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Autism Aspergers Advocacy Australia

**A4's submission in response to
DSS's Discussion Papers on a
National Autism Strategy**

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Submission in response to DSS Discussion Papers on a National Autism Strategy

Introduction

Autism Aspergers Advocacy Australia, known as A4, is pleased to contribute to the DSS Discussion on a National Autism Strategy and welcomes positive change to ensure that Australians with autism are provided with the opportunity and effective support to assist them in reaching their full potential.

Autism Aspergers Advocacy Australia (A4) is the Disability Representative Organisation (DRO) for autism listed on DSS's website. A4's role is to try to represent the diverse, sometimes conflicting views of Autistic Australians, their families, carers and others associated with them. There are numerous other people and organisations advocating for Autistic Australians, but A4 is one of the few that is Autistic lead and tries to represent the whole of the autism spectrum, including people who are severely and profoundly Autistic, with the result that they cannot represent themselves in political processes such as the development of a National Autism Strategy.

The Discussion Paper

It is clear that the development of a National Autism Strategy is necessary to provide improvements to Australia's Disability Strategy, which is failing on many fronts to support autistic Australians. This is evidenced by data provided by the ABS, which has reported specifically and repeatedly on the especially poor outcomes for Autistic Australians.

There is a specific section on Autism in the reports over more than the last decade from the ABS Survey of Disability, Ageing and Carers (SDAC) showing particularly poor outcomes, even when compared to outcomes for people with disabilities generally. It is A4's view that there is much work to be done.

The ADS is not alone in ignoring autism. The DRC has been informed repeatedly about especially poor outcomes for Autistic Australians but has had relatively little to say on the subject in its findings.

The NDIS Review found that the NDIS, in its 10 years of operation, has not engaged adequately with the full autism sector, nor has it sought to develop appropriate policies and programs for Autistic NDIS participants.

The "needs section" of DSS's NAS Discussion Paper has failed to outline the reasons that the NAS is required. Concerningly, in relation to the DSS's ADS, the NAS Discussion Paper failed to mention that:

- Autistic Australians have exceptionally poor outcomes and need disability-specific strategies; and
- the National Disability Advocacy Program lacks adequate advocacy support for Autistic Australians.

The following submission relates to [the engagement process](#) for DSS's Discussion paper: What we have heard: moving towards the Development of a National Autism Strategy.

Links to the full discussion paper are:

- [Discussion paper \(PDF 393kB\)](#)
- [Discussion paper \(DOCX 213kB\)](#)

Links to the summary paper are

- [Summary paper \(PDF 222kB\)](#)
- [Summary paper \(DOCX 156 kB\)](#)

Autism as a distinct category

It is the position of A4 that, for these reasons, Australia requires a national autism strategy that is properly developed, that recognises and respects autism as a distinct disability type and is not just part of some other disability type (such as Intellectual or Cognitive Disability). The autism sector does not need more of the same – the approach that left autism out of Australia’s Disability Strategy in the first place.

Alternatively, the government could recognise either:

- a neurological category of disabilities (the category that contains ASD in the DSM-5); or
- disability associated with neuro-diversity.

The focus of the National Autism Strategy must be on improving outcomes for Autistic Australians; it is not about the conduct of government.

Autistic Australians, their families, carers, and workers are best placed to provide valuable information when formulating policies and strategies. NAS development must properly engage with the entire autism sector.

Autism & Human Rights

Australia is a signatory to various United Nations treaties and conventions but repeatedly fails to deliver on its human rights commitments to people with disabilities. Autistic Australians do not have human rights under Australian law, something that the United Nations reiterates. It is dishonest to claim the government is committed to human rights or that the Australian Government protects or promotes human rights. A4 is pleased to see that the DRC recommended disability rights legislation, and we look forward to a positive response from the government to this recommendation.

The key focus of a National Autism Strategy must be to improve the lives of Autistic Australians.

The indication that autism as a standalone form of disability does not warrant focus is alarming. Autism itself is a sufficient indicator of a need for focus. While most Autistic Australians have other complications in their lives, there should be no need to identify further factors or “intersectional (overlapping) disadvantage” as a prerequisite for attention and support. There are many Australians whose autism results in excessive discrimination and disadvantage. The Australian Government needs to approach NAS development with a view that the autism community is not united and advocacy groups often have different or even conflicting agendas. The nature of autism means that there simply are no unified views. Sectors within the Autistic Community often require different needs, supports and policies because the condition is varied. For example, some autistic Australians may crave more social engagement and inclusion, while others may require greater autonomy and even seclusion. Areas prioritised by the government may benefit many Autistic Australians, but as with Aboriginal Australians, there are no specific efforts that will benefit *all* Autistic Australians. That idea is a fantasy.

There is no single *national approach* that would benefit all Autistic Australians across the country. The government must come to terms with the requirement for a NAS that recognises and respects the differing individual needs of Autistic Australians.

The Lack of Respect in Terminology

A key concern is that the discussion paper fails to include a proper definition and section addressing; Who are Autistic Australians?

A4's submission to the Oversight Committee suggested that "autism" is short for Autism Spectrum Condition (ASC). ASC is a broader term than the clinically defined Autism Spectrum Disorder (ASD).

It is concerning that this issue of terminology has not been addressed in the discussion paper. Over the last decade, "autism" has come to be used much more broadly than it was in the past. "Autistic" now describes people who are disadvantaged by their neurological differences and who need society, employers, and government to accept and appreciate their neurodivergence.

These Autistic people claim correctly that they don't need their autism to be "fixed" and that their autism is not the problem; but the failure of others to recognise their differences and appreciate the potential benefits.

Some Australians on the autism spectrum do not need treatment or therapy for their ASC. They may require treatment for anxiety, depression, trauma, and other types of mental illness that are consequences of their Autistic lives in an intolerant society. It would be more respectful if government policy and approaches accepted this position from the outset.

Similarly, people with ASC but not ASD, and many who meet the autism ASD criteria, object to historical descriptions of autism.

For example, the DSM-5 still says, "Only a minority of individuals with autism spectrum disorder live and work independently in adulthood; those who do tend to have superior language and intellectual abilities and are able to find a niche that matches their special interests and skills."

This description is demeaning for many people who are now considered (or consider themselves) Autistic.

The number of Autistic adults being diagnosed now shows that many of them lived and worked independently before they were diagnosed.

At the same time, increasingly inclusive education, employment, and a more neuro-affirming community mean Autistic Australians have better prospects for living and working independently in adulthood. Inclusion, when it works properly, accommodates more Autistic differences, and as a well-implemented social model of Autistic disability, reduces perceptions of "disorder" often characterised in a medical model of disability. Less of the autism spectrum is characterised as a "disorder".

Differing Autistic Views

Autistic people are not united in their response to this broader recognition of autism.

- Some Autistic people are 'proudly Autistic' and celebrate their difference and the advantages it brings them.
- Some Autistic people, even with greater acceptance, would prefer to be less Autistic – they struggle with their "difference" and not fitting into a largely neurotypical society.
- Even with greater autism acceptance, there are Autistic people who need substantial support and who cannot "live and work independently in adulthood".

Membership in these groups *is not fixed*. There are Autistic Australians who can learn skills to live more independently as adults if they get appropriate support to help them do that. The challenge here is that research has yet to develop clear strategies for identifying which Autistic people benefit from which approaches.

The NAS consultation process must appreciate that Autistic self-advocacy is strongest in the first of the above groups, people who are proudly and comfortably Autistic. The other parts of

the autism sector have fewer autistic voices, and much of the disability sector is less willing to hear their voices and representatives.

A challenge for a NAS is to seek outcomes for all Autistic Australians, not just the strongest self-advocates. The needs of Autistic Australians can only be met through a wide spectrum of strategy elements that meet all the individual needs of Autistic Australians across the full spectrum.

What is the Autism Spectrum?

As previously stated, A4's view is that the "autism spectrum" in the ASD part of ASC describes the substantial variety of features of the ASD diagnosis criteria. When Part A of the criteria says, "deficits in social communication and social interaction", it means that an Autistic person might engage either in what is "normally" considered excessive or insufficient social interaction or be socially inappropriate in other ways. Either too much or too little is a deficit. Or that there are many ways to be regarded as "inappropriate" or "unappreciated" in social interaction by neurotypicals.

Similarly, Part B of an ASD diagnosis identifies "Restricted, repetitive patterns of behaviour, interests, or activities". Restricted interests or activities can be either very positive or negative in a person's life. Some employers appreciate an Autistic person's restrictive interests that may result in extremely focused and high-quality work. However, the same trait may be detrimental to social interactions. Often, restricted interests mean that the person has enormous difficulty performing essential tasks needed to live.

Some Autistic people are especially sensitive to sound, light, smell, touch, etc., while others may be insensitive. Again, Autistic people may present with different skills and problems. An Autistic person may have a combination of these various differences: hence, the autism spectrum is not linear, it is multi-dimensional. It is beyond being verbal or non-verbal, social or anti-social, etc.

Further, there is a spectrum of associated conditions. Few Autistic people are "just Autistic"; most of us have other health and/or disabilities compounded with their autism.

This spectrum nature of autism underpins Dr Shore's famous truism that, "If you've met one person with autism, you've met one person with autism." It is a fact that autistic people are rarely alike. It means that a NAS strategy must assume that all Autistic Australians are different and often surprising.

Of course, there are a variety of views about what "the autism spectrum" means.

Lack of Data and Evidence

The discussion paper does not appear to have been authored by an Oversight Committee or any working groups, given the lack of data or referenced evidence. It appears to have been authored by government officials with insufficient oversight from the NAS Oversight Committee. The Discussion Papers ...

1. emphasise the government's perspective on "intersectionality" without understanding the issues of the autism sector. Many Autistic people and their families report that the autism in the family isolates them from their community sector. Too often, they are isolated from everyone, and their cultural origin becomes irrelevant.
2. fail to recognise that the needs of autistic women and girls differ from many males, who often prefer more secluded/isolated lives.
3. ignore the increased demand for neuro-affirming services and supports.

The Autism Perspective

Sadly, like many government documents and policies, the discussion paper appears to have not been formulated with the inside perspective of Autistic Australians. Most recognisably, it does not address the diversity of the spectrum.

Many important issues are not addressed, and there is insufficient time for the autism sector to formulate a full and proper response.

There is a tone here that autism is not an issue – it is only an issue for an individual in the context of other disability issues.

Discussion areas

Social Inclusion

The poor understanding of autism shown in the NAS development process is alarming.

In the housing space, many Autistic adults live with their parents because they can't get the disability support they need. The government doesn't understand the unique challenges that Autistic Australians face.

Unusual behaviour brings Autistic people into contact with police and legal systems. Police often interact inappropriately with autistics, with trauma as a common result. There are severe and frequent autistic-related issues in the child protection system, and these issues seem to have been neglected in the DRC report. The legal system must start to develop its understanding of Autistic people and their rights.

The NAS provides a new opportunity to recognise and support autism or neuro-diverse communities.

The NDIS and other disability services need to expand their awareness of autism, deliver comprehensive and impartial information and advice relating to autism, and recognise and offer an extensive spectrum of evidence-based practice that improves outcomes for Autistic Australians. Then, it is only with proper measurement and reporting that Autistic Australians will realise improved outcomes.

Discussion questions

1. What has prevented you from being included in your community?
2. How could services and supports be improved to help you live the life you want?
3. How can we improve community attitudes towards Autistic people?
4. How would you describe better social inclusion for Autistic people?

Responses to Social Inclusion Questions

1. What has prevented you from being included in your community?

It is important to not assume all Autistic Australians want *normal* (whatever that is) levels of “social inclusion”.

There need to be several perspectives on what is “preventing” Autistic Australians “from being included in the [mainstream] community”.

- some autistic people are told by others to go somewhere else; intolerance of others prevents them “from being included in [their] community”.
- social and communication differences are Part A of their diagnosis. A credible autism strategy recognises that increased/improved “social inclusion” is a goal for some

Autistic people but not for others. Some Autistic people (possibly more Autistic males) prefer seclusion at least some of the time. A NAS must respect personal preferences.

- for some Autistic people, their Autistic difference makes them stand out when they are in social settings – and their consequent embarrassment and stigma from the difference is their barrier.
- Some Autistic people have other issues like social anxiety or various phobias that limit their social participation.

Lack of Advocacy

For Autistic Australians needing support for their autism, advocacy is a major barrier. By definition, Autistic people have difficulty communicating. Often, they need help with advocacy, but that help is not available.

Neither the National Disability Advocacy Program nor state/territory governments fund advocacy services for Autistic Australians.

Generic advocacy services focus on *Inclusion* which does not help an Autistic person who requires support after being traumatised in so-called Inclusive settings.

For this reason, many Autistic people are denied access to advocacy services, or funded disability advocates trivialise their support needs. Many funded disability advocacy services have a deep understanding of autism.

The Senate Inquiry report has a whole section of recommendations about advocacy.

The NAS needs to provide very clear directions in relation to “safety, rights and justice” for Autistic Australians. The government in Australia has failed persistently and deliberately to recognise and address behaviour supports and restrictive practices.

2. *How could services and supports be improved to help you live the life you want?*

Too often, services and supports simply do not recognise and respect the needs of Autistic Australians. The NDIS is the prime example: after a decade of operation, the NDIS still has not engaged with the autism sector to understand, appreciate, and respect the diverse needs of severely Autistic Australians.

Examples include:

- the lack of individual advocacy services for Autistic Australians – most individual advocacy services regard Inclusion in the mainstream as the only meaningful outcome of their work. Often, this is not what their Autistic clients need.
- Employment services think IT is the only workplace for Autistic people, and even in that sector, successes are limited.

3. *How can we improve community attitudes towards Autistic people?*

The first step is by example: both DSS and the NDIA need to substantially improve their understanding of the diversity of autistic Australians so they then may improve their approach to a range of supports.

4. *How would you describe better social inclusion for Autistic people?*

Better social inclusion for Autistic people requires respecting Autistic people’s preferences.

There are two aspects.

- a. Respecting Autistic people's preferences for managing their personal level of social interaction and seclusion; and
- b. Appreciating and supporting that there are Autistic subcultures; just as there are AUSLAN social groups, Autistic social groups can be clearly observed in things like the *Love on the Spectrum* TV series.

Economic Inclusion

The ABS SDAC has repeatedly described the inclusion challenges that Autistic Australians pose to the economic performance of our nation. These data might provide a baseline that the success of this aspect of the NAS might be measured against. Unfortunately, these data have not been reported since 2018, before the NDIS achieved full rollout. Hopefully, new data will be provided soon.

While data describing Autistic participation in the Australian economy indicate that a NAS has serious potential for improved outcomes, the commitment to this purpose is hard to discern in the processes of government.

While the government expects that the National Disability Data Asset (NDDA) will provide even better measurement and reporting, its pilots failed to report autism measures appropriately ... and its education example was seriously problematic.

Discussion questions

1. What has prevented you from being able to fully participate in education and employment or to get access to transport?
2. How could services and supports be improved to help you participate in education or work, have a career or have your own business?
3. How else do you think we can better support Autistic people in education, employment and the workforce?
4. How would you describe better economic inclusion for autistic people?

Responses to Economic Inclusion Questions

1. What has prevented you from being able to fully participate in education and employment or to get access to transport?

There are three parts to this question: parts on education, employment, and transport.

The latest [ABS SDAC 2018 data on autism](#) indicates especially poor outcomes in education and employment for Autistic Australians. The National Disability Strategy 2010-20 did little or nothing to even lift outcomes for Autistic Australians to be comparable to disability outcomes generally. Its replacement, [Australia's Disability Strategy \(ADS\) 2021-31](#), does not acknowledge these especially poor outcomes or attempt to improve them.

Education is one of the biggest issues for a NAS. The consultation timeframe is too short to discuss this issue adequately with the responsible parts of state & territory governments who are primarily responsible for education in Australia.

The DRC recommended that all segregated education cease. As discussed below, parts of the autism sector do not agree with such a recommendation ... with good reason.

Employment follows on from education: good employment outcomes depend on good education outcomes ... and much more. Also, the issue of employment outcomes for Autistic Australians needs to be discussed with the [Department of Employment and Workplace Relations](#) (DEWR) whose website does not mention autism.

Transport is a challenge for autistic people. While many Autistic Australians can access mainstream transport options, the transport needs of Autistic Australians who cannot use mainstream transport are usually ignored. For example, access to day programs for Autistic Australians often depends on Informal Carers providing drop-off and pick-up. This means that the Autistic individual does not have basic access to their service and support.

2. How could services and supports be improved to help you participate in education or work, have a career or have your own business?

The Senate Autism Inquiry asked this question ... and received comprehensive information from much of the autism sector. The NAS must start from Recommendations 46 to 57 in the Inquiry Report on this subject.

Notably, Recommendation 47 relates to bullying of autistic students, a subject that has a huge impact on autistic students. Bullying of autistic students is a prevalent form of violence and abuse of autistic students that got inadequate attention in the recent Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability [final reports](#). Bullying is a primary cause of school refusal for autistic students, where the resulting trauma requires subsequent education in segregated or secluded settings. The DRC's recommendation to close segregated education settings is a strategy to deny traumatised autistic student education, contrary to their basic right to education. ***The DRC recommendation conflicts with Recommendation 54. The NAS must address and resolve these issues.***

Recommendation 48 calls for monitoring of students with disabilities, including autistic students. However, governments and their education departments have demonstrated that they simply do not know which students have autism.

The state and territory governments originally estimated the numbers of autistic NDIS participants were grossly in error, demonstrating that those governments and their education departments were unaware of autistic student numbers. [The NDDA education to employment pilot](#) showed that the SA state education system reported around 2,000 autistic students, while the NDIS reported around 10,000 autistic NDIS participants in the age range of 7 to 14 years. Presumably, there are even more Autistic South Australians aged 6 to 16 or 18 years who are meant to be in the state's education system.

There is no prospect of monitoring and reporting education outcomes for autistic students if the states don't know they are there or who they are.

There is little prospect for Recommendation 52 when the government remains reluctant to discuss issues and concerns raised by the Autism DRO, the Australian Autism Alliance and other relevant autism-related stakeholders and representatives.

3. How else do you think we can better support Autistic people in education, employment and the workforce?

The DSS and the IADS need to recognise and respect that autism is a distinct disability and needs to be recognised and treated as such, or at least neuro-divergent disabilities and need a greater focus.

There is clear evidence that demonstrates that outcomes for Autistic Australians in education and employment are substantially worse than other parts of the disability sector and must improve.

Clearly, generic approaches, or approaches targeting other disability types, do not improve education and employment outcomes for Autistic Australians, rather, a genuine NAS is needed.

4. How would you describe better economic inclusion for autistic people?

This requires a fresh approach.

Diagnosis, services and supports

Discussion questions

1. What has prevented you from getting a diagnosis or accessing services and supports that would help you live the life you want?
2. What has helped you to access diagnosis, services or supports?
3. How can we better make sure that diagnosis, services and support for Autistic people are strengths-based, culturally responsive and trauma-informed?
4. How would you describe what better access to diagnosis, services, and support looks like for Autistic people?

Responses to questions on diagnosis, services and supports

The Senate Inquiry recommendations 38 to 42 relate specifically to diagnosis. Recommendations 43 to 45 relate to early intervention.

The NDIS prefers functional assessments to diagnoses, especially for young children. While autism diagnosis is grossly underfunded (the Medicare refund is a small fraction of the cost), few families can afford the un-funded functional assessments that the NDIS requires so that young Autistic children can access the Scheme.

In many instances, the NDIS refuses to even record diagnoses of co-occurring conditions.

1. What has prevented you from getting a diagnosis, or accessing services and supports that would help you live the life you want?

There are many things that prevent or inhibit people from getting an autism diagnosis in a timely manner.

- Lack of awareness of early signs/indicators of autism. This relates to parents, health/medical staff, childcare and education staff, etc.
- Too many health staff advise a “wait and see” approach to children not achieving developmental milestones – this is often not good advice
- Unacceptable waiting lists for diagnostic services ... presumably related to inadequate capacity in the workforce
- Diagnosis cost is a major inhibitor for many families
- Mis-diagnosis: people, especially women and girls, being diagnosed incorrectly with other conditions and being diverted to the wrong supports
- Access to clinicians for people in rural and remote settings
- Some people avoid the stigma, exclusion, discrimination, and social separation due to disability or neuro-divergence

2. What has helped you to access diagnosis, services or supports?

For many Autistic Australians, the NDIS has become their primary, often only, source of formal support. Mostly, the NDIS has helped Autistic Australians, but there are also many people who have enormous difficulty with the NDIS. The NDIS is a mixture of good and bad – it seems to be polarising, so little in the middle.

Autistic Australians who are not NDIS participants have very little access to services and supports for their autism.

The failure of the NDIA to broadly engage with Autistic Australians has led to government distrust and even denigration of often impressive Informal Supports. A fortress mentality has led to the NDIA disregard of often superior solutions and opinions.

The implementation of the NDIS annihilated most state/territory, local government, charity, and community supports for Autistic Australians. State/territory-funded diagnosis services are mostly reported to have waitlists in excess of 2 years – which is far too long to wait to access essential early intervention.

The problem with the NDIS approach to allowing in (undiagnosed) Autistic children who are labelled instead with “developmental delay” (as defined in Section 9 of the *NDIS Act 2013*) is that their families are usually mis-advised about early intervention. Most clinicians advise that Autistic children need ASD-specific early intervention; generic early intervention for Autistic children is most likely contrary to s34 of the *NDIS Act 2013*.

The autism sector is divided over early intervention. A4’s view is that this is due largely to ASD having been coalesced; previously, approaches to Autistic Disorder were usually regarded as distinct from Asperger’s disorder (and PDD-NOS had insufficient attention). Now that there is one label, researchers and some clinicians are looking for a more uniform approach to autism as a whole. But a uniform approach to “the spectrum” just will not work.

The Health Autism Roadmap working group is tackling issues relating to Health services and supports.

3. How can we better make sure that diagnosis, services and supports for Autistic people are strengths-based, culturally responsive and trauma-informed?

The first step for government, and especially DSS, is to recognise and respect autism as a distinct disability with its own distinct needs. Some autism needs overlap with other types of disability, but some essential areas are distinctly associated with autism. The government needs to appreciate that generic disability services often fail to support Autistic Australians.

Many in the community and in support areas like education, employment, and accommodation, must understand that the benefits from autistic strengths sometimes have associated differences. Learning to accept differences or recognising that benefiting from an autistic person’s strengths may also require acceptance/tolerance of their differences. These are extremely difficult issues for the government. It may well be that we all need to better understand the underlying aspects before we can design strategies that are likely to be effective – so more targeted research may be needed to unpick the features of the challenge to better harness to diverse strengths of Autistic Australians. The existence of areas of employment spikes in a few areas (such as IT) shows that strength-based strategies can be very effective for Autistic people.

Issues of being “culturally responsive” in an autism context must be better defined. Or perhaps the primary problem is that the government and the general community do not recognise sufficiently Autistic sub-cultures. Being autistic often displaces people from their ethnic or social cultures and places them in distinct, isolated, and usually unrecognised Autistic sub-cultures. There is little or no recognition of or support for those sub-cultures, so they struggle to even exist.

4. How would you describe what better access to diagnosis, services and supports looks like for Autistic people?

The Senate Inquiry report has a section of recommendations relating to improving diagnosis services.

Autism diagnoses need to be timely; currently waiting lists are far too long in all jurisdictions. There is a substantial workforce and skills shortage.

In some places, there exists a culture of “wait and see” for autism. This is detrimental for Autistic children who need early intervention. Delayed autism diagnoses are exacerbated by the NDIA’s approach to developmental delay.

Better diagnosis would mean diagnostic reports contain the information the DSM-5 says they should contain (see <https://a4.org.au/dsm5-asd> - it asks clinicians to “specify” a list of items but few of these appear on most diagnosis reports provided). Government must work with clinicians and researchers to decide a) whether the two severity ratings are meaningful, and if so b) how they should be standardised for use in Australia.

In many instances, families cannot make informed choices about services and supports for their Autistic children because they are not sufficiently informed about evidence-based service and support options for their children’s autism. The NDIS abolished the HCWA Autism Advisors ... and the various replacements provide insufficient and often incorrect information.

Many Autistic Australians have difficulty accessing services and support for their autism. Often, they cannot even get on a waiting list. The government is not making a discernible attempt to measure, let alone address, deficits and deficiencies in the relevant parts of the workforce.

Better access to diagnosis, services and support would be affordable, immediate (no waitlists or worse), and high-quality.

National Roadmap to Improve the Health and Mental Health of Autistic People

There is a well-established working group for this part of the NAS development. That group was not consulted about this material.

Discussion questions

1. Are there other health and mental health issues experienced by Autistic people that the National Autism Strategy should help to address?
2. What needs to improve about health and mental health services and supports?
3. How else do you think we can support better health and mental health outcomes for Autistic people?

Experiences like Caleb’s (see [*Caleb has autism, needs dialysis and a new kidney but Canberra Hospital says it can’t help him*](#)) are unacceptable.

The entire health sector needs a reset: from the outset, the health workforce is trained and acculturated in ableism and elitism. The health sector devalues the lives of people with disabilities, using this prejudice as an excuse for delaying or denying access to underfunded and over-stretched health services.

Many in the health sector misunderstand disability. There are many examples of health policy being based on the false belief that around 70% of Autistic Australians also have Intellectual Disability ... or that Autism is just an optional feature of Intellectual Disability (when the DSM-IV and DSM-5 both characterise autism as primary and ID, when present, as co-occurring at best).

The Health and Mental Health Working Group for the NAS is being run by the Health Department. It is operating more independently and appears at this stage to be functioning relatively well.

Response to Senate Inquiry Report

The Senate Inquiry Report provided 81 recommendations that it classified into 12 categories. The following table shows A4's view of which of DSS's NAS working groups are most responsible for the Inquiry's categories.

Senate Inquiry Recommendations category	best NAS Working Group
A National Autism Strategy	OC
The adequacy of available services and supports	Social, Diagnosis
Supports and services for specialised groups	<i>all</i>
Research and data collection	OC
Advocacy	Social
Diagnosis	Diagnosis & Health
Early intervention and support	Social & Diagnosis
Education	Economic
Employment	Economic
Health and mental health	Health
Housing	Social & Economic
Justice	Social

The autism community needs and deserves specific and comprehensive responses to all 81 Recommendations.

Response to DRC final report

The NAS needs to acknowledge that the DRC failed to properly recognise and address distinct issues of violence, abuse, neglect, and exploitation of Autistic Australians. For example, the profound effect of prevalent violence, abuse, and neglect in the form of bullying of Autistic students received insufficient attention.

Concluding remarks

A NAS needs specific engagement on:

- quality and timeliness of diagnosis and functional assessment
- Respect/appreciate the full autism spectrum, including profound autism
- early intervention for the whole spectrum – need a spectrum of solutions ... much greater respect from bureaucrats and clinicians for the knowledge and experience of Informal Carers
- complex needs, behaviour support, & restrictive practice must be fully addressed
- autism in Australia's legal system needs to be fully addressed

Summation

Australia's future strategy must incorporate and respect the diverse views of the entire autism sector to achieve substantially improved outcomes.