# Autistics Australians and Health Systems in Australia

A briefing document for Health officials (July 2022)

This document has been prepared in response to the request of senior Health Department officials resulting from the meeting held on the 17/01/2022. That is:

> **Request 1: Context and Call to Action: Autism Related Competency Framework**
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> The 2021-22 Budget included funding for the development of a competency framework for health professionals to better manage the health of people with intellectual disability. The Department is open to the potential extension of this project to cover competencies for managing autistic people. "Ahead of our next meeting, we would welcome information from your organisations on health competencies specific to autism management for health professional training. This will assist us in thinking about possible links the education and training project which has just begun."
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> **Request 2: Context and Call to Action: Autism and the ID Health Roadmap**
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> Department officials invited the organisations at the meeting (A4, Amaze, Australian Autism Alliance) to review the Department's Roadmap for Improving the Health of People with Intellectual Disability, looking for initiatives which would also be relevant for autistic people as this could help identify potential areas for early collaboration.

This document augment's A4's previous Autism Brief developed for the meeting held on the 17/01/2022 with Health officials. For convenience relevant points have been included in Annex A. below.

The communiqué from the previous meeting also listed the following subjects for further discussion:

1. A4's request, documented previously, "that the Commonwealth Department of Health and Ageing now recognise formally
   a. growing diagnosis rates of autism diagnoses in Australia, and
   b. the substantial impact of autism on the health of autistic people".
2. Health officials invited further discussion of "sensory issues".
3. Jenny (Australian Autism Alliance) described the need for co-design in Health policy relevant to autistic people.
4. A4 (and others) are keen to emphasise the substantial problems for autistic people in accessing mental health services. We note that a previous federal budget has funding specifically for mental health of autistic Australians.

## 1. Introduction

Since our previous meeting, a National Autism Strategy has emerged as a significant issue to be addressed:

- The Senate Select Committee on Autism says in its *report on Services, support and life outcomes for autistic Australians* (March 2022) that "At the centre of the committee's proposed reform pathway is a National Autism Strategy", and

- The Labor party outlined an Autism Strategy as an election commitment that captured both the National Autism Strategy and the creation of a National Roadmap to specifically target **health and mental health** outcomes, with a $300,000 investment to begin work immediately.

Further to this:

- The Senate Select Committee on Autism report (Services, support and life outcomes for autistic Australians) made a number of recommendations identifying that generic disability approaches have failed to address the discrete challenges and enablers of autistic people. Despite the excellent work that has been done in cross-disability policy, key indicators and outcomes for autistic people in Australia have not advanced. The large numbers of autistic people, the distinct challenges and enablers our community face, and the opportunity to make significant gains with a well targeted and tailored response reinforce the need for ASD specific strategies. This includes health needs to be specifically addressed by a Health/ Mental Health Roadmap for Autism (refer Annex D for further detail).
- The Disability Royal Commission, in its report on Health care and services for people with cognitive disability (where it includes autistic people in people with cognitive disability), recognised that the ID Roadmap does not address the needs of autistic people and recommended substantial improvements be made to support people with cognitive disability in the health system.

We applaud the further step in the right direction that has occurred since our last meeting with the increases in the items that can be claimed and the expanded age range for the *Helping Children with Autism* (HCWA) Medicare items, to 25 years old. However, it was identified that this needed further consideration. Limiting ASD diagnosis Medicare items to age 25 years is regarded by the autism community as age and disability discrimination, though it is clearly protected as "lawful discrimination" under s 45 Special Measures of Australia's *Disability Discrimination Act 1992*. An ASD diagnosis, at any age, can generate significant wellbeing benefits and support social, educational, and economic participation.

## 2. Autism-related competency framework

An ASD related competency framework is necessary to support that ASD is a distinct condition. ASD is not a version of ID, or somehow related, unless a person is both autistic and with ID (Annex C. below highlights more relevant points regarding ASD in the context of ID). Health care professionals are not confident in working with this population due to their unique needs. This includes a range of issues that are common to other disabilities but require quite distinct solutions such as communication. There are also quite distinct issues unique to ASD such as the processing of pain in both how the individual experiences it and their external representation of it or lack thereof, particularly in comparison to neurotypical responses. We are happy to provide individual case studies for context if this would be useful.

An overseas report about the health of autistic people is alarming and provides further support. Recent research[1] summarised the health of autistic people:

> *Autistic individuals are more likely to experience chronic physical and mental health problems than their peers without ASD. Additionally, those on the autism spectrum are more likely to report inadequacies in health care services provided to them.*

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[1] See https://neurosciencenews.com/asd-health-care-20689/

An ASD-related competency framework also presents an opportunity to support workforce capacity by training autistic health care providers.

To this end, the UK have developed a national autism core capabilities framework to identify key capabilities for those working with and for supporting Autistic people. A tiered approach is used:

- Tier 1 for those who require a general understanding of autism but may not regularly work for autistic people;
- Tier 2 for those who provide care and support for autistic people but are not autism specialists;
- Tier 3 for those who work intensively with autistic people.

This would be a great starting point.

Some key points are outlined below for consideration.

**Diagnostic Practice**

There are major concerns over diagnostic practise relating to autistic children. Parents on average identify concerns two years before they on average receive a diagnosis, and it can be 1-2 years between getting an initial appointment (which may have taken 2 years to get) and receiving a diagnosis and support. At present, many children are ask their GP or are referred for an ASD diagnosis and told “Maybe it’s Autism Spectrum Disorder” or “Wait/wait to see another person” (but that doesn’t happen). This results in no direction of what to do, or they hit another wait list which resulting in another 1-2 year wait if they dependent on the public health system. Even the private sector has 6-12 months wait lists with associated high costs. All while parents are bombarded with messages of “early intervention” means better outcomes. Note:

- ASD may be reliably diagnosed from around 2 years of age [2] [3]
- Average age of diagnosis in Australian children is between 4-6 years [4][5] (or 7-9 years according to diagnosis rate data by age)
- Parents identify concerns much earlier, average of 23 months and consult professionals on average 8 months later with a gap of 1-2 years or more between consultation and diagnosis[6]

Or their assessment yields a Developmental Delay or Global Developmental Delay diagnosis. These diagnoses usually delay access to the ASD-specific early intervention that they need for best outcomes. There are several problems with these pathways:

- Public pathways may have two years or more wait, during which a crucial opportunity for support is missed
- Private pathways are cost prohibitive with significant wait-times to see paediatricians or child psychiatrists for a referral for assessment with rebates nowhere near the cost of a private assessment (which still has 6-12 month+ waitlists) even with proposed increased item numbers-

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[2] Barbaro, J., & Dissanayake, C. (2017). Diagnostic stability of autism spectrum disorder in toddlers prospectively identified in a community-based setting: Behavioural characteristics and predictors of change over time. Autism, 21(7), 830–840. https://doi.org/10.1177/1362361316654084

[3] Lord, C., Risi, S., DiLavore, P. S., Shulman, C., Thurm, A., & Pickles, A. (2006). Autism from 2 to 9 years of age. Archives of General Psychiatry, 63(6), 694–701

[4] C.A. Bent, C. Dissanayake, J. Barbaro Mapping the diagnosis of autism spectrum disorders in children aged under 7 years in Australia, 2010-2012

[5] The Medical Journal of Australia, 202 (6) (2015), pp. 317-320, 10.5694/mja14.00328

[6] Gibbs, V., Aldridge, F., Sburlati, E., Chandler, F., Smith, K., & Cheng, L. (2019). Missed opportunities: An investigation of pathways to autism diagnosis in Australia. *Research in Autism Spectrum Disorders, 57, 55-62*

e.g., APS recommended fee per hour for a psychologist is $280 whereas Medicare rebates are $87.45 leaving an almost $200 gap per session, with assessment costs $2000-$3000…

- Significant workforce shortages are driving greater delays, particularly in regional areas.
- Families are not informed that DD or GDD are placeholder diagnoses that last until age 6 or 5 years respectively and need to be reassessed as early as possible so the most appropriate and effective interventions for their conditions can be tried.
- A specialist ASD diagnostic service may miss other crucial aspects of a child's diagnosis through their focus purely on autism.
- In contrast a sole-practitioner single practitioner diagnostician (e.g., clinical psychologist) may need to refer (to another waitlist!) for additional assessment e.g., language/Speech Pathologist.

Other areas of focus are:

- The whole health system needs to learn about "inclusion". Clinicians and health support staff need to understand and accept the diversity of disability. They need to learn that sometimes, things need to be done differently to get best, or even good, outcomes.
- The health sector needs to tackle "ableism" and the negative impact it has in delivery of health services. Research into barriers (and enablers) to accessing healthcare for autistic people should occur and co-design with autistic people.
- They also need to understand that autistic people have different communication & language skills. Their social skills are different. Autistic people have different behaviour; and when they are stressed or if their language is limited, they may communicate through behaviour and sometimes, or for some people, their behaviour is challenging for others. Furthermore, up to 65% of individuals on the spectrum have difficulties reading with comprehension[7].
- Australia has insufficient behavioural clinicians. Training is inadequate and we have no Australian registration.
- The mental health sector needs major reform in its approach to autistic patients. The mental health sector would benefit from understanding and respecting neurodivergence. People can be different and have a good life. Being depressed is not good, but the solution is being *not depressed* rather than being normal. Value being *not depressed*; recognise that people do not have to be normal to have a good life.
- Allied health clinicians need to be required to acquire and maintain competencies in autism before they are allowed to work on skill acquisition with autistic clients.
- The health sector needs to review and revise its use of restrictive practices on people with disability, including autistic patients.

## 3. ASD and Health's ID Roadmap

We commend the ID Roadmap as being both necessary and beneficial for people with intellectual disability.

A4 and others in the autism sector reviewed Heath's ID Roadmap to identify initiatives that are potentially relevant for autistic people as areas for commonality. This section contains an overview to set the context for our specific comments in Annex B. below. Table 1 in Annex B identifies specific actions that are identified for early collaboration by being marked as "relevant" without any qualification.

In principle the elements contained in the ID Roadmap including the vision and key objectives are relevant to autistic people and the autism community. As stated in the ID Roadmap it:

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[7] Nation, K., Clarke, P., Wright, B., & Williams, C. (2006). Patterns of reading ability in children with autism spectrum disorder. *Journal of autism and developmental disorders*, *36*(7), 911-919

- sets out a vision for a targeted set of reforms across the health system to ensure that it meets the needs of people with intellectual disability in an integrated and holistic way, to improve their health outcomes.
- the actions outlined in the ID Roadmap will help develop a health system in which people with intellectual disability are valued and respected and have access to high quality, timely and comprehensive health care that supports them to attain the best possible health outcomes across the course of their lives.
- the Commonwealth Department of Health will establish a governance group that includes health and disability sector stakeholders, to oversee and provide advice on implementation of the ID Roadmap throughout its lifespan

However, the context, actions needed, and governance stakeholders need to be autistic specific to be effective since ASD is distinct from ID, as has been reinforced through the various recent events as outlined in the Introduction section above.

Between 30% and 70% of autistic Australian have an intellectual disability but, in most cases, their ASD is a primary disability, and their ID is considered secondary. Both the DSM-IV and the DSM-5 expect that for an autistic person with ID, their ASD is usually their primary disability, and their ID is another factor in their life. The ICDs follow this approach.

ASD is characterised by significant differences (and need for support) in social communication and restricted and repetitive behaviours. In terms of social communication differences this can range from limited abilities to express oneself[8] to having a strong vocabulary but more subtle difficulties with the social use of language. Across this spectrum this can have significant impacts on health outcomes through difficulties recognising and sharing with other people one's distress, pain, or emotions- this can lead to missed diagnosis and treatment and may explain the high mortality and morbidity (> 20 years earlier). Differences in understanding social rules and expectations may influence the ability to seek and respond to health care and the ability of others to recognise understanding, distress, pain. A profile of greater expressive language than receptive can mean a person may appear to understand more than they are as they are able to talk, but to miss valuable health information. In terms of RRBIs- sensory processing differences occur in almost all individuals on the spectrum and can include senses being "turned up" or "Turned down"- sometimes even within the same modality. For example, the client who is very sensitive to noise may modulate this by making noise themselves. In an environment such as a hospital that is bright, noisy, and unpredictable this can cause considerable distress and suffering and result in avoidance even at significant health risk. With respect to rigid thinking, changes in routine or expectations can be intolerable and overwhelming and impact accessing healthcare in the first place.

These challenges **unique to ASD** and cannot be encapsulated in understanding of ID which focuses on intellectual challenges which may **compound** challenges but **do not explain** the unique experiences of each autistic individual.

The diversity of ASD presentation is also impacted by the high number of co-occurring physical and psychiatric conditions experienced by autistic people. Commonly co-occurring conditions include, besides ID, developmental delays, language delay, motor difficulties, epilepsy, sleep problems, anxiety, depression, attention deficit hyperactivity disorder (ADHD), unusual eating behaviours, and

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[8] An ASD diagnosis report specifies "With or without accompanying language impairment".

gastrointestinal symptoms. ND Australia provided the following estimation of the rate of certain comorbidities: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

Refer to Annex C. for more information regarding ASD in the context of ID and diagnosis rates.

It is noted in the Health ID Roadmap that there is very little specific reference to autism. It is noted that autism is rarely mentioned in other Health's documents also. For example, Health COVIDSafe information for Health and Mental Health Workers includes autism in “developmental disability” rather than neurodevelopmental.

By focusing on ID and ignoring their primary disability presents a significant risk mostly in lesser outcomes as this cannot encompass the unique features of ASD such as uneven social-communication (e.g., expressive to receptive cannot be assumed, pragmatic difficulties, neologisms, and echolalia) and anxiety/distress-provoking impacts of RRBIs (e.g., sensory overload, meltdowns due to intolerance of uncertainty etc). There is a real prospect that Health services for people with ID are as likely as other parts of the health system to deny autistic people services because a person is autistic. It is likely that an autistic person with ID is likely to be denied an ID-related service in precisely the same way as an autistic person with mental illness gets denied mental health services because they are autistic.

Autistic women and girls are also especially vulnerable and experience notably poor health outcomes. Health systems need to recognise, respect and address their increased vulnerability. As an aside, we are surprised that the ID Roadmap does not recognise the increased vulnerability of women and girls with ID, and particularly poor outcomes for women with ID.

The Health Department suggests 450,000 Australians have ID based on the AIHW's estimate 1.8% of Australia's 25 million population have ID. Studies estimate the actual prevalence of ASD in Australia at between 2.4 and 4.4 per cent of the population, or between 600 000 and 1 million people. This identifies the impact a Health component of a National Autism Strategy would have.

## 4. Discussion

At the coming meeting, Health officials want to discuss:

- the relevance of the ID Roadmap to autistic Australians, and
- the relevance and significance of work on a competency framework in Health to autism.

In addition to the topics that Health officials raised, we are keen to discuss:

1. having Health recognise formally that:
    a. the number of autistic Australian has grown substantially in recent decades;
    b. massive differences between ASD diagnosis rates for children and adults, by gender, and between states all require comprehensive investigation and explanation; and
    c. ASD is distinct from ID and typically is a primary disability (according to the DSM-IV and DSM-5)
2. recognition that health outcomes for Autistic Australians are unsatisfactory and must improve with reference to:
    a. recommendations of the Senate Select Committee on Autism, and
    b. the Disability Royal Commission's recommendation in its report on Education and training of health professionals in relation to people with cognitive disability
3. co-design and collaboration on Health's component of the National Autism Strategy to ensure equitable health and mental health outcomes for Autistic Australians – including collaboration on governance
4. improving ASD-related competencies including diagnostic practice in line with the DSM-5 (and the diagnostic report it describes), professionalisation of early intervention and behaviour support, etc.
5. serious effort to recognise and address severe deficits in mental health supports for autistic Australians throughout the nation. This should include an assessment and lessons learnt of the funding for mental health of Autistic Australians that was allocated in the 2021-22 budget
6. a traceability matrix to the Senate Inquiry Report recommendations to identify health gaps
7. improving Health's data collection and research relating to ASD
8. shifting existing health sector culture, attitudes, appreciation, and competencies around neurodiversity (and disability generally) with a focus on "Inclusion" throughout health systems.

Health needs to re-engineer the entire health landscape for autistic Australia: autistic people need readily navigable pathways (even superhighways) that deliver them reliably to good health outcome destinations. Autistic people need more than an aspirational roadmap of a non-existent landscape; they need effective pathways to good health outcomes that are real and accessible.

## Acknowledgement

This document reflects collaboration between A4, the Ms Jenny Karavolos of Australian Autism Alliance and Dr J Paynter of ASfAR.

## Annex A. Points from our previous Brief (17/01/2022)

1. Many health officials need to recognise that:
    a. autism is not a rare disorder – it is now diagnosed increasingly often; and
    b. substantially few than 70% of autistic people have intellectual disability, so autism cannot be treated as a subtype of ID.
2. Over 3% of Australian children are NDIS participants with autism as their primary disability (there are many more autistic children are not NDIS participants, and many NDIS participants with autism/ASD listed as a secondary disability).
3. Health's joint submission[9] to the Senate Autism Committee said there were over 200K autistic Australians in 2018 increasing at around 25% in 3 years. Autism rates are increasing significantly while disability rates generally are decreasing slightly. The reasons for increasing autism numbers are unknown.
4. Medicare funds ASD assessments that may result in some ASD diagnoses in children up to age 13 years. At least 10,060+ new ASD diagnoses are needed each year to sustain the current diagnosis rates for autistic children in Australia. Medicare contributed to 13,447 ASD assessments in 2019. Data on how many diagnoses result from those assessment are not available.
5. Most autistic Australians are aged under 25 years which means the ASD diagnosis rate varies substantially with age. The diagnosis rate for autistic adults is much lower (1/10th) than for children. The lack of funding for ASD diagnoses for people over 13 years of age is a likely contributor[10] to low adult diagnosis rates.
6. ASD diagnosis rates for school age children vary considerably between states; the variation is reflected by NDIS participation rates for autistic children (only part of the overall autistic community) that varies from 2% to 6%. Reasons for this factor of 3 variation are unknown.
7. ASD diagnosis rates vary between males and females with a ratio of about 3-4:1 . Again, reasons for the variation and its changing are unknown.
8. ASD should be regarded usually as a primary disability, not as a subtype of ID.
9. There are numerous reports of extremely bad health outcomes for autistic people and for autistic Australians[11].

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[9] Download (July 2020), quoted estimates from the Australian Bureau of Statistics.

[10] The lack of clear methodology for adult diagnosis of ASD is also a likely contributor to low diagnosis rates for Australian adults.

[11] See for example, evidence the Trollor and Lennox gave to the Disability Royal Commission on health and wellbeing outcomes for people with disability including ASD.

# Annex B. Autism and Health's Roadmap for people with Intellectual Disability

The following is the response to the request "to review the Department's *Roadmap for Improving the Health of People with Intellectual Disability*, looking for initiatives which would also be relevant for autistic people as this could help identify potential areas for early collaboration."

It is recommended as a further action that we develop a traceability matrix to the Senate Inquiry Report recommendations to identify gaps. Refer Appendix D for an extract of high-level recommendations from the Senate Inquiry report on Autism released March 22.

Our approach was to provide:

1. An overview under each main element of the Health's ID Roadmap
2. An assessment against relevance to autism of the National ID Roadmap at a Glance Table in the National Intellectual Disability Road Map (refer Table 1 below)

Health's ID Roadmap describes landscaped terrain that does not exist, so it isn't really a roadmap. It's more a proposal for changing the landscape that are yet to be realised. If the work is done, people might (or might not) use the roadmap to navigate the health services they need, though the roadmap will need updating.

Addressing each of the main elements in the ID Roadmap:

## A. Improved support for people with intellectual disability and their families and carers

For autistic people with ID, that is people whose primary disability is their ASD, the process of making "informed, supported decisions about their health care" requires people involved in and helping with decision-making to also have knowledge of the person's autism. The ID Roadmap does not appear to recognise or address:

- the significance of autistic people's autism-related accommodation and supports needs when they try to access effective health care;
- the frequent requirement to accommodate autism-related needs of autistic people in Health settings.
- specifically, autism in anyway, making this ineffective, as is, for a substantial number of its target population, that is autistic people with ID.

Unfortunately, strategies aimed at people with ID are less effective, and often fail, for autistic people with ID because communication strategies for people with ID may not address some key communication, social, behavioural, and sensory accommodations that autistic patients need.

It is unclear from the Roadmap as to what improvements, including for autistic patients, will be measured and reported, when and how?

## B. Models of care for people with intellectual disability

All of the sections are relevant for autistic people and are necessary for improving their health outcomes. However, most of these items need autism-specific elements to be effective for the reasons outlined in this paper. Autistic people, with and without ID, will be left behind unless their autism-related needs are recognised, addressed and their outcomes measured/monitored.

Other areas for improvement:

- It is requested that the reviews in the future are co-designed with autistic people. It was noted that the 2019 review of HCWA-related MBS items did not involve autistic people.
- Too often the experience for autistic people in the Health system "coordination of care for an autistic person" translates as "since you are autistic you should go away and find the services and supports you need elsewhere (not here in my part of the health services sector)". Unfortunately, there is a need for an integrated eco system as health-related services and supports for autistic person are often not unavailable anywhere. That is "coordination of care for an autistic person" means referring the person to someone else (possibly in another sector) who cannot help them since the services and supports they need either don't exist or are in such short supply that the best possible outcome is to be placed on a long waiting list.

## C. Support for health care professionals to provide better care for people with intellectual disability

This is very relevant to ASD; autistic people have autism-specific needs that health care professionals need to address. Health care professionals need autism-specific awareness, training, and experience, too.

## D. Improving oral health for people with intellectual disability

This is very relevant to autistic people. Sensory issues are a significant part of an ASD diagnosis and present issues with oral health for autistic people. It is noted, however, this issue was not identified in the DRC's recommendations for Health care and services for people with cognitive disability.

## E. Research, data and measurement to support continuing improvement

It is recognised that the Health Department produced an initial report on early intervention for ASD and a booklet[12]. Disappointingly, these documents disappeared from Health's website some time ago.

Areas for improvement:

- Health department's involvement in research relating to ASD;
- Collection, analysis, and application of ASD related data

The notion of "continuing improvement" is extremely patchy. In some areas, health services can be very progressive, but in others (such as disability) it is moribund. The Department's minimal response to the Senate Autism Committee was disappointing as this provided the opportunity to recognising and improving outcomes for autistic patients.

## F. Emergency preparedness and response

This is very relevant to autism. It has been reported in a number of forums that the COVID, bushfire and flood "emergency" responses resulted in poor outcomes for autistic people. The current government committed to prioritising people with disability, including ASD.

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[12] The report is available for downloading at https://a4.org.au/sites/default/files/2006RobertsPriorreport.pdf and the booklet at https://a4.org.au/sites/default/files/2006PriorRobertsbooklet.pdf.

## G. Arrangements for oversight, monitoring and implementation of the National Roadmap

This is very relevant to autism and is an area for collaboration. Key comments:

- We would be keen to see what monitoring of and reporting on the ID Roadmap will tell us about autistic people with ID. It would be beneficial for data on people's other disabilities be captured and reported (and made available to us).
- Many agree that autistic people are already subject to far too much oversight (meaning "failure to notice" – the word, "oversight", has contradictory meanings).

## 5. National Roadmap at a glance modified to identify elements relevant to Autism

| Element | Short term (1-3 years) | Relevance to Autism | Medium term (4-6 years) | Relevance to Autism | Long term (7-10 years) | Relevance to Autism | Desired outcomes | Relevance to Autism |
|---|---|---|---|---|---|---|---|---|
| **A. Improved support for people with intellectual disability and their families and carers** | • Develop resources to improve health literacy and advocacy skills among people with intellectual disability, their families and carers<br>• Support people with intellectual disability to become advocates and health ambassadors<br>• Develop models of health navigators and disability liaison officers in health services<br>• All government health authorities to routinely use formats such as plain language and Easy Read resources in health communications to support better communication with people with intellectual disability about health issues and health care. These should also be culturally appropriate for Aboriginal and Torres Strait Islander and culturally and linguistically diverse (CALD) communities | • Relevant. Require distinct resources for people with autism<br>• Relevant. Target autistic people<br>• Relevant. Require specific knowledge if autism<br>• Relevant. | • Support the active participation of people with intellectual disability as part of the multi-disciplinary team, including participation in decision-making and case-conferences<br>• Better promote mental health and reproductive health services to people with intellectual disability, and connect existing services to a National Centre of Excellence in Intellectual Disability Health<br>• Commonwealth Department of Health to work with PHNs, professional colleges and disability advocacy organisations to ensure balanced, evidenced-based information about intellectual disability and related diagnosis (e.g. Down syndrome) is available to parents during the pre- and post-natal period | • Relevant. Target autistic people<br>• Relevant. Target autistic people<br>• Relevant. Tailor to autism evidenced based information and related diagnosis | | | People with intellectual disability have improved health literacy and are supported, along with their families and carers, to make informed decisions about their health care in consultation with their health care providers. | Relevant. Applies equally to autistic people wanting the same outcomes |
| **B1. Developing models of health care** | • Identify and promote best-practice models of care, especially for transition to adulthood<br>• Develop tools for health professionals to support provision of reasonable adjustments and supported decision making<br>• Develop and implement best practice guidelines and clinical standards to support the needs of people with intellectual disability | • Relevant. Require specific knowledge if autism<br>• Relevant. Require specific knowledge if autism<br>• Relevant. Require specific knowledge if autism<br>• work with states and territories to promote the Health direct Video Call Service for rural and remote patients as well as those patients who have difficulty leaving their residences | • Refine digital health solutions to better support digital communication among medical and other specialists, primary health care providers, and people with disability and their families | • Relevant | • Ensure digital health technology supports best practice models of care for people with intellectual disability<br>• Commonwealth, state and territory governments to address the health needs of people with intellectual disability in future key strategies, plans, policies, initiatives, roadmaps and agreements. This includes the:<br>• Australia's Disability Strategy<br>• National Preventive Health Strategy<br>• National Oral Health Plan<br>• National Mental Health and Suicide Prevention Plan<br>• National Diabetes Strategy<br>• National Aboriginal and Torres Strait Islander Health Plan | • Relevant with specific application for autistic people<br>• Relevant addressing the health needs of autistic people | Better models of care are developed that provide people with intellectual disability with quality health care that is person-centred, trauma-informed, and enables reasonable adjustments. | Relevant. Applies equally to autistic people wanting the same outcomes |
| **B2.Better use of existing MBS items** | • Implement measures to better promote the use of annual health assessments and other relevant MBS items to people with intellectual disability, their families, carers and support workers<br>• Support GPs, practice nurses, people with intellectual disability and their supporters to access and use the Comprehensive Health Assessment Program (CHAP) tool | • Relevant. Identify any specific MBS items relevant to autism<br>• Relevant. Approach may differ | • Measure uptake of annual health assessments and evaluate measures to increase uptake<br>• Review and consider potential modifications to MBS items for people with intellectual disability<br>• Consider changes to primary health care funding models to support extra time doctors need to provide appropriate care for people with intellectual disability | • Relevant<br>• Relevant with specific application to autistic people<br>• Relevant. Should capture people identify as autistic | | | People with intellectual disability regularly undertake annual health assessments which identify and action unmet health needs and promote good health. | Relevant. Applies equally to autistic people wanting the same outcomes |
| **B3. Continuity of care, and better care coordination and integration within the health system** | • Continue MBS telehealth access for general practice, allied health and specialist care<br>• Promote voluntary patient registration with general practice<br>• Strengthen connections between primary health networks, local hospital networks and local disability services including through development of care pathways for people with intellectual disability<br>• Promote better use of My Health Record by clinicians, and people with intellectual disability, their families, carers and disability support workers | • Relevant.<br>• Relevant<br>• Relevant with specific application for autistic people<br>• Relevant with specific promotion to autistic people<br>• Relevant with specific promotion of autistic people | • Promote uptake of case-conferencing technology that facilitates multidisciplinary team-based care<br>• Identify ways of expanding local multidisciplinary intellectual disability health services | • Relevant<br>• Relevant with specific application to autism | | | The health system is better integrated across all levels of care, allowing for more coordinated, multidisciplinary health care. People with intellectual disability have improved continuity of care, including across key transition periods. | Relevant. Applies equally to autistic people wanting the same outcomes |

| Element | Short term (1-3 years) | Relevance to Autism | Medium term (4-6 years) | Relevance to Autism | Long term (7-10 years) | Relevance to Autism | Desired outcomes | Relevance to Autism |
|---|---|---|---|---|---|---|---|---|
|  | • Leverage existing digital platforms and programs for health providers to promote the health of people with intellectual disability |  |  |  |  |  |  |  |
| **B4. Better coordination with other sectors** | • Develop resources and pathways to connect health and disability services<br>• Develop resources and training to improve health literacy of disability support providers<br>• Develop best practice quality standards for prescribing psychotropic medication<br>• Review NDIS Practice Standards and Quality Indicators for updates to support healthy lifestyles and optimal access to health services | • Relevant with specific identification of relevant disability services for autism<br>• Relevant with specific identification of relevant disability support providers for autism<br>• Relevant with specific adaption for prescribing to autistic people<br>• Relevant with review of indicators relevant to autism | • Consider funding models and options for better supporting NDIS participants' access to health services<br>• Identify opportunities to embed reforms that enable better coordination between the health and disability sectors in the next National Health Reform Agreement with states and territories | • Relevant<br>• Relevant | • Commonwealth Department of Health to identify opportunities to embed reforms that enable better coordination between the health and disability sectors in the next National Health Reform Agreement with states and territories. This could include, for example, conducting a pilot study evaluating the impact of in-reach hospital services in supported accommodation, in reducing avoidable emergency department presentations and admissions. | • Relevant | The health and disability systems have better linkages, supporting more effective communication and coordination between health care professionals, disability support providers and people with intellectual disability, their families and carers. | Relevant. Applies equally to autistic people wanting the same outcomes |
| **C. Better support for health care professionals to provide better care for people with intellectual disability** | • Continue to support roll-out of the Primary Care Enhancement Program (PCEP) which will provide greater support for primary health care professionals to provide more effective care to people with intellectual disability<br>• Design and develop intellectual disability competencies, curricula content, and tools and resources to develop health professionals' knowledge of intellectual disability and instil positive attitudes<br>• Consult on establishing a National Centre of Excellence in Intellectual Disability Health<br>• States and territories to consider implementing measures that make public hospital and community health services accessible, trusted and safe for people with intellectual disability. This could include guidance along the lines of 'The Essentials' produced by the Intellectual Disability Network of the NSW Agency for Clinical Innovation | • Relevant but needs to be extended to include Autism<br>• Relevant but needs to be specific to autism and not as a subset of ID<br>• Relevant as a National Centre of Excellence in Autism Health<br>• Relevant tailored to achieve accessible, trusted and safety for autistic people | • Embed training and continuing professional development in medical, nursing and midwifery, allied health, oral health, and pharmacy training programs<br>• Work with states and territories to build on the proposed establishment of a National Centre of Excellence, by further developing a national network of specialised intellectual disability health services | • Relevant. Requires specific training relevant to autism<br>• Relevant. Develop a network of specialised autism health services | • Work with states and territories to expand the national network of specialised intellectual disability health services to ensure it supports people with intellectual disability living in every state and territory | • Relevant. Establish/ enhance national network of specialised autism disability health services to ensure supports autistic people | Health care professionals have appropriate knowledge, skills and attitudes to provide quality, appropriate and disability-informed health care for people with intellectual disability. | Relevant. Applies equally to autistic people wanting the same outcomes |
| **D. Improving oral health for people with intellectual disability** | • Promote access to existing dental services including the Child Dental Benefits Schedule<br>• Support implementation of 'hub and spoke' models of care in oral health<br>• Expand workforce training in oral health care for people with intellectual disability and develop professional development modules<br>• Expand oral health promotion to people with intellectual disability and their carers and support workers | • Relevant<br>• Relevant<br>• Relevant but requires autism specific training and professional development modules<br>• Relevant but promotion through autism networks | • Consider options for establishing an oral health data collection related to people with disability, including intellectual disability<br>• Work with peak oral health groups and states and territories to develop the National Oral Health Plan 2025-2035, with stronger data sharing arrangements | • Relevant<br>• Relevant |  |  | People with intellectual disability are supported to maintain dental/oral hygiene as a vital preventive health measure; and their oral health care is integrated into general health care. | Relevant. Applies equally to autistic people wanting the same outcomes |
| **E. Research, data and measurement to support continuing improvement** | • Examine options for intellectual disability identifiers to be used that generate new data sets and can be linked with existing data sets and the proposed National Disability Data Asset<br>• Develop options for targeted national research that builds the evidence base on strategies to improve health outcomes for people with intellectual disability<br>• Improve data collection on the prevalence and impact of communicable diseases on people with intellectual disability. | • Relevant. Identify autism identifiers<br>• Relevant. Focus on having a lens of improved outcomes for autistic people.<br>• Relevant, Data collection expanded to autistic people | • Develop national data asset that captures and routinely reports on health outcomes for people with intellectual disability<br>• Work with health care providers to adapt existing patient experience surveys to capture the experiences of people with intellectual disability throughout the patient journey | • Relevant. Capture outcomes for autistic people<br>• Relevant. Adapt to capture experiences of autistic people | • Maintain investment and focus on national, population-based data collection and data linkage on the health of people with disability, to inform continuous improvement and further policy refinement and development | • Relevant. Ensure datasets capture autism | Health data on people with intellectual disability is routinely recorded and reported on at a national level, and evidence is used to drive improvements to health and health services. | Relevant. Applies equally to autistic people wanting the same outcomes |
| **F. Emergency preparedness and response** | • Incorporate learnings from Australia's COVID-19 response for people with disability into emergency planning and future emergency responses<br>• Provide greater clarity on Commonwealth, state and territory agency roles and responsibilities for responding to health emergencies for people with disability and the disability sector |  |  |  |  |  | Emergency preparedness planning and emergency responses consider the needs of people with intellectual disability, including tailored responses where appropriate. | Relevant. Applies equally to autistic people wanting the same outcomes |

**Table: National Roadmap at a glance modified to identify elements relevant to Autism**

*Note further work needs to be done to identify possible more areas for collaboration in the detailed action plan

# Annex C. ASD in the context of ID

We observe various Health officials suggesting 70% of autistic people also have ID. People in the autism sector are likely to suggest 30-50% of autistic people have ID. A recent review[13] says the median percentage of ASD cases with co-occurring intellectual disability was 33.0%.

But reality is more complicated. While around 2.2% of the population has an IQ at or below 70 IQ points (in line with ID criteria in DSM-5), officials in Australia feel around 1.8% of Australians of all ages have ID. For many, ID is not listed as their primary disability. And the NDIS had eligibility for people with ID needing IQ below 55 IQ points for access.

ASD diagnosis rates vary widely with age. Autistic diagnosis rates for Australian school-age children are over 3% while the diagnosis rate for adults (over 35 years of age) is below 0.3%. Adults are diagnosed at less than 1/10th the rate of children.

It is likely that ID comorbidity with ASD varies substantially with age. It is possible that adults with ID were more likely to be detected as children than those without as we see increases in diagnosis in those without ID. This would explain why we've moved over time from 70% ID to 30% as increase in diagnosis is those without ID.

The autistic diagnosis rate is rising rapidly among young adults as autistic children age into adulthood. The lack of a trained workforce and appropriate health services, especially mental health services, should seriously concern health officials.

It is not known, but it seems likely, that actual ASD prevalence in adults resembles autistic prevalence in children; that the difference is due to historic chronic under-diagnosis more than any actual prevalence increase. If so, there is now chronic under-diagnosis of autistic adults. The ABS data indicates that increased diagnoses is not primarily due to diagnosing milder cases.

While bureaucrats and politicians are inclined to believe there is massive over-diagnosis of autistic children, the government's attempt to find evidence of ASD overdiagnosis (see https://a4.org.au/node/1213) found the opposite.

As A4 has noted on numerous occasions (including our previous brief to health), in 2011 the Health Department, answering a question on notice, advised:

> The Department does not collect data on autism prevalence. The Department is not aware of any evidence of any major shifts in prevalence of autism in Australia.

The following table from the Government's submission to the Senate Select Committee on Autism shows data collected by the Health Department with mostly increasing diagnosis rates. Only the ACT has ASD diagnosis rates generally decreasing[14].

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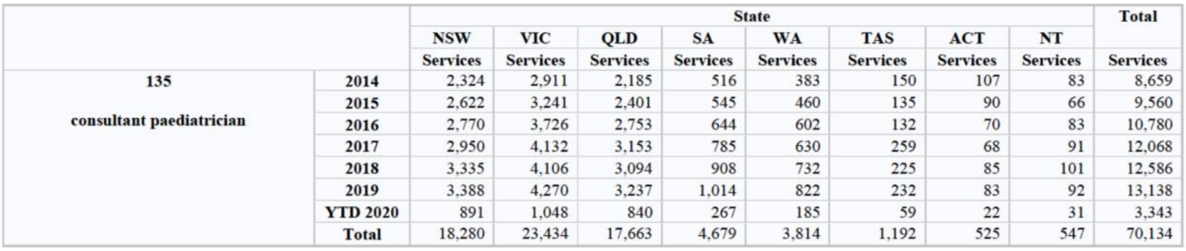
[13] Zeidan J, Fombonne E, Scorah J, Ibrahim A, Durkin MS, Saxena S, Yusuf A, Shih A, Elsabbagh M. Global prevalence of autism: A systematic review update. Autism Res. 2022 Mar 3. doi: 10.1002/aur.2696. Epub ahead of print. PMID: 35238171.

**Table 1: Item 135 service volume by time (row) and state (Cols) from Jan 2014 to April 2020**

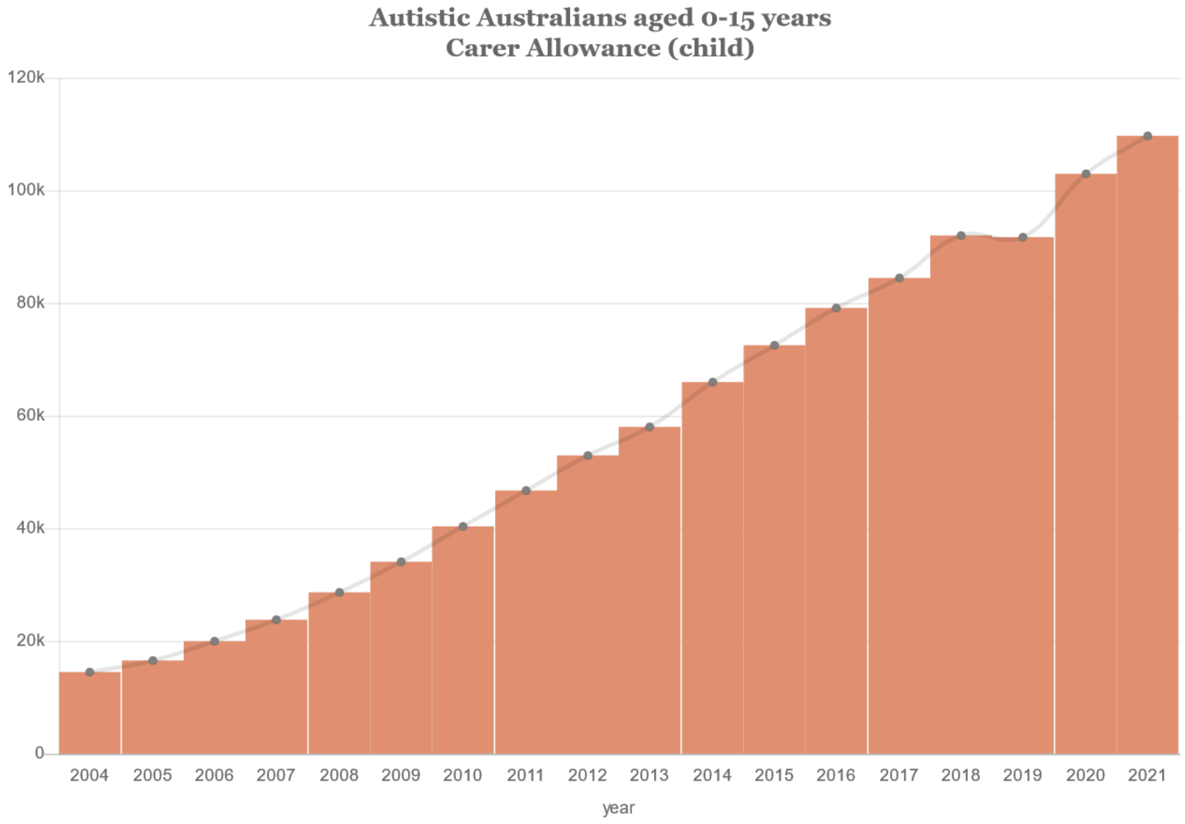


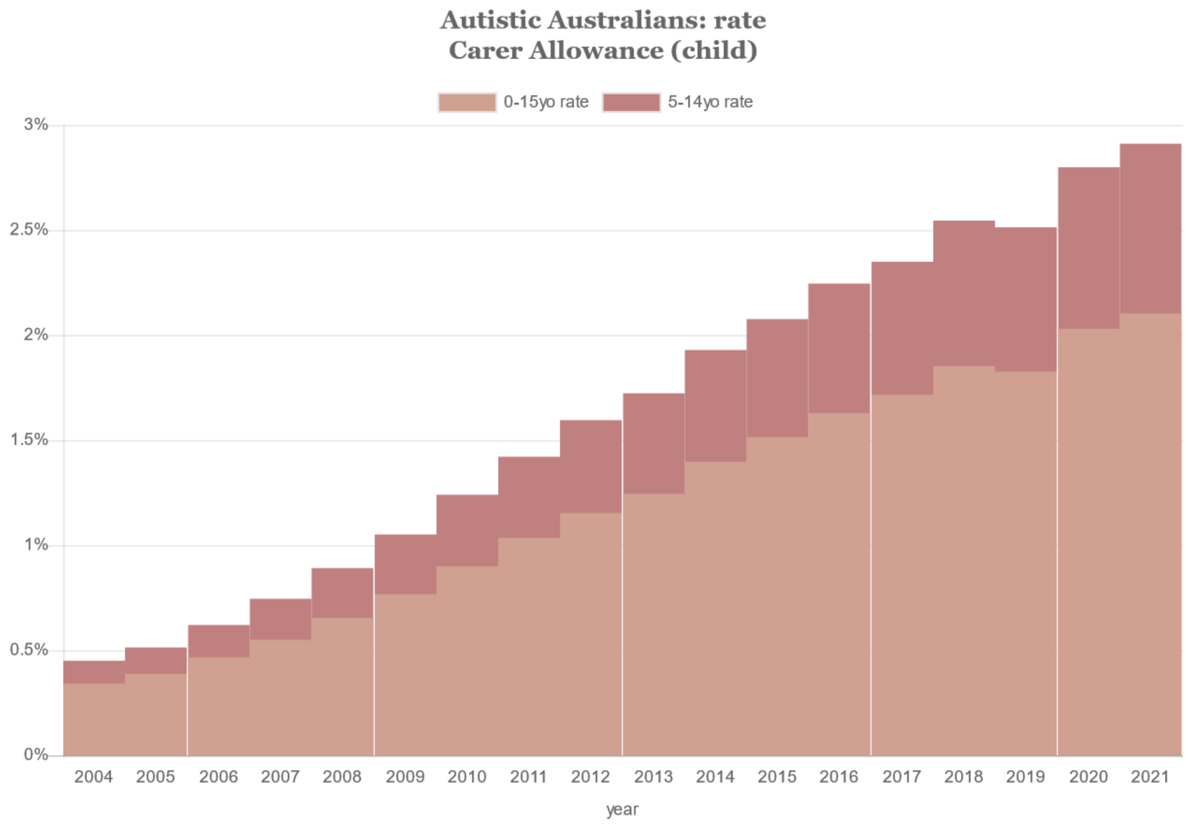
| | | State | | | | | | | | Total |
|---|---|---|---|---|---|---|---|---|---|---|
| | | NSW | VIC | QLD | SA | WA | TAS | ACT | NT | |
| | | Services | Services | Services | Services | Services | Services | Services | Services | Services |
| 135<br>consultant paediatrician | 2014 | 2,324 | 2,911 | 2,185 | 516 | 383 | 150 | 107 | 83 | 8,659 |
| | 2015 | 2,622 | 3,241 | 2,401 | 545 | 460 | 135 | 90 | 66 | 9,560 |
| | 2016 | 2,770 | 3,726 | 2,753 | 644 | 602 | 132 | 70 | 83 | 10,780 |
| | 2017 | 2,950 | 4,132 | 3,153 | 785 | 630 | 259 | 68 | 91 | 12,068 |
| | 2018 | 3,335 | 4,106 | 3,094 | 908 | 732 | 225 | 85 | 101 | 12,586 |
| | 2019 | 3,388 | 4,270 | 3,237 | 1,014 | 822 | 232 | 83 | 92 | 13,138 |
| | YTD 2020 | 891 | 1,048 | 840 | 267 | 185 | 59 | 22 | 31 | 3,343 |
| | Total | 18,280 | 23,434 | 17,663 | 4,679 | 3,814 | 1,192 | 525 | 547 | 70,134 |

The overall increases in these data are consistent with ASD diagnosis data from other government sources including the ABS SDAC and DSS/Centrelink Carer Allowance (child) data.

The increased incidence, 8,659 in 2014 to 13,138 in 2019, is 51.7% increase in 5 years or an average growth of 8.7% per year. This growth is in the same range as reported by the ABS SDAC.

Our previous brief included data on autism from the ABS SDAC. The following are charts based on autistic children (aged up to 16 years), getting Carer Allowance (child) which means they provided documentary evidence from a clinician of the ASD diagnosis.




Autistic Australians: rate
Carer Allowance (child)
0-15yo rate
5-14yo rate
3%
2.5%
2%
1.5%
1%
0.5%
0%
2004
2005
2006
2007
2008
2009
2010
2011
2012
2013
2014
2015
2016
2017
2018
2019
2020
2021
year

## Annex D. Health’s role in the National Autism Strategy

Recently, Australia’s governments have recognised our need for a National Autism Strategy (NAS). The autism community is keen to see Health’s contribution to the National Autism Strategy.

Some relevant recommendation from the Services, Supports and Life Outcomes for Autistic Australians (Senate Inquiry report released March 22) follow.

### Overview of 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.