] Australian Autism Alliance, *Submission 52*, p. 5.

[44] New South Wales Government, *Submission 6*5, p. 9.

[45] Australian Autism Alliance, *Submission 52*, p. 21.

> …to which I replied, 'There is no blood test.' He asked me how I knew and I said I had done the research. He promised to do the research too and … told me to come back to him for 'treatment for my Aspergers' and gave me his business card.[46]

14.31 Another submitter described the impact on her autistic son of a dental procedure that failed to account for her son's sensory needs:

> He recently had a dental surgery where the doctor administered a local anaesthetic to his mouth, even though he had a general anaesthetic. My son has extreme oral sensory issues which is how he ended up being treated as he was. Waking with numb lips and mouth was incredibly distressing for him, and he could not understand what had happened. He bit his lips repeatedly, which became severely infected and became a bigger issue than the recovery for his surgery and prior presenting issues.[47]

14.32 For hospital emergency departments, the survey results were even worse, with the Autism Alliance reporting that 45 per cent of respondents rated the autism knowledge in those settings as poor.[48] Monash University also noted the 'paucity of trained staff in hospital settings to manage children with autism, especially at times of high-risk behaviours'.[49]

14.33 According to the Autism Alliance, health care professionals themselves also recognise that a lack of autism understanding, experience and resources contributes to their difficulties in providing adequate care. It noted the results of a recent Australian study which found that while 59 per cent felt confident in providing care, over 80 per cent wanted additional training, 'particularly in communication, behaviour and mental health management'.[50]

14.34 These results seem to be reflected in the findings of an international review (including Australian studies) which found:

- the complexity of working with autistic patients was beyond the usual role of service providers;
- limited knowledge and resources negatively affected service provision to autistic patients and their families;
- a lack of training or prior experience with autistic patients was a barrier to care; and
- a need for information and training to improve service provision.[51]

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[46] Name withheld, *Submission 2*, p. 9.

[47] Name withheld, *Submission 119*, p. 8.

[48] Australian Autism Alliance, *Submission 52*, p. 21.

[49] Monash University, *Submission 94*, p. 26.

[50] Australian Autism Alliance, *Submission 52*, pp. 21–22.

[51] OTARC, *Submission 55*, pp. 15–16.

14.35 As with diagnosis, stakeholders also raised particular concerns about a lack of knowledge in relation to autism in adults, as well as its presentation in females.[52]

14.36 In response, multiple stakeholders called for better training and professional development for health care providers.[53] For example, the Autism Alliance proposed that a 'systemic approach' be taken to 'strengthen the autism competency of healthcare professionals, with a particular focus on GPs, emergency staff and mental health practitioners'.[54] In a similar vein, the University of Queensland and RMIT suggested that minimum training requirements be mandated for all health professionals, with a 'strong focus on autism in adulthood and the experiences of autistic women'.[55]

14.37 UNSW 3DN also supported mandatory autism training for medical, psychological and nursing students, as well as all staff in public health facilities. It suggested that the training for university students should be informed by an audit of the autism content for relevant courses—similar to work done in relation to intellectual disability. UNSW 3DN also advocated for:

- enhanced training and career pathways for existing medical speciality groups, such as GPs, paediatricians, psychiatrists, rehabilitation physicians and emergency physicians;
- scoping of the need for, and feasibility of, subspecialty training in key medical specialties; and
- career pathway development in key medical specialties to ensure that funded specialist positions are available in the public health system.[56]

14.38 In terms of career pathways, stakeholders, such as the Office of the Public Advocate Victoria (OPA Victoria), suggested that a cohort of autism specialists could be employed within hospital networks to educate other staff and advise on 'best practice approaches to patient management' for autistic people.[57]

14.39 St Vincent's also suggested the introduction of autism liaison services for all general hospitals. These services could help 'prepare autistic patients and

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[52] See, for example, Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 2]; OTARC, *Submission 55*, p. 9; Coalition of Autistic Women, *Submission 125*, pp. 12–13; Speech Pathology Australia, *Submission 87*, p. 10.

[53] See, for example, Autism Aspergers Advocacy Australia (A4), *Submission 54*, p. 11; UNSW 3DN, *Submission 95*, pp. 6 and 13–14; Marymead Autism Centre, *Submission 128*, p. 11; Name withheld, *Submission 2*, p. 4.

[54] Australian Autism Alliance, *Submission 52*, p. 4.

[55] Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 3].

[56] UNSW 3DN, *Submission 95*, pp. 13–15.

[57] Office of the Public Advocate, Victoria, *Submission 80*, p. 4.

hospitals for the admission, assist with reasonable adjustments, provide training and education on [autism] and related mental health or behavioural issues, and provide expert input to prevent and minimise problems'.[58]

14.40 Stakeholders also noted the opportunity to make better use of existing tools and resources. For example, the Autism CRC indicated it had developed 'a number of tools to upskill the clinical workforce on autism and its presentation', including:

- the Comprehensive Health Assessment Protocol for Autism (CHAP-A), a self-health assessment tool for autistic adults to share with GPs;
- development of an autism pathway that is embedded in the national HealthPathway system used by health professionals, including GPs; and
- resources and professional development modules made available to GPs across Australia (with almost 4000 logged completions to date).[59]

14.41 However, the Autism Alliance noted that uptake of these tools has not been widespread and suggested that a systemic approach to upskilling is required.[60] The Autism CRC concurred and noted that dissemination and use of these tools 'has been via direct engagement with clinicians', whereas broader implementation would require 'a systemic approach through national and state health service sectors'.[61]

14.42 To this end, UNSW 3DN suggested that a national training centre and resources clearing house be established to develop, collate and disseminate resources aimed at helping health professionals improve practice for people with intellectual or developmental disabilities, including autism.[62]

Diagnostic overshadowing

14.43 In addition to a general lack of autism understanding in the health care system, stakeholders, such as OTARC, raised concerns that insufficient knowledge of co-occurring conditions is leading to diagnostic overshadowing.[63]

14.44 As described by the University of Queensland and RMIT, diagnostic overshadowing occurs when 'medical professionals attribute a sign or symptom

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[58] St Vincent's Health Australia, *Submission 72*, pp. 6–7.

[59] Autism CRC, *Submission 46*, p. 18. The Comprehensive Health Assessment Protocol for Autism (CHAP-A) tool is built upon the successful Comprehensive Health Assessment Protocol (CHAP) tool developed at the University of Queensland and used around the world for individuals with an intellectual disability.

[60] Australian Autism Alliance, *Submission 52*, pp. 21–22.

[61] Autism CRC, *Submission 46*, p. 18.

[62] UNSW 3DN, *Submission 95*, p. 15.

[63] OTARC, *Submission 55*, p. 15.

to the person's autism rather than seeking a medical cause'.[64] According to Professor Keith McVilly of the University of Melbourne, this means that a person's autism can come to 'define them as a person', as well as 'overwhelmingly and inappropriately' guiding their treatment in many cases.[65] As noted by Autism Aspergers Advocacy Australia (A4), this can turn an autism diagnosis into another barrier to accessing adequate health care:

> Too many clinicians cannot see beyond a person's autism, attributing everything to autism and ignoring other ailments. Too many autistic people have undiagnosed chronic health conditions. Autistic people experiencing trauma or mental illness are denied services and supports for other illnesses because they are excluded from services or their needs are not recognised.[66]

14.45 Autistic people's concerns about diagnostic overshadowing were reflected in the results of an Autism Alliance survey which found that 35.7 per cent of autistic adults were concerned that obtaining an autism diagnosis would overshadow their other health needs.[67]

14.46 Diagnostic overshadowing was also seen as a particular issue in relation to co-occurring mental health conditions. As Professor McVilly explained:

> We need to recognise that a person with autism might have anxiety or depression. Indeed, our research tells us that a very high proportion of people will. We also need to acknowledge that many people presenting with anxiety and depression may well have undiagnosed autism, and our practitioners need to be able to have the knowledge and the skills to work in that very murky world of differential diagnosis. It's not 'I've got autism' or 'I've got depression'. Oftentimes it might be both.[68]

14.47 UNSW 3DN also noted that diagnostic overshadowing was more likely to occur in situations where autistic people 'struggle to identify or communicate their internal experiences of mental distress or physical discomfort to clinicians'.[69]

14.48 In addition, the University of Queensland and RMIT suggested that a lack of holistic care means that patterns or links between symptoms are frequently

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[64] Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 6].

[65] Professor Keith McVilly, Professor of Disability and Inclusion, School of Social and Political Sciences, University of Melbourne, *Proof Committee Hansard*, 12 February 2021, p. 27.

[66] A4, *Submission 54*, p. 10.

[67] Australian Autism Alliance, *Submission 52.2*, p. 4.

[68] Professor Keith McVilly, Professor of Disability and Inclusion, School of Social and Political Sciences, University of Melbourne, *Proof Committee Hansard*, 12 February 2021, p. 27.

[69] UNSW 3DN, *Submission 95*, p. 10.

missed by health professionals—a situation it argued is made worse by the push for GPs to discuss only one patient issue or problem per visit.[70]

14.49 In response, submitters such as OTARC and the Autism CRC advocated for better education for health care providers on the presentation and management of co-occurring conditions.[71] OTARC also called for training in the 'appropriate use of validated tools to identify and treat these conditions'.[72]

14.50 Similarly, the University of Queensland and RMIT proposed the introduction of mandatory minimum training requirements in relation to co-occurring conditions. They also suggested encouraging the use of 'a Medicare item or items allowing the discussion of multiple health problems in one consultation'.[73]

Autism-friendly health care environments

14.51 A number of stakeholders, including UNSW 3DN, observed that the delivery of health care services can be affected by 'core features of autism', including 'communication differences, sensory sensitivities and adaptive functioning difficulties'.[74] As St Vincent's explained:

> …noise, bright lights, lots of movement, being touched, and different smells can be incredibly aversive and precipitate severe distress and behavioural meltdowns. Social communication impairments can result in the person experiencing difficulty coping with new environments, changes in routine, and not knowing exactly what to expect. Difficulties with planning, sequencing, understanding complex instructions and processing information are also reported by many individuals.[75]

14.52 Accordingly, many stakeholders observed that the current lack of autism-friendly health care environments poses a significant challenge to effective care provision for autistic people.[76]

14.53 This was also reflected in the views of autistic patients. For example, an Autism Alliance survey found that almost 85 per cent of respondents experienced

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[70] Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 6].

[71] OTARC, *Submission 55*, p. 2; Autism CRC, *Submission 46*, p. 18.

[72] OTARC, *Submission 55*, p. 2.

[73] Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 7]. It was suggested that the current Medicare items that subsidise health assessments for people with intellectual disability could be extended to autistic people.

[74] UNSW 3DN, *Submission 95*, pp. 9–10.

[75] St Vincent's Health Australia, *Submission 72*, p. 5.

[76] See, for example, St Vincent's Health Australia, *Submission 72*, p. 5; Scope-University of Melbourne Partnership, *Submission 83*, p. 24; Coalition of Autistic Women, *Submission 125*, [p. 13]; Yellow Ladybugs, *Submission 49*, p. 28.

sensory barriers to accessing health services. These included sensitivities to bright lights, odours, touch, patterns and textures. Likewise, over 90 per cent reported that anxiety linked to health care environments was a challenge to accessing care, while 76.6 per cent reported that communication issues also created access challenges.[77] Similarly, the Commissioner for Children and Young People Western Australia cited anxiety, sensory overload, fear of crowds, and an inability to use public transport as deterrents to young autistic people seeking treatment on their own.[78]

14.54 Some stakeholders, such as the Marymead Autism Centre, noted that hospital settings are especially problematic and can be 'disorienting and difficult places for autistic people', particularly for those with sensory issues who can feel 'barraged by questions in a physical environment that can feel loud and distressing' due to electronic noises, fluorescent lights, and colours that can be overwhelming. This can be exacerbated by the way hospitals operate, time pressures on hospital staff, and significant variation in the knowledge, experience and willingness of hospital staff to make adjustments for autistic patients.[79] As one autistic individual told the Autism Alliance:

> The world is chaotic... it's hard to exist in when everything is louder, brighter, noisier and smellier. It would be nice for all health professionals to understand that the anxiety and sensory overwhelm is very real and, instead of trying to devalue the experience, provide support for it instead.[80]

14.55 Another submitter described the lack of accommodations made for her autistic son, who is mostly non-verbal:

> Hospitals and the accessing health care can be confronting for my son, doctors' visits and testing procedures need to be carefully planned for, as most places have no non-verbal or [augmentative and alternative communication] assisted capacity, nor the know how in any meaningful way to communicate with my son. We constantly need to remind staff at x-ray rooms and pathology, that our son needs alternatives and understanding, we are constantly sent to other specialists and special needs clinics, or we have to teach him tolerance, and provide step by step education for the procedure ourselves, along with the help and advice of his therapists, in order for my son to understand and sit through and cooperate in a simple dental x-ray, or have a blood test taken. This needs to be addressed, doctors' clinics, dentists and hospitals need to have policies and protocols in place to support autistic individuals, and alternative means of communication.[81]

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[77] Australian Autism Alliance, *Submission 52*, pp. 19 and 22.

[78] Commissioner for Children and Young People Western Australia, *Submission 42*, p. 4.

[79] Marymead Autism Centre, *Submission 128*, p. 11.

[80] Australian Autism Alliance, *Submission 52*, p. 22.

[81] Name withheld, *Submission 148*, p. 12.

14.56 According to Scope-UoM, not accommodating autistic people's needs can leave them unable to 'describe their symptoms, communicate pain, and/or have their symptoms validated and taken seriously'. In addition to affecting the quality of care autistic people receive, this can also result in higher costs (if symptoms and supports needs become acute) and can also contribute to disproportional mortality.[82] It can even prevent access to health care altogether, as observed in the following reports to Speech Pathology Australia from its members:

> A young man who cannot tolerate wearing clothing. His care staff asked the doctor's office to avoid a waiting room environment due to this, so time with clothing was minimised. This was not accommodated, which led to the young man undressing himself in the waiting room. He was then asked to leave and was unable to attend his neurology appointment.
>
> A man's family requested an appointment be conducted in the van outside as he becomes agitated in new environments and with new people (including demonstrating behaviours of concern that would have put members of the public at risk). This was refused and consequently, he has still not been able to see a neurologist.[83]

14.57 Even when autistic people can communicate their support requirements, stakeholders such as Marymead Autism Centre explained that a lack of autism understanding means this information is not always acted on.[84] For example, the Coalition of Autistic Women commented that when women try to self-advocate by describing their sensory needs, 'health care professionals frequently ridicule or dispute the diagnosis and refuse to consider accommodations'.[85]

14.58 Conversely, the Autism Alliance pointed to the significant gains that can be made when 'attentive and considered clinicians' make small changes. As one autistic person reported to the Autism Alliance:

> My local GP is brilliant. Appointments are made for late morning before they have their break or late in the afternoon. We usually have double appointments so I have time to answer questions and discuss health concerns. This is great for my children who I am teaching how to self-advocate in health care settings. Before we go into the room, he always has the blind open and the flickering fluoro lights that cause me pain are off.[86]

14.59 The contrast in results for health professionals who adjust their approaches, compared to those who do not, was also highlighted in a case study provided by autistic advocate, Ms Geraldine Robertson (see Box 14.2).

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[82] Scope-University of Melbourne Partnership, *Submission 83*, p. 24.

[83] Speech Pathology Australia, *Submission 87*, pp. 11–12.

[84] Marymead Autism Centre, *Submission 128*, p. 11.

[85] Coalition of Autistic Women, *Submission 125*, [p. 13].

[86] Australian Autism Alliance, *Submission 52*, p. 22.

Box 14.2 Case Study – 'L'

L. was admitted to a psychiatric ward. He was frequently restrained for not following instructions.

His autistic advocate explained to staff that he would follow instructions if they were provided in the format of 'reason' followed by 'instruction'.

The problem was that if L. did not want to follow the instruction immediately, his processing speed, which is often slow for autistics, did not enable him to make connections between instructions which could be negotiated and those which could not.

Giving the reason first, for example, 'Someone is upset and needs space. You need to go to your room immediately.' resulted in a rapid and appropriate response to staff members who listened to the advocate.

Those who continued to give instructions without reason, or followed by reason, continued to need to apply restraints.

Source: Ms Geraldine Robertson, Submission 165, [p. 3].

14.60 Multiple submitters argued that health care settings must improve accessibility for autistic people. Suggested actions included:

- introducing autism-friendly universal design principles across major health infrastructure, including quiet, low-sensory emergency departments, waiting and treatment rooms in public hospitals;[87]
- implementing longer consultation times and reduced wait times for autistic people (expedited triage of care);[88]
- giving patients the option to make appointments online, and providing training for health professionals on how to adjust their communication to meet the needs of their autistic patients;[89]
- encouraging broader uptake of existing initiatives to reduce communication barriers, such as the care passports and communication boards used in the Frankston Hospital emergency department (see Box 14.3);[90]
- adapting measures that are in place to improve health care responsiveness for other cohorts (for example, actions to address cultural needs include alternative signage and modified clinic times and locations);[91]

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[87] Australian Autism Alliance, *Submission 52*, p. 4.

[88] OTARC, *Submission 55*, p. 2.

[89] Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 7].

[90] Australian Autism Alliance, *Submission 52*, p. 23.

[91] Australian Autism Alliance, *Submission 52*, p. 23.

- adapting autism-specific initiatives from other sectors for use in health care settings (for example, Coles 'quiet hour');[92] and
- funding further research into how to improve the accessibility of health care services for autistic people.[93]

Box 14.3 Frankston Hospital – adjustments for autistic patients

In 2017, the Frankston Hospital emergency department introduced care passports and communication boards to help improve the care provided to autistic patients. These initiatives were based on a paper written by emergency department nurse and mother of two autistic children, Antje Walter, as well as suggestions generated by consumer feedback.

Care passports can be completed by autistic individuals or their carers when they attend the emergency department and are used to identify additional social needs, sensory needs, communication needs and behavioural needs. This can include information about whether an autistic patient is verbal or non-verbal, whether they are sensitive to noise, lights, touch or pain, and whether there are particular factors that can trigger behavioural challenges.

The hospital's communication boards are based on the exchange communication system and are developed using Boardmaker software. One board is used to help autistic patients communicate their needs—for example, pointing to the site of pain without having to communicate verbally. A second board is used to communicate the emergency department assessment process to autistic patients.

Source: Peninsula Health, The Emergency Department Nurse and Mum making a trip to hospital less stressful for kids with autism, 28 September 2017, www.peninsulahealth.org.au/2017/09/28/emergency-department-nurse-mum-making-trip-hospital-less-stressful-kids-autism/ *(accessed 8 December 2021).*

Restrictive practices

14.61 At its most extreme, a lack of autism knowledge and a failure to provide autism-appropriate supports and adjustments in health care settings, can contribute to the use of restrictive practices to manage complex behaviour. As described by the NSW Government, restrictive practices include:

- prescription of psychotropic medications to manage behaviours of concern;
- restricting a person's access to environments or objects;
- the use of restraint devices or physical restraint; and
- seclusion.[94]

14.62 According to the NSW Government, the use of restrictive practices is exacerbated by the difficulties service providers have in 'accessing registered

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[92] UNSW 3DN, *Submission 95*, p. 11.

[93] UNSW 3DN, *Submission 95*, p. 11.

[94] New South Wales Government, *Submission 65*, p. 8.

behaviour support practitioners to provide strategies for the positive and proactive management of challenging behaviour'.[95] A shortage of trained behaviour support therapists appeared to be a common theme among stakeholders, with a Victorian-based submitter describing a situation where a positive behaviour specialist was flown from Sydney to Melbourne 'on a regular basis to provide behaviour supports'.[96]

14.63 While concerns about restrictive practices were raised most frequently in relation to school education (see Chapter 12), a number of stakeholders also identified concerns in relation to their use in health care settings.[97]

14.64 The use of restrictive practices in hospitals was identified as a particular concern. For example, Monash University submitted that acute care staff are not adequately trained in managing the needs of autistic children, including managing behaviours such as aggression. As a result, 'they lack confidence in preventing and managing externalising behaviours, including those that place the child, family or staff at risk'.[98]

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[95] New South Wales Government, *Submission 65*, p. 8.

[96] Name withheld, *Submission 126*, p. 16.

[97] See, for example, Office of the Public Advocate Victoria, *Submission 80*, p. 11; A4, *Submission 54, Attachment 1*, p. 23; Speech Pathology Australia, *Submission 87*, p. 11; Name withheld, *Submission 126*, p. 22.

[98] Monash University, *Submission 94*, pp. 26. Monash University notes that a child's behaviours in a hospital setting may be primary (that is, present in all settings), or secondary (due to the changes and nature of the hospital setting). Either way, Monash University suggested that hospital-based staff should be trained to prevent behaviours that place the child, family or staff at risk and to ameliorate when they occur.

14.65 Other stakeholders, such as the OPA Victoria, also pointed to an overreliance—at least in Victoria—on the common law doctrine of necessity. As illustrated by Oliver's story (see Box 14.4), this may be related to a lack of skilled support for autistic people with complex needs.[99]

Box 14.4 Office of the Public Advocate Victoria: case study (Oliver)

Oliver—a young, non-verbal autistic man with an intellectual disability—was admitted to hospital for treatment of significant physical injuries sustained in an accident. The OPA Victoria became involved with Oliver as a guardian and advocate after Community Visitors found Oliver naked and restrained to a bed by four-point shackles.

OPA Victoria discovered that restrictive practices had been used on Oliver for many months and that he was subject to three restraint mechanisms: psychotropic medication to quieten him, shackles to physically restrain his movements, and containment to prevent him from leaving the unit.

As a result, Oliver's level of agitation steadily increased, with behaviours related to rectal digging, taking off his clothes and wanting to be naked, defecating on the floor, and at times being very physically agitated.

Initially, Oliver was unable to comply with medical advice so there was a clinical need for physical restraints to enable his injuries to heal. Once healed, the treating team continued with these measures because of concerns for staff safety.

After some months, the Department of Health and Human Services agreed to fund behaviour specialists to work with Oliver while in hospital. These specialists worked with Oliver for up to 12 hours a day, during which time it was possible to remove the shackles to reduce his agitation. While nursing staff were invited to remain in the room to learn engagement strategies, they instead observed from outside the room.

Similarly, Oliver's family found the hospital reluctant to let them educate staff on how to support their son. Further, the hospital would not allow Oliver's family to take him into the hospital grounds with a wheelchair. When the disability workers or his parents were unavailable, Oliver remained under restraint for the entire day.

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[99] Office of the Public Advocate Victoria, *Submission 80*, pp. 11–12. The common law doctrine of necessity can justify an action when (a) there is a necessity to act when it is not practicable to communicate with the assisted person, and (b) the action taken is such as a reasonable person would in all the circumstances take acting in the best interest of the assisted person. However, the doctrine is uncertain in terms of the period of time for which it can apply without oversight or review. It is also unclear whether it applies to actions that are necessary for the benefit of others, such as hospital staff. Office of the Public Advocate guardians work with people with cognitive impairment who are subject to restrictive practices in hospitals on an ongoing basis where the justification for the practices is the safety of staff. However, health practitioners have no obligation to report the circumstances in which they use restrictive practices or for how long. The lack of formal legal authority is one part of the problem. In many cases, it is unclear whether such deprivations of liberty are substantively necessary or justifiable.

Oliver was also not provided physiotherapy or occupational therapy because staff were too scared to interact with him unless he was shackled.

Source: Office of the Public Advocate Victoria, Submission 80, pp. 11-12.

14.66 In light of these concerns, stakeholders such as the OPA Victoria advocated for training to upskill health care staff in the management of complex behaviour, including the lawful use of restrictive practices and compliance with relevant human rights legislation.[100] As an example, Monash University drew attention to a 'high-fidelity simulation training program' it has developed for hospital staff to support management of challenging behaviour. The program includes web-based learning for working with children with autism, as well as a simulation-based group education session.[101]

14.67 Other stakeholders called for a 'nationally consistent framework for eliminating restrictive practices, across all service settings, including health and mental health'.[102] Similarly, the OPA Victoria proposed that all Australian health ministers develop 'a legislated safeguarding framework to oversee the use of restrictive practices by health practitioners in hospital settings'.[103]

14.68 To this end, the NSW Government indicated that it is 'working towards the elimination of restrictive practices' including by 'promoting alternative evidence-based practices, improving access to behaviour supports and developing frameworks that limit the use of restrictive practices unless no other alternative exists'.[104]

14.69 The Department of Social Services, Department of Education, Skills and Employment and the Department of Health (the departments) also highlighted the existence of the NDIS (Restrictive Practices and Behaviour Support) Rules 2018 (the Rules). While relevant to NDIS providers only, the Rules establish the conditions applying to behaviour support services and restrictive practices, 'including the requirement to develop a behaviour support plan and report the use of restrictive practices to the NDIS Commission'. The departments also

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[100] Office of the Public Advocate Victoria, *Submission 80*, p. 4.

[101] Monash University, *Submission 94*, pp. 26–27. According to Monash University, staff found the program to be an acceptable mode of training which they would recommend to colleagues. Preliminary data analysis of the simulation training program involving adolescents with autism suggests that it is acceptable and increases confidence levels in managing aggression and complex behaviours.

[102] Name withheld, *Submission 126*, p. 22.

[103] Office of the Public Advocate Victoria, *Submission 80*, p. 4.

[104] New South Wales Government, *Submission 65*, p. 8.

noted that the aim of the NDIS Commission behaviour support function is to reduce and ultimately eliminate the use of restrictive practices.[105]

Maternal health care

14.70 Various stakeholders cited maternal health care as a particular challenge for autistic women.[106] For example, the Autism Alliance claimed that the difficulties autistic people experience when accessing healthcare 'coalesce for many women during pregnancy, childbirth and postnatally'.[107]

14.71 As noted by submitters such as A4 and the Autism Alliance, research has found that:

- 40 per cent of autistic women experience prenatal depression and 60 per cent of autistic women experience postnatal depression (compared with 12 per cent in the general population);
- 34 per cent of autistic women said the process of birth was not explained well to them;
- 64 per cent of autistic women have difficulties breastfeeding their first child and 51 per cent have difficulties breastfeeding their second child;
- 61 per cent of autistic mothers said they needed additional support from service providers but only 14 per cent received the required support when they asked for it;
- 60 per cent of mothers experienced anxiety speaking to professionals, with 44 per cent experiencing selective mutism due to their anxiety; and
- 80 per cent of autistic mothers worried that the attitude of professionals would change towards them after disclosure of their autism.[108]

14.72 These findings were reflected in evidence from Yellow Ladybugs, which also reported that autistic women were 'more likely to find motherhood an isolating experience, to worry about others judging their parenting, or feel unable to turn to others for support in parenting'.[109]

14.73 As with general health services, unaccommodating environments and a lack of autism understanding were commonly cited barriers to effective maternal health care. For example, the Autism Alliance described the 'triggers and stressors' that may be present in mainstream health settings:

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[105] Department of Social Services, Department of Education, Skills and Employment and the Department of Health, *Submission 53*, p. 24.

[106] See, for example, Australian Autism Alliance, *Submission 52*, p. 20; A4, *Submission 54*, p. 15; Yellow Ladybugs, *Submission 49*, p. 5.

[107] Australian Autism Alliance, *Submission 52*, p. 20.

[108] A4, *Submission 54*, p. 15. See also, Australian Autism Alliance, *Submission 52*, p. 21.

[109] Yellow Ladybugs, *Submission 49*, p. 5.

> …bright lights and loud, busy birthing suites can be overwhelming sensory experience; inattention to appropriate communication; different understandings of consent to touch and a broad lack of understanding about how an autistic mother might be processing an already stressful situation can cause pain and suffering and can severely limit access to mainstream medical facilities.[110]

14.74 Similarly, the Coalition of Autistic Women explained that sensory issues can affect the way autistic women experience sensory information. This can include being less sensitive to pain:

> …some women have reported that their progression through childbirth was at the later stages of completion before being given assistance as they outwardly did not present in a way maternity staff could relate to.[111]

14.75 In response, stakeholders proposed a range of actions that could be adopted to improve maternal health care. These included:

- better training for health care professionals, including lactation consultants;[112]
- autism-specific tools and processes to screen for and identify pre- and post-natal depression in autistic mothers;[113] and
- targeted support to combat mental health distress.[114]

Mental health

14.76 Multiple stakeholders observed that while autistic people are more likely to experience poorer mental health than the general population, they often struggle to access appropriate mental health care tailored to their needs.[115] For instance, St Vincent's noted consistent reports by individuals and families about 'difficulty accessing mental health services across the entire continuum of care, including primary health, mainstream mental health, emergency and crisis support, and specialist services'. St Vincent's also pointed to the results of a 2013 study by Autism Spectrum Australia (Aspect) which found that only half of autistic adults were receiving help for their mental health conditions.[116]

14.77 A more recent Autism Alliance survey produced similar results. For example, while 75.2 per cent of respondents had a diagnosed mental illness and 69.7 per

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[110] Australian Autism Alliance, *Submission 52*, pp. 20–21.

[111] Coalition of Autistic Women, *Submission 125*, [p. 13].

[112] Australian Autism Alliance, *Submission 52*, p. 21. See also, A4, *Submission 54*, p. 15; Yellow Ladybugs, *Submission 49*, p. 5.

[113] Australian Autism Alliance, *Submission 52*, p. 4. See also, A4, *Submission 54*, p. 15.

[114] Yellow Ladybugs, *Submission 49*, p. 5; A4, *Submission 54*, p. 15.

[115] See, for example, St Vincent's Health, *Submission 72*, p. 9; The Royal Australasian College of Physicians, *Submission 29*, p. 8; ND Australia, *Submission 87*, [p. 3]; OTARC, *Submission 55*, p. 15.

[116] St Vincent's Health, *Submission 72*, pp. 4–5.

cent had seen a mental health practitioner in the previous 12 months, only 57.3 per cent had been about to get appropriate support. A further 29.1 per cent had been unable to get appropriate support, while 3.6 per cent of respondents had not tried to get support. In terms of 'usefulness' in addressing mental health needs, survey respondents reported similar results for GPs, psychologists and psychiatrists (see Table 14.1).[117]

Table 14.1 Autistic adults views on the usefulness of practitioners in addressing mental health needs

Rating	GP (per cent)	Psychologist (per cent)	Psychiatrist (per cent)
Very useful	52.5	62.9	54.8
Somewhat useful	44.1	35.9	37.8
Not at all useful	3.1	4.2	6.9
Unsure	0.3	0	0.5

Source: Australian Autism Alliance, Submission 52.2, p. 18.

14.78 According to the Autism Alliance, this reflects the 'dual burden' of health and mental health professionals who are not well-equipped to work with autistic people, as well as limits on publicly-funded mental health care.[118] This appears to align with the more commonly mentioned challenges to accessing appropriate mental health care, which include:

- the cost of mental health treatment;
- a lack of autism knowledge and understanding; and
- disconnected service systems.

The cost of mental health treatment

14.79 Currently, the Better Access initiative provides Medicare benefits for mental health services provided by GPs, other medical practitioners, psychologists, social workers and occupational therapists. Eligible patients can receive up to ten individual and ten group allied mental health services per calendar year.[119]

14.80 However, the Autism Alliance noted that high rates of co-occurring mental health conditions means that autistic people and their families are left with 'the impossible choice between rationing appointments to spread access across the

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[117] Australian Autism Alliance, *Submission 52.3*, pp. 15, 17 and 18.

[118] Australian Autism Alliance, *Submission 52*, p. 24.

[119] Department of Health, *Better Access initiative*, 7 December 2021, www.health.gov.au/initiatives-and-programs/better-access-initiative (accessed 8 December 2021).

year or facing ruinous out-of-pocket costs to maintain care'.[120] Indeed, according to an Autism Alliance survey, 78 per cent of autistic adults reported that cost was the reason they had not received support for their mental health condition, while more than 46 per cent said they lacked the funding to access mental health services.[121]

14.81 While the Autism Alliance noted that this issue was not limited to the autistic community, it argued that the 'cost burden is disproportionately felt given their high rates of mental ill-health and low rates of employment and workforce participation'.[122] UNSW 3DN expressed a similar view and argued that the current structure of the MBS 'does not enable general practitioners and psychiatrists to support the health needs of people on the autism spectrum with more complex health needs'.[123]

14.82 As a result, the Autism Alliance supported the recommendations made by the Mental Health Reference Group as part of the Medicare Benefits Schedule (MBS) Review. These recommendations included extending the Better Access initiative for at-risk patients, increasing the maximum number of sessions per GP referral, introducing a tiered system for patients with a diagnosed mental illness (with more sessions available to those with higher needs), and enabling families and carers to access therapy.[124] However, most of these recommendations were not endorsed by the MBS Review Taskforce for Government consideration.[125]

14.83 Similarly, UNSW 3DN recommended that MBS item numbers be reviewed to ensure 'financial viability for health care providers working to meet the needs of people with complex needs, including people with autism and co-occurring health and mental health issues'.[126]

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[120] Australian Autism Alliance, *Submission 52*, p. 26.

[121] Australian Autism Alliance, *Submission 52*, p. 25.

[122] Australian Autism Alliance, *Submission 52*, p. 25.

[123] UNSW 3DN, *Submission 95*, p. 16.

[124] Australian Autism Alliance, *Submission 52*, p. 26.

[125] Medicare Benefits Schedule Review Taskforce, *Report on Primary Care*, June 2020, pp. 146, 149, 152 and 158. The objective of the recommendation for a tiered support system was supported but the Taskforce suggested that the proposed model of care would be better placed outside the MBS. The recommendation for family and carer access to therapy was endorsed with amendment. The Taskforce did endorse recommendations to 'reduce the minimum number of participants in groups sessions' and to 'establish a new working group or committee to review access to, and rebates for, Better Access sessions delivered by different professional groups'.

[126] UNSW 3DN, *Submission 95*, p. 16.

Autism knowledge and understanding

14.84 As noted by Aspect, 'it is critical that individuals on the autism spectrum are able to access mental health services with staff who have an understanding of autism'.[127]

14.85 However, mental health care services for autistic people are currently compromised by a lack of autism knowledge and understanding among the mental health care workforce.[128] For example, according to the results of an Autism Alliance survey, of those autistic adults who had seen a mental health practitioner in the preceding 12 months, only 55.4 per cent rated the autism knowledge and understanding of their mental health practitioner as good, while 28.4 per cent rated as okay and 14.4 per cent rated it as poor. In addition, 68.8 per cent of autistic adults said that it was 'difficult to find a mental health practitioner who understands autism; and difficult to find a mental health practitioner who understands their specific situation'.[129]

14.86 As with general health services, this lack of knowledge is likely to contribute to diagnostic overshadowing. For example, the NSW Government recognised that mental illness can be difficult for clinicians to identify, with 'diagnostic uncertainty and overshadowing' creating barriers to mental health care.[130]

14.87 A lack of knowledge and diagnostic overshadowing can also feed the misconception that mental ill health is an intrinsic characteristic of autism. For example, the University of Queensland and RMIT commented that 'health professionals incorrectly consider mental health issues an inherent part of autism, when in fact much mental illness in autism is a consequence of an absence of understanding and acceptance'.[131] A similar view was expressed by a psychologist whose autistic son who took his own life in July 2020:

> I am a psychologist and I believe have been ignorant as are many medical and allied health practitioners. For example, it does not necessarily follow that autistic people get depressed because they are autistic. There are higher correlations, certainly, but perhaps we accept it as inevitable rather than unusual or urgent. We accept it too easily. Many of us just think that it goes with the territory. This stops us from asking more questions and delving deeper into whether it is an endogenous (brain based) depression or a reactive one (the circumstances of your life are tough). This is vital. When an endogenous depression is met with a lot of behavioural intervention,

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[127] Autism Spectrum Australia (Aspect), *Submission 64*, p. 13.

[128] See, for example, Australian Autism Alliance, *Submission 52*, p. 19; Name withheld, *Submission 119*, p. 7.

[129] Australian Autism Alliance, *Submission 52.2*, pp. 15 and 16; Australian Autism Alliance, *Submission 52*, p. 25.

[130] New South Wales Government, *Submission 65*, p. 8.

[131] Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University, *Submission 51*, [p. 6].

> encouragement and well meaning pep talks, the sufferer may feel even more hopeless.[132]

14.88 According to OTARC, this situation may be exacerbated by a lack of appropriate diagnostic tools—given that the current tools for diagnosing mental health conditions are designed for non-autistic people. The use of existing tools may be problematic because autistic individuals can experience symptoms differently or they might understand or answer questions in an unfamiliar way. Also, clinicians may misinterpret symptoms of autism as features of a different clinical condition, or may overlook co-occurring conditions, assuming they are part of autism.[133]

14.89 In some cases, an autism diagnosis has repeatedly resulted in autistic people being excluded from mental health services, including Headspace and Orygen Youth Mental Health (Orygen).[134]

14.90 The apparent inability of mental health services to address the needs of autistic people with co-occurring mental health conditions is particularly concerning given autistic people's vulnerability to suicide. One mother recalled her distress at hearing the head of Orygen on radio encouraging early detection of mental health issues to prevent suicide, given that a few days earlier Orygen had determined that they couldn't help her son as his was a 'disability' issue, not a 'mental health' issue. As she explained:

> I'm not sure how receiving text messages from your 18 year old son threatening to kill himself, drink poison, or throw himself under a truck can be classed as 'disability' more than 'mental health'.
>
> I'm not sure how the need … for the CAT team to take my then 15 year old son to the hospital after threats of suicide and harm to others can be classed as 'disability' more than 'mental health'?
>
> But I can tell you that this is our experience, and that this is also the experience of others—just like in education and in housing and in employment, there doesn't seem to be a 'place' for autistic people who are also experiencing mental health issues.[135]

14.91 As noted by St Vincent's, this can be a particular issue for autistic people with highly complex needs, who 'are not identified as eligible for a mainstream mental health service as they do not meet the diagnostic criteria'. In some cases, their severe behaviours (that may or may not be related to mental health problems) can leave them without appropriate accommodation options and

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[132] Name withheld, *Submission 150*, [p. 1].

[133] OTARC, *Submission 55*, p. 15.

[134] See, for example, ND Australia, *Submission 97*, [p. 3]; Name withheld, *Submission 11*, [p. 13].

[135] Name withheld, *Submission 11*, p. 13.

they are placed in mental health units or medical wards under the care of clinicians who often have 'little or no understanding' of autism.[136]

14.92 According to OTARC, the issue is twofold. Firstly, mental health professionals feel unqualified to work with autistic people and, secondly, autism specialists are not well-trained in mental health treatment.[137] A similar view was expressed by the Autism Alliance which noted that mental health professionals experienced a lack of autism training, as well as a lack of accessible information and guidance for supporting autistic people with mental health conditions.[138]

14.93 More than one submitter highlighted the need to build the skills of mental health practitioners to better support people with autism. For example, Different Journeys reported that an audit of Orygen clinicians' knowledge and confidence showed that they found the care of autistic individuals with co-occurring psychiatric conditions to be 'challenging'. In addition, they reported 'low confidence in providing interventions, and perceived less progress during episodes of care than when working with neurotypical young people'.[139]

14.94 Similarly, St Vincent's pointed to analysis of referrals to the Victorian Dual Disability Service that showed that mental health services have 'considerable difficulty' differentiating between disorders. It argued that significant expertise would be required to provide autistic people with an acceptable standard of care:

> Difficulties with communication, atypical presentation of mental health problems, challenges with assessment and diagnosis, and the need for a modified approach to treatment and management means that significant reasonable adjustments to practice, a high level of psychiatric expertise, and a good understanding of autism by clinicians is needed to provide this vulnerable population with the same standard of health care as afforded to the general population.[140]

14.95 According to the Autism Alliance, the need to upskill health providers has also been recognised internationally. For example, clinical guidelines in the United Kingdom contain:

- recommendations regarding the necessary knowledge and understanding of autism for relevant staff supporting autistic people;
- considerations regarding advice that should be sought; and
- possible adaptations to behavioural and clinical interventions.[141]

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[136] St Vincent's Health, *Submission 72*, p. 6.

[137] OTARC, *Submission 55*, p. 15.

[138] Australian Autism Alliance, *Submission 52*, p. 24.

[139] Different Journeys, *Submission 30*, p. 2.

[140] St Vincent's Health, *Submission 72*, p. 4.

[141] Australian Autism Alliance, *Submission 52*, p. 25.

14.96 As a result, a number of submitters advocated for more training for mental health practitioners. The Autism Alliance proposed mandatory, quality-controlled 'training in autism for all public and private mental health services'.[142] Similarly, Aspect recommended autism training for 'frontline workers in mental health',[143] while the OPA Victoria suggested that mental health practitioners 'undertake professional education about Autism Spectrum Disorder and its interaction with mental illnesses, especially anxiety and depression'.[144] Likewise, St Vincent's recommended including autism content in relevant undergraduate training courses, upskilling current clinicians and introducing mandatory training in autism and mental health for all frontline mental health staff.[145]

14.97 The Autism Alliance also suggested introducing an accreditation scheme to make it easier for autistic people to identify 'mental health practitioners with proficiency in autism'.[146]

14.98 To this end, the NSW Government highlighted work underway to improve mental health care for people with disability, including people with autism. This includes development and implementation of *The Guide: Accessible Mental health Services for People with an Intellectual Disability* and the *Intellectual Disability Mental Health Core Competency Framework* and Toolkit for Mental Health Professionals. These tools are designed to support the development of skills and resources in the mental health system to better meet the needs of people with intellectual disability and cognitive impairment.[147]

Disconnected service systems

14.99 As noted by St Vincent's, it is often impossible to differentiate between mental illness and developmental disability, meaning that they 'require a coordinated collaborative approach between services'.[148]

14.100 Despite this, the committee heard that a disconnected service environment continues to perpetuate poor service provision for autistic people with mental health conditions. For example, St Vincent's suggested that 'limited collaboration' between the NDIS, public mental health services, primary health,

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[142] Australian Autism Alliance, *Submission 52*, p. 25.

[143] Aspect, *Submission 64*, p. 13.

[144] Office of the Public Advocate Victoria, *Submission 80*, p. 4.

[145] St Vincent's Health, *Submission 72*, p. 6.

[146] Australian Autism Alliance, *Submission 52*, p. 25.

[147] NSW Government, *Submission 65*, p. 8. NSW Health has worked closely with Professor Julian Trollor, Chair of Intellectual Disability Mental Health and UNSW 3DN to develop and implement the guide, framework and toolkit.

[148] St Vincent's Health, *Submission 72*, p. 5.

and private providers leads to inadequate support or considerably delayed services.[149] This situation was summed up by Different Journeys:

> Anxiety is a mental health condition … that is intertwined with autism, yet no expert in the world has been able to identify how to separate autism from the anxiety. Nor can the individual separate their autism from their mental health condition ... However, it appears services can—the disability sector generally identifies the autism but not the mental health … stating it is a medical issue, and the mental health professionals advise it is too complex and often do not assist. The … NDIS contributes to this argument, often advising mental health is medical and therefore they are not funded by the NDIS. However, community mental health services will not assist the person as they are in receipt of NDIS. Often the community mental health provider does not understand that the individual has not been funded for psychosocial disability or will refuse access due to their belief that autism and mental health conditions are too complex, without any consideration for the autistic individual or their families.[150]

14.101 This situation was also observed by Aspect which agreed that some autistic people have been declined mental health services 'if they are also accessing NDIS funded supports (even though the presenting issue is a mental health issue)'.[151] At least one submitter also noted the 'extraordinary' pressure that this disconnected service environment places on parents and carers.[152]

14.102 According to St Vincent's, this situation is also compounded by the limited and fragmented specialist services that are available.[153] A similar view was expressed by another submitter:

> …there seem to be very few crossover areas and specialists that can work with both conditions at the same time. This may be due to the fact that there hasn't been enough research done in this area. It may be because there are not enough specialists available. Certainly it is because there is a disconnect between the sectors of mental health and disability, and this must be rectified.[154]

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[149] St Vincent's Health, *Submission 72*, p. 5.

[150] Different Journeys, *Submission 30*, pp. 17–18.

[151] Aspect, *Submission 64*, p. 11.

[152] Name withheld, *Submission 11*, [p. 14].

[153] St Vincent's Health, *Submission 72*, p. 5.

[154] Name withheld, *Submission 11*, [p. 14].

14.103 As a result, ND Australia recommended 'funding relevant pathways for mental health services, as well as appropriate education and training for professionals, so these vulnerable people are not turned away and are able to access the help they need'.[155]

14.104 St Vincent's—which runs the Victorian Dual Disability Service (see Box 14.5)—proposed introducing state-wide services for autism and mental health that could provide 'specialised assessment, treatment planning, and interdisciplinary interventions for those with multiple complex needs, or in situations where there is controversy over diagnosis or management'.[156]

14.105 To this end, the NSW Government indicated that it has invested $4.4 million over four years for people living with an intellectual disability who need treatment for mental illness. This funding provides access to a specialist service, where people can be assessed and supported by clinicians who are experienced in the care of people with both conditions.[157]

Box 14.5 Victorian Dual Disability Service

The Victorian Dual Disability Service (VDDS), located at St Vincent's Hospital Melbourne, is a specialist state-wide mental health service for people with neurodevelopmental disabilities (including autism) aged 16 years of age and over.

The VDDS works with mental health services and the NDIS across Victoria to provide assessment and consultation in relation to developmental disability mental health. The VDDS also provides education and training for mental health clinicians and disability sector workers. The VDDS vision is that people with developmental disabilities should have access to the best possible mental health care and the service works with consumers, families, carers, and service providers to help individuals achieve the highest attainable standard of mental health and wellbeing.

A review of individuals referred to the VDDS over 2015–2019 found that autistic people comprised 23 per cent of those referred to the service and that this population had significant multiple complex needs—including high rates of concurrent mental and behavioural disorders—but that they experienced difficulty accessing appropriate mental health services.

Source: St Vincent's Health Australia, Submission 72, p. 2.

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[155] ND Australia, *Submission 97*, [p. 3].

[156] St Vincent's Health, *Submission 72*, p. 6.

[157] NSW Government, *Submission 65*, p. 7.

Committee view

14.106 Autistic Australians have a life expectancy more than 20 years shorter than the general population. Unbelievably, there appears to be very little acknowledgement of this outside the autism community and no dedicated plan to improve autistic people's health outcomes. As some stakeholders suggested, this situation simply would not be tolerated for any other group in society.

14.107 As with other sectors, health services are not well prepared to meet the needs of autistic people. The committee notes that the need to increase the capability of providers to meet the needs of people with disability is an identified policy priority under *Australia's Disability Strategy 2021–2031*.[158]

14.108 The current lack of capability in relation to autistic patients appears to be driven largely by poor autism understanding, which results in diagnostic overshadowing and inappropriate treatment approaches, as well as a scarcity of autism-friendly health care environments. There also appears to be a lack of data and evidence that could help monitor and improve outcomes. This includes:

- a lack of routine analysis and reporting of population health outcomes, including health status, service utilisation, and mortality data;
- insufficient understanding of the risk factors, causes and presentation of co-occurring conditions, including intellectual disability and mental health conditions;
- a lack of evaluation of clinical interventions; and
- a lack of understanding of autistic people's experiences and interactions with the health system.

14.109 While the committee heard accounts of individual practitioners who provided autism-friendly health care, there were also numerous accounts of autistic people suffering unnecessarily due to treatment approaches or care settings that were not adjusted to meet their needs. In some cases, this reflected a lack of knowledge about the specific needs of autistic patients. However, the committee was also disturbed to hear that some providers are actively ignoring, refusing or ridiculing patient requests for adjustments.

14.110 A lack of knowledge also leads to diagnostic overshadowing, meaning that autistic people deal with unrecognised and untreated medical conditions because clinicians do not know any better, or because these cases are simply too complex. This is a particular issue for co-occurring mental health conditions. The committee heard devastating accounts of autistic people being turned away by both disability and health services because they did not feel equipped to deal with both autism and mental health issues. Even more concerningly, autistic people are being released from psychiatric care with no plan for ongoing support. While this is a problem that affects the mental health sector more

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[158] Department of Social Services, *Australia's Disability Strategy 2021–2031*, p. 26.

broadly, it is particularly concerning for autistic people who may lack the ability to understand what is happening and to care for their own health.

14.111 Accordingly, the committee believes there is a need for better training about autism, beginning in undergraduate courses and extending through to ongoing professional development for health professionals. This is particularly relevant for mental health service providers and all frontline staff, including paramedics and hospital emergency department staff.

14.112 However, training alone is not sufficient, particularly in hospital settings which have been described as especially challenging for autistic people. To this end, there is a need for state and territory governments to support hospitals and public health care settings to improve the experience of autistic people in their care. This could include guidance about reasonable adjustments or the use of autism liaison officers to facilitate treatment in a range of health care settings.

14.113 Given the complexity of the health care system and the breadth of issues identified over the course of this inquiry, the committee believes there is a need for a national roadmap to improve health services for autistic people. This could be modelled on the *National Roadmap for Improving Health Services for People with Intellectual Disability*. This roadmap should also be accompanied by an associated National Autism Mental Health Plan aimed specifically at improving the treatment of autistic people with co-occurring mental health conditions.

14.114 At the same time, there is a need to make sure that the needs of autistic people are explicitly addressed in all national health and mental health plans.

Recommendation 61

14.115 The committee recommends that the Department of Health work with the taskforce established to develop the National Autism Strategy to develop a National Roadmap for Improving Health Services for Autistic People, similar to the *National Roadmap for Improving Health Services for People with Intellectual Disability*. This roadmap should include, but not be limited to, actions that address:

- **best practice models of care for autistic people, including mental health care;**
- **the alignment of Medicare Benefit Schedule items with best practice models of care for autistic people;**
- **reasonable adjustments for autistic people in health care settings;**
- **the availability and appropriateness of tools and resources to support diagnosis of comorbidities (including mental health conditions) and the provision of reasonable adjustments for autistic people in health care settings;**

- **better connections between health care service sectors, including mental health services, disability services and the National Disability Insurance Scheme;**
- **the elimination of restrictive practices in health care settings; and**
- **improved autism education and training for health professionals.**

Recommendation 62

14.116 The committee recommends that the new National Roadmap for Improving Health Services for Autistic People include an associated National Autism Mental Health Plan aimed specifically at improving the treatment of autistic people with co-occurring mental health conditions. This Plan should also align with the National Mental Health and Suicide Plan.

Recommendation 63

14.117 The committee recommends the Australian Government work with state and territory governments and relevant stakeholders to encourage hospitals and public health care settings to adopt measures to improve the experience of autistic people in their care. This may include measures such as providing guidance about reasonable adjustments or employing autism liaison officers to facilitate health care services for autistic people.

Recommendation 64

14.118 The committee recommends that the health and wellbeing priority under the new National Autism Research Framework include a focus on:

- **routine analysis and reporting of population health data for autistic people, including health status, health service utilisation, health outcomes and mortality data;**
- **the risk factors, causes and presentation of comorbidities; and**
- **evaluation of health and mental health interventions for autistic people.**

14.119 While the NDIS has been beneficial for many autistic people, the committee recognises that it has added another layer of complexity in terms of service access. The committee heard that parents and carers are not interested in who provides the service or which system funds it—they simply want a 'one-stop-shop' where they can go to access support. The committee supports calls for the implementation of integrated models of care for autistic people, as well as clearer clinical pathways to help autistic people navigate the mainstream health services.

14.120 Encouragingly, the committee heard that some states are piloting specialised services for autistic people that provide a one-stop-shop approach. However, there is a concern these are focused on people in crisis or who have experienced a failure in the system. These should be more widely available and available earlier.

14.121 In addition, the committee notes that the *Disability Discrimination Act 1992* requires information to be provided in a non-discriminatory, accessible manner. However, a lack of understanding means this does not always happen for autistic people. It is hard to believe that autistic people—who often have cognitive, communication and adaptive functioning challenges—are required to navigate the health care system without adaptions to the content or form of available information. The committee suggests that this could be remedied by the provision the development of a national standard for information accessibility which could help service providers more easily adapt information for autistic individuals.

Recommendation 65

14.122 The committee recommends that the Australian Government work with state and territory governments and relevant stakeholders to develop and widely promote clinical care pathways to help autistic people navigate the health care system, including mental health services.

Recommendation 66

14.123 The committee recommends that the Australian Government work with state and territory governments and relevant stakeholders to implement specialised care models targeted to meet the needs of autistic people, including mental health care needs. These models should offer tiered services and supports that are available to autistic people and their families throughout their health care journey, with a particular focus on mental health services and on preventing individuals and families from falling through the cracks between systems or reaching a crisis point.

Recommendation 67

14.124 The committee recommends that a national standard for information accessibility be developed under the auspices of the National Autism Strategy. This standard should align with existing accessibility standards but should also be tailored to meeting the needs of autistic people.

Chapter 15
Housing

15.1 This chapter describes the experiences of autistic people in relation to housing. This includes discussion of current housing outcomes, the availability of affordable and appropriate housing stock, as well as the difficulties autistic people encounter when trying to access public housing or the private rental market.

Overview

15.2 According to the Australian Institute of Health and Welfare, housing provides the shelter, safety and security that are critical to the health and wellbeing of people with disability. Affordable and appropriate accommodation helps people 'participate in the social, economic and community aspects of everyday life'.[1]

15.3 The range of accommodation options for autistic people reflects the breadth of need across the spectrum. For example, some autistic people live independently in their own home (with or without support), while others live with family, or with friends in a group care arrangement. Other accommodation options include supported living arrangements that can be either shared or independent.[2]

15.4 Accommodation and housing support for autistic people can be accessed privately (including owning or renting), through social housing, or via disability service providers. The cost of accommodation and housing support can be met privately but may also be supported by various government initiatives, such as Commonwealth Rent Assistance, the National Rent Affordability Scheme and the National Disability Insurance Scheme (NDIS)[3] (see Table 15.1 for further details).

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[1] Australian Institute of Health and Welfare (AIHW), *People with disability in Australia*, 2 October 2020, www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/housing (accessed 14 November 2021).

[2] The Spectrum, *Autism support and services in the community*, www.thespectrum.org.au/autism-support-services/community/, (accessed 13 November 2021).

[3] The Spectrum, *Support for adults with autism*, www.thespectrum.org.au/autism-support-services/adults/#accommodation-and-housing, (accessed 13 November 2021). See also, National Disability Insurance Scheme (NDIS), *What is specialist disability accommodation?*, 10 November 2021, www.ourguidelines.ndis.gov.au/supports-you-can-access-menu/home-and-living-supports/specialist-disability-accommodation/what-specialist-disability-accommodation (accessed 14 November 2021). The NDIS does not generally fund accommodation other than Specialist Disability Accommodation.

Table 15.1 Funding of housing supports for autistic people

NDIS funded supports	Supports funded by other systems
Capacity building to live independently in the community, improve living skills, money and household management, social and communication skills and behavioural management	Social and community housing Homelessness and emergency accommodation services
Home modifications to a participant's own home or private rental property (on a case by case basis in social housing)	Commonwealth Rent Assistance to help eligible participants with the cost of housing National Rental Affordability Scheme
Personal care support, such as showering and dressing	
Help around the home (such as cleaning and laundry) where a participant's disability prevents them from doing these activities	

Source: National Disability Insurance Scheme, What housing supports are included, 4 December 2020, www.ndis.gov.au/participants/home-and-living/what-housing-supports-are-included (accessed 14 November 2021).

15.5 While there is a lack of definitive data on housing outcomes for autistic people, Autism Aspergers Advocacy Australia (A4) indicated that, anecdotally, many autistic people in Australia live with their parents until their parents die or can no longer support them.[4]

15.6 This anecdotal evidence aligns with research cited by La Trobe University's Olga Tennison Autism Research Centre (OTARC) which found that 'only 10 per cent of young autistic adults in Australia reported living independently from family'.[5] It is also reflected in the results of a 2017 survey of parents of autistic adolescents and adults by Autism Queensland which found that:

- 85.5 per cent were living in the family home;
- 5.8 per cent were in a supported/group home;
- 5.8 per cent were living independently alone;

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[4] Autism Aspergers Advocacy Australia (A4), *Submission 54*, p. 22. See also, A4, *Submission on autistic Australians and Group Homes to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*, March 2020, www.disability.royalcommission.gov.au/system/files/submission/ISS.001.00226.PDF (accessed 13 November 2021).

[5] La Trobe University – the Olga Tennison Autism Research Centre (OTARC), *Submission 55*, p. 24.

- 2.9 per cent were living independently with housemates; and
- 1.4 per cent living independently with a partner.[6]

15.7 By comparison, the Household, Income and Labour Dynamics in Australia Survey showed that only 56.4 per cent of men and 53.9 per cent of women in the general population (aged 18–29 years) lived with their parents in 2017.[7]

15.8 In terms of home ownership and housing tenure, an Australian Autism Alliance (Autism Alliance) survey of autistic adults and parents/carers of autistic adults revealed that:

- 19.7 per cent of autistic adults owned a home; and
- 18.6 per cent of autistic adults were renting a home.[8]

15.9 This compares to home ownership and home rental rates of 67 per cent and 32 per cent respectively across the general population.[9]

15.10 Evidence presented to the committee suggests that the high proportion of autistic people who remain in the family home reflects:

- the degree of support needed for some autistic people to live out of home;
- a lack of appropriate and affordable housing stock; and
- difficulties accessing public housing and the private rental market.[10]

Support required to live independently

15.11 The committee heard that many autistic people need support to live independently. The type of support required can range from assistance with personal care, such as showering, eating and dressing, to assistance with home management, budgeting and paying bills.[11]

15.12 Perhaps reflecting the high reliance on informal care arrangements for autistic people, the Autism Queensland survey found that 79 per cent of those living independently relied on regular support from their parents. The primary types of required living support were household support (19 per cent), budgeting/financial support (18 per cent), organisational support (12 per cent), general activities of daily living (9.46 per cent), specialist support (8 per cent), and social support (8 per cent). Other identified support needs included mental

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[6] Autism Queensland, *Submission 129*, p. 22.

[7] Melbourne Institute: Applied Economic & Social Research, University of Melbourne, *The Household, Income and Labour Dynamics in Australia Survey: Selected Findings from Waves 1 to 17*, 2019, p. 112.

[8] Derived from data contained in Australian Autism Alliance, *Supplementary Submission 52.2*, p. 12.

[9] AIHW, *Home ownership and housing tenure*, 30 June 2021, www.aihw.gov.au/reports/australias-welfare/home-ownership-and-housing-tenure (accessed 13 November 2021).

[10] See, for example, Name withheld, *Submission 11*, [pp. 9–10]; Name withheld, *Submission 123*, [p. 11]; Name withheld, *Submission 38*, p. 3]

[11] Australian Autism Alliance, *Supplementary Submission 52.2*, p. 13.

health support, emotional support, medical support and study support, as well as help with transportation, grooming and hygiene.[12]

15.13 For those living out of home, the need for assistance also extends to the search for appropriate accommodation that is affordable, accessible and safe while allowing choice and independence.[13]

15.14 The committee heard that the high proportion of autistic people living at home—and the level of care and support that may be required—places significant pressure on families and carers. One parent described his worries in relation to both his autistic son and his non-autistic daughter who will take on the primary caring role once he dies:

> …my son lives in a self-contained bungalow in our backyard. Although he is independent in many ways, he is dependent on me for daily support—emotional, economic/financial management, coordinating activities and provision of meals. When I die I expect his support to be taken over by his younger sister … His sister will also have the responsibility for our other son (with Down syndrome) and her own children. I worry for her ability to sustain this heavy burden, although she appears to accept the responsibility.[14]

15.15 Parents also raised concerns that the NDIS is not supporting long-term strategies that would allow autistic participants to transition to independent living prior to the death of their parents or carers. For example, Mrs Roslyn Ward told the committee that her son's previously tailored plan—designed to transition her son to supported independent living—had been replaced by a 'cookie cutter plan' along with cuts in their son's funding supports. This new plan excluded necessary elements of support and disregarded the need for the transition process.[15]

15.16 The impact of ageing parents also creates significant anxieties for autistic people themselves, particularly in the absence of other supports. As one autistic woman explained:

> The reality is that at 46 years old I'm single, childless and I have less than $5 000 in the bank. I don't own property, I have exactly 400 Telstra Shares, I share a car with my mum and if you sold every possession I own I might get $2 000. I live in the top half of my parent's home so if they have to sell the house I become homeless. As I age the risk factor that I will become even

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[12] Autism Queensland, *Submission 129*, pp. 22-23. Household support includes activities such as chores and maintenance. Organisational support includes assistance with scheduling and making appointments. Specialist support includes support provided by professionals such as psychologists and social workers. Medical support includes help with taking medication and attending appointments.

[13] Australian Autism Alliance, *Supplementary Submission 52.2*, p. 13.

[14] Name withheld, *Submission 38*, [p. 3].

[15] Mrs Roslyn Ward, *Proof Committee Hansard*, 29 April 2021, p. 9.

> less finically secure and homeless goes up. My parents are ageing and with their increasing health issues I don't know how long they have to live, my sisters live overseas and I do not have close friends or family to turn for support.[16]

Availability of affordable and appropriate housing stock

15.17 The committee heard that a lack of affordable and appropriate housing stock contributes to poor housing outcomes for autistic people.[17]

Affordable housing

15.18 Broadly, housing affordability in Australia has declined since the early 1980s, with low-income households in the private rental market most affected by high housing costs.[18]

15.19 Given the poor health, education and employment experiences of many autistic people, they may be more likely than the general population to experience housing stress, insecure housing and homelessness.[19] The link between employment and the ability to afford housing was seen as particularly critical.[20] For example, Mr Cameron Boyd noted that:

> To be able to afford housing typically you need to be in employment, and as people on the autism spectrum experience significant barriers to employment …, there is a subsequent flow on effect and these barriers also exist to finding suitable housing.[21]

15.20 While more affordable public housing is available and prioritised for people with the greatest need (such as those experiencing homelessness) and people with a special need for assistance (such as those with disability),[22] access can be

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[16] Name withheld, *Submission 9*, p. 12.

[17] See, for example, Spectrum Labor, *Submission 1*, [p. 12]; Ethnic Disability Advisory Centre, *Submission 75*, p. 9; Mr Philip Gluyas, *Submission 8*, [pp. 5–6]; Name withheld, *Submission 119*, pp. 12–13; Name withheld, *Submission 11*, pp. 9-10.

[18] Matthew Thomas and Alicia Hall, 'Housing Affordability in Australia' in *Briefing Book: Key Issues for the 45th Parliament*, Parliamentary Library, Canberra, 2016, p. 86.

[19] See, for example, Marymead Autism Centre, *Submission 128*, p. 12; Aspergers Victoria, *Submission 90*. [p. 5]; Name withheld, *Submission 9*, pp. 10-12; Name withheld, *Submission 123*, p. 11. See also, A4, *Autistic people at greater risk of becoming homeless – new research*, 14 June 2018, https://a4.org.au/node/1782 (accessed 20 October 2021).

[20] See, for example, Queensland Law Society, *Submission 124*, p. 5; Spectrum Labor, *Submission 1*, [p. 12]; Name withheld, *Submission 123*, [p. 11].

[21] Mr Cameron Boyd, *Submission 157*, [p. 10].

[22] AIHW, *Housing assistance in Australia: priority groups and waiting lists*, 30 June 2021, www.aihw.gov.au/reports/hou/325/housing-assistance-in-australia/contents/priority-groups-waiting-lists (accessed 13 November 2021).

challenging. The difficulties autistic people experience in accessing public housing are discussed later in this chapter.

Appropriate housing

15.21 The committee heard that the appropriateness of housing relates both to its physical design, as well as its style—that is whether it is individual or shared.

Physical design of accommodation

15.22 For many autistic people, the built environment, including housing, can create sensory overload, stress and anxiety which impact on their safety and wellbeing.[23]

15.23 According to Amaze, housing design that caters for autistic characteristics can help to 'reduce anxiety and increase independence and social participation of autistic people'.[24] They noted that common barriers to appropriate housing for autistic people include 'lighting, acoustics, smells, colours, spatial features and flow, flooring and other design elements'.[25]

15.24 This view was shared by one autistic mother who identified temperature, lighting and acoustics as potential sources of stress for autistic people. She also noted that sensory issues might mean that some autistic people require a bath rather than a shower or may need sufficient space in which to move in order to meet their sensory needs. In addition, motor dyspraxia in some autistic people could result in stairs or uneven surfaces in a home becoming a safety issue.[26]

15.25 The same submitter also described the additional challenge involved in finding appropriate housing for autistic children who are unable to assess risk:

> This is an area that is hugely neglected and difficult to navigate, because safety is a big issue—whether it be main roads, waterways, open spaces ... Multi story homes, balconies and windows all become jump/fall risks. When looking at accommodation options, it is very difficult to find options that are

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[23] Enabling Spaces, *Different buildings for different minds*, www.enablingspaces.com.au/ (accessed 13 November 2021).

[24] Amaze, *Submission to the Australian Building Codes Board Accessible Housing Options Paper*, November 2018, p. 6.

[25] Amaze, *Submission to the Australian Building Codes Board Accessible Housing Options Paper*, November 2018, p. 6. While these are common barriers, they are experienced differently by autistic people. For example, an autistic person who is hyper-sensitive to noise or lighting may experience sensory overload, anxiety and/or be unable to interact, participate or remain in an environment. However, a person who is hypo-sensitive may respond similarly if the environment does not meet their sensory needs in relation to touch or visual stimuli.

[26] Name withheld, *Submission 119*, p. 13. Dyspraxia affects movement and coordination and may create issues with balance or physical movement.

> safe primarily for my son, before I can even entertain affordability, or choice of comfort and preferences.[27]

15.26 While noting that the needs of autistic people can vary significantly, Amaze identified the following measures which could improve the accessibility of housing for autistic people:

- involving potential occupants (and/or family/carers) in the design process as early as possible;
- sound proofing, limiting external noise to a prescribed level indoors;
- neutral flooring and colouring; and
- lighting prescriptions, including no fluorescent lighting and mandatory dimmer switches.[28]

15.27 To this end, another submitter suggested looking at the work of Shelly Dival from Enabling Spaces, who is 'leading the way in educating builders and organisations' about housing design that meets the needs of autistic people.[29]

Style of accommodation

15.28 As described previously, accommodation options for autistic people include both shared and individual housing. While there was some support for shared accommodation as a means of preventing social exclusion and homelessness,[30] other submitters pointed out that social difficulties prevented some autistic people from living in shared housing arrangements. For example, the Ethnic Disability Advocacy Centre observed that some of its autistic clients do not understand 'the nature and requirements of sharing accommodation with other people'.[31] This view was supported by another submitter who described the potential consequences of forcing an autistic person to live in unsuitable accommodation:

> Even for 'high functioning' autistic individuals such as my son, sharing a living space with someone else can be too much, and leads to meltdowns, panic attacks and trauma. Their behaviour can in some instances become verbally abusive and sometimes physically threatening towards others as a result of the trauma and confusion that shared accommodation expectations create. Living with other people is simply not an option, unless managed with medication <u>that may not be necessary were they allowed to live on their own</u>.[32]

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[27] Name withheld, *Submission 119*, p. 12.

[28] Amaze, *Submission to the Australian Building Codes Board Accessible Housing Options Paper*, November 2018, p. 8. See also, Name withheld, *Submission 126*, p.26.

[29] Name withheld, *Submission 119*, p. 12.

[30] Name withheld, *Submission 123*, [pp. 11 and 12].

[31] See, for example, Name withheld, *Submission 11*, [p. 9]; Ethnic Disability Advisory Centre, *Submission 75*, p. 9.

[32] Name withheld, *Submission 11*, [p. 9].

15.29 Spectrum Labor also raised the potential for abuse in shared supported accommodation settings.[33] This was reflected in evidence from the Office of the Public Advocate Victoria (OPA Victoria) that an 'unsuitable' client mix—resulting from a combination of complex support needs and a one-size-fits-all approach—can lead to shared homes becoming violent places. In these cases, the OPA Victoria noted that it is the client who 'bears the brunt and the costs of an inadequate solution to the problem of a lack of appropriate housing'. Accordingly, it argued that:

> More innovative solutions are required for people with have complex support needs that look to a range of housing options apart from the sole option of 24/7 shared supported accommodation with five residents who did not choose to live together.[34]

15.30 This proposition was also supported by the Ethnic Disability Advocacy Centre which called for 'appropriate individual housing' to be made available for autistic people.[35]

Availability of appropriate housing

15.31 Multiple stakeholders noted an insufficient supply of appropriate housing options for autistic people.[36] For example, the Ethnic Disability Advocacy Centre described a shortage of individual housing and a 'long wait for accessible, safe housing'.[37] This view was also shared by the mother of an autistic individual who submitted that:

> The lack of public housing, and the long waiting list is discriminatory towards adults who **must** live on their own. In turn, this means that many families need to keep their autistic loved one at home with them for the long term, to care for them, as the parents/carers themselves move into their twilight years.

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[33] Spectrum Labor, *Submission 1*, [p. 12].

[34] Office of the Public Advocate Victoria, *Submission 80*, pp. 18–19. This submission cited two examples of violence in group homes. The first case involved the violent behaviour of an autistic resident which forced the other four residents to move out. After many emergency interventions, the resident was eventually moved to a purposed built house where he was the sole occupant. The second case involved an autistic man who was assaulted by another resident in his home. He remained in a mental health unit for seven weeks and did not want to return to his accommodation while the other resident remained there.

[35] Ethnic Disability Advisory Centre, *Submission 75*, p. 9.

[36] See, for example, Ethnic Disability Advisory Centre, *Submission 75*, p. 9; Spectrum Labor, *Submission 1*, [p. 12]; Name withheld, *Submission 11*, [p. 10].

[37] Ethnic Disability Advisory Centre, *Submission 75*, p. 9.

15.32 In addition, the Northern Territory Office of the Public Guardian observed that the lack of housing stock took away the ability to offer 'real choice and control' to autistic people.[38]

15.33 The Queensland Law Society suggested that a lack of appropriate housing may be a specific challenge for elderly autistic people who may struggle to find retirement accommodation options able to support their needs. Accordingly, it suggested consultation to address the current shortfalls in appropriate housing for autistic people.[39]

15.34 The committee also heard that there were particular issues in relation to the availability of NDIS Specialist Disability Accommodation for autistic people with complex support needs. These are discussed in more detail below.

NDIS Specialist Disability Accommodation

15.35 NDIS Specialist Disability Accommodation (SDA) is 'housing designed for people with extreme functional impairment or very high needs'.[40] Participants with autism make up the third largest group of participants with SDA at 11 per cent.[41] Of the four SDA design categories (see Box 15.1), the committee heard that the 'robust' category would be the most likely to be funded for autistic people with complex support needs.[42]

Box 15.1 SDA design categories

1. Improved liveability—housing with better physical access. It also has more features for people with sensory, intellectual or cognitive impairments. For example, you may need walls and floors that are very easy to see, living areas that mean your support workers can see you easily, or very few stairs in your home.

2. Fully accessible—housing with a high level of physical access features for people who have lots of physical challenges. For example, you need to use a manual or powered wheelchair at home, or can’t use steps.

3. Robust—housing that is very strong and durable, reducing the need for repairs and maintenance. The way it is built should make it safe for you and others. This type of design category may suit people who need help managing complex and challenging behaviours. We think about how often you currently cause property damage, and the extent of the damage.

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[38] Northern Territory Office of the Public Guardian, *Submission 20*, p. 5.

[39] Queensland Law Society, *Submission 124*, p. 8.

[40] NDIS, *What is specialist disability accommodation*, 10 November 2021, www.ourguidelines.ndis.gov.au/supports-you-can-access-menu/home-and-living-supports/specialist-disability-accommodation/what-specialist-disability-accommodation (accessed 14 November 2021).

[41] NDIS, *NDIS specialist disability accommodation 2020-21 quarter 4 report*, 27 September 2021, p. 13. The two largest participant groups with Specialist Disability Accommodation (SDA) are those with intellectual disability (48 per cent) and those with cerebral palsy (12 per cent).

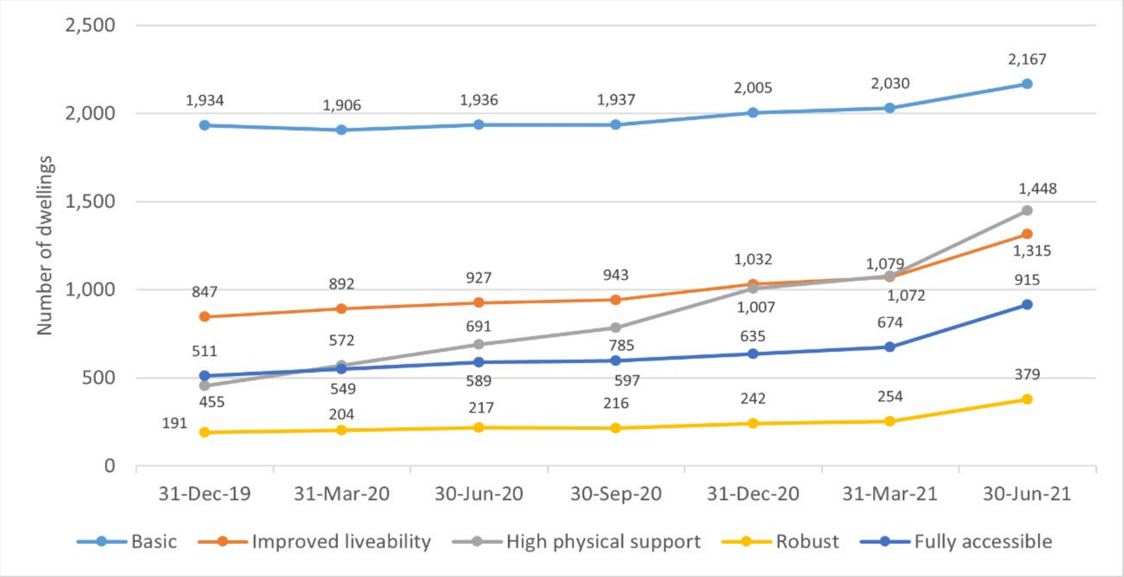
[42] Name withheld, *Submission 60*, [p. 3].

> **4. High physical support**—housing that includes a high level of physical access for people who need very high levels of support. For example, you may need a ceiling hoist, backup power supply, or home automation and communication technology.

Source: National Disability Insurance Scheme, What are the specialist disability accommodation design categories?, 11 November 2021, www.ourguidelines.ndis.gov.au/supports-you-can-access-menu/home-and-living-supports/specialist-disability-accommodation/what-kind-specialist-disability-accommodation-will-we-fund/what-are-specialist-disability-accommodation-design-categories *(accessed 14 November 2021).*

15.36 Both St Vincent's Health Australia (St Vincent's) and the Tasmanian Government pointed to a shortage of 'robust' NDIS SDA for people whose support needs 'cannot be met by family or within "standard" service options'.[43] This view was shared by the Queensland Government which reported that shortages of SDA have resulted in some NDIS participants being unable to use the funding allocated in their plans.[44] This appears to be reflected in the most recent NDIS report on SDA which shows that the supply of robust category housing is lower than the other three design categories (see Figure 15.1).[45]

Figure 15.1 Growth in dwelling enrolments by design categories



Source: National Disability Insurance Scheme, NDIS specialist disability accommodation 2020–21 quarter 4 report, 27 September 2021, p. 5.

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[43] Tasmanian Government, *Submission 19*, p. 8. See also, St Vincent's Health Australia, *Submission 72*, p. 6.

[44] The Hon Coralee O'Rourke MP, Queensland Minister for Communities, Queensland Minister for Disability Services and Seniors, *Submission 101*, Attachment 1, p. 20.

[45] NDIS, *NDIS specialist disability accommodation 2020-21 quarter 4 report*, 27 September 2021, p. 5.

15.37 Stakeholders also commented on the inappropriate use of hospitals or hotels to house autistic people with complex needs who cannot be accommodated elsewhere. For example, the Tasmanian Government noted 'episodes of hospital admissions and extended stays in hospital' due to the lack of alternative options for people with complex needs.[46]

15.38 Similarly, St Vincent's submitted that there is 'a small but significant number' of autistic people who are unable to remain in their accommodation because of their behaviours or complex needs. St Vincent's explained that these people can be placed in mental health units or medical wards 'for lengthy periods' and cared for by clinicians with 'little or no understanding' of autism. In some instances, they are housed in hotel rooms with NDIS-funded carers, 'usually at a 2:1 ratio, 24 hours a day, 7 days a week. In many instances these carers have limited training, supervision or support in either [autism] or mental health'.[47]

15.39 The OPA Victoria suggested that disputes about who is responsible for housing people with complex needs exacerbate poor outcomes for outcomes for individuals. It cited the case of an autistic man with mental health issues who spent seven weeks in a mental health unit after being assaulted by a resident of his group home. While it was eventually agreed that the man should move out of the group home, neither the National Disability Insurance Agency (NDIA) nor the Victorian Department of Health and Human Services (DHHS) accepted responsibility for his rehousing:

> Eventually, it was accepted that he should move, however, the NDIA said that it could not fund housing. Meanwhile, DHHS said that, in an NDIS environment, it was not its responsibility to rehouse the co-resident. To facilitate his discharge from hospital, NDIS funding was utilised for temporary accommodation for the assault victim, however, this reduced the amount available to him for other purposes.[48]

15.40 This reflected evidence from other stakeholders suggesting that more work is needed to clarify the interface between NDIS-funded accommodation and mainstream services. For example, the Government of Western Australia (WA Government) indicated that the state's role in implementing SDA was 'yet to be determined'.[49] The Queensland Government stated that although states are responsible for housing, 'the NDIA is responsible for stimulating the supply' of SDA housing.[50]

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[46] Tasmanian Government, *Submission 19*, p. 8.

[47] St Vincent's Health Australia, *Submission 72*, p. 6.

[48] Office of the Public Advocate Victoria, *Submission 80*, pp. 19–20.

[49] Government of Western Australia, *Submission 103*, p. 5.

[50] The Hon Coralee O'Rourke MP, Queensland Minister for Communities, Queensland Minister for Disability Services and Seniors, *Submission 101*, Attachment 1, p. 16.

15.41 However, the Tasmanian Government argued that state governments must also play a role in providing robust SDA accommodation given 'service development for this very specific accommodation response is not typically attractive to property developers or service providers'.[51] This view was supported by one submitter who contended that SDA providers were focused instead on the high physical support category which 'receive higher returns'.[52]

15.42 Market failure in relation to robust SDA housing was also highlighted by a parent who spent two years trying to find an SDA provider for their son:

> We have been fortunate to find (eventually) an SDA provider who is going to build a home for my son and another NDIS participant, but this has been after a solid two–three years of contacting over 50 disability organisations, many of whom said that building robust was a problem and that they would not be providing this sort of housing (once again picking and choosing which disability to help—and it's not people with autism).[53]

15.43 In response, the Tasmanian Government observed that its *Affordable Housing Strategy 2015–25* includes:

> …funded commitments to construct new homes that are purpose built for those participants of the NDIS with complex and exceptional needs who require a tailored form of integrated housing and support. This includes NDIS participants with SDA approved in their plan or who have NDIS Supported Independent Living packages for supported accommodation.[54]

15.44 The *Affordable Housing Strategy 2015–*25 will also include a 'portfolio plan for SDA' which will focus on the future management of SDA.[55]

15.45 Similarly, the WA Government indicated that it is working with the NDIA on 'a joint agreement that will prioritise NDIS participants in urgent critical need of an SDA assessment'. According to the WA Government, this is expected to play a key role in stimulating the supply of SDA housing for NDIS participants.[56]

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[51] Tasmanian Government, *Submission 19*, p. 8.

[52] Name withheld, *Submission 60*, [p. 3].

[53] Name withheld, *Submission 60*, [p. 3].

[54] Tasmanian Government, *Submission 19*, p. 8.

[55] Tasmanian Government, *Submission 19*, p. 8. The majority of SDA accommodation in Tasmania is owned by the Tasmanian Government and currently head leased to NDIS providers. In turn, these providers provide secure leases to NDIS participants.

[56] Government of Western Australia, *Submission 103*, p. 5.

Accessing to social housing and the private rental market

15.46 As described earlier, an Autism Alliance survey of autistic adults and parents/carers of autistic adults indicated that 18.6 per cent of autistic adults were renting a home.[57]

15.47 While there is a lack of data on the split between social housing and private rentals for autistic people, the Australian Institute of Health and Welfare (AIHW) found that people with disability are more likely to live in social housing than rent in the private market (see Table 15.2).

Table 15.2 The most common types of landlords for people with disability

Landlord type	% with disability	% without disability
Real estate agent	42.0	63.0
State or territory housing authority	16.0	4.1
Parent or relative in same dwelling	12.0	8.1
Other person not in same dwelling	12	12

Source: Australian Institute of Health and Welfare, People with Disability in Australia, 2 October 2020, www.aihw.gov.au/reports/dis/73-1/people-with-disability-in-australia/contents-1/housing/living-arrangements *(accessed 14 November 2021).*

15.48 In addition, the AIHW found that those with severe or profound disability are less likely to rent in the private market (36 per cent) and are more likely to rent from a state or territory housing authority (17 per cent) or have a parent or relative in the same dwelling as their landlord (19 per cent).[58]

15.49 Regardless of whether autistic people accessed social housing or the private market, the committee heard that autistic people faced significant challenges in accessing suitable housing.

Social housing

15.50 The committee heard that autistic people face long wait times to access social housing, with two submitters reporting wait times of 10 and 17 years respectively.[59]

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[57] Australian Autism Alliance, *Submission 52.2*, p. 12.

[58] AIHW, *People with Disability in Australia*, 2 October 2020, www.aihw.gov.au/reports/dis/73-1/people-with-disability-in-australia/contents-1/housing/living-arrangements (accessed 14 November 2021).

[59] Name withheld, *Supplementary Submission 131.2*, p. 2; Mr Phillip Gluyas, *Submission 8*, [pp. 5–6].

15.51 While there does not appear to be any autism-specific data for social housing, wait times can be affected by both the location and type of housing required. For special needs households in 2019–20, the AIHW reported that around:

- 23 per cent (2 400 households) waited for less than 3 months;
- 29 per cent (3 000 households) waited between 3 months and less than 1 year;
- 38 per cent (3 900 households) waited between 1 year to less than 5 years; and
- 10 per cent (1 000) households waited for more than 5 years.[60]

15.52 Once in social housing, autistic people reported that their experiences were impacted by a lack of understanding of autism. For example, one autistic woman described being 'bullied, intimidated, stood over and traumatised' by public housing authorities as a result of being disorganised and untidy—a symptom of her executive functioning difficulties caused by autism. Similarly, she also reported being wrongly depicted as a hoarder because she has 'a lot of stuff' that relate to her interests.[61]

15.53 A lack of systemic understanding of autism also means that autistic people are reliant on the knowledge of individual housing authority offices or staff members. For example, Mr Phillip Gluyas explained that he ended up moving to a different office in part because the manager at the first office 'was distinctly averse to autistic needs'.[62] Another submitter described the management of their property as changing from 'benevolent' to 'brutal' after they were assigned to a different office.[63]

The private rental market

15.54 The private rental market is generally more competitive and less affordable than social housing.[64] However, the primary issues identified by stakeholders in relation to the private market were discrimination and a lack of understanding of autism by real estate agents and landlords.

15.55 For example, the committee heard one account of an autistic individual being evicted from private housing because they were perceived as 'strange' by their

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[60] AIHW, *Housing Assistance in Australia*, 30 June 2021, www.aihw.gov.au/reports/housing-assistance/housing-assistance-in-australia/contents/entries-exits-transfers-and-wait-times (accessed 14 November 2021).

[61] Name withheld, *Submission 131*, p. 2.

[62] Mr Phillip Gluyas, *Submission 8*, [pp. 5–6].

[63] Name withheld, *Supplementary Submission 131.2*, p. 2.

[64] AIHW, *People with disability in Australia*, 2 October 2020, www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/housing (accessed 14 November 2021).

landlord.[65] Another individual reported being turned away from properties despite having a 'flawless rental history', outstanding references and not having made 'a single late payment in 20 years of renting'.[66]

15.56 The committee also heard that process of securing rental accommodation can become a vicious circle. For example, failing to secure accommodation can increase stress and anxiety to a point where it affects their presentation and makes it harder to secure accommodation. Yellow Ladybugs described the experience of an autistic person who was required to move house five times in nine months:

> Being at the mercy of property manager after property manager, having them decide my fate, whether I was worthy enough to get a roof over my head or not; me excruciatingly aware of how mentally ill I appeared to others as I could no longer hide it, knowing this would affect my presentation and ability to gain rental housing. And it did.[67]

15.57 When a person chooses to disclose their autism, a lack of understanding can also lead to misinterpretations and negative outcomes. For example, Yellow Ladybugs relayed the experience of one autistic individual who informed a property manager that they 'really needed' a specific property because it suited their needs:

> I was treated with what I can only describe as 'disgust at my entitlement'. They assumed I felt entitled to priority over other applicants because I disclosed my disability and they said as much to me.[68]

15.58 Accordingly, submitters called for better education and training in relation to the needs of autistic people.[69]

15.59 In addition, given there will always be a need for people with disability to rent in the private market, there was also a desire for private rentals to become more disability friendly and for landlords to be more accepting of 'reasonable requests' from autistic tenants.[70]

Committee view

15.60 The committee recognises the importance of secure, appropriate and affordable housing to the life outcomes of autistic Australians. The committee also notes that affordable and accessible housing—as well as choice and control over

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[65] Name withheld, *Supplementary Submission 131.2*, p. 1.

[66] Yellow Ladybugs, *Submission 49*, p. 22.

[67] Yellow Ladybugs, *Submission 49*, p. 21.

[68] Yellow Ladybugs, *Submission 49*, p. 22.

[69] Yellow Ladybugs, *Submission 49*, p. 10.

[70] Yellow Ladybugs, *Submission 49*, p. 22.

where people live and who they live with—are identified as policy priorities in *Australia's Disability Strategy 2021-2031*.[71]

15.61 Over the course of the inquiry, the committee heard that insecure housing contributes to poorer outcomes across health, education and employment domains. It is also a predictor of ongoing engagement with the justice system and has been cited as a factor in the heartbreaking decisions families have made to place their children in state care.

15.62 The housing statistics for autistic people and their families are troubling, with only 10 per cent of young autistic adults living independently from their parents. While the committee recognises the important role informal care plays in supporting many autistic individuals, it is not clear to the committee that an appropriate balance of formal and informal supports has been achieved. The committee is concerned that an ongoing failure to support independent living will only serve to increase the burden on the health, welfare and public housing systems—particularly as parents and carers age and are no longer able to provide the informal support upon which their children rely.

15.63 The committee also believes the National Disability Insurance Scheme (NDIS) must be more responsive to participants' long-term housing goals. For those participants living at home, this process must not just account for the immediate needs of the participant but must also establish systems and supports that will enable independent living following the death of their parents or carers.

Recommendation 68

15.64 The committee recommends, as part of the inquiry into the National Disability Insurance Scheme proposed in Recommendation 6, that the effectiveness of funded supports to enable autistic people to live independently be reviewed. This should have particular reference to:

- **the high proportion of autistic adults living in their family home;**
- **the impact (and appropriateness) of the informal care burden on parents and carers; and**
- **the need for long-term accommodation planning to enable independent living following the death of a participant's parents or carers.**

15.65 The committee also acknowledges stakeholder concerns about a lack of housing that accommodates the specific needs of autistic people. This includes housing designed to meet autistic people's sensory needs, as well as the need for more single-person accommodation where an individual's social challenges mean that shared accommodation is not an appropriate housing solution.

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[71] Department of Social Services, *Australia's Disability Strategy 2021–2031*, pp. 9 and 10.

Recommendation 69

15.66 The committee recommends that the National Disability Insurance Agency work with relevant stakeholders to review the Specialist Disability Accommodation Design Standard to ensure it accounts for the sensory issues experienced by autistic participants.

Recommendation 70

15.67 The committee recommends that the Australian Government work with state and territory governments and relevant stakeholders to develop housing strategies to encourage the construction of social housing that responds to the needs of autistic people in relation to housing design and type.

15.68 For autistic people with complex needs, it is even more difficult to find appropriate accommodation. Disturbingly, in the absence of suitable alternatives, the committee heard that hospitals have become de facto accommodation providers for autistic people with complex presentations.

15.69 This appears to reflect evidence provided to the committee about a shortage of Specialist Disability Accommodation (SDA) in the 'robust' category, as well as broader concerns about the intersection of NDIS-funded and mainstream supports.

15.70 The committee believes that more needs to be done to identify and address market failure in the provision of appropriate housing options for autistic people, particularly in the development of more 'robust' SDA.

Recommendation 71

15.71 The committee recommends that the National Disability Insurance Agency work with state and territory governments and non-government housing providers to increase the supply of the 'robust' category of Specialist Disability Accommodation.

Recommendation 72

15.72 The committee recommends the National Disability Insurance Agency work with state and territory governments to clarify the intersection of responsibilities in relation to housing for people with complex support needs.

Chapter 16
Justice

16.1 This chapter describes the experience of autistic people in relation to their interactions with the justice system in Australia. This includes discussion of:

- the overrepresentation of autistic people in the justice system;
- factors contributing to that overrepresentation; and
- transitions out of detention settings and into the community.

Overrepresentation of autistic people in the justice system

16.2 The committee heard that there are no definitive statistics available in relation to autistic people and the justice system.[1] However, a number of stakeholders asserted that autistic people are at greater risk of involvement with the justice system[2] and are also overrepresented in detention settings.[3] This aligns with evidence provided by Speech Pathology Australia (SPA) and others about the general overrepresentation in the justice system of people with neurodevelopmental disorders and cognitive disabilities.[4]

16.3 While a lack of data means the extent of overrepresentation is not clear, underdiagnosis of autism may mean it is even greater than the anecdotal evidence suggests. For example, SPA told the committee that its members had reported 'a number of people they consider having undiagnosed autism in prison'.[5]

16.4 Other stakeholders, such as the Commissioner for Children and Young People Western Australia and Positive Youth Incorporated (Positive Youth), pointed out that certain cohorts of autistic people may feature disproportionately within broader overrepresentation statistics. This includes autistic First Nations peoples and those from lower socio-economic backgrounds, who are more likely

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[1] See, for example, Department of Developmental Disability Neuropsychiatry, University of New South Wales (UNSW 3DN), *Submission 95*, p. 11; Queensland Family and Child Commission, *Submission 36*, p. 7.

[2] Autism Spectrum Australia (Aspect), *Submission 64*, p. 15.

[3] See, for example, NSW Government, *Submission 65*, p. 4; UNSW 3DN, *Submission 95*, p. 11; Positive Youth Incorporated, *Submission 85*, p. 2; Mr Phillip Morris, *Submission 25*, [pp. 3–4]; Name Withheld, *Submission 126*, p. 23.

[4] Speech Pathology Australia, *Submission 87*, p. 13. This includes disorders with associated speech, language and communication needs, such as autism, Attention Deficit Hyperactivity Disorder (ADHD) and Foetal Alcohol Spectrum Disorders (FASD). See also, Commissioner for Children and Young People Western Australia, *Submission 42*, p. 7; Queensland Family and Child Commission, *Submission 36*, p. 7.

[5] Speech Pathology Australia, *Submission 87*, p. 13.

to be undiagnosed[6] and may also have greater difficulty accessing services and supports that may prevent involvement with the justice system.[7]

16.5 In addition, Autism Spectrum Australia (Aspect) explained that sensory issues, anxiety, a 'tendency toward compliance and difficulties with information processing' also leave autistic people more vulnerable than the general population once they enter the justice system.[8] According to Positive Youth, a lack of appropriate support within detention settings can end up 'potentially exacerbating – and in some cases, deepening' people's engagement with the system.[9] Similarly, SPA suggested that rates of recidivism among undiagnosed autistic people may be increased by 'unrecognised speech, language and communication needs' which mean they 'struggle to access treatment and rehabilitation programs delivered verbally'.[10]

Contributing factors

16.6 As emphasised by the Office of the Public Advocate Victoria (OPA Victoria), 'cognitive disability does not inherently lead to criminal or offending behaviours'.[11] Indeed, Autistic-led Organisations Australia (ALOA) stressed that most autistic people who come into contact with police are the victims of crime, rather than the perpetrators.[12]

16.7 The OPA Victoria submitted that interaction with the justice system arises from 'the cumulative effect of social and economic disadvantages faced by many people with disability'.[13] This view was reflected in evidence provided to the committee which suggested that a confluence of factors had led to the overrepresentation of autistic people in the justice system. These included:

- a failure to provide preventative services and supports;
- poor understanding of autism within the police and court systems; and

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[6] Commissioner for Children and Young People Western Australia, *Submission 42*, p. 7; Positive Youth Incorporated, *Submission 85*, p. 3.

[7] See, for example, See also, Commissioner for Children and Young People Western Australia, *Submission 42*, p. 2; Queensland Family and Child Commission, *Submission 36*, pp. 6-7; Queensland Law Society, *Submission 124*, p. 5.

[8] Aspect, *Submission 64*, p. 15.

[9] Positive Youth Incorporated, *Submission 85*, p. 3.

[10] Speech Pathology Australia, *Submission 87*, p. 13.

[11] Office of the Public Advocate Victoria, *Submission 80*, p. 16.

[12] Autistic-led Organisations Australia (ALOA), *Submission 121*, [p. 5]. See also, Name withheld, *Submission 126*, p. 23.

[13] Office of the Public Advocate Victoria, *Submission 80*, p. 16.

- a lack of adequate services and supports within the justice system.[14]

Preventative services and supports

16.8 The committee heard about the role adequate support plays in reducing the likelihood of contact with the justice system in Australia.[15] This appears to reflect international experience. For example, Positive Youth referred to a 2019 report by the United Kingdom's Joint Committee on Human Rights which stated that:

> …the detention of young people 'is usually the result of a long and predictable series of failures to appropriately support them and their family'.[16]

16.9 Other factors that were seen to increase the risk of interaction with the justice system included late (or no) diagnosis, insecure housing, poor educational experiences, and a lack of resources.[17]

16.10 In addition to difficulties in accessing preventative services, this at-risk cohort is also affected by a lack of service integration. This is a particular issue for autistic people with complex needs. For example, Positive Youth noted that poor service integration works against the kind of multidisciplinary approach that may be needed to address more complex needs. It also contended that the outcome of a lack of integration can be that 'responsibility for addressing these problems often ends up falling to the juvenile justice system'.[18] This aligns with the OPA Victoria's concerns that the prison system has become a default 'provider of last resort' for people with complex needs.[19]

16.11 Accordingly, Positive Youth argued for the provision of holistic, wraparound services incorporating community supports. It suggested this could create stronger support for at-risk autistic young people and prevent them from 'falling through the cracks and becoming involved with the juvenile justice system'.[20]

16.12 Services for autistic people with complex needs are also impacted by a dearth of specialist service providers, including providers of last resort. Evidence submitted to the committee suggests this is a particular issue for services funded

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[14] See, for example, Northern Territory Office of the Public Guardian, *Submission 20*, [p. 5]; Office of the Public Advocate Victoria, *Submission 80*, p. 16; Positive Youth Incorporated, *Submission 85*, pp. 3–5; BioAutism Ltd, *Submission 93*, p. 23; Spectrum Labor, *Submission 1*, p. 11.

[15] See, for example, Northern Territory Office of the Public Guardian, *Submission 20*, [p. 5]; Queensland Family and Child Commission, *Submission 36*, p. 7; BioAutism Ltd, *Submission 93*, p. 23].

[16] Positive Youth Incorporated, *Submission 85*, p. 4 (citation omitted).

[17] See, for example, Positive Youth Incorporated, *Submission 85*, pp. 3, 4 and 5; The Queensland Family and Child Commission, *Submission 36*, p. 7.

[18] Positive Youth Incorporated, *Submission 85*, p. 4.

[19] Office of the Public Advocate Victoria, *Submission 80*, p. 15.

[20] Positive Youth Incorporated, *Submission 85*, p. 7.

under the National Disability Insurance Scheme (NDIS). For example, stakeholders raised concerns that the individualised NDIS funding model is not suited to funding intersecting services—such as those at the interface of justice and disability. This may have exacerbated service segregation and led to specialist providers exiting the market.[21]

16.13 However, in relation to support for people with complex needs, the National Disability Insurance Agency (NDIA) pointed to the establishment of the Complex Support Needs Pathway. This pathway supports participants whose ability to engage with NDIS is affected by factors such as 'situational or personal factors, such as mental health issues, homelessness or incarceration'. The pathway also includes a focus on maintaining participants' critical supports in order to mitigate the risks of service failure.[22]

16.14 While the Complex Support Needs Pathway was welcomed by stakeholders, the committee heard concerns that access to the pathway happens too late. For example, Learning for Life Autism Centre stated that access is only granted once a participant's behaviours have escalated to the point where the participant is already interacting with other support systems, including the justice system.[23]

16.15 Other stakeholders such as the OPA Victoria called for greater transparency and consultation with stakeholders around the NDIA's Maintaining Critical Supports Framework (MCS Framework). Among other priorities, the OPA Victoria argued that the MCS Framework should focus on ensuring that:

- providers of last resort mechanisms are established as an ongoing component of the NDIS market;
- multiple designated providers of last resort are clearly identified, adequately resourced, and have specialised experience and skills relevant to the specific needs of participants;
- there are clear procedures in place to guide NDIS planners, Local Area Coordinators and Support Coordinators when the need for provider of last resort arises; and
- participant plans are flexible enough to respond to situations where a provider of last resort is required, including the ability to access contingency funding.[24]

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[21] See for example, Office of the Public Advocate Victoria, *Submission 80*, p. 21; Samaritans, *Submission 99*, p. 7; Professor Julian Trollor, Chair, Intellectual Disability Mental Health; and Head, UNSW 3DN, *Proof Committee Hansard*, 15 April 2021. p. 40.

[22] National Disability Insurance Agency (NDIA), *Submission 56*, pp. 16 and 17.

[23] Learning for Life Autism Centre, *Submission 144*, p. 6.

[24] Office of the Public Advocate Victoria, *Submission 80*, p. 21.

Lack of autism understanding

16.16 As with other service sectors, poor understanding of autism within the police force and the court system affects autistic people's experiences and outcomes. According to Marymead Autism Centre, a lack of systemic understanding means that responses to autistic people within the justice system are dependent on the experience of individual officials.[25]

16.17 A recent study by Aspect found 'considerable dissatisfaction' with police handing of interactions with autistic people. This included reports of frequent misunderstandings arising from communication differences.[26] Similarly, Mr Philip Morris pointed to the findings of a similar study in the United Kingdom. That study found that 69 per cent of autistic adults and 74 per cent of parents of children with autism were dissatisfied with their experiences with the police service.[27]

16.18 This reflected stakeholder concerns that autistic characteristics, such as social and communication difficulties, can be misinterpreted by staff within the justice system. This, in turn, can increase the likelihood of arrest, longer sentences, and greater difficulties within detention settings.[28] The potential for misinterpretations to lead to poor outcomes was illustrated in two case studies provided by autistic advocate, Ms Geraldine Robertson (see Box 16.1).

Box 16.1 Examples of autism advocacy in the justice system

Case study – 'J'

A young man, J., looking at lights through his fingers and describing the patterns in a mechanical and monotone voice, was asked by the police to move on. He did not understand why and demanded an explanation. After instructions made in official language, J. became confused, flapping his hands.

The police placed him in protective custody, which was technically the correct thing to do, but J. did not know what protective custody was. He became frantic with fear, not knowing if he would go to prison or how long he would be detained.

It would have been helpful if the young constable had recognised flapping as a sign of autism and understood that he should speak in short, simple sentences that J. would understand. In reality, J. injured his face when banging his head against a cell wall and required surgery and ongoing counselling after the experience.

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[25] See, for example, Marymead Autism Centre, *Submission 128,* p. 9; Professor Robyn Louise Young, Private capacity, *Proof Committee Hansard*, 16 November 2021, pg. 22.

[26] Aspect, *Submission 64*, p. 16.

[27] Mr Philip Morris, *Submission 25*, [p. 3].

[28] Aspect, Submission 64, pp. 15–16. See also, Professor Robyn Louise Young, *Proof Committee Hansard*, 16 November 2020, p. 24; Queensland Family and Child Commission, *Submission 36*, p. 7.

T. was summonsed to appear in court after failure to follow a police directive, which he did not understand. His lawyer advised him to plead not guilty after the advocate helped T. to explain the situation.

On being called before the magistrate, T. suddenly started yelling that he was guilty. He demanded to be charged so that he could pay the fine and go home. This was sparked by sheer terror at an unfamiliar situation, stressful for most people. Nothing that the lawyer or magistrate could do would change T.'s mind about pleading guilty.

The autistic advocate was permitted to speak with him—the information that a criminal record would prevent this man from entering Japan to attend anime and manga events (special interests which dominate his life) provided the reason to persuade him to cope with the court case so that justice could prevail.

Source: Ms Geraldine Robertson, Submission 165, pp. 3-4.

16.19 In addition, SPA contended that autistic people are also at higher risk of unnecessary exclusion or restraint due to a lack of understanding that a person's meltdowns or challenging behaviours are linked to their autism.[29]

16.20 According to ALOA, inaccurate and negative police perceptions of autism—including that autism is a mental illness, or that all autistic people are violent or unable to communicate—can make people reluctant to disclose their diagnosis:

> Once I disclosed my diagnosis, they treated me like a child and made me report sexual offences committed against me on video because they said I am an unreliable witness. … I now do not disclose anything to police.[30]

16.21 The Commissioner for Children and Young People Western Australia pointed out that system officials are also unlikely to realise that autistic people 'may not understand the laws they break or comprehend the effect they have on others'. In addition, they may not understand that certain autistic characteristics, such as misreading social cues and fixated behaviours, may be 'contributing factors in illegal activities', or that social exclusion and difficulties interpreting intent can lead to autistic people being 'unwittingly manipulated' into criminal activity.[31]

16.22 This view was shared by the Coalition of Autistic Women (CoAW) who told the committee that 'difficulties in reading the emotions and intentions of others' can lead to autistic women becoming 'victims of opportunists'. As an example, the CoAW described the experience of an autistic woman who committed crimes to gain the approval of her boyfriend. To survive her time in prison, she became a

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[29] Speech Pathology Australia, *Submission 87*, p. 14.

[30] ALOA, *Submission 121*, [p. 5].

[31] Commissioner for Children and Young People Western Australia, *Submission 42*, p. 7.

'social chameleon' to such an extent that she ended up identifying with being a criminal. This resulted in her spending the next few years in and out of prison.[32]

16.23 The tendency for females to camouflage and lose their identities was reinforced in evidence from Professor Robyn Young, who told the committee that:

> Most of the adult females that I diagnosed have lost themselves completely. They have no idea who they are anymore because there's this chameleon of characters that they've developed along the way.[33]

16.24 Yellow Ladybugs also contended that a lack of knowledge about autism is evident in Family Court dealings with autistic mothers,[34] with children sometimes removed from their mother's care 'for no other reason than their disability'.[35] The committee also heard evidence that courts sometimes disbelieve autism diagnoses if children don't conform to a stereotype of autism. This particularly affects females who mask their autism:

> I was accused of having Munchausen syndrome by my partner and his lawyers because my daughter's autism didn't match their limited stereotypical view. … the court-appointed psychologist also questioned it, stating she was not autistic – she was 'too social' and could look at him in the eyes. This is an absolutely outdated and tragically damaging stance and had huge ramifications for her and me.[36]

16.25 Where a lack of understanding intersects with issues such as family violence, the consequences can be particularly devastating. The CoAW relayed the experience of one autistic woman who ended up living with violence for many years after her attempt to take out a restraining order through the courts ended in humiliation:

> The magistrate went off at me for stepping in the box when he had told me not to. I looked around and realised that he was talking about the witness box. If he had said 'Do not step in the witness box,' I would have known what he meant. The whole court was laughing at me. I left straight away because I was so embarrassed, I could not speak. I didn't get a restraining order. We lived with violence for many years.[37]

16.26 Echolalic speech was identified by Professor Robyn Young as another sign of autism with the potential for damaging consequences if not recognised by police or the court system:

> You say, 'Do you understand this was right or wrong?' They say, 'Wrong.' And you say, 'Do you know whether this was legal or illegal?' and they say,

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[32] Coalition of Autistic Women, *Submission 125*, [pp. 21–22].

[33] Professor Robyn Louise Young, *Proof Committee Hansard*, 16 November 2020, p. 24.

[34] Yellow Ladybugs, *Submission 49*, p. 15.

[35] Coalition of Autistic Women, *Submission 125*, [p. 20].

[36] Yellow Ladybugs, *Submission 49*, pp. 10–11.

[37] Coalition of Autistic Women, *Submission 125*, [p. 21].

> 'Illegal.' So, all of a sudden, you've got admissions. I have to go through transcripts and point out all these other cases where they've engaged in echolalic speech, and they weren't actually admitting to that.[38]

16.27 The Queensland Family and Child Commission observed that these inadequate responses to autistic behaviours can serve to drive people further into the justice system.[39] Accordingly, numerous stakeholders called for better education and training of personnel within the justice system, including in the areas of trauma-informed approaches and positive behaviour support.[40]

16.28 However, Professor Robyn Young also highlighted the importance of educating autistic people about how to interact with the justice system. In doing so, she cited one particular case where she felt an autistic man had been jailed 'largely on the basis of the way he interacted with police.[41] This was reflected in the experience of another submitter who felt he was punished for his responses in his police interview.[42]

16.29 Some stakeholders also suggested placing a greater emphasis on community policing approaches. This included introducing or replicating initiatives such as:

- the United Kingdom's Police Community Support Officers (who support outreach to vulnerable communities),[43]
- the 'coffee with a cop' program run by Victoria Police in the Brimbank area;[44] or
- autistic contact officers who could better connect first responders and the autistic community.[45]

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[38] Professor Robyn Louise Young, *Proof Committee Hansard*, 16 November 2020, p. 23. Echolalic speech refers to repeating phrases or expressions that have been heard. Echolalia can be immediate or delayed.

[39] Queensland Family and Child Commission, *Submission 36*, p. 7.

[40] See, for example, Marymead Autism Centre, *Submission 128*, p. 4; Queensland Family and Child Commission, *Submission 36*, p. 5; Commissioner for Children and Young People Western Australia, *Submission 42*, p. 7; Aspect, *Submission 64*, p. 16; Autism Family Support Association, *Submission 22*, Attachment 1, p. 1; ALOA, *Submission 121*, [p. 5]; Name withheld, *Submission 38*, [p. 1]; Professor Robyn Louise Young, *Proof Committee Hansard*, 16 November 2020, p. 22.

[41] Professor Robyn Louise Young, *Proof Committee Hansard*, 16 November 2020, pp. 23–24. Professor Young also referred to the UK system where they have introduced cards for young autistic people that inform the police (or whoever they are interacting with) that this person needs to talk to a lawyer or call a particular person.

[42] Name withheld, *Submission 37*, p. 3.

[43] Name withheld, *Submission 155*, pp. 21–22.

[44] Spectrum Labor, *Submission 1*, [p. 11].

[45] ALOA, *Submission 121*, [p. 5].

Services and supports within the justice system

16.30 Despite ongoing efforts to reform the justice system, the OPA Victoria noted that it is still 'ill-equipped and under-resourced to respond effectively to the needs of people with disability'.[46]

16.31 While stakeholders emphasised the importance of accessing diagnostic services and treatment in the justice system,[47] service provision appears to be inconsistent. For example, SPA noted that while there are 'speech pathologists employed in several youth justice facilities, such as in Queensland and South Australia' this is not consistent across detention settings.[48]

16.32 The committee also heard suggestions that there should be more use of diversionary programs. For example, the OPA Victoria advocated for treatment-based detention models, such as the Supervised Treatment Orders (STOs) available to people with intellectual disability in Victoria (see Box 16.2). According to the OPA Victoria, the STO model allows 'intervention at an earlier point than the criminal justice system' which can 'divert persons away from the criminal justice system into the community, albeit with augmented supports and supervision'.[49]

16.33 In addition to the matters raised above, evidence provided to the committee also suggests there are particular issues with:

- a lack of advocacy and access to legal services;
- a lack of appropriate adjustments to justice settings; and
- a lack of clarity about the intersection of justice-sector supports and those funded under the NDIS.[50]

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[46] Office of the Public Advocate Victoria, *Submission 80*, p. 16.

[47] See, for example, Queensland Family and Child Commission, *Submission 36*, p. 6; Name withheld, *Submission 126*, p. 23.

[48] Speech Pathology Australia, *Submission 87*, p. 15. According to SPA, supporting 'speech, language and communication needs' may reduce recidivism via better engagement in 'verbally mediated criminogenic programs and restorative justice practices' and an improved ability to maintain social networks.

[49] Office of the Public Advocate Victoria, *Submission 80*, pp. 18–19.

[50] See, for example, Name withheld, Submission 31.1, p. 1; Positive Youth Incorporated, *Submission 85*, p. 4; Speech Pathology Australia, *Submission 87*, p. 13.

Box 16.2 Supervised Treatment Orders (STOs) (Victoria)

One form of specialist support available to some people with disability is through compulsory treatment under the *Disability Act 2006* (Vic).

The *Disability Act 2006* (Vic) sets out a legal framework for the civil detention and compulsory treatment of people with intellectual disability who are found to pose a significant risk of serious harm to others.

This form of detention is non-punitive and non-custodial. Detention is community-based or in a purpose-built facility. The STO regime aims to bring greater fairness and scrutiny to decisions affecting the personal liberties of people with intellectual disability.

The legislation requires that the person with an intellectual disability derives a 'benefit' from being placed on an STO, and that the levels of restrictions on the person's life be incrementally reduced over time.

An STO can be made by the Victorian Civil and Administrative Tribunal for no longer than 12 months, at which point a new application has to be made and again tested against the legislative criteria.

Source: Office of the Public Advocate Victoria, Submission 80, pp. 18-19.

Advocacy and access to legal services

16.34 Autistic people report difficulties accessing legal advice and representation. For example, one autistic stakeholder stated that of the two free legal services available in their area, one operated for two hours each week and the other for two hours per month. They also reported that their attempt to access the Disability Legal Service was unsuccessful due to resourcing levels that meant there was only one solicitor available to service a large geographical area.[51]

16.35 Even when legal support is available, it is not always useful due to a lack of autism-specific knowledge.[52] In some cases, the committee heard, it can even be detrimental to the interests of autistic clients. For example, an autistic man described how his lawyer did not make an effort to keep him informed about his court case and did not produce any witnesses or exhibits on his behalf. This included not calling witnesses (relatives of the 'purported victim') who had wanted to help him clear his name.[53]

16.36 Accordingly, suggested improvements included the provision of training for all staff involved in court processes, the inclusion of disability advocates throughout court processes, and the introduction of autistic liaison personnel in

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[51] Name withheld, *Submission 131.1*, p. 1.

[52] Name withheld, *Submission 131.1*, p. 1.

[53] Name withheld, *Submission 37*, p. 2.

all courts.[54] Similarly, the OPA Victoria proposed expanding initiatives such as Victoria's Independent Third Person program (see Box 16.3).[55]

Box 16.3 Independent Third Persons (ITP) program (Victoria)

The ITP Program provides independent volunteers on a 24/7 basis. These volunteers help people with cognitive disability, who are attending police interviews, to understand their rights either as suspects, victims or witnesses.

The ITP program has supported more than 40,000 interviews over 32 years. Anecdotally, it has been observed that the ability of people with disability and/or mental illness to communicate their experience and understand their rights increases with the assistance of an ITP volunteer.

Despite the steady and increasing demand for the ITP program, funding has not kept pace, hampering the ability of the program to ensure trained ITPs are available when required.

Current estimates show that about 10 per cent of requests for an ITP do not receive a response. This represents an average of 42 interviews per month where a person misses out on support due to volunteer unavailability, remote location of police stations, or gaps in the roster.

Source: Office of the Public Advocate Victoria, Submission 80, pp. 14-15.

Adjustments to justice settings

16.37 The committee heard that many justice settings were unresponsive to the needs of autistic people. For example, one stakeholder described being forced to participate in a NSW Civil and Administrative Tribunal (NCAT) hearing via telephone. This occurred despite the individual having auditory processing disorder, which means they are unable to process auditory information quickly. The individual had also advised NCAT on two occasions prior to the hearing that they may have difficulties at the hearing because of their autism.[56]

16.38 Similarly, Yellow Ladybugs conveyed the experience of an autistic mother who described how she was unable to access any information—from either Family Court staff or advocacy organisations—about her rights to adjustments during her trial. She also described the Family Court process as rigid and unresponsive to her needs. This included requiring her to participate in verbal interview and attend an assessment in unfamiliar surroundings, as well as the failure of the assessor to take account of her child's autism which resulted in 'inadequate custody recommendations'.[57]

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[54] Yellow Ladybugs, *Submission 49*, pp. 11 and 18.

[55] Office of the Public Advocate Victoria, *Submission 80*, pp. 14–15.

[56] Name withheld, *Submission 131.1*, p. 2.

[57] Yellow Ladybugs, *Submission 49*, p. 15.

16.39 Given the communication difficulties experienced by autistic people, SPA also pointed to the need for justice settings to recognise and accommodate augmentative and alternative communication systems. It also suggested the use of 'trained communication intermediaries' who could work with autistic people to understand their communication needs and provide support during police interviews and in court.[58]

16.40 A similar view was expressed by Mr Philip Morris, who pointed to the importance of involving family, friends and professionals who know the autistic individual in the police interview process. Mr Morris also argued that the physical interview environment should take account of sensory needs.[59]

16.41 Other suggested improvements included the provision of autism-friendly information—including social stories—on court websites, allowing visits to court facilities prior to hearing dates, and the availability of sensory rooms within court facilities.[60]

The intersection of justice-sector and NDIS-funded supports

16.42 The Australian Government's response to the final report of the Joint Standing Committee on the NDIS on its inquiry into NDIS planning made clear that:

> …all governments have agreed that states and territory criminal justice systems continue to be responsible for meeting the needs of people with disability while they are in detention and for reasonable adjustment in such settings. Supports, above reasonable adjustments made by the criminal justice systems, may be funded by the NDIS and accessed by the participant during their incarceration.[61]

16.43 However, it appears from evidence presented to the committee that the demarcation of responsibility for service provision may not be clearly understood by autistic people and their families. For example, one submitter stated that 'people in the criminal justice system cannot get access to paid therapies and supports through the NDIS'.[62]

16.44 While stakeholders such as the OPA Victoria did recognise the divide in responsibilities, it called for governments to 'abide by the *Principles to Determine the Responsibilities of the NDIS and Other Service Systems* … with specific reference to the principles applying to the criminal justice system'.[63]

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[58] Speech Pathology Australia, *Submission 87*, p. 14.

[59] Mr Philip Morris, *Submission 25*, [p. 4].

[60] Yellow Ladybugs, *Submission 49*, p. 18.

[61] Senator the Hon Richard Colbeck, Minister for Sport and Minister for Senior Australians and Aged Care Services, *Senate Hansard*, 23 February 2021, p. 1329.

[62] Name withheld, *Submission 126*, p. 23.

[63] Office of the Public Advocate Victoria, *Submission 80*, p. 18.

Transitions out of detention settings

16.45 The move from a detention setting into the community is a high-risk transition point for autistic people.[64] The OPA Victoria cited a 2015 Victorian Ombudsman report which found an increased risk of death—mostly from causes related to mental health—in the months following release. It also identified housing insecurity as a key predictor of a return to prison. Both the risk of re-offending and the increased mortality risk were linked to 'a failure to organise wrap-around supports at a time when individuals are rebuilding their lives'.[65]

16.46 The OPA Victoria argued that quality 'through care', including pre-release planning, is critical to the success of prisoners' transitions into the community. Quality through care relies on correctional staff engaging prisoners in the planning process, the involvement of the NDIA (where applicable), as well as the availability, integration and coordination of support services, including community-based specialised supports.[66]

16.47 However, the OPA Victoria also noted that there was a shortage of community-based supports for transitioning prisoners. The reasons for this shortage were thought to include limited funding, provider unwillingness to take on offenders, and an increase in the 'prevalence and severity of mental illness and disability among prisoners'.[67] The experience of a prisoner named 'Mark' was used to illustrate the effect of poor through care and a lack of supports for those leaving prison settings (see Box 16.4).

Box 16.4 Case study: OPA Victoria – Mark

OPA Victoria received a letter from Mark, who identified as having autism, mental health issues, and substance abuse. For many years, he cycled in and out of prison.

Mark has good insight into the risk he can pose if he is not well-supported when living in the community. He expresses a strong desire to contribute positively to his community but acknowledges that he needs supports to do this and is proactive in seeking them. For instance, in preparation for a previous release from prison, he requested a prison support worker to establish a transition support plan where he requested assistance with housing, Centrelink, mental health, and substance abuse services.

However, a few days before his release, he had not yet heard back from the support worker to know how to access the supports on release. He reminded the prison staff of his request but never received an answer. Mark was released in the evening with none of the supports he identified and nowhere to go.

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[64] Office of the Public Advocate Victoria, *Submission 80*, p. 16.

[65] Office of the Public Advocate Victoria, *Submission 80*, p. 17.

[66] Office of the Public Advocate Victoria, *Submission 80*, pp. 16 and 17.

[67] Office of the Public Advocate Victoria, *Submission 80*, p. 16.

When OPA spoke to Mark, in response to his letter, he was in custody in a maximum-security prison with an upcoming release date. He was distressed about returning to the community and while he hoped this release would be more successful than the last, he had not received any support from prison staff to set himself up for a successful transition back to the community. OPA asked Mark whether he had an NDIS plan, but he was not aware of the scheme or how to access it. He remained optimistic and sought assistance from OPA in the absence of any pre-release planning.

Source: Office of the Public Advocate Victoria, Submission 80, pp. 16-17.

16.48 In addition, there were also mixed views about the success of the NDIS in supporting transitions out of detention settings, particular for those with complex needs. For example, the Northern Territory Office of the Public Guardian noted that the NDIS Complex Support Needs Pathway has had positive impacts on the outcomes of autistic prisoners transitioning into the community.[68] Similarly, both the Government of Western Australia and OPA Victoria welcomed the introduction of NDIS Justice Liaison Officers (see Box 16.5).[69] However, the OPA Victoria also identified challenges in relation to establishing NDIS plans for prisoners prior to release, as well as the need to address provider of last resort arrangements.[70]

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[68] Northern Territory Office of the Public Guardian, *Submission 20*, [pp. 6-7].

[69] Government of Western Australia, *Submission 103*, p. 8; Office of the Public Advocate Victoria, *Submission 80*, p. 20.

[70] Office of the Public Advocate Victoria, *Submission 80*, pp. 17 and 20. Providers of last resort may be needed in address gaps in a market-based system like the NDIS. These gaps may relate to a lack of appropriate, skilled providers, or situations where providers choose not to take on clients with complex needs.

Box 16.5 NDIS Justice Liaison Officers (JLOs)

JLOs provide a single point of contact for workers within state and territory justice systems to coordinate support for NDIS participants in youth and adult justice systems.

Th scope of the JLO role includes:

- promoting understanding of the NDIS within prisons and correctional facilities to support prison entry and discharge and community transition;
- promoting awareness of the scope of supports and services provided through the NDIS to key justice staff and stakeholders;
- building connections between government and community services and the NDIA to ensure the right information is available for the planning process;
- working with Local Area Coordinators and Planners as appropriate; and
- providing strategic advice to the broader NDIA on improving the capability of NDIS representative in relation to the justice interface.

Source: Department of Social Services, Department of Education, Skills and Employment, Department of Health, Submission 53, p. 22; NDIS Complex Support Needs Briefing, www.communityservices.act.gov.au/__data/assets/powerpoint_doc/0005/1455242/02-Coyne.pptx *(accessed 13 November 2021).*

Committee view

16.49 Effective justice system responses to the complex needs and vulnerabilities of people with disability is an identified policy priority in *Australia's Disability Strategy 2021–2031*.[71] However, as with other service sectors, the committee is disturbed by the poor experiences and outcomes of autistic people who come into contact with the justice system.

16.50 The committee is also concerned about the lack of accurate data on the numbers of autistic people in the justice system. Without this data, it is impossible to monitor the extent of overrepresentation, or whether reforms to the justice system are making a difference in outcomes for autistic people. However, the committee notes that there is work underway to improve data sharing between the National Disability Insurance Scheme (NDIS) and state and territory justice systems and encourages this work to be expedited.

16.51 Overall, autistic people's interactions with the justice system appear to be the result of underlying disadvantage, such as poverty and insecure housing, as well as compounding service delivery failures. Again, it is autistic people with complex support needs that tend to fare the worst.

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[71] Department of Social Services, *Australia's Disability Strategy 2021-2031*, p. 18.

16.52 The committee notes that the introduction of the Complex Support Needs Pathway has been welcomed by stakeholders as a positive development. However, the committee was troubled by evidence that this pathway appears to react to, rather than avert, escalating needs and behaviours. Based on the evidence provided, it is likely that earlier access to the Complex Support Needs Pathway could prevent some autistic people from coming into contact with the justice system.

16.53 Given the poor outcomes for justice-engaged autistic people, the committee suggests that there is also a need to investigate options for diversionary programs where appropriate.

Recommendation 73

16.54 The committee recommends that, as part of the inquiry into the National Disability Insurance Scheme proposed in Recommendation 6, the Complex Support Needs Pathway be reviewed to ensure its focus is on preventing (rather than responding to) escalating behaviours that may result in interactions with the justice system.

Recommendation 74

16.55 The committee recommends that the Australian Government work with states and territory governments and relevant stakeholders to investigate options for diversionary programs, rather that custodial sentences, where appropriate.

16.56 As with other service sectors, understanding of autism within the justice system is poor. Unsurprisingly, this has led to poor experiences for autistic people and a subsequent lack of trust between the autistic community and those working in the police and court systems.

16.57 Of particular concern to the committee is the impact this lack of trust has on the willingness of autistic people to disclose their diagnosis. While the committee understands this hesitancy, it is concerned that non-disclosure results in autistic people missing out on appropriate supports.

16.58 Accordingly, the committee supports stakeholder calls for better education and training for justice system personnel, as well as a greater emphasis on community policing approaches to improve relationships between the police and the autistic community.

16.59 There is also a need to focus on building a culture within all justice system settings, where autistic people feel supported to disclose their diagnosis, or seek a diagnosis where autism may be suspected.

Recommendation 75

16.60 The committee recommends embedding autism as part of initial education courses and ongoing professional development requirements for all

personnel involved in the justice system, including police, lawyers, and court staff.

Recommendation 76

16.61 **The committee recommends that all jurisdictions encourage the adoption of community policing approaches in order to build understanding and trust between police and the autistic community.**

Recommendation 77

16.62 **The committee recommends that the Australian Government work with states and territory governments to promote a culture in the justice system where autistic people feel supported to disclose their diagnosis and where people with undiagnosed disabilities feel comfortable requesting an assessment.**

16.63 Evidence provided to the committee suggests there is a failure in most justice settings to make adjustments that accommodate the needs of autistic people. In the committee's view, there is a need to develop additional guidance to inform changes to the way information is provided to autistic individuals, as well as adjustments to physical environments and police and court processes.

16.64 The committee also notes that Victoria appears to be the only Australian jurisdiction with an 'independent third person' program designed to help people with disability who are engaged with the justice system. The committee believes that programs such as this are an important safeguard that should be implemented more widely to support autistic people.

Recommendation 78

16.65 **The committee recommends that the Australian Government work with state and territory governments and relevant stakeholders to develop nationally consistent guidance on the type of adjustments that should be made available to autistic people in justice settings. This should include:**

- **the provision of autism-friendly information resources;**
- **the involvement of disability advocates as standard practice in police interviews and during court proceedings; and**
- **adjustments to physical environments and police and court interview processes.**

16.66 The committee notes that, as with other service sectors, the interface between the justice sector and NDIS-funded services is a long-standing issue, which has been the subject of recommendations of the Joint Standing Committee on the NDIS in both 2017 and again in 2020. These recommendations related to the need to:

- clarify what approved supports are available to NDIS participants in custody and how the National Disability Insurance Agency (NDIA) monitors and ensures NDIS participants access the supports they are entitled to while in custody;
- establish a NDIA unit specialising in the interaction of the NDIS with the criminal justice system;
- consider the appropriate division of responsibility for the funding of supports for participants in the criminal justice system; and
- develop, publish and implement a strategy for engaging with participants in custody to ensure that these participants:
  - are not unfairly disadvantaged in planning; and
  - are assigned to planners who have the expertise to work with them.[72]

16.67 In light of evidence provided to the committee, it is not clear whether the response to these recommendations has been adequate or effective.

Recommendation 79

16.68 The committee recommends that, as part of the inquiry into the National Disability Insurance Scheme proposed in Recommendation 6, the effectiveness of the National Disability Insurance Agency's response to previous recommendations of the Joint Standing Committee on the NDIS be assessed in relation to support for autistic people within the justice system.

16.69 While transitions out of prison can be difficult for many people, they are a particularly high-risk time for autistic individuals. In addition to reports of a lack of community supports for transitioning prisoners, the committee heard mixed reports about the adequacy of NDIS support for these transitions, including in relation to:

- the Complex Support Needs Pathway;
- the introduction of Justice Liaison Officers;
- challenges establishing NDIS plans for prisoners prior to release; and
- provider of last resort arrangements.

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[72] Joint Standing Committee on the National Disability Insurance Scheme, *NDIS Final Planning Report*, December 2020, pp. 87 and 110.

16.70 The committee notes that the Joint Standing Committee on the National Disability Insurance Scheme has previously recommended that the NDIA:

- publish information about the Complex Supports Needs pathway, including about who is eligible, and how the NDIA defines the term 'complex support needs';[73] and
- as a matter of urgency, publicly release the outcomes of the Maintaining Critical Supports project and its policy on provider of last resort arrangements.[74]

16.71 Based on the evidence provided to the committee, it is not clear what actions have been taken in response to these recommendations.

Recommendation 80

16.72 The committee recommends that the National Disability Insurance Agency publish:

- **the findings of its review into the Complex Support Needs Pathway; and**
- **the Maintaining Critical Supports Framework, including its policy on provider of last resort arrangements.**

Recommendation 81

16.73 The committee recommends that, as part of the inquiry into the National Disability Insurance Scheme proposed in Recommendation 6, the effectiveness of the Justice Liaison Officer program be assessed in relation to supporting the transition of autistic people from detention settings into the community.

Senator Hollie Hughes
Chair

Senator Carol Brown
Deputy Chair

Senator Jim Molan AO DSC
Member

Senator Marielle Smith
Member

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[73] Joint Standing Committee on the National Disability Insurance Scheme, *NDIS Final Planning Report*, December 2020, p. 199.

[74] Joint Standing Committee on the National Disability Insurance Scheme, *Market readiness for provision of services under the NDIS*, September 2018, p. 78.

Australian Greens Senators' dissenting report

1.1 The Australian Greens are deeply grateful for the advocacy, submissions, time and expertise contributed to this inquiry by autistic people. We acknowledge that the scrutiny of this committee has at times been confronting, requiring great vulnerability and significant emotional labour. Your continued involvement has allowed for the voices of those with lived experiences to be heard. The Australian Greens also acknowledge the valuable engagement of autistic-led organisations, family members of autistic people and family led advocacy organisations.

1.2 The inquiry undertaken by this committee had significant potential. Rarely has the parliament been presented with a chance to engage so deeply with a group within the Australian community whose neurodiversity offers such a profound opportunity for transformative change. The committee also had the opportunity to dedicate itself to centring the lived experience of autistic people and systematically examining the barriers which ableism creates for them. We had the opportunity to listen authentically to the perspectives of parents of autistic children and unpack the complex power dynamics that exist at the intersection of disability rights, the rights of the child, parental rights and the right to self-determination. We had the opportunity to scrutinise foundational assumptions regarding 'normalised' forms of social interaction, the nature of disability and the meaning of accessibility.

1.3 It is with genuine sadness that the Australian Greens express the view that the committee did not embrace these opportunities and as a result has produced a report that, while containing some recommendations we support, stops far short of calling for the bold, transformational changes that we believe are needed.

Flawed conceptual basis

1.4 This committee should have always prioritised an evidence-informed, human rights-based conception of disability at its centre, which the recommendations and conclusions produced should be aligned with.

1.5 Instead, the report has been built through the lens of the medical model of disability,[1] which places the autistic individual at the centre of the problem to be inherently 'fixed'. This model encourages the idea that a disabled person should be cured and that the 'real' issue is the individual rather than the ableist barriers with the society around them. Recommendations that are based on this framework are not sufficient for creating meaningful change for autistic people as they will almost always focus on what is 'wrong' with them, rather than what

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[1] Disability Australia Hub, *Disability*, https://www.disabilityaustraliahub.com.au/disability/.

can be done to improve their access to personalised supports which meet their individualised needs.

1.6 Disability should always be viewed as a result of the way that society is organised, rather than by an individual's impairment. The Australian Greens utilise the social model of disability[2] which champions this and encourages the removal of barriers that are preventing disabled people from participating in society on an equivalent basis with those around them. Providing solutions that are centred on these barriers in society is crucial to improving the ability of disabled people to thrive and contribute to their communities in a meaningful, positive and equal manner. The social model acknowledges that ableism exists and constantly enforces the barriers that autistic and neurodiverse people face. When combined with the affirmative model, which embraces disability as an identity, it celebrates the contribution that neurodiverse and autistic people make to society, with an assertion of their right to have that contribution and their humanity recognised separate to that of their families.

1.7 The Australian Greens have repeatedly made informed choices about the language used to describe disabled people. In doing so, we have consistently emphasised the significant contribution made by disabled people, autistic people, to their communities. These decisions are crucial to ensuring that no individual in a community feels ostracised, neglected, incorrectly defined, or stereotyped by the policies informing their standards of living. We are concerned about a lack of consideration in this report for the unique lived experiences of those with varying access and support needs. The language pertains to descriptions utilised in the medical model of disability, often describing a shared experience rather than acknowledging the lived realities across the entire autistic community. The implications of this language throughout this report could be highly consequential for perceptions and stigmas of the community. This includes placing individuals on a spectrum as to their level of autism, as often utilised in a medical framework, which implies assumptions about the person and the environment they live in. The Australian Greens support a linguistic approach that does not further stigmatise the autistic community, but rather, that champions the strengths and contributions of this cohort in our society.

1.8 Our concern regarding language choices extends to those relating to the best support and decisions for an autistic child. For example, implying that support for families and carers should include respite facilities suggests that the family needs a break from their child, potentially reinforcing the young person's view that they are a burden on their family. Rather, the report should focus on the individual developing skills and recuperation through out of home care and

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[2] https://jordon-steele-john.greensmps.org.au/articles/jordon-steele-john-social-model-disability.

support. Reframing these discussions to focus on the growth and success of the child are essential.

Case Study: Inclusive education

1.9 Research has supported inclusive education for decades, while many suggestions in the report may intentionally, or unintentionally, allow for the consideration of a segregated classroom setting. Temporary segregated settings, as mentioned in this report, are also springboards for more permanent settings of this nature and replicate current obstructions to employment that an autistic child will experience throughout their life. By failing to explicitly call for a transition to a fully inclusive mainstream education system, the recommendations leave open the possibility of continued segregated education.

1.10 The Australian Greens will lead the transition to a fully inclusive education system by 2030, through investing an initial $10 million over four years to co-design a National Inclusive Education Transition Plan with disabled people, families, disability representative organisations, education experts, teachers, and their unions. The Australian Greens are committed to building inclusive education into tertiary qualifications and giving all pre-service and in-service teachers and principals the opportunity to train, retrain and regularly upskill in inclusive education practices by investing $400 million over four years.

1.11 The Australian Greens position on inclusive education for autistic children and disabled people is supported by the Royal Commission into Institutional Responses to Child Sexual Abuse, which identified segregation of children with disabilities as a setting-based factor resulting in an increased risk of abuse of children with disabilities.[3] Further, the UN Committee on the Rights of Persons with Disabilities provides the following useful definition in its general comment on the right to education under Article 24, as practices that must be distinguished from inclusive education:

> Exclusion occurs when students are directly or indirectly prevented from or denied access to education in any form.
>
> Segregation occurs when the education of students with disabilities is provided in separate environments designed or used to respond to a particular or various impairments, in isolation from students without disabilities.
>
> Integration is a process of placing persons with disabilities in existing mainstream educational institutions, as long as the former can adjust to the standardised requirements of such institutions.[4]

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[3] Royal Commission into Institutional Responses to Child Sexual Abuse, *A Brief Guide to the Final Report: Disability*, December 2017, p. 4.

[4] Committee on the Rights of Persons with Disabilities, *General comment No. 4 (2016), Article 24: Right to inclusive education*, p. 4, https://allmeansall.org.au/wp-content/uploads/2021/12/General-Comment-No.4.pdf.

1.12 The Australian Greens also have concerns about the elevation of 'expert advice' over the lived experience of autistic people. Many experts almost always come from a medical approach, applying clinical or therapeutic approaches without understanding the reasonable adjustments required in a regular classroom. Any adjustments to ensure an inclusive setting should be person centred and agreed with students and families with input from educators and 'experts'. Additionally, a consideration that being surrounded by peers is the key to deconstructing feelings of isolation and limiting the potential for a society of ableism should remain at the forefront of any new arrangements.

1.13 There are currently no incentives for the regular schooling system to change their practices in relation to inclusive education, with no oversight mechanisms and punishment for 'gatekeeping'. The Australian Coalition for Inclusive Education Roadmap calls for; a national zero tolerance approach and punitive consequences for gatekeeping practices, insists that families and schools be assisted to have a better understanding of what this is and when it occurs, plus have access to robust, transparent and effective mechanisms to make complaints and have them remedied at a school level, and access to an independent national oversight body/commission if the complaint is not resolved. Schools should also be required to record the number of enrolments they have refused or discouraged and the reasons why.[5] Schools should be accountable for their ratios of disabled students.

Key issues in the report's outline for the construction and role of a National Autism Strategy

1.14 The Australian Greens commend that this report has placed the development of a National Autism Strategy as a primary recommendation. However, we have concerns about its design and the consultative process as laid out in this report. Below, we have outlined concerns relating to the strategy as pertaining to this recommendation:

> That the Australian Government develop a National Autism Strategy and accompanying implementation within 12 months to drive nationally coordinated action to improve services and supports for autistic Australians. The National Autism Strategy should:
>
> - be both person- and family-centred;
> - address whole-of-life needs for people across the breadth of the spectrum;
> - align with other national strategies, including the National Disability Strategy; and

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[5] Australian Coalition for Inclusive Education, *Driving change: A roadmap for achieving inclusive education in Australia*, February 2021, p. 10, https://acie105204494.files.wordpress.com/2021/02/acie-roadmap-final-11-feb-2021.pdf.

- be informed by the recommendations of this inquiry and the Disability Royal Commission.

The implied intersection between the needs of the autistic individual and those of the family member

1.15 This report is widely based on an assumption that the family of an autistic person knows that person the best and can therefore make the best decisions for them. The outcome of this assumption can be clearly seen in the recommendation that the National Autism Strategy 'be both person- and family-centred'. This conflation of the needs of the family and the needs of the autistic person risks prioritising the rights of the parents at the expense of autistic children and adults, particularly relating to their autonomy in decision making. The access needs and supports required for these groups often are unique and should not be considered inherently aligned.

1.16 It is essential that the voices of those with lived experiences are uniquely considered in the development and implementation of a National Autism Strategy. Developed alongside this strategy that focuses on the needs of an autistic individual, should be a separate strategy which targets research, direction and support for family members and carers of autistic people considered closely with, but separate from, the National Autism Strategy. This would not take away from the validity of the experiences of family members but would allow this perspective to be assessed and policy changes recommended in an independent environment that does not overshadow the views of autistic individuals. This separate strategy should support family members to journey alongside autistic members of their family in achieving human rights-based outcomes for the people that they care about.

Co-design process

1.17 Whilst the National Autism Strategy should account for the recommendations of this inquiry, its design and implementation should be driven by genuine co-design process, driven by autistic people and their chosen support networks. This co-design process should cover all elements of the strategy and its metrics of success, developing a strategy that is meaningful, meets the needs of the autistic community and can be a successful driver for change.

Recognition of comorbidities

1.18 Autism has an extremely high comorbidity rate with other disabilities. In order to adequately respond to this, the National Autism Strategy should be closely integrated with the National Disability Strategy, ensuring that they do not contradict each other and so that the latter has a strong emphasis on addressing barriers for autistic people These strategies should complement each other, rather than work in parallel.

Recommendation 1

1.19 That the Australian Government takes urgent steps to ensure that all policies relating to autistic people:

- **place the perspective of autistic people at the centre;**
- **are evidence informed and human rights-based;**
- **are informed by the social and affirmative model of disability; and**
- **are aligned with Australia's commitments under the United Nations Convention on the Rights of People with Disabilities.**

Recommendation 2

1.20 That the National Autism Strategy:

- **closely align with the National Disability Strategy to recognise the interaction between autism and other disabilities and mental illnesses;**
- **focus on the autistic community and that a separate strategy is considered which focuses on the families and carers to recognise the individual access needs and support requirements of these two groups; and**
- **is created through a process of co-design with autistic people and those they choose as support people, the Disability Royal Commission and stakeholder groups, with the recognition that its design may or may not align with the recommendations of this report.**

Recommendation 3

1.21 That the Australian Government transition to a fully inclusive education system by 2030, through a National Inclusive Education Transition Plan with disabled people, families, disability representative organisations, education experts, teachers, and their unions.

Recommendation 4

1.22 All further research, education and training relating to autistic people should be co-designed and co-delivered by autistic people.

Recommendation 5

1.23 That an easy-read version of the committee's report and this dissenting report be distributed so that it is widely accessible to the autistic community.

Senator Jordon Steele-John
Member

Appendix 1
Public hearings and witnesses

Monday, 27 July 2020
Committee Room 2S3
Parliament House
Canberra

Marymead Autism Centre
- Ms Camilla Rowland, CEO
- Ms Mitzi Polacsek, Team Leader

Imagine More
- Ms Adrienne Gault, Director

Autism Aspergers Advocacy Australia
- Mr Bob Buckley, Convener

Krofne Donuts
- Mrs Danijela Vrkic, Founder
- Dr Matthew Yoxall, Consultant

National Disability Insurance Agency
- Mr Martin Hoffman, CEO
- Mr Peter De Natris, Strategic Adviser-Early Childhood Intervention and Autism
- Ms Sarah Johnson, Scheme Actuary

Department of Social Services
- Ms Sarah Hawke, Branch Manager, Participant Outcomes
- Mr Peter Broadhead, Group Manager, Participants and Performance

Tuesday, 28 July 2020
York Room, The Grace Hotel
77 York Street
Sydney

Autism Awareness Australia
- Ms Nicole Rogerson, CEO

Australian Autism Alliance
- Mr Terry Burke, Alliance Co-Chair
- Mr Paul Micallef, Alliance Co-Chair
- Ms Fiona Sharkie, Amaze CEO

- Prof Sandra Jones, National Operations Manager

Xceptional

- Mr Michael Tozer, CEO
- Ms Nicole Done, Head of Training & Coaching
- Ms Sarah Eglington, Software Engineer (via teleconference)

Mr Rhett Ellis, Private capacity

The Royal Australasian College of Physicians

- Dr Jacqueline Small, President-Elect

SDN Children's Services

- Ms Kay Turner, CEO

Autism Advisory and Support Service

- Mrs Grace Fava, OAM, CEO

NSW Health

- Dr Murray Wright, NSW Chief Psychiatrist
- Dr Matthew O'Meara, NSW Chief Paediatrician (via teleconference)

Friday, 31 July 2020

Cataline Dehavilland Room
Royal on the Park
152 Alice Street
Brisbane

Autism CRC

- Mr Andrew Davis, CEO
- Prof Suzanne Carrington, Program Director, School Years Program
- Prof Andrew Whitehouse, Research Strategy Director (via teleconference)

SunPork Farms

- Ms Kirsty Richards, Autistic and Agriculture Employment Program Manager

Autism Queensland

- Ms Pam Macrossan, CEO
- Ms Frances Scodellaro, COO

Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University

- Dr David Harley, Director
- Dr Kate Brooker, Postdoctoral Research Fellow
- Ms Pia Bradshaw, PhD Scholar

- Dr Anna Urbanowicz, Postdoctoral Research Fellow (via teleconference)
- Mrs Hayley Clapham, Autistic Advisor (via teleconference)
- Mr Chris Tanner, Autistic Advisor (via teleconference)

Ashton's Place

- Ms Viryan Collins-Rubie, Founder

AEIOU Foundation

- Ms Nicola Morgan

Queensland Department of Education

- Mrs Deborah Dunstone, Assistant Director-General

Monday, 16 November 2020

James Alexander Room
Mecure Grosvenor Hotel
125 North Terrace
Adelaide

Mr Domenic Mittiga, Private capacity

Autism SA

- Ms Jenny Karavolos, Chief Executive Officer

Dr Peter Walker, Private capacity

Professor Robyn Young, Private capacity

JFA Purple Orange

- Mr Robbi Williams, Chief Executive Officer
- Ms Skye Kakoschke-Moore, Policy and Research Leader
- Ms Letitia Rose, Project Specialist - Inclusive Education

Emerging Minds

- Mr Brad Morgan, Director, National Workforce Centre for Child Mental Health

Commissioner for Children and Young People, South Australia

- Ms Helen Connolly

Thursday, 11 February 2021
Flinders Room
Mantra on Russell
222 Russell Street
Melbourne

Irabina Autism Services

- Ms Debra Goldfinch, Chief Executive Officer
- Dr Jose Molina, Chief Practitioner

Amaze

- Ms Fiona Sharkie, Chief Executive Officer
- Ms Chloe Hayden, Autism Advocate & Actor
- Ms Janet Bailie, Autism Connect Advisor

Autism Behavioural Intervention Association (ABIA)

- Ms Susie Pavey, Chief Executive Officer
- Dr Erin Leif, Vice President, ABIA Board

I CAN Network Ltd

- Mr Chris Varney, Chief Executive Officer & Founder
- Mr David Legge, Deputy Chair
- Ms Stacey McEwan, National Online Program Manager
- Dr James Ong, Evaluation, Program Support and Policy Analyst
- Mr Adon Skaltsis, Student Mentee

Different Journeys

- Ms Mel Spencer, Executive Officer & Co-founder
- Mrs Merrin Ayton, Co-founder

Yellow Ladybugs

- Ms Natasha Staheli, Strategic Relationships and Policy Advisor

Specialisterne Australia (via teleconference)

- Mr Jason White, National Manager, Business Development and Engagement

DXC Technology

- Mr Michael Fieldhouse, DXC Dandelion Program Executive & Social Impact Practice Leader

Learning for Life Autism Centre

- Ms Sarah Wood, Head of Psychological Services
- Ms Emma Miller, Clinical Director

Monash University

- Dr Amanda Brignell, Postdoctoral Research Fellow and Speech Pathologist, Department of Paediatrics
- Dr Alexandra Ure, Research Fellow and Clinical Psychologist, Department of Paediatrics
- Dr Georgina Cox, Research Fellow and Clinical Psychologist, Department of Paediatrics
- Dr Katrina Williams, Professor of Paediatrics and Head of Department

Friday, 12 February 2021

Flinders Room
Mantra on Russell
222 Russell Street
Melbourne

Australian Autism Alliance

- Ms Fiona Sharkie, Alliance Co-Chair
- Mr Paul Micallef, Alliance Co-Chair
- Mr Ben Biro, Community Member

Aspergers Victoria Inc.

- Mrs Tamsin Jowett, President
- Mrs Carla Tatulaschwili, General Manager
- Ms Ellen Gould, Youth Representative
- Mr Jack Jowett
- Ms Sofia Neale, Employment Project Manager

The Autistic Realm Australia

- Ms Anna Colbasso, Co-Founder and Board Member
- Mrs Kylieanne Derwent, Co-Founder and Vice Chair
- Mrs Kathy Isaacs, Chair of the Board

Scope-University of Melbourne Partnership

- Professor Keith McVilly, Professor of Disability & Inclusion
- Ms Stephanie Weir, Speech Pathologist

La Trobe University - the Olga Tennison Autism Research Centre (OTARC)

- Professor Cheryl Dissanayake, Director and Chair
- Professor Alison Lane, Deputy Director
- Professor Amanda Richdale, Professorial Research Fellow

Mindful

- Associate Professor Sandra Radovini, Director
- Ms Frances Saunders, State-wide Autism Spectrum Disorder (ASD) Training Coordinator

Wednesday, 3 March 2021
Avro Room
Royal on the Park
152 Alice Street
Brisbane

Autism CRC
- Mr Andrew Davis, Chief Executive Officer
- Professor Suzanne Carrington, Researcher/Program Director
- Professor Andrew Whitehouse, Research Strategy Director (via teleconference)

SunPork Farms
- Ms Kirsty Richards, Program Lead, Autism and Agriculture

Ashton's Place
- Ms Viryan Collins-Rubie, Founder

Autism Queensland Ltd
- Ms Pam Macrossan, Chief Executive Officer
- Ms Frances Scodellaro, Chief Operations Officer

Ms Laura Lewis, Private capacity
- Mr Clay Lewis, (individual capacity)

Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University
- Dr Katie Brooker, Postdoctoral Research Fellow
- Dr David Harley, Director
- Ms Pia Bradshaw, PhD Scholar

AEIOU Foundation
- Mr Alan Smith, Chief Executive Officer
- Mr Shane Klintworth, General Manager, Operations and Corporate Services
- Dr James Morton, Founder, Board Director and Patron
- Mr Sean Redmond, NDIS Transition Support Coordinator

The Sycamore School
- Ms Jodi Schmidt, Board Chair
- Mrs Cindy Corrie, Founder and Board Director

Queensland Department of Education
- Mrs Deborah Dunstone, Assistant Director General, State Schools - Disability and Inclusion

Thursday, 15 April 2021

York Room
The Grace Hotel
77 York Street
Sydney

ND Australia

- Professor Adam Guastella, Chief Clinical Advisor and Founder

PEERS Australia

- Ms Beverley Witherington, Director

Family Planning NSW

- Ms Ee-Lin Chang, Senior Health Promotion Officer - Disability
- Ms Eliza Basheer, Senior Policy Officer

WithYouWithMe

- Mr Tom Moore, Co-Founder and CEO
- Mr Rhett Ellis, Autism Specialist

Auticon

- Mr Bodo Mann, Chief Executive Officer & Managing Director

Department of Developmental Disability Neuropsychiatry (3DN), Faculty of Medicine, UNSW Sydney

- Dr Samuel Arnold, Lecturer and Postdoctoral Research Fellow, Department of Developmental Disability Neuropsychiatry, School of Psychiatry, UNSW
- Professor Julian Trollor, Chair, Intellectual Disability Mental Health Head, Department of Developmental Disability Neuropsychiatry Professor, School of Psychiatry UNSW

Wednesday, 28 April 2021

Chancellor Rooms 3 and 4
Hotel Grand Chancellor
29 Cameron Street
Launceston

Ms Geraldine Robertson, Private capacity

Mr Philip StEvens, Private capacity

Mr David Donald, Private capacity

atWork Australia

- Mrs Joanne Shires, Service Manager

St Giles Society Limited
- Mr Andrew Billing, Chief Executive Officer
- Ms Kathryn Fordyce, General Manager - Specialist Services

Thursday, 29 April 2021

Marina Room
Hobart Function and Conference Centre
1 Elizabeth St Pier
Hobart

Autism Tasmania
- Mr Kieran McDonald, Board Chair
- Mrs Donna Blanchard, Chief Executive Officer

Mrs Roslyn Ward, Private capacity
- Mr Mark Ward

Tertiary Autism Mentoring Community of Practice
- Ms Debbie Hindle, Specialist Peer Mentor Program Coordinator

Ms Rosie Martin, Private capacity

Cassie's Place - Child and Adolescent Psychology
- Mrs Cassie Xintavelonis, Clinical Psychologist

Mr Daniel Zomerdyk, Private capacity

Dr Lisa Gershwin, Private capacity

Ms Christine Wright, Private capacity

Appendix 2
Submissions and additional information

1 Spectrum Labor
  - Attachment 1
  - Attachment 2
  - Attachment 3

2 *Name Withheld*
3 *Name Withheld*
4 *Name Withheld*
5 *Name Withheld*
6 *Name Withheld*
7 *Name Withheld*
8 Mr Philip Gluyas
  - 8.1 Supplementary to submission 8
  - Attachment 1
  - Attachment 2
  - Attachment 3
  - Attachment 4
  - Attachment 5
  - Attachment 6
  - Attachment 7
  - Attachment 8

9 *Name Withheld*
10 Mr Garry Burge
11 *Name Withheld*
12 *Name Withheld*
13 Australian National Audit Office
14 Ms Tamika Hicks
15 CliniKids
16 *Name Withheld*
17 Royal Australian and New Zealand College of Psychiatrists
  - 17.1 Supplementary to submission 17

18 Dr Kerry Chillemi
19 Tasmanian Government
20 Northern Territory Office of the Public Guardian
21 Autism Advisory and Support Service
  - 21.1 Supplementary to submission 21

22 Autism Family Support Association
  - 22.1 Supplementary to submission 22

- 22.2 Supplementary to submission 22
- 22.3 Supplementary to submission 22
- Attachment 1
- Attachment 2
- Attachment 3

23 Dr Martina Waring
24 Reframing Autism Ltd
25 Mr Philip Morris
26 TALi Health
27 Audiology Australia
28 Family Planning NSW
29 The Royal Australasian College of Physicians
30 Different Journeys
31 *Name Withheld*
32 *Name Withheld*
33 *Confidential*
34 *Confidential*
35 The Royal Australian College of General Practitioners (RACGP)
36 The Queensland Family and Child Commission (QFCC)
37 *Name Withheld*
38 *Name Withheld*
39 Dr Bruce Baer Arnold
40 Australian Medical Association
41 *Name Withheld*
42 Commissioner for Children and Young People – Western Australia

- Attachment 1

43 Assistance Dogs Australia
44 SDN Childrens Services
45 Mr Rhett Ellis
46 Autism CRC
47 Autism Awareness Australia
48 Xceptional
49 Yellow Ladybugs
50 AEIOU Foundation

- Attachment 1

51 Queensland Centre for Intellectual and Developmental Disability, University of Queensland and the Social Global Studies Centre, RMIT University
52 Australian Autism Alliance

- 52.1 Supplementary to submission 52
- 52.2 Supplementary to submission 52
- 52.3 Supplementary to submission 52

53 Joint submission from the Department of Social Services, Department of Education, Skills and Employment, and Department of Health

54 Autism Aspergers Advocacy Australia (A4)

- Attachment 1

55 La Trobe University - the Olga Tennison Autism Research Centre (OTARC)

56 National Disability Insurance Agency

57 Krofne

58 Ashton's Place

59 *Name Withheld*

60 *Name Withheld*

61 *Name Withheld*

62 *Name Withheld*

63 *Name Withheld*

64 Autism Spectrum Australia (Aspect)

65 NSW Government

66 Services Australia

67 Specialisterne Australia

68 DXC Technology

- Attachment 1
- Attachment 2
- Attachment 3
- Attachment 4
- Attachment 5

69 Queensland Nurses and Midwives' Union

70 ABIA

71 Carers NSW

72 St Vincent’s Health Australia

73 Mentoring Autism Community of Practice

74 Australian Institute of Health and Welfare (AIHW)

75 Ethnic Disability Advocacy Centre (EDAC)

76 Early Start Australia

77 *Name Withheld*

78 *Name Withheld*

79 *Name Withheld*

80 Office of the Public Advocate - Victoria

81 *Name Withheld*

82 *Name Withheld*

83 Scope-University of Melbourne Partnership

84 JFA Purple Orange

85 Positive Youth Incorporated

86 The Autistic Realm Australia

87 Speech Pathology Australia

88 Commissioner for Children and Young People, South Australia

89 Emerging Minds
90 Aspergers Victoria Inc.
91 Exercise & Sports Science Australia (ESSA)
92 Untapped Holdings Pty Ltd
93 BioAutism Limited
94 Monash University
95 Department of Developmental Disability Neuropsychiatry (3DN), Faculty of Medicine, UNSW Sydney
96 Australian Association of Social Workers
97 ND Australia
98 National Disability Services (NDS)
- 98.1 Supplementary to submission 98

99 Samaritans
100 Victorian Department of Health and Human Services
- Attachment 1

101 The Hon Coralee O'Rourke MP, Queensland Minister for Communities, Queensland Minister for Disability Services and Seniors
- Attachment 1

102 People with Disability Australia
103 Government of Western Australia
104 National Aboriginal Community Controlled Health Organisation
105 Playgroup Australia
106 Department of Defence
107 I CAN Network Ltd
108 PEERS Australia
- Attachment 1

109 Children and Young People with Disability Australia
110 Australian Psychological Society
111 *Name Withheld*
112 *Name Withheld*
113 *Name Withheld*
114 *Name Withheld*
115 Mr Shawn Stevenson
116 *Name Withheld*
117 Mansfield Autism Statewide Services (MASS)
118 The Sycamore School
119 *Name Withheld*
120 *Name Withheld*
121 Autistic-led Organisations Australia (ALOA)
- Attachment 1
- Attachment 2

122 *Name Withheld*
123 *Name Withheld*
124 Queensland Law Society
125 Coalition of Autistic Women
126 *Name Withheld*
127 Australian College of Nurse Practitioners (ANCP)
- Attachment 1
- Attachment 2

128 Marymead Autism Centre
- Attachment 1
- Attachment 2

129 Autism Queensland Ltd
130 Irabina Autism Services
131 *Name Withheld*
132 *Confidential*
133 *Confidential*
134 *Confidential*
135 *Confidential*
136 *Confidential*
137 *Confidential*
138 *Confidential*
139 *Confidential*
140 *Confidential*
141 *Name Withheld*
142 Ms Alexa McLaughlin
143 Mr David Staples
144 Learning for Life Autism Centre
145 *Name Withheld*
146 *Name Withheld*
147 *Name Withheld*
148 *Name Withheld*
149 *Name Withheld*
150 *Name Withheld*
151 Communication Rights Australia
152 Ms Julie Phillips
153 Disability Discrimination Legal Service
154 Amaze
- 154.1 Supplementary to submission 154

155 *Name Withheld*
156 Triple P International
- Attachment 1

157 Mr Cameron Boyd

158 WithYouWithMe
159 Dr Julie McMillan
160 Auticon
  - Attachment 1

161 *Confidential*
162 Mindful
  - Attachment 1
  - Attachment 2

163 *Confidential*
164 *Confidential*
165 Ms Geraldine Robertson
166 Ms Cathie Davies
  - 166.1 Supplementary to submission 166

167 *Name Withheld*
168 Food Intolerance Network

Additional Information

1 Correspondence from The Hon Stephen Dawson MLC, Western Australia Minister for Disability Services to the committee (received 14 January 2020).
2 Letter of clarification regarding evidence given at 27 July hearing, Autism Aspergers Advocacy Australia (A4) (received 15 August 2020).
3 Final Evaluation Report for the Inclusive School Communities project from JFA Purple Orange (received 9 December 2020).
4 Autism Queensland Support of Inclusive Education for Students on the Autism Spectrum (received 22 March 2021).
5 Ms Geraldine Robertson on the efficacy of Applied Behaviour Analysis (received 30 April 2021).

Answer to Question on Notice

1 Royal Australasian College of Physicians, answers to questions on notice, 28 July 2020 (received 21 August 2020).
2 Department of Social Services, answer to question on notice (number 2 of 4), 27 July 2020 (received 21 August 2020).
3 Xceptional, answers to questions on notice, 6 August 2020 (received 21 August 2020).
4 SDN Children's Services, answer to question on notice, 28 July 2020 (received 24 August 2020).
5 Autism Awareness Australia, answer to question on notice, 6 August 2020 (received 24 August 2020).
6 Department of Social Services, answer to question on notice (number 3 of 4), 27 July 2020 (received 24 August 2020).

7 NSW Health, answers to questions on notice, 28 July 2020 (received 24 August 2020).
8 Department of Social Services, answer to question on notice (number 4 of 4), 6 August 2020 (received 26 August 2020).
9 Department of Social Services, answer to question on notice (number 1 of 4), 27 July 2020 (received 28 August 2020).
10 Australian Autism Alliance, answers to questions on notice, 6 August 2020 (received 25 August 2020).
11 NDIS Quality and Safeguards Commission, answers to questions on notice, 17 August 2020 (received 31 August 2020).
12 National Disability Insurance Agency, answers to questions on notice, 27 July 2020 (received 1 September 2020).
13 National Disability Insurance Agency, answers to questions on notice, 6 August 2020 (received 1 September 2020).
14 atWork Australia - Launceston, answers to questions on notice, 28 April 2021 (received 27 July 2021).

Correspondence

1 Correspondence from the South Australian Minister for Child Protection (received 9 November 2021).
2 Correspondence from the South Australian Minister for Education (received 11 November 2021).
3 Correspondence from the Victorian Minister for Employment (received 23 November 2021).
4 Correspondence from the SA Minister for Police, Emergency Services and Correctional Services (received 24 November 2021).
5 Correspondence from the SA Minister for Human Services (received 26 November 2021).
6 Correspondence from the Queensland Minister for Seniors and Disability Services (received 30 November 2021).
7 Correspondence from the Premier of Tasmania (received 3 December 2021).
8 Correspondence from the WA Minister for Disability Services (received 29 November 2021).
9 Correspondence from the Northern Territory Department of Territory Families, Housing and Communities (received 13 December 2021).
10 Correspondence from NSW Health and the NSW Department of Education (received 17 December 2021).

Media Releases

1 Media Release

Tabled Documents

1 Document detailing survey data on the ways Different Journeys has supported its community, tabled by Ms Mel Spencer, Executive Officer of Different Journeys, at a public hearing in Melbourne on 11 February 2021.

2 Statistical evidence supporting a National Autism Strategy, tabled by Mr Ben Biro, Community Member of Autism Alliance, at a public hearing in Melbourne on 12 February 2021.

Appendix 3
Additional supporting material

This appendix provides further supporting material that is referred to through the main report.

Appendix 3.A — DSM-5 Autistic Diagnostic Criteria

The Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) is the standard for diagnosing autism spectrum disorder. The table below outlines the autistic diagnostic criteria as referred to in chapter 2.

Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history	
Deficits in social-emotional reciprocity	For example, abnormal social approach and failure of normal back-and-forth conversation; reduced sharing of interests, emotions; failure to initiate or respond to social interactions.
Deficits in nonverbal communicative behaviours used for social interaction	Poorly integrated verbal and nonverbal communication; abnormalities in eye contact and body language; total lack of facial expressions and nonverbal communication.
Deficits in developing, maintaining, and understanding relationships	Difficulty adjusting behaviour to suit social contexts; difficulty sharing imaginative play or in making friends; absence of interest in peers.
Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history	

Stereotyped or repetitive motor movements, use of objects, or speech	Simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases.
Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behaviour	Distress at small changes, difficulty with transitions, rigid thinking patterns, need to take same route or eat same food every day.
Highly restricted, fixated interests that are abnormal in intensity or focus	Strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest.
Hyper- or hypo-reactivity to sensory input or unusual interests in sensory aspects of the environment	Apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement.
Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life)	
Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning	
These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay	

Source: Autism Speaks, Autism Diagnosis Criteria: DSM-5, www.autismspeaks.org/autism-diagnosis-criteria-dsm-5 *(accessed 23 June 2021).*

Appendix 3.B — *The Scottish Strategy for Autism 2011—2021* Vision

That individuals on the autism spectrum are respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives.

Values

- **Dignity**: people should be given the care and support they need in a way which promotes their independence and emotional well-being and respects their dignity.
- **Privacy**: people should be supported to have choice and control over their lives so that they are able to have the same chosen level of privacy as other citizens.
- **Choice**: care and support should be personalised and based on the identified needs and wishes of the individual.

- **Safety**: people should be supported to feel safe and secure without being over-protected.
- **Realising potential**: people should have the opportunity to achieve all they can.
- **Equality and diversity**: people should have equal access to information, assessment and services; and health and social care agencies should work to redress inequalities and challenge discrimination.

Outcomes and priorities (for 2018–2021)

- **A healthy life**: autistic people enjoy the highest attainable standard of living, health and family life and have timely access to diagnostic assessment and integrated support services.
- **Choice and control**: autistic people are treated with dignity and respect and services are able to identify their needs are responsive to meet those needs.
- **Independence**: autistic people are able to live independently in the community with equal access to all aspects of society. Services have the capacity and awareness to ensure that people are met with recognition and understanding.
- **Active citizenship**: autistic people are able to participate in all aspects of community and society by successfully transitioning from school into meaningful educational or employment opportunities.

Goals

Foundations (by year two)

- Access to mainstream services where these are appropriate to meet individual needs.
- Access to services which understand and are able to meet the needs of people specifically related to their autism.
- Removal of short-term barriers such as unaddressed diagnoses and delayed intervention.
- Access to appropriate post-diagnostic support for families and individuals (particularly when there is a late diagnosis).
- Implementation of existing commissioning guidelines by local authorities, the NHS, and other relevant service providers.

Whole-life journey (by year five)

- Access to integrated service provision across the lifespan to address the multi-dimensional aspects of autism.
- Access to appropriate transition planning across the lifespan.
- Consistent adoption of good practice guidance in key areas of education, health and social care across local authority areas.
- Capacity and awareness-building in mainstream services to ensure people are met with recognition and understanding of autism.

Holistic-personalised approaches (by year 10)

- Meaningful partnership between central and local government and the independent sector.
- Creative and collaborative use of service budgets to meet individual need (irrespective of what the entry route to the system is).
- Access to appropriate assessment of needs throughout life.
- Access to consistent levels of appropriate support across the lifespan including into older age.

Implementation and reporting

An Autism Strategy Review Group was established to help monitor and coordinate implementation of the strategy. The Autism Strategy Review Group reports regularly to the Cross-Party Group on Autism. In 2020, the Cross-Party Group published a progress report on implementation of the strategy. In 2021, the impact of the strategy will be evaluated and reported to the Scottish Parliament.

Appendix 3.C — *National strategy for autistic children, young people and adults: 2021–2026* (UK)

Priority areas

- Improving understanding and acceptance of autism within society.
- Improving autistic children and young people's access to education, and supporting positive transitions into adulthood.
- Supporting more autistic people into employment.
- Tackling health and care inequalities for autistic people.
- Building the right support in the community and supporting people in inpatient care.
- Improving support within the criminal and youth justice systems.

Key steps in 2021–2022

- Improving public understanding of autism and inclusion across the public sector.
- Making transport and communities more autism-inclusive.
- Improving educational professionals' understanding of autism and inclusive cultures within schools.
- Improving how the Special Educational Needs and Disability system supports autistic children and young people.
- Supporting positive transitions into adulthood.
- Continuing to support autistic children and young people during the COVID-19 pandemic.
- Improving employment support and the welfare system.
- Including autistic people in plans for restoration and recovery from the COVID-19 pandemic.

- Improving early identification and reducing autism diagnosis waiting times.
- Improving health and care professionals’ understanding of autism.
- Reducing the health and care inequalities autistic people face.
- Improving crisis prevention and avoidable admissions into inpatient settings.
- Improving the quality of inpatient care for autistic people and facilitating timely discharges from inpatient care
- Addressing the use of restrictive practice
- Improving understanding of autism across the criminal and youth justice systems
- Improving access to services for autistic people in touch with the criminal and youth justice systems

Enabling actions

- Improving autism research, innovation and examples of best practice.
- Improving data collection and reporting to monitor implementation of the strategy and drive system improvement,
- Strengthening governance, leadership and accountability.

Implementation and reporting

The full list of commitments in 2021–2022 is set out in the national strategy implementation plan. Implementation will be overseen by an Executive Group that reports directly to the relevant Ministers at biannual accountability meetings. Progress will be monitored against measures of success defined in the national strategy implementation plan.

Appendix 3.D — National funding and initiatives supporting autism research

Autism CRC	The Autism CRC was established as the world's first national autism cooperative research centre. Initial funding for the Autism CRC included $31 million from the Australian Government, as well as over $74 million in cash and in-kind contributions. The Autism CRC also receives funding from other Australian Government and state and territory government grants, as well as cash and in-kind contributions from participating universities and organisations. The Autism CRC undertakes innovative research to directly improve the lifetime prospects of individuals with autism, provide guidance, support and direction for their families, and enable medical practitioners, educators, therapists, support

	workers and employers to work effectively with people with autism. The Autism CRC provides government with access to robust, contemporary evidence about best practice.
National Health and Medical Research Council (NHMRC)	The NHMRC is the Australian Government's main health and medical research funding body. The Australian Government allocates funds for health and medical research primarily through the Medical Research Endowment Account (MREA) and the Medical Research Future Fund (MRFF). NHMRC administers the MREA and some MRFF funds through grant programs. Since 2010, the NHMRC has provided $33 826 231 in funding towards autism research.
Autism Specific Early Learning and Care Centres (ASELCCs)	The Department of Social Services has funded six ASELCCs to collect clinical data, held in a centralised database, and to conduct and publish research to further understanding of best practice early intervention for children with autism and the efficacy of the ASELCC model for children and families. By June 2018, the ASELCCs and associated research institutions and partners had published 57 peer reviewed academic publications and five research reports.
Medical Research Future Fund (MRFF)	The MRFF provides grants to support health and medical research and innovation to improve the health and wellbeing of Australians. It operates as an endowment fund with the capital preserved in perpetuity. At maturity, the MRFF will reach $20 billion. The MRFF provides a long-term sustainable source of funding for endeavours that aim to improve health outcomes, quality of life and health system sustainability. The MRFF is in addition and complementary to research funding through the NHMRC. MRFF investments are guided by the Australian Medical Research and Innovation Strategy 2016–2021 and related set of Australian Medical Research and Innovation Priorities 2018–2020 developed by the independent and expert Australian Medical Research Advisory Board following extensive national public consultation. $2.5 million over five years is being provided from the MRFF – Emerging Priorities and Consumer Driven Research Initiative from 2019-20 to understand the causes of autism.

Disability Research Strategy	In December 2019, the Disability Reform Council agreed to a disability research strategy with the Australian Government already committing: • $15 million for the development of the National Disability Data Asset; and • $2.5 million to the Melbourne Disability Institute at the University of Melbourne to further develop a National Disability Research Partnership with other interested research and community organisations. Over the next three years, the disability research strategy will seek to: • establish a national framework and approach to collaboration on shared research priorities across government; • build capacity, capability and partnerships within the disability research community; • improve the quality, availability and utility of data to inform disability research; and • maximise the value of research in improving service models practicing and outcomes for people with disability in Australia.

Source: Department of Social Services, Department of Education, Skills and Employment, Department of Health, Submission 53, pp. 25–27.

Appendix 3.E — Summary of progress on recommendations from the ECEI Implementation Reset

Table 3.2 ECEI Implementation Reset Progress

Recommendation	Progress
Explain and rename the early childhood early intervention approach.	Complete
Develop and publish new early childhood operational guidelines	Complete
Clearly explain developmental delay and practical guidance to make decisions	Complete
Explain how the approach to supporting families and children helps them reach their full potential	Complete

Create a delegate/planner workforce for young children	In the next 12 months
Working with state, territory and federal governments to find and fill gaps and strengthen services	In the next 12 months
Tailored support for families in remote and very remote areas	In the next 12 months
Publish guidance about what is considered 'reasonable and necessary' when making support decisions for children on the autism spectrum	In the next 12 months
Improving support and information sharing for families when transitioning from the Scheme	In the next 12 months
Focussing on best practice early intervention by making Scheme access decisions under section 25 of the NDIS Act	In the next 12 months
Make the 'provider outcomes report' mandatory to evaluate provider's effectiveness in delivering supports and services	In the next 12 months
Improve provider compliance with NDIS Best practice standards on early childhood supports and increase awareness of these providers	In the next 12-24 months
Help early childhood partners give families clear advice about the best providers for their child and situation	In the next 12-24 months
Understand what disadvantaged and vulnerable families need, and create culturally appropriate services and resources	In the next 12-24 months
Help partners connect with more families in communities experiencing hardship or disadvantage	In the next 12-24 months
Help families connect to local support networks and services	In the next 12-24 months
Do more research on outcomes for young children after receiving early intervention support	In the next 12-24 months
Increase partner capacity to provide more short-term early intervention support for children under 6 with developmental concerns	Over the next 24 months
Increase capacity and flexibility of early childhood providers to help families navigate NDIS plans and connect to supports	Over the next 24 months

Change the age limit for the early childhood approach to children younger than 9	Over the next 24 months
Introduce a 'capacity building support in natural settings' item in the NDIS Price Guide	Over the next 24 months
Create a transition plan to help children and families move to the next stage of their lives	Under review, may not be required
A tailored independent assessments approach for young children and their families	Discontinued

Source: ECEI reset recommendations update, https://www.ndis.gov.au/community/we-listened/you-said-we-heard-post-consultation-reports/supporting-young-children-and-their-families-early-reach-their-full-potential/how-were-improving-way-we-support-young-children-and-their-families/ecei-reset-recommendations-update (accessed 21 December 2021)