Parent and Carers of Autistic People

Focus Group Report

Date/time:

- 15th May 2024, from 6:30pm AEST
- 22nd May 2024, from 6:30pm AEST
- 10th July 2024, from 6:00pm AEST

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Acknowledgement of Country

The Australian Government and the National Autism Strategy Oversight Council acknowledge the Traditional Owners of Country throughout Australia on which we gather, live and work. We acknowledge all Traditional Custodians, their Elders past, present and emerging and we pay our respects to their continuing connection to their culture, community, land, sea and water.

Acknowledgement of Autistic people and their families and the autism community

The Australian Government and the National Autism Strategy Oversight Council acknowledge Autistic people, their families, carers and support networks, representative organisations and the Autistic and autism community who have worked tirelessly and campaigned long and hard for the establishment of this National Autism Strategy.

Content Warning

Please be aware that this document contains information that may be distressing to readers. It includes information about the experiences of Autistic people and their carers and families and some of the barriers they face. If you need support to deal with difficult feelings after reading this document, there are free services available to help you.

Beyond Blue Support Service

- Telephone 1300 224 636, 24 hours a day, 7 days a week.
- Website: Beyond Blue Support Service.

Lifeline Crisis Support

- Telephone 13 11 14, 24 hours a day, 7 days a week.
- Website: Lifeline Crisis Support.

1800RESPECT – National domestic, family and sexual violence counselling, information and support service

- Telephone 1800 737 732, 24 hours a day, 7 days a week.
- Website: 1800RESPECT.

13 YARN

- 13YARN (13 92 76), 24 hours a day, 7 days a week.
- Website: 13 YARN

Autism Connect

- Telephone 1300 308 699, 8am to 7pm, Monday to Friday.
- Website: Autism Connect.

Background

People within the Autistic and autism communities have called for a dedicated National Autism Strategy. In 2022, the Australian Government announced the development of a National Autism Strategy.

A National Autism Strategy will improve life outcomes for all Autistic people in Australia. It will provide, for the first time, a coordinated national approach to services and supports for Autistic Australians and their families.

The National Autism Strategy will be for all Autistic Australians. It will cover key reform areas including access to services, education, and employment. It will help to guide a more coordinated, national approach supporting Autistic people at each stage of life.

The National Autism Strategy will sit alongside Australia's Disability Strategy 2021-2031.

The National Roadmap to Improve the Health and Mental Health of Autistic people in Australia), which is being led by the Department of Health and Aged Care (DoHAC), is being developed separately to the Strategy, in order to address health and mental health needs in greater detail.

The draft National Autism Strategy was released by the Department of Social Services for public feedback from 2 April 2024 to 31 May 2024. It is expected that the final Strategy will be considered by Government by the end of 2024.

In order to ensure that a diverse and intersectional range of perspectives were considered, the DSS hosted a series of targeted consultations with specific groups. As reported in the Senate Committee Inquiry on Autism report the well-being of parents and carers are critical to the success of Autistic people. Two online targeted consultations with parents and carers of Autistic people were organised for the 15th and 22nd May 2024 at 6:30pm AEST.

The Microsoft Teams sessions were facilitated by Jenny Karavolos, a member of the National Autism Strategy Oversight Council, Co-Chair of the Australian Autism Alliance and the parent of an Autistic teenager. A total of 15 and 19 parents/ carers of Autistic children participated.

As a result of this a number of recommendations were identified. This were presented verbally on the 10th July 24 to a group consisting of parent/carer representatives from the 15th May and 22nd May 2024 consultations.

This report also captures the feedback to a series of questions by themes and some de-identified direct quotes to illustrate the discussion content. This report is not intended to be a transcript of all the discussions.

Overview of Feedback

Overall, group participants saw some good elements in the strategy, particularly if it is to represent Autistic people who have the ability to advocate themselves and achieve mainstream education and employment. However, there is significant concern that the strategy fails fundamentally to reflect the full diversity of Autistic people resulting in the strategy having a number of identified gaps.

The most significant gap was that the strategy poorly recognises and captures the needs of people with autism requiring very substantial supports (aka profound autism, severe autism, severe and profound autism, high support needs, high dependency needs, profound needs, very significant supports requiring intensive support and those who require more intensive support).

> *"Individuals who are severely impacted by autism need targeted attention in order to ensure that the improvement in quality of life is achieved for them under the Strategy"*

The strategy also failed to recognise the families and carers of people with profound autism (aka requiring very substantial supports). As reported in the Senate Committee Inquiry on Autism report[1] despite the well-being of parents and carers being critical to the success of Autistic people, there is overwhelming evidence that support for parents and carers is currently inadequate. The indirect economic costs of caring are well known and were one of the factors that led to the establishment of the National Disability Insurance Scheme (NDIS). [2]

> *"My son, my son, had to go under a general anaesthetic just for his first dentist appointment, …..I think that the most important thing is that people in this group are continuously involved in these conversations…. And what the commentary has been is that the document has been designed with Autistic people who have a capacity to communicate and have very different fulfilling lives".*
>
> *"we need to have profound autism recognised with all of its challenges. And then that comes with different educational programs and different employment settings and doctors and diagnosis and all those things."*
>
> *"I think truth and descriptors are important and we need to reflect the full spectrum of the impact of autism and we're not reflecting it …. that the people that are on the profound end are vastly different in so many ways from people that are not".*
>
> *"There are concerns of the marginalisation and inappropriate categorisation of those with Severe and Profound Autism (SPA) resulting in deficient outcomes*

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[1] Senate Select Committee report on Autism, March 2022. Services Support and Life Outcomes for Autistic Australians, Chapter 4

[2] The Productivity Commission estimated that about $1.5 billion per annum of economic benefits would occur from carers re-entering the workforce

> *for many of the most vulnerable".*

The different terminology used to reference this important cohort highlighted an issue in itself - that there is a need for a consensus definition to avoid the risk of their unique challenges and needs not being recognised and being diluted.

For the purposes of this strategy the following two descriptors will be used interchangeably - that is, profound autism (aka requiring very substantial support needs) or requiring very substantial supports (aka profound autism). This is until a consensus definition can be reached (refer Recommendation 1). What is most important is that we come to a consensus definition for the purpose of the National Autism Strategy to ensure consistency and relatedness with the Australian Government who will be responsible for driving the outcomes. Even more importantly than the "one or few words" used to capture the definition, is the elements that comprise it. This is further elaborated on in the Section titled Statement on Autism.

> *"And even though what we talk about a spectrum, they have very specific needs of their life experience (and), of our life experience as parents is very, very different".*

The feedback identified that the lack of recognition was evidenced throughout every section of the strategy starting from the introduction and statement of language through to the vision, goals and guiding principles, commitments, governance, research and reporting.

> *"Those with the most needs are falling through the cracks…… and I don't think the strategy in general captures any of it"*

Many of the group participants, as a result, could not relate to the strategy.

The specific reference and targeted action being required is supported by the Senate Select Committee on Autism report that stated:

"The committee is also aware that within the broad framework of a National Autism Strategy, targeted action will be needed to support cohorts that face additional challenges and compounding disadvantage"[3]

The Senate Select Committee on Autism report also recognised the diverse views:

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

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[3] Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [x]

autism community around a shared set of goals. Accordingly, the committee believes that an inclusive co-design process—drawing on the autistic community, as well as parents, carers, researchers, and policy makers—must underpin development of the strategy."[4]

It was also identified that the Strategy needs:

a) to make a clearer statement of what is meant by autism;
b) an accurate and complete reflection of the diversity of autism; and
c) have specific subsections dedicated to very substantial support needs (aka profound autism).

It was also identified that within these subsections there needed to be emphasis on marginalised cohorts such as culturally and linguistically diverse (CALD) and First Nations.

Furthermore it was highlighted that just as importantly the strategy overlooked a clear recognition that autism is a disability and that Autistic people experience challenges. While everyone loves and respects being different the strong emphasis on "neuro-affirming" and "strengths based" leaves no room for recognising that there are times that challenges need to referred to in non neuro-affirming way that is factual to ensure the safety and/or appropriate responses for loved ones, in a current society that lacks awareness, understanding and accepting.

> *"And I really feel in the framework of all this, we really haven't described what is a disability within the framework of autism".*
>
> *"the challenge here is that those with the most needs, those that ……..will require intensive care for the term of their lives will require very specialised support and supports for the term of their natural lives are not represented by this strategy and therefore those with the most needs".*
>
> *" some commitments are not inclusive of SPA. Vital issues including restrictive practices, abuse, research, schooling, health, housing and augmented communication and general services are inadequately addressed."*

Some expressed a preference for a separate National Autism Strategy focussed on Autistic people with profound needs (aka requiring very substantial support) and their carers if the above could not be achieved.

It was also identified that there were areas that had not been considered at all. These are outlined in the Section titled Gaps and include:

a) Housing

b) Justice and Child Protection

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[4] Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [x-xi]

c) Transportation and Accessible Supports

d) Carers

e) Workforce

f) Autism Specific Independent Advocacy; and

g) Early Investment (Intervention).

In summary it was considered that if the National Autism Strategy is to achieve its stated goal of “ALL” Autistic people, it needs to be substantially revised to address Autistic people requiring very substantial support (aka profound). This was particularly important as the National Autism Strategy will set the tone for future generations of people with autism.

More specific and extensive feedback is captured in this paper below including recommendations.

Summary of Recommendations

Statement on Autism

Recommendation 1: Develop a consensus definition for profound autism (aka requiring very substantial support for the purpose of the National Autism strategy. Include this definition on the Glossary. A final recommendation by the Family and Carers group will be provided by the group prior to the National Autism Strategy Oversight Council meeting on the 14th August 2024.

Recommendation 2: Include as part of the first-year action plans:

a) a review and development of a consensus definition for Autistic people requiring very substantial support (aka profound autism).
b) A review and development of a consensus definition of what autism is.

Recommendation 3: Create a "Statement on Autism" in the draft Strategy that sits under the Statement on Autism to capture what autism means and reflect the full diversity of Autistic people. Some of the themes identified to be addressed are in Appendix 1. Appendix 1 also includes an extract of the Autistic Society UK version as an example.

Recommendation 4: Acknowledge the challenges and barriers that Autistic people face in the Statement on Autism, as well as strengths.

Recommendation 5: Add a statement recognising that Autism is a disability.

Statement on Language

Recommendation 6: The National Autism Strategy alternates between the use of identity-first language and person-first language so that a wider range of the community feels equally represented.

Recommendation 7: A statement be included in the Statement on Language that some people identify with being neurodivergent and others do not.

Recommendation 8: Add to the Statement of Autism the theme that:

a) inclusion and participation has different connotations for different Autistic people and their families. Hence protections need to exist based on individual choice and opportunity. For instance, inclusion may be social inclusion and to be part of mainstream community events. For others inclusion may mean that they would like "inclusion/ participation" in a environments more comfortable and suitable to them. Individual choice and opportunity is not to be interpreted that this does not mean there needs to be a strong a shift towards community inclusiveness.

b) recognise that there is a spectrum of solutions and/or supports needed in context for the individual.

Recommendation 9: A check needs to be done in general that the National Autism Strategy has adequately captured the diversity of the Autistic population.

Statement on Neurodiversity

Recommendation 10: The statement on neurodiversity is contained to neurodevelopmental neurodivergence and shifted to the glossary. Also recognise language that is factual indicating challenges (non-neuro-affirming) is necessary, particularly in our current society where there is a still a significant need for education.

Recommendation 11: Add definitions of 'Lived Experience' to the Glossary" to capture and differentiate between:

- "lived experience" of an Autistic person
- "lived experience of a parent/unpaid carer and recognise that an Autistic person could have both lived experiences – Autistic and parent/ unpaid carer

Statement on Communications

Recommendation 12: A section regarding communications is captured in the National Autism Strategy similar to the Statement on Language. This is to outline reference to a sub-strategy capturing a co-design protocol, and communication framework that support the diversity, rights, and autonomy of Autistic people who have complex communication needs (CCN). Items identified are:

a. identification of CCN subgroups;
b. the range of communication devices and methods that Autistic people use
c. supported decision making

Refer to Appendix 3 for detailed recommendations to achieve the inclusion of CCN within co-design protocol and communication framework or action plans.

Recommendation 13: Remove from the Strategy ableist language such as "voice". Consider replacing with "contribution".

General Improvements

Recommendation 14: Address gaps throughout the draft Strategy, including clear reference and/or commitments to Autistic people with profound autism (aka requiring very substantial support) and families and carers and vulnerable intersectional cohorts. This is to include specific subsections as relevant.

Recommendation 15: The diversity of the autism population is to be better reflected throughout the strategy including the Preamble, Vision, Goal, Guiding Principles, Commitments Actions and Glossary particularly a) Autistic people requiring very substantial support (aka profound autism) and b) parents/carers.

Recommendation 16: Ensure that reference to codesign, codevelop etc captures the full diversity of Autistic people with specific reference to Autistic people with profound autism (aka requiring very substantial support) and those of parents and carers.

Recommendation 17: Include sections dedicated to groups of Autistic people who experience intersectional marginalisation, specifically CALD and First Nations Autistic people.

Recommendation 18: Remove the term 'evidence-based' from the draft Strategy, except for reference in the Research Commitment to Best Practice (see Recommendation 33 below).

Recommendation 19: Review the drafting of the Guiding Principles to remove ambiguity.

Recommendation 20: Review the Commitments to better capture the end goal to enable the commitment to be measurable against the three action plans. For example: Under Social Inclusion 4. Ensure consideration of the needs of Autistic people in future amendments to or reviews of the Disability Discrimination Act 1992. "Ensuring consideration" is too subjective.

Recommendation 21: Review the use of the word 'improve' throughout the document.

Recommendation 22: Add 'trauma-informed' to the Foundations.

Recommendation 23: Insert the word "all" before reference to "Autistic people" as relevant.

Strategy Overview – Vision, Goal and Guiding Principles

Vision

Recommendation 24: The Vision be reviewed to be more ambitious, recognise the need for an accessible society and the need for the right individualised supports. There may also be value in defining "safe" if the word remains in the Vision, recognising the dignity of risk.

Refer Appendix 4 for the options identified incorporating feedback and suggestions. A final selection will be provided by the Family and Carers group prior to the National Autism Strategy Oversight Council meeting on the 14th August 2024.

Goals

Recommendation 25: The Goal be reviewed to be:

a. more accountable by being more measurable, with the possibility of more than one goal leading to one aspirational goal or vision,
b. more ambitious - replace word 'improve' in the Goal with something more ambitious like thrive; and
c. capture the sentiment for Autistic people to have the rights, choices, and experiences in life that every other Australian enjoys to close the gap.

Options that were preliminary tested with the Family and Carer forum participants based on their feedback is in Appendix 4. A final selection will be provided by the Family and Carer group prior to the National Autism Strategy Oversight Council meeting on the 14th August 2024.

Strategy Foundations and Guiding Principles

Recommendation 26: Provide greater clarity and emphasis as to how the operation of the Strategy Foundations and Guiding Principles fit with the Vision, Goals, Commitments, Governance, Research, Reporting and Evaluation to improve the understanding.

Recommendation 27: Replace references to the Biopsychosocial Model of Disability with reference to the Human Rights Model of Disability.

Recommendation 28: Ensure that the Statement of Autism has clear reference to autism as a distinct disability and not based on intersectional aspects.

Guiding Principles

Recommendation 29: Make the guiding principles agnostic so they did not emphasise any particular subcategory of autism groups.

Note: A number of the group agreed that a simple solution would be to make the guiding principles agnostic by stripping out any ideological or partisan positions and the jargon. Specific feedback was provided further below which may contradict with Recommendation 29. For the avoidance of doubt the preference is for this Recommendation 29.

Recommendation 30: Guiding Principle 1 In partnership - Nothing about us, without us be amended to:

a. refer to only "In Partnership" as the headliner.
b. capture an additional statement that activities of co-design, co-produce, co-review, and co-delivery will involve representatives from and reflect the diversity within the Autistic and autism community, including those with complex communication needs. For example, non-speakers, minimally speaking, those that are able to type, those that are able to spell those that are able to voice, etc; and
c. recognise that Autistic people communicate in a range of methods and that they should have choice and control over the device(s) and/or method(s) they use.

Recommendation 31: Guiding Principle 2 Accessible based on Universal Design be amended to inclusive of Autistic people with support needs and their family/ carer representatives.

Recommendation 32: Guiding Principal 3 Acceptance and Inclusivity be amended to make reference to supported decision making and dignity.

Recommendation 33: Guiding Principal 4 Aligned and Accountable Outcomes be amended to remove reference to "evidence-based" OR Remove term 'evidence-based' from the Strategy, with the exception under Research OR Remove term 'evidence-based' from the Strategy and replaced with the term Best Practice as relevant elsewhere in the Strategy.

Recommendation 34: Guiding Principal 5 Acceptance and Inclusivity be amended to reflect the diversity of autism. A suggestion made is to reword as follows:

The Strategy recognises the lack of community understanding and acceptance of Autistic people and will take practical steps to educate the community about autism, and promote acceptance of Autistic people, to achieve genuine inclusion and equity.

Recommendation 35: Guiding Principal 6 Rights be amended to be stronger than "uphold" and instead reflect "taking explicit and transparent steps to defend the rights of..."

Recommendation 36: Guiding Principal 6 Rights be amended to incorporate in the following paragraph suitable wording to capture "safe" includes a supported decision-making protocol and protections to safeguard individuals including financially, particularly when they no longer have family support network available.

Recommendation 37: Guiding Principal 7 Individualised and Holistic be amended to reflect:

a. the inclusion of older Autistic people stronger than just 'across the whole life' as a deeply unrepresented group with significant disadvantage, extremely high underdiagnosis rates and specific challenges.
b. the complexity of Autistic people requiring very substantial support (aka profound autism), including complex communication needs and also Autistic parents
c. severity of autism so that Autistic people requiring very substantial support (aka profound autism) are not at the risk of being marginalised or being categorised as an intersectional attribute.
d. Remove reference to neurodiversity-affirming, as this is applied too broadly in this context.

Commitments - Social Inclusion

Recommendation 38: Review Commitment 1a) under Social Inclusion so that it better reflects that a better understanding of autism is not specifically called out only for workplaces (as it currently reads).

Recommendation 39: Ensure that the action plan for Commitment 1a) captures that a better understanding of autism includes:

a. a representation and understanding of the full diversity of presentations of autism;
b. a better understanding across all of society (including businesses, transport, community locations, shopping centres, first responders etc) and government bodies and agencies;
c. the impact social isolation from the community has including adversely impacting mental health, education, social and economic outcomes;
d. an understanding of complex communication needs and respecting choice and control of communication styles across all aspects within society
e. the range of barriers that prevent Autistic people from full and equal participation in the community and society;
f. the impact of unaccommodating built environments and the low levels of supported independent living.[5];
g. the lack of services designed specifically to cater for Autistic people with Autistic people often having to 'make do' with generic services or services designed for people with intellectual and cognitive disabilities.[6];
h. the experience and barriers of intersectional discrimination
i. the experience and additional barriers of people with autism requiring very substantial supports (aka profound autism), including on individuals, and families/ carers. This includes additional considerations of safety, health, and well-being in the home and in public places (including absconding, water, fire and other hazards both to the individual and also the family/ carers).
j. increase understanding and reduce stigma in First Nations and CALD communities.
k. how to support Autistic people, including the serious risk related to online safety and mental health.

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[5] Senate Select Committee on Autism (2022) 'Services, Support and Life Outcomes for Autistic Australians,' *Australian Government*, Canberra, pp. 34.

[6] Senate Select Committee on Autism (2022) 'Services, Support and Life Outcomes for Autistic Australians,' *Australian Government*, Canberra, p 92.

l. unnecessary restrictive practices like over medication and physical restraints.
m. the role of families and carers and advocacy organisations as advocates
n. how society can support individuals, families, carers and advocacy organisations to feel empowered to raise their need for support
o. the many interests and talents that Autistic people have that are not limited to IT.

Recommendation 40: For Social Inclusion Commitment 1b) be qualified so the representation be “increasing visibility and representation of different Autistic people in the media according to Autistic people and families and carers so that the community views Autistic people according to how they have been chosen to be viewed”.

Recommendation 41: For Social Inclusion Commitment 1c) to capture that “increasing accessible and -sensory friendly public and online spaces need to be free access and/or affordable to ensure that it is inclusive of those individuals and families who do not have economic privilege/ are facing financial hardship.

Recommendation 42: For Social Inclusion Commitment 1d) to
1) be expanded to include Autistic people, their families and support networks.
2) replace “increasing capability” with “resourcing”; and
3) capture the education of Autistic people and their families and carers in their rights.

Recommendation 43: For Social Inclusion Commitment 2 to be clear that:
1) increasing social connections and peer supports is for all Autistic people (as may imply currently only related to NDIS);
2) this needs to include families and carers;
3) this should include a special focus on First Nations and CALD communities; and
4) social connections and peer supports are Autistic and Non-Autistic

Recommendation 44: For Social Inclusion Commitment 3 to be expanded to include for all of government to be demonstrably the exemplar organisation for autism inclusion practice through investment in a change in narrative and culture including mandatory training capturing organisation-wide knowledge, skills, and confidence in engaging with and including Autistic people, their families, and carers.

Recommendation 45: Add an overarching commitment under the Social Inclusion Commitments to address the significant levels of social isolation and discrimination faced by parents and carers to improve their wellbeing and meet the unique support needs of people with profound autism (aka requiring very substantial supports).

Recommendation 46: For Social Inclusion Commitment 4 to be expanded to reflect that the Australian Government ensures that all existing and future policies, strategies, programs, interventions, and research relating to Autistic people have an “autism-lens” applied, the National Autism Strategy is referenced where relevant and there is appropriate representation of Autistic people, their families and autism community, as relevant, on reference groups.

Recommendation 47: For Social Inclusion Commitment 5 to be expanded to reflect:

a) that the reduction of all forms of discrimination, violence, abuse, bullying, vilification, and exploitation should not rely on the Autistic person, their families and support networks to enable this to have effect but there are independent mechanisms to safeguard the effective operation.

b) other forms of “safety and welfare” include chemical and physical restraints, public areas such as beach, parks etc, mouthing unsafe items, household poisons, unsanitary practices etc.
c) financial abuse and the increased risk profile of individuals who do not have family and carer support networks and need to rely on guardianship and trustee arrangements.

Recommendation 48: For a specific commitment to be introduced for National Standards for Autism Friendly Environments and Services Across Government Business and Community Organisations.

Commitments - Economic Inclusion

Employment

Recommendation 49: Create a separate commitment that develops a National Autism Employment Framework (possibly relabelled as a National Autism Economic Framework) and includes:

a) understanding and meeting the employment support needs of people with profound autism (aka requiring very substantial support), and vulnerable intersectional cohorts (choice and opportunities in all environments). This includes complex communication needs.
b) protection/ safeguard mechanisms for significantly disadvantaged due to very substantial support needs and intersectionality issues; and
c) economic inclusion options for Autistic people who may never be in a position to be gainfully employed to meet immediate and long-term support needs. This may include:
    i) a sustainable disability support pension,
    ii) Medicare to be expanded in coverage for age and the reduction in payment gaps,
    iii) ability to loan/lease/sell back equipment and communication devices.
    iv) volunteering opportunities

Recommendation 50: Create a similar commitment as under Commitment 10 for Education Inclusion for Economic Inclusion referencing quality and accessibility to advocacy services, as well as resources, for employees. This is to address shortfalls in supported decision-making, complex communication needs and employer discrimination, among other things.

Recommendation 51: Interface with relevant DRC Recommendations that government endorses regarding Supported Employment to ensure an autism lens and the codesign, co-production and co-implementation with people with autism across the full diversity and their families and carers.

Education

Recommendation 52: Add in a Commitment under the Economic Inclusion section which addresses the economic disadvantage experienced by parents and carers. This includes:

a) provision for increasing accessibility and flexible work options available to carers. This could be supporting fully remote and / or work from home options, job sharing employment opportunities.
b) business / government grants that are accessible for self-employment.
c) funded education to kickstart career or investigate and build employment capacity.
d) funding to support building a business such as accounting and tax advice, legal advice and website establishment.
e) mentor / peer support to support into the employment world.
f) addressing the superannuation gap
g) meeting the support needs of parents and carers who are unable to work.

Recommendation 53: Expand Economic Inclusion Commitment 10 to capture specifically "accommodations and complex communications needs" and make reference to capture people with autism requiring very substantial support (aka profound autism) and vulnerable intersectional students.

Recommendation 54: Introduce a specific Tertiary Education commitment that addresses a Tertiary Education roadmap inclusive of the safety and well-being of Autistic Tertiary students and capture of lead indicator data such as dropouts and transfers. This should include consideration of the CCN Framework

Recommendation 55: Expand Economic Inclusion Commitment 6 to include a restoration channel and strategy to close the gap for those students who have disengaged, past and present.

Recommendation 56: Expand Economic Inclusion Commitment 11, that makes specific reference to improving the safety and welfare of Autistic people, to have:

a) a restoration channel and strategy to close the gap for those students who have school refusal, and/or have been unfairly victimised so as to re-engage disengaged students, past and present.

b) a review of the Disability Standards for Education with an autism lens in the short-term action plan with a view to addressing strategies to
  i) enable choice and opportunities -mainstream, special school, hybrid etc.
  ii) suspension and expulsion

Recommendation 57: Expand Economic Inclusion Commitment 6 to include career pathways and better school transition supports and captures early investment in the development of:

a) employment readiness skills in readiness for employment at eligibility age (14-15yrs); and
b) Life readiness skills such as money management skills, budgeting, avoiding fraud / scams, and learning to understand and navigate things like tax, utility bills, renting, etc.

Commitments – Diagnosis, Services and Supports

Recommendation 58: Commitments 12 and 13 make specific reference to "all Autistic people" and vulnerable intersectional cohorts so this includes Autistic people with profound autism (aka requiring very substantial supports) and First Nations/ CALD (CARM) etc.

Recommendation 59: Amend the Best Practice definition in the Glossary to capture that all three elements are equal.

Recommendation 60: The Australian Government support the National Autism Strategy by implementing a national autism core capabilities framework to identify key capabilities for those working with and for supporting Autistic people including those requiring very substantial supports (aka profound autism):

- values and behaviours that underpin all the capabilities in the framework.
- evaluation methodology:
  - individual assessment of knowledge and/or competence
  - impact on practice
  - impact on quality of service (e.g., measuring service user outcomes and/or levels of satisfaction from Autistic people and their families).
- continuous monitoring and annual reporting requirements.
- built-in timelines for review of the framework (every 3 years).

Recommendation 61: That Recommendation 60 is also to apply to:

a) professional bodies hence supporting current issues highlighted regarding diagnosis, behaviour support practitioners and other existing and emerging roles due to the NDIS and DRC Review. For example, the staff or experts need to have to undergone specific behaviour management courses or psychology specialisations before they are assigned to be responsible for the care of Autistic individuals requiring these areas of expertise.

b) Building capability in universal service platforms, particularly maternal and child health services and General Practitioners to detect warning signs and refer young children for assessment.

Recommendation 62: Professionals to make available Autistic-affirming parental supports, as an alternative to mainstream parent support options, during the pre-and post-natal period to support Autistic parents in developing necessary skills.

Recommendation 63: Remove the age limit and remove (or as a minimum reduce) the rebate restriction on diagnostic assessments under the Medicare Benefits Schedule. (for Health Roadmap)

Recommendation 64: Create and publish information tailored to the needs of Autistic people and their families with a particular focus on addressing, complex communication needs, supported decision-making, dignity of risk and substitute decision-making.

Recommendation 65: Provide post diagnosis supports and resources to assist Autistic people particularly those with profound autism (aka requiring very substantial supports), and their families/ carers, to connect to therapies, peers and community.

Recommendation 66: Ensure the definition of "Best Practice" captures for it to be culturally safe to Autistic people, including people requiring very substantial supports (aka profound needs) and their families/carers.

Commitments - Governance, Research & Reporting

Commitments –Governance

Recommendation 67: Commitment 21 further captures the following for clarity and consistency:

a. underpinned by the Guiding Principle
b. 21a) is expanded to include "to measure and ensure that each of our commitments and actions are achieved'.
c. a suitable statement reflecting page 18 of the Draft National Autism Strategy. That is establishing a governance framework:
    i. that is representative of the diversity within the Autistic and autism community,
    ii. that adopts an inclusive process for consultations,
    iii. that designs actions with people with profound autism (aka requiring very substantial supports) and their families and carers and support networks to address the multiple and overlapping structural barriers they experience; and
    iv. provides ways for Autistic people and their families and carers and support networks to communicate with the Australian Government in a way that suits them.

Recommendation 68: Commitment 21 captures a suitable statement reflecting pages 28-29 of the Draft Autism Strategy Plan including proposed timelines, three action plan periods and the length of the National Autism Strategy.

Recommendation 69: Commitment 21 captures that the detailed strong accountability and governance structures outlined in each of the three Action Plans will include an evaluation of the existing accountability and governance structures supporting change where evidence supports that these have not been successful to date, and outcomes are poor. This includes reviewing contemporary policies so that legislation and policy are aligned and consistent Nationally.

Recommendation 70: That the Strategy is viewed alongside any other policy initiatives (including NDIS review and Disability Royal Commission (DRC)) and supported by adequate, ongoing funding.

Recommendation 71: Existing legislation and policies are reviewed to identify their effectiveness and where there are shortfalls address to support the rights of Autistic people.

Recommendation 72: Appoint an oversight taskforce with paid governance roles that includes Autistic people including those with complex communication needs and families and carers of those Autistic people requiring very substantial support (aka profound autism).

Commitments –Research

Recommendation 73: Commitment 22 is amended to capture the following:

a. As well as Develop, “Design and Implement” autism research that can best be fostered and applied to policy and service delivery; and
b. this research is linked to the National Autism Strategy Commitments, Evidence Framework and Evaluation and Reporting.

Recommendation 74: Commit to developing a National Autism Research Framework as recommended in the Senate Select Committee on Autism Recommendation 26. The Framework should:

a. commit to Best Practice approaches to ensure the involvement of the diversity of the Autistic and autism community, including often overlooked cohorts such as people requiring very substantial support (aka profound autism), complex communication needs, supported decision making, vulnerable cohorts including older Autistics, families/carers and Autistic researchers.
b. identify how to connect with and learn from research that's happening globally so that actions which underpin the strategy are evidence-led and aligned.

Recommendation 75: Fund autism research to realise the National Autism Research Framework. Fund as a first project for the identification of the size of the Australian autism population, development of a consensus definition to advance and improve the lives of people requiring very substantial supports (aka profound autism) needs and identify how to best research, measure and collect for this cohort.

Commitments – Evidence Framework

Recommendation 76: Commitment 23 is amended to capture the following:

1. “and underpinned by the Strategy’s Guiding Principles”;

2. the National Autism Strategy Framework developed with the National Autism Strategy Oversight Council will form the baseline for the development of the National Autism Strategy Evidence Framework.

Recommendation 77: Commitment 21 captures accountability measures that will include:

a. **clear** and **measurable** outcomes, goals, actions, targets, milestones, and data requirements;
b. an **implementation plan** with clearly defined responsibilities;
c. **continuous monitoring, adjustment of actions as relevant** and **annual reporting requirements**;
d. **evaluation reports** through re-engagement with the **Autistic and autism community no less frequently than every 3 years**;
e. **built-in timelines** for **review** and **renewal** of the strategy (every 5 years) based on the aforementioned monitoring and re-engagement process. This should include a review of contemporary lessons learnt Internationally, Nationally and State/Territory Jurisdictions regarding relevant Strategy.

Recommendation 78: Commit to undertake a review and incorporate as relevant the Senate Select Committee on Autism's Recommendations regarding data collection, including for a National Autism Register.

Commitments – Evaluation and Reporting

Recommendation 79: Commitment 24 is amended to capture the following:

a. "and underpinned by the Strategy's Guiding Principles"
b. inclusion of family and carers, Autistic community
c. that is representative of the diversity within the Autistic and autism community, including Autistic people with profound autism (aka requiring very substantial support).

Recommendation 80: A definition of co-led is added to the Glossary and includes reference to representation for Autistic people with profound autism (aka requiring very substantial support).

Gaps

Housing

Recommendation 81: Include a Commitment in the National Autism Strategy under the Social Inclusion Commitments to Develop and Implement a Strategy to support Autistic People to have choice and control of Affordable, Accessible and Safe Housing Options in populated areas as well as regional. This includes Supported Independent Living, Homelessness, Effective Emergency Accommodation and transitioning from service or institutional settings as a priority for Autistic people in alignment with any National Strategies. This should include a specific commitment to:

a. supporting Autistic people to live as independently as possible, including people requiring very substantial support (aka profound autism) and vulnerable intersectional cohorts.
b. improving equal access to, and choice and control over, safe and accessible housing options including public housing, rental, owner occupied with the potential for incentives [7] for the private rental market.

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[7] UK Autism Research Charity Autistica (https://www.autistica.org.uk)

c. creating nationally consistent autism accessibility guideline for all housing types, including “robust” housing.
d. integrate the need to accommodate supported independent living into the early stages of all urban planning & development. This should include a mandate that an age of diverse living options to be included in the planning like essential services - public transport hubs, retail areas, parks & open spaces.

Justice and Child Protection

Recommendation 82: Include a Commitment in the National Autism Strategy under the Social Inclusion Commitments to Develop and Implement a Strategy to Arrest the Overrepresentation of Autistic people dealing with the Justice System and Child Protection issues and Achieve Effective Informed Interactions. This includes:

a. Co-designed Autism training, including the diversity of autism, complex communication needs, positive behaviour responses, restrictive practices and supported decision making for the Justice System Workforce including first responders, correctional services, and Child Protection workforce including Family and Child Commission
b. Diversion programs, including to therapeutic approaches and settings.
c. Prison-to-community transitions
d. Improvement of Child Protection processes
e. Medicare benefit scheme access remains active while incarcerated.
f. NDIS Plans reactivation before release from incarceration.
g. Incorporation of DRC Recommendations 8.4, 8.12, 8.14, 8.16, 8.21 and page 286 Collect and publish data relating to people found unfit to plead, or not guilty by reason of cognitive or mental health impairment, broken down by disability type, sex and First Nations Status.

Recommendation 83: Provide support for the implementation of a Disability Rights Act (DRA), as per the recommendation in the Disability Royal Commission final report.

Transportation and Accessible Supports

Recommendation 84: Include a Commitment in the National Autism Strategy to Develop and Implement a Strategy to Address Transport Accessibility, Availability, Safety and Affordability Challenges, in consultation with Autistic people, including people requiring very substantial support (aka profound autism) and their families and carers. Safety includes undoing seat belts in the back seat, behavioural challenges in the car and public transport.

Carers

Recommendation 85: Include a Commitment in the National Autism Strategy to Develop and Implement a Strategy to Build a Sustainable Carer Economy including:

a. access to peer parent networks;
b. parenting support needs (well-being); and
c. respite which may include expanding this within existing systems such as Care2Serve and the NDIS

Recommendation 86: Government endorsement and funding for the development of a framework for safeguarding and maintaining long-term care of Autistic children (legal and other formal arrangements) to ensure succession of care planning. This should include the development and implementation of succession of care disability standards and build capacity and capability to create and administer succession case plans. This also needs to make reference to a supported decision-making protocol.

Refer to Recommendation 52 Economic Inclusion to address the economic disadvantage experienced by parents and carers.

Workforce

Recommendation 87: Include a Commitment in the National Autism Strategy to Develop and Implement a Workforce and Innovation Strategy that results in a productive, skilled, resilient, value-based workforce and optimises the human capability of Autistic people with a particular recognition of the unique needs and challenges of people requiring very substantial support (aka profound autism).

Autism Specific Independent Advocacy

Recommendation 88: Include a Commitment in the National Autism Strategy to Develop a Model and Fund Independent Specialised Autism Advocacy delivered locally in the changing environment. This is to include specialised services to support complex communication needs (CCN).

Early Investment (Intervention)

Recommendation 89: A further commitment be added to Diagnosis, Services and Supports that captures the development of a strategy regarding Early Investment (Intervention) and how this will interface with the NDIS Review regarding foundational supports and the Federal Early Years strategy to ensure the needs of Autistic people and their families are met. This is to include ensuring an autism lens and co-design and implementation with the full diversity of Autistic people and parents and carers.

Other Comments

Recommendation 90: Enable this draft report regarding Families and Carers of Autistic People to be a working paper with feedback to be incorporated up until 9th August 2024, where differences will be summarised by J Karavolos, NASOC member for the Oversight Council's consideration of the 14th August 2024.

STATEMENT ON AUTISM

Feedback was provided that there needed to be a clearer and more representative statement of what is meant by “autism”, so as to capture the diverse representation of autism across the spectrum as currently there is a range of understandings and conflicting definitions in existence and many, if any, capture the spectrum accurately.

> *“ We need to actually take a look at the way we define autism”*
>
> *“I don't know how radical that idea is, but when my children were first diagnosed 17 years ago, it was a very different thing to what I'm looking at now, and I think it's led to a huge I guess misunderstanding among some quarters of the community of what my children face with their quite high needs and to the point that I don't think my children would necessarily recognise themselves in some of the ways autism is portrayed. There was Asperger's and what we now know is classic autism. And now it's all sort of one thing, and I wonder if that has done us a disservice to create one big one size fits all thing”.*

Autism as a spectrum needs to be individualised, with no one dominant view and multiple solutions. An acknowledgement needs to exist that that every Autistic person has their own individual diversity, capacity, experiences and aspirations. It also needs to be recognised that autism is a distinct disability in its own right and not driven by intersectional aspects or a subset of another disability such as intellectual disability.

The statement of “all Autistic people” in the Vision is not enough to address this. It was expressed that the Strategy should embrace what full inclusion looks like for each individual and their family members, recognising this can look different for all Autistic people.

It was emphasised that it was very disappointing that those with the highest support needs were currently not directly referenced in the documents supporting the development of the Strategy, despite this cohort being highly vulnerable and representing a significant percentage of Autistic people.

> *“the challenge here is that those with the most needs, those that ……..will require intensive care for the term of their lives will require very specialised support and supports for the term of their natural lives are not represented by this strategy and therefore, those with the most needs”.*
>
> *“The draft contains not a single mention of ‘profound’, ‘severe’, ‘severity’, ‘behaviours of concern’ (BOC), ‘self-injurious behaviours’ (SIB), pica, absconding and other everyday terms in the Severe and Profound Autism space.*
> *By contrast, ‘autistic burnout’, ‘camouflaging’, and ‘masking’ are listed.”*

There was a variation of views as to how to refer to Autistic people with the most needs. This included:

- people with autism requiring very substantial support,
- profound autism,
- severe and profound autism,
- high support needs;
- very significant supports; and
- high dependency needs;

A consensus definition to refer to this cohort does not exist, in society or research[8].

There were some very strong opinions from the consultations as to why “profound” should specifically be used and not used.

> *“ ……I strongly oppose the use of the words "profound" and "severe" to be used in the National Autism Strategy to describe Autistic Australians. ………He's not profound, he certainly has a lot to say (through letter board), so I certainly wouldn't be using that terminology at all. I think we'll take it backward step if we use that terminology ……”*
>
> “*so the studious wish to avoid words like profound and words that recognize the significant difference …….is not helpful. This very high needs end of the spectrum …….Having it for the want of a better way of putting it washed away because others don't like that language is extraordinarily offensive ……….”*
>
> *“we surveyed 80 parents around the term classical autism and overwhelmingly preference was profound and severe”.*
>
> *"Lifelong" is appropriate. "Profound" and "Severe" are pathologising and I feel alternatives need to be considered”.*
>
> *“That's why I use that language because it's the only way I can get across their needs to people, and even then, I can't get their needs across to people……”*

This is not a discussion limited to these focus groups but is an ongoing discussion that has not been resolved worldwide. Other research identified:

- profound and multiple learning disabilities (PMLD) or profound and intellectual and multiple disabilities (PIMD). The use of terms emphasises the specific needs and support requirements of individuals without implying a hierarchy of severity.
- profound needs to focus on the person’s needs rather than as a descriptor on than as descriptor of the person.

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[8] Dr Matthew Siegel, ASfAR Australian conference 2024

- those who require more intensive support (Australian Human Rights Commission [9] and UN General Assembly (A /RES/61/106).[10]
- the use more descriptive language that focuses on the individual’s specific needs and strengths, rather than using broad labels. For example, describing someone as needing significant support with communication or daily living skills can be more precise and respectful.

For more information regarding this topic and the rationale regarding the use of specific terminology please refer to Appendix 2.

For the purposes of this strategy the following two descriptors will be used interchangeably i.e. profound autism (aka requiring very substantial support) and requiring very substantial support (aka profound autism).

While the referred to terminology was not agreed, what was agreed is:

1. there is a need for a consensus definition to be developed to ensure that the needs of this important cohort are not overlooked, and support and services are appropriate, available and affordable to advance their needs. It was very important:

   i. to be careful not to use terms that oversimplify a complex condition, dilute the recognition that they are lifelong permanent, impede research, and may fail to meet individual support needs.

   ii. it is recognised that there are unique, devastating, and often unseen experiences and challenges that require solutions, for the individual and the carer.

   iii. to recognise that people can opt in what terminology is used based on their individual choice. There was an emerging theme that often the language of “profound” is used in situations as this is what society currently understands. For instance, setting goals with NDIS, education supports and even emergency callouts.

   > *“The language has been ruthlessly sanitised, and I think the reason is probably starting from a good intention to try and bring a more positive outlook. And certainly, that's a positive framework for a lot of people, but it comes with a massive cost and that's the people like our son are completely ignored and left on the side of the road as roadkill. And we think that's not OK we think that they both need to be captured and we think they need to be done separately because they're so different and their needs are so different.”*

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[9] Convention on the Rights of Persons with Disabilities - Human rights at your fingertips - Human rights at your fingertips | Australian Human Rights Commission

[10] https://www.un.org/en/development/desa/population/migration/generalassembly/docs/globalcompact/A_RES_61_106.pdf

> *"As a general observation in this highly charged space, we think it is really important that the different cohorts, in this massively heterogenous spectrum, respect each other's experience and not claim to represent other cohorts in other areas of the spectrum. We hope that caring for our own child, who is so very different to those who can reflect on their own traumatic childhoods and scrutinising the best available professional advice (sometimes it is poor advice, and we have regrets), and using language/terminology that we are comfortable with, does not make us an enemy. We only ask for mutual respect and for people to stay in their lanes."*

Refer also to the Section Social Inclusion which further elaborates on what is required to achieve awareness and understanding.

iv. it is not assumed that Autistic people requiring very substantial support do not have cognitive ability or any other elements of human capacity like feelings.

> *"If we omit things, they erase the needs and over time, it's like we never existed"*

> *"……It is offensive to someone who presumes competence always, including non-speakers, minimally speaking individuals and unreliable speakers. I have seen so many times people make assumptions about the understanding and intellectual capacity of Autistic people I know which are inaccurate and limiting".*

> *"It is important to recognise that non-speaking people often can absorb more information than they can readily share. I have met numerous Autistic adults with later-life access to communication, with deeply saddening experiences of being spoken about in ways that made them feel as if they were burdens and reduced the likelihood of their preferences and goals being understood."*

The members of the focus group were respectful in emphasising that:

- each person was passionate, with a personal commitment and desire for their own children and others to live their best life and thrive.
- this has progressively become an issue since the introduction of the DSM5 and how autism is diagnosed with the removal of Aspergers.
- the DSM V has combined all the prior categories of autism (4-5) in the DSM IV, so autism is now a much broader category despite the vast heterogeneity of the spectrum.
- Each person's needs to relay what works for them.

> *"But at the end of the day, we, you know, in certain cases of our kids go missing if they're in danger, we need to be able to differentiate that they have a profound Disability".*

> *"Our experience and their experience are very different from others and that's why we want to use that language and we choose to use it. And I believe that we should be able to".*

2. is that there was a need to not only have specific reference in the Strategy to this important cohort but also dedicated subsections as they are at risk of abuse, exploitation and/or marginalisation.

> *"Vital issues including restrictive practices, abuse, research, schooling, health, housing and augmented communication and general services are inadequately addressed."*

> *"Results of a 30-year longitudinal study showed that the outcomes of people with profound autism are drastically different than those of people who are not-profound. This suggests if the outcomes are very different that probably is because the supports needed are differently by Dr Matthew Siegel, ASfAR Conference 2024"*

Specific reference and targeted action being required was supported by the Senate Select Committee on Autism report:

"The committee is also aware that within the broad framework of a National Autism Strategy, targeted action will be needed to support cohorts that face additional challenges and compounding disadvantage"[11]

The Senate Select Committee on Autism report also recognised the diverse views:

"The inquiry found that the diversity of views within the autism community is linked, at least in part, to the breadth of the spectrum itself. The divergence in views was most apparent between autistic self-advocates and parents of autistic children with more complex presentations, who are heavily or completely reliant on parent or carer advocacy. However, tensions are also apparent within the autistic community itself, with stakeholders describing a lack of acceptance among some autistic advocates for views that do not accord with their own. To this end, the committee views the National Autism Strategy as an opportunity to identify common ground and unify the broader autism community around a shared set of goals. Accordingly, the committee believes that an inclusive co-design process—drawing on the autistic community, as well as parents, carers, researchers, and policy makers—must underpin development of the strategy."[12]

It was also agreed that:

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[11] Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [x]

[12] Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [x-xi]

3. the strategy failed to recognise the families and carers of people with profound autism (aka requiring very substantial support needs).

   "And even though what we talk about a spectrum, they have very specific needs of their life experience (and), of our life experience as parents is very, very different".

4. Autistic people requiring very substantial support needs (aka profound autism) is very distinct from having complex needs and should be separated out.

   "And the fact is, my eldest son, who goes to university, has an opportunity that my son, who's two years younger, that's completely nonverbal with behaviours of concern and requiring 2 to one care. It's like chalk and cheese. And then I've got my daughter. who's struggling to finish school at 19 and she's in the top 3% of intelligence. So where does she fit in? So, there's just such a huge spectrum, …..".

   It was also recognised that there should be no references to level of functioning such as low or high. The reality is that those who may have higher functioning does not mean that they don't deserve support or don't have a real disability.

   "This is not a competition. Everybody loses if we treat it like one".

5. there was a need to remove any ableist language such as "the voice" or implies "needing to be verbal" and ensure that various ways of communication are captured.

   "There is a danger in our admirable desire to "bust" myths and "break" stereotypes of Autism, that we make those with severe challenges invisible in discussions and planning."

6. where the current Strategy only references "Autistic people" or "Lived Experience" it is being interpreted as excluding Autistic people who are less able to advocate for themselves. The goal is to ensure that all views are represented. Some Autistic people require the support of their families and carers. This important role needs to be reflected in the Strategy where the parent/carer is supporting an Autistic person to be represented or is representing on their behalf.

   "so much of the time, the spoken voice for our children is the adult autistic voice which does not have a shared experience of our children's journey."

   "Self-advocacy is important and important to give Autistic people a voice but what happens when don't have a voice - need to go to carers".

Critical Elements for a Consensus Definition

Some of the critical elements that were raised to support a consensus definition:

a. adaptive functioning (refer Appendix 1) requiring 24-hour access to an adult who can care for them if concerns arise, being unable to be left completely alone in a residence, and not being able to take care of basic daily adaptive needs".

   or in the words of Judith Ursitti (refer Appendix 1) "Can I leave this person alone and go to my neighbours house and borrow a cup of sugar"

b. significant person-to-person care and support with daily living skills and personal care;

c. complex communication needs/ language impairment which include being nonverbal, minimally verbal or unreliable speakers with complex representations;

d. constant or significant monitoring due to safety concerns such as self-injurious behaviours, pica, and absconding. This includes as adults.

e. life-long/permanent

f. adaptive behaviour score

Some of the elements that were identified should NOT be considered as critical elements:

a. IQ (decouple from autism). Identified that may be unreliable as this can be dramatically impacted due to environmental and other factors;
b. behavioural support needs/ behaviours of concern;
c. complex;
d. severe as severe has been more closely associated with IQ;

Recommendation 1:

Develop a consensus definition for profound autism (aka requiring very substantial support for the purpose of the National Autism strategy. Include this definition on the Glossary. A final recommendation by the Family and Carers group will be provided by the group prior to the National Autism Strategy Oversight Council meeting on the 14th August 2024.

Recommendation 2:

Include as part of the first-year action plans:

c) a review and development of a consensus definition for Autistic people requiring very substantial support (aka profound autism).
d) A review and development of a consensus definition of what autism is.

Recommendation 3:

Create a “Statement on Autism” in the draft Strategy that sits under the Statement on Autism to capture what autism means and reflect the full diversity of Autistic people. Some of the themes identified to be addressed are in Appendix 1. Appendix 1 also includes an extract of the Autistic Society UK version as an example.

Recommendation 4:

Acknowledge the challenges and barriers that Autistic people face in the Statement on Autism, as well as strengths.

Recommendation 5:

Add a statement recognising that Autism is a disability.

STATEMENT ON LANGUAGE

The Autistic population is divergent and divergent views need to be recognised.

Feedback has been heard from the community that:

- It would be preferred that the National Autism Strategy alternates between identity-first language and person-first language so that a wider range of the community feels equally represented.
- A statement be included that “some people identify with being neurodivergent and others do not”.
- A statement recognising that Autistic people requiring very substantial support (aka profound autism) face unique life experiences including communication methods, safeguarding needs, disadvantage, isolation, and life outcomes.

> *“These statements show partiality and marginalise the viewpoints of those with different preferences”*
>
> *“Valuing each person for who they are is of course important and right, however conflating their Autism and identity is inappropriate for many. ……. That person’s Autism may never be core to their self-identity either. Accordingly, person-first terminology is seen by many as more respectful and valuing of the person. Many of our family members live with Autism, which can’t be cured, but which also doesn’t define them.”*

There was also feedback that there is reference in the National Autism Strategy and society in general regarding inclusion and participation. This has different connotations for different Autistic people and their families based on their choice and opportunity. For instance, inclusion may be social inclusion and to be part of mainstream community events. For others inclusion may mean that they would like “inclusion/ participation” in a segregated environment.

Recommendation 6:

The National Autism Strategy alternates between the use of identity-first language and person-first language so that a wider range of the community feels equally represented.

Recommendation 7:

A statement be included in the Statement on Language that some people identify with being neurodivergent and others do not.

Recommendation 8:

Add to the Statement of Autism the theme that:

c) inclusion and participation have different connotations for different Autistic people and their families. Hence protections need to exist based on individual choice and opportunity. For instance, inclusion may be social inclusion and to be part of mainstream community events. For others inclusion may mean that they would like "inclusion/ participation" in environments more comfortable and suitable to them. Individual choice and opportunity are not to be interpreted that this does not mean there needs to be a strong a shift towards community inclusiveness.

d) recognise that there is a spectrum of solutions and/or supports needed in context for the individual.

Recommendation 9:

A check needs to be done in general that the National Autism Strategy has adequately captured the diversity of the Autistic population.

STATEMENT ON NEURODIVERSITY

Feedback has been heard from the community that the significant statement upfront regarding neurodiversity in the National Autism Strategy is detracting and confusing as to who the strategy is meant to cover.

> *"The proposition is made that many neurodivergent people believe that there is no "normal" or "healthy" type of brain or mind. …… This appears to present a risk that the NAS may foster the normalisation of behaviours of concern (BOC), lack of functional communication, limited interaction with others, self-harm (SIB), absconding and endangering life"*

> *"The push for neutral language robs the scientific community of the ability to describe, with accuracy, the day-to-day realities of life of people with autism, particularly those with profound autism. No one should have the power to limit language to exclude the observable realities of autism. Clinicians and scientists need access to the full semantic toolbox to describe the multiple realities of autism and make progress toward understanding patient experiences and*

> *needs, the various underlying causes and the future for meaningful treatments".* [13]
>
> *"Neurodiversity-affirming" supports and services are appropriate to some Autistic people, but not others. We recommend the inclusion of other viewpoints and paradigms to reflect the very substantial diversity of the Autism spectrum…….. The tragic irony of the neurodiversity movement, which has dominated federal autism policy for a decade or more, is that, while it is a potent civil rights movement, it has itself resulted in the denial of basic human rights to those suffering with profound autism."*
>
> *They are greatly valued as unique individuals, but their "neurodiversity" is not always something to be celebrated or "affirmed".*

It has been highlighted that:

a) as a minimum that reference to "neurodiversity" should be contained to neurodevelopmental neurodivergence" so that it refers to autism and ADHD
b) ideally, this is removed from having such a prominent place in the strategy and that it be contained in the glossary.
c) there are instances where to elicit an appropriate timely response language that is not neuro-affirming is necessary. For instance, when an Autistic person is in danger and an emergency response is needed.

> *"….. he got out of the boundaries on Saturday night at 8 on 8:30 PM at night, and the only way that I could get the police's attention was to give a description of him that was not affirmative in any way. And it worked. I explained that he was profoundly Autistic. He was nonverbal and that he will run towards cars. He will not respond to his name and he has no understanding of language and within 3 minutes I had three police cars turn up. All the streets around us were cordoned off and there was a mass search with all our neighbours and everyone because I was able to use that language in a shameless way ……that is where my son sits on the spectrum and looking at this document, there's nothing that includes my son."*
>
> *"It's great and helpful for some. ……, so then trying to force fit it to everybody, it's not appropriate".*

It has also been identified that the use of the terminology relating to "level of functioning" is offensive and subject to misinterpretation. This is a very important aspect to be captured as we move towards shaping a new narrative.

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[13] A full semantic toolbox is essential for autism research and practice to thrive - Singer - 2023 - Autism Research - Wiley Online Library

Recommendation 10:

The statement on neurodiversity is contained to neurodevelopmental neurodivergence and shifted to the glossary. Also recognise where language that is factual indicating challenges (non-neuro-affirming) is necessary particularly in our current society where there is a still a significant need for education.

Recommendation 11:

Add definitions of 'Lived Experience' to the Glossary" to capture and differentiate between:

- "lived experience" of an Autistic person
- "lived experience of a parent/unpaid carer and recognise that an Autistic person could have both lived experiences – Autistic and parent/ unpaid carer

STATEMENT ON COMMUNICATIONS

It was highlighted in feedback that the diverse communication styles of Autistic people are often overlooked and needs to be recognised and accommodated in the Strategy. This includes how people receive information and how they communicate themselves.

It was also emphasised that communication methods need to be the choice of the individual to suit their preferences and needs. This could be through assistive technologies, visual aids, or alternative communication techniques.

This is critical not only for society to understand but to be directly referenced in the Strategy otherwise codesign efforts will exclude those who can communicate but not though verbal communication.

> *"I agree totally that we need to validate spellers and refer to them directly in the Strategy".*
>
> *"I would like the needs of non-speakers like me and people with apraxia receive special consideration as we have severe disadvantages. I see independence as a goal that I have to reach to live a good life. In order for people with CCN to have a positive life big change with a long-term strong commitment needs to be incorporated in the strategy. A commitment to help us to live a good life may involve building a sub strategy within the larger strategy. This will help to ensure that we don't get lost in the crowd. A lot of the load of caring for us has been carried by our families. The load has been high due to services not understanding that with weaknesses come strengths. Many of us with CCN have shown that we have skills such as literacy. This has not been acknowledged by service providers and families have struggled with their own skills and other resources to help us. Outcomes would have been better if we had received appropriate assessments and support at the right age. I hope the Strategy will address this need in an effective way. Many of us are limited to a life of dependency due to 'presumption of incompetence'. Assessment tools, learning pathways and therapy services*

> *need to be upgraded".*

Furthermore, ableist language implied or overtly needs to be removed from the Strategy such as reference to "voice".

> *"An ableist paradigm is evident, inferring that disability is something to be ashamed of or denied".*

Hence more was identified needed to be done to make information and communication more accessible, particularly for those with complex communication needs (CCN) as non-speakers make up 27% to 33 % of the Autistic population.

It was called out for there to be a subsection in the Strategy to reflect this.

This subsection should also recognise supported decision making:

> *"Supported Decision Making is more about respecting the individual and having consistent (not ever changing) supports that can learn to translate their clients' preferences and needs through the intimacy of their understanding of minor cues - it's also about training and creating manuals etc that support new workers in understanding them etc. It is the only alternative communication for many".*

Recommendation 12:

A section regarding communications is captured in the National Autism Strategy similar to the Statement on Language. This is to outline reference to a sub-strategy capturing a co-design protocol, and communication framework that support the diversity, rights, and autonomy of Autistic people who have complex communication needs (CCN). Items identified are:

d. identification of CCN subgroups;
e. the range of communication devices and methods that Autistic people use;
f. supported decision making.

Refer to Appendix 3 for detailed recommendations to achieve the inclusion of CCN within co-design protocol and communication framework or action plans.

Recommendation 13:

Remove from the Strategy ableist language such as "voice". Consider replacing with "contribution".

GENERAL IMPROVEMENTS

Recommendation 14:

Address gaps throughout the draft Strategy, including clear reference and/or commitments to Autistic people with profound autism (aka requiring very substantial support) and families and carers and vulnerable intersectional cohorts. This is to include specific subsections as relevant.

Recommendation 15:

The diversity of the autism population is to be better reflected throughout the strategy including the Preamble, Vision, Goal, Guiding Principles, Commitments Actions and Glossary particularly a) Autistic people requiring very substantial support (aka profound autism) and b) parents/carers.

Recommendation 16:

Ensure that reference to codesign, codevelop etc captures the full diversity of Autistic people with specific reference to Autistic people with profound autism (aka requiring very substantial support) and those of parents and carers.

Recommendation 17:

Include sections dedicated to groups of Autistic people who experience intersectional marginalisation, specifically CALD and First Nations Autistic people.

Recommendation 18:

Remove the term ‘evidence-based’ from the draft Strategy, except for reference in the Research Commitment to Best Practice (see Recommendation 33 below).

Recommendation 19:

Review the drafting of the Guiding Principles to remove ambiguity.

Recommendation 20:

Review the Commitments to better capture the end goal to enable the commitment to be measurable against the three action plans. For example: Under Social Inclusion 4. Ensure consideration of the needs of Autistic people in future amendments to or reviews of the Disability Discrimination Act 1992. “Ensuring consideration” is too subjective.

Recommendation 21:

Review the use of the word ‘improve’ throughout the document.

Recommendation 22:

Add ‘trauma-informed’ to the Foundations.

Recommendation 23:

Inset the word “all” before reference to “Autistic people” as relevant.

Vision and Goal

Our Vision and Goal

The National Autism Strategy's **vision** is for a **safe** and **inclusive society**, where all Autistic people can fully participate in all aspects of life, in line with international human rights.

The **goal** of the National Autism Strategy's is to **improve life outcomes** for all Autistic people.

National Autism Strategy | Help shape the change

Overall, the feedback on both the Vision and Goal was that they needed to be more ambitious and that they required amendments to more accurately reflect the diversity of autism.

Feedback on the Vision

The majority of the group thought it was good that the Vision remained broad.

Suggestions for improvement included:

a. encapsulating words such as "thrive" and/or "live their best lives".

b. recognition of an accessible society

> *"It's not just changing society but then making it an accessible society for everyone."*

c. the need for the right individualised supports to enable Autistic people to live their best lives.

> *"We need some acknowledgement in this goal that it's not just about is for a safe and inclusive society, ……… there needs to be mention in there about the supports that are needed".*
>
> *"the recognition that there is a spectrum of support required as well is extraordinarily important".*

d. the terminology needs to recognise and respect the diversity of Autistic people, including those who have different goals. There are concerns in particular that "fully participate in all aspects of life" is not achievable for some and also not desirable.

> *" some autistic people have limited social participation aspirations".*

> *“It's way too blanket. That's just assuming that you can take one nice ideal and apply to everybody, and that's it's unrealistic. It won't be able to be done and ……. you'll fail before you start …….it’s too one solution fits all. For example, our son xxxx, he can't go to school because he's not safe at school….. That would require that it to be done in a way it's not in their best interest and that they could be at serious, umm, risk …… in order to achieve that. So he's now got an exemption where on the grounds of schools, are not in his best interests.*
>
> *“Getting my son to fully participate may be an unrealistic goal - there are more appropriate goals”.*
>
> *“Maintaining and not deteriorating is for some a huge achievement”.*
>
> *“How about "relevant aspects of life" - so in the case of my son's complex needs participating in community program is the most he can manage”.*
>
> *“So I think somehow in that terminology it needs to be taken into account to, you know, to the best of their capabilities or to the best that is affordable to them. I don't know what the right terminology is, but my child will never have the same and ability to fully participate in all aspects of life as any neurotypical child”.*

Recommendation 24:

The Vision be reviewed to be more ambitious, recognise the need for an accessible society and the need for the right individualised supports. There may also be value in defining “safe” if the word remains in the Vision.

Refer Appendix 4 for the options identified incorporating feedback and suggestions. A final selection will be provided by the Family and Carers group prior to the National Autism Strategy Oversight Council meeting on the 14th August 2024.

Feedback on the Goal

Suggestions for improvement included:

a. it was not ambitious enough, particularly “improve” as this does not mean on par with other people in society.

b. reference to just “improving life outcomes” did not speak to people. There needed to be reference to more such as agency, autonomy, self-determination or a definition of “improving life outcomes”.

c. it reads like something you would find on a provider’s website.

> *“I just think I just think improve life outcomes is something you see on a provider’s website where they take people who spend to go to day programs and take them bowling”.*

d. it was unclear how this would be measured to recognise if it's been realised. Suggestions made were for the following words to be used:
    i. "social equity" to achieve human rights.
    ii. "thrive" to replace "improve".
    iii. reference to "experiences" as well as "outcomes" as it's the day to day lives of Autistic people that need to be improved as well.

e. several people commented on having one goal was not sufficient and that it was vague. It was suggested that rather than a single goal that there be a list of more specific goals that captured concrete concepts that are meaningful, measurable and achievable. The concern was also that the goal was open ended and could be interpreted according to the narrative at the time. It was also suggested and endorsed that a more concrete and measurable goal is to "close the gap" with other Australians.

> *I would love to see ……. is we commit to closing the gap between nonautistic Australians and autistic Australians…….*

Overall, the sentiment was to have more clear achievable goals that are measurable that works toward either an aspirational goal or aspirational vision.

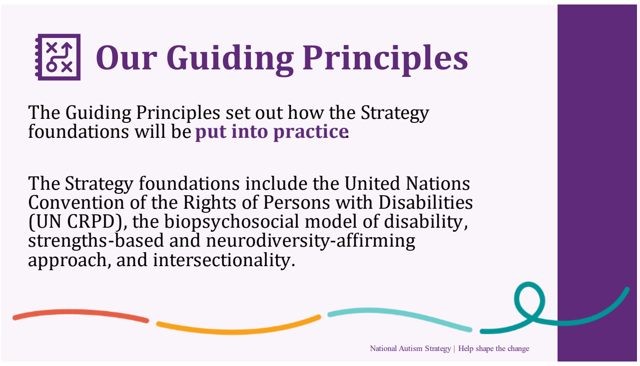
Recommendation 25:

The Goal be reviewed to be:

a. more accountable by being more measurable, with the possibility of more than one goal leading to one aspirational goal or vision,
b. more ambitious - replace word 'improve' in the Goal with something more ambitious like thrive; and
c. capture the sentiment for Autistic people to have the rights, choices, and experiences in life that every other Australian enjoys to close the gap.

Options that were preliminary tested with the Family and Carer forum participants based on their feedback is in Appendix 4. A final selection will be provided by the Family and Carer group prior to the National Autism Strategy Oversight Council meeting on the 14th August 2024.

Guiding Principles



Our Guiding Principles

The Guiding Principles set out how the Strategy foundations will be **put into practice**

The Strategy foundations include the United Nations Convention of the Rights of Persons with Disabilities (UN CRPD), the biopsychosocial model of disability, strengths-based and neurodiversity-affirming approach, and intersectionality.

National Autism Strategy | Help shape the change

Our Guiding Principles

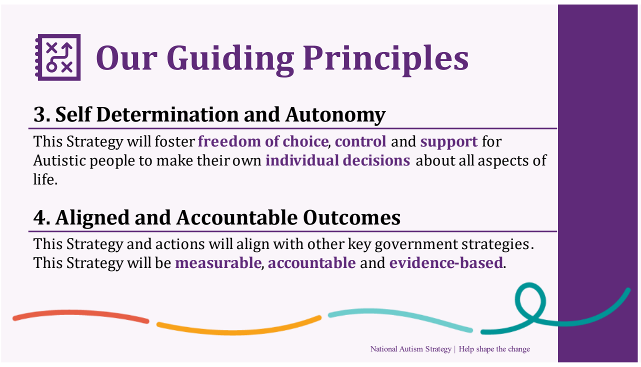
1. In partnership - Nothing about us, without us

This Strategy will be **co-designed**, **co-produced**, **co-reviewed** and **co-delivered** with Autistic people, and their families and carers and support networks.

2. Accessibility based on Universal Design

The development and implementation of this Strategy will be accessible and based on **Universal Design principles**.

National Autism Strategy | Help shape the change



Our Guiding Principles

3. Self Determination and Autonomy

This Strategy will foster **freedom of choice**, **control** and **support** for Autistic people to make their own **individual decisions** about all aspects of life.

4. Aligned and Accountable Outcomes

This Strategy and actions will align with other key government strategies. This Strategy will be **measurable**, **accountable** and **evidence-based**.

National Autism Strategy | Help shape the change

Our Guiding Principles

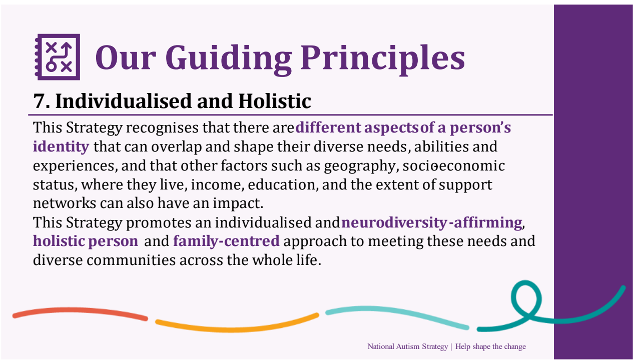
5. Acceptance and Inclusivity

This Strategy will reflect that every Autistic person has unique strengths, abilities and attributes. This Strategy will seek to **foster community understanding** and **acceptance of all Autistic people** for who they are, and for their many contributions to Australia.

6. Rights

This Strategy will uphold the rights of all Autistic people to **be respected** and **safe** from all forms of discrimination, vilification, violence, and abuse everywhere in their lives.

National Autism Strategy | Help shape the change



Our Guiding Principles

7. Individualised and Holistic

This Strategy recognises that there are **different aspects of a person's identity** that can overlap and shape their diverse needs, abilities and experiences, and that other factors such as geography, socioeconomic status, where they live, income, education, and the extent of support networks can also have an impact.
This Strategy promotes an individualised and **neurodiversity-affirming**, **holistic person** and **family-centred** approach to meeting these needs and diverse communities across the whole life.

National Autism Strategy | Help shape the change

Feedback on the Strategy Foundations and Guiding Principles

Overall, group participants were dissatisfied with the Strategy Foundations and the guiding principles.

General Improvements

It is relayed in the Strategy that the Guiding Principles set out how the Strategy foundations will be put into practice.

There is need to better emphasise the operation of the Strategy Foundations and Guiding Principles in relation to the Vision, Goals, Commitments, Governance, Research, Reporting and Evaluation as how they fit was not commonly understood.

Recommendation 26:

Provide greater clarity and emphasis as to how the operation of the Strategy Foundations and Guiding Principles fit with the Vision, Goals, Commitments, Governance, Research, Reporting and Evaluation to improve the understanding.

Strategy Foundations Feedback

Biopsychosocial model

There was concern regarding the reference to the Biopsychosocial Model as often Autistic people's needs are not met. It was thought that it was interesting that there was not a greater focus on Human Rights.

There was a suggestion to including a statement similar to the Disability and Inclusion Act of 2003 #3 to reflect the diversity of autism, "people with a disability, whatever the origin, nature, type and degree of disability, have the same basic human rights as other members of Australian society."

This would better reflect the need for equity/ equal opportunity in all areas of society and across the lifespan, so society makes room for Autistic people and their families. This is critical to enable the commitments in the rest of the Strategy to enable "life outcomes" due to the same opportunities as other Australians with at least Maslow's Hierarchy of Needs being met.

"*We should see this strategy draft through the 'lens' Maslow's Hierarchy - for a good life everyone needs somewhere to live, something to do and someone to love."*

Maslow's hierarchy of needs

Recommendation 27:

Replace references to the Biopsychosocial Model of Disability with reference to the Human Rights Model of Disability.

Intersectionality

As mentioned above under the Statement of Autism, group participants thought that the strategy needed to better reflect experiences of people requiring very substantial support (aka profound autism) with unique and daily risks of harm, disadvantage, isolation and poor life outcomes throughout the Strategy. It was highlighted during this discussion that this is not an aspect of intersectionality but just an aspect of autism for some people hence it was important that people requiring very substantial support (aka profound autism) was referenced in the right context.

"The Strategy intends to include a focus on intersectional (overlapping) disadvantage or discrimination experienced by autistic people. However, this focus appears to marginalise or even replace the much-needed focus on those with SPA. At best it conceals them and inappropriately categorises their profound disability as an intersectional attribute."

"people with high support needs and their unique disadvantage .....It's a bit lost in the guiding principles, and so then that's not at all present in the commitments that follow"

'Complex support needs', although an inadequate proxy for SPA, is only mentioned once and well down the list of "intersectional" categories. It is certainly not central to the Strategy at all. It should not be classified as intersectional; it is part of the presentation of Autism.

Recommendation 28:

Ensure that the Statement of Autism has clear reference to autism as a distinct disability and not based on intersectional aspects.

Guiding Principles Feedback

The strongest feedback overall was that the Guiding Principles are divisive. The principles did not reflect Autistic people with profound autism (aka requiring very substantial support). It also ignored those who may not be able to advocate for themselves and in areas relied on Autistic people who do have a "voice" represent their lived experience on their behalf.

> *"From the orientation established in these principles, the draft strategy appears limited to a course that fails to adequately consider the diverse circumstances, needs, challenges and preferences of many autistic people and their families. In particular, the principles appear to force-fit a neurodiversity-affirming approach too broadly, and to prioritise intersectionality over severe and profound autism. Many elements of the strategy are filtered by these contentious perspectives".*
>
> *"Implementation of strategies made for SPA, but not with them, creating trauma and confusion."*

Note: A number of the group agreed that a simple solution would be to make the guiding principles agnostic by stripping out any ideological or partisan positions and the jargon. Specific feedback was provided further below which may contradict with Recommendation 29. For the avoidance of doubt the preference is for this Recommendation 29

Recommendation 29:

Make the guiding principles agnostic so they did not emphasise any particular subcategory of autism groups.

In partnership - Nothing about us, without us

This Strategy will be co-designed, co-produced, co-reviewed and co-delivered with Autistic people, and their families and carers and support networks.

The reference to "partnership" was strongly supported as it went beyond codesign.

However, the words "Nothing about Us, Without Us has certain connotations that are perceived as excluding non-speaking Autistic people and those requiring very substantial support (aka profound autism), who should be fully and deeply involved at all levels, including leadership.

It was reiterated by the parents and carers in the groups that there was a need to make sure the Strategy respects and support the role of parents and carers ensuring that those they care for have a voice, and that their rights, choice and decision making is supported.

Wikipedia identified that "**Nothing about us without us**" *(Latin: Nihil de nobis, sine nobis*) is a slogan used to communicate the idea that no policy should be decided by any representative without the full and direct participation of members of the group(s) affected by that policy.

> *"The acute challenges of SPA are not like those of many self-advocates. Both types of experience are important and valid, but very different ….. the Strategy must go much further in adding SPA representation."*

It was also identified that while there is statements with reference to co-design, co-production, co-review, and co-delivered with all Autistic people, there needs to be specific reference within the Strategy to complex communication needs and recognise that Autistic people use a range of communication devices and methods and that they should have choice and control over the device(s) and/or *method*(s) they use. Otherwise, those with complex communication needs (and requiring substantial support) will be left out as we won't be targeting these people. It also needs to be recognised that sometimes this might be through the family.

Hence there is also a key subgroup missing which is parents and Autistic parents.

"And so, when we talk about the challenges of, you know, children making or being able to be empowered to make their own decisions and things like that, it's the parent that makes those

decisions. And when that parent is also dealing with their own Autistic challenges, how are we supporting Autistic parents?

"So, unless we explicitly outline what we mean by this within the strategy, and then put in those strategies in place to ensure that those individuals actually have commentary and not a voice, ………It's dialogue and it's spelled words or gestures, and I think we need to get away from just using the word voice."

"Formal and non-formal communication methods are important to validate and make a commitment to be included. "

"the Autistic subgroup with Complex Communication Needs is around 33% of the entire autistic population, …….they have largely been ignored in the autism discourse."

" You could say co-delivered within the Autistic community that is inclusive of everyone, those who have a voice, those who do not have a voice, their families and carers and support networks. That by itself, by saying inclusive in the community, the whole Autistic community you're talking about everyone. But just to say Autistic people, you're already excluding. And then the ones who do not have a voice, who can't go from point A to point B without having the moms with them or their care with them because they can't do anything on their own where is their voice in this strategy?"

"My son, my son, had to go under a general anaesthetic just for his first dentist appointment, …..I think that the most important thing is that people in this group are continuously involved in these conversations…. in partnership needs to include people like this in these boardrooms, strategy sessions…..this document has been designed with Autistic people who have a capacity to communicate and have very different fulfilling lives…….

Recommendation 30:

Guiding Principle 1 In partnership - Nothing about us, without us be amended to:

a. refer to only "In Partnership" as the headliner.
b. capture an additional statement that activities of co-design, co-produce, co-review, and co-delivery will involve representatives from and reflect the diversity within the Autistic and autism community, including those with complex communication needs. For example, non-speakers, minimally speaking, those that are able to type, those that are able to spell those that are able to voice, etc; and
c. recognise that Autistic people communicate in a range of methods and that they should have choice and control over the device(s) and/or method(s) they use.

Accessible based on Universal Design

The development and implementation of this Strategy will be co-led by Autistic people and the Australian Government. It will be accessible and based on Universal Design principles.

It was identified that this prescribes co-leadership by Autistic people and the Australian Government. As prescribed by the Senate committee report (2002), “an inclusive co-design process— drawing on the Autistic community, as well as parents, carers, researchers, and policy makers—must underpin development of the strategy.”

> *"co-led by Autistic people" is exclusive of the people that this group represents.”*

Recommendation 31:

Guiding Principle 2 Accessible based on Universal Design be amended to inclusive of Autistic people with support needs and their family/ carer representatives.

Self Determination and Autonomy

This Strategy will foster freedom of choice, control and support for Autistic people to make their own individual decisions about all aspects of life.

It was discussed that this needs to reflect those who have complex communication needs and require supported decision making to ensure an individual’s needs, preferences and dignity are respected.

Recommendation 32:

Guiding Principle 3 Self Determination and Autonomy be amended to make reference to supported decision making and dignity.

Aligned and Accountable Outcomes

This Strategy and actions will align with other key government strategies. This Strategy will be measurable, accountable and evidence based.

There was considerable discussion around the reference to evidence based. While the autism community generally views evidence-based practices (EBPs) as essential for ensuring effective and ethical support for individuals with autism.

However, there are challenges in translating these practices into real-world settings and are not always informed by Autistic people and their families, including individuals who should have the right to communicate how they need to and for it to be respected.

It was also questioned whether “"evidence-based' had lost its meaning and was dangerous, particularly as “evidence” depends so much on research choices and progress”. It was thought that it should be dropped in this context and also that Best Practice is made referenced to in other parts of the Strategy as relevant.

Recommendation 33:

Guiding Principle 4 Aligned and Accountable Outcomes be amended to remove reference to “evidence-based” OR Remove term ‘evidence-based’ from the Strategy, with the exception under Research OR Remove term ‘evidence-based’ from the Strategy, and replaced with the term Best Practice as relevant elsewhere in the Strategy.

Acceptance and Inclusivity

This Strategy will reflect that every Autistic person has unique strengths, abilities and attributes. This Strategy will seek to foster community understanding and acceptance of all Autistic people for who they are, and for their many contributions to Australia.

It was considered this statement was patronising and reinforced the lack of societal acceptance and inclusion of Autistic people. The statement does not recognise that there are days that present as very challenging with individuals suffering, harming and/or isolating themselves.

Recommendation 34:

Guiding Principal 5 Acceptance and Inclusivity be amended to reflect the diversity of autism. A suggestion made is to reword as follows:

The Strategy recognises the lack of community understanding and acceptance of Autistic people and will take practical steps to educate the community about autism, and promote acceptance of Autistic people, to achieve genuine inclusion and equity.

Rights

This Strategy will uphold the rights of all Autistic people to be respected and safe from all forms of discrimination, vilification, violence, and abuse everywhere in their lives.

Feedback includes:

a. the word “uphold” is not strong enough;
b. “rights” of Autistic people should extend to their families and carers.
c. rights need to be supported by appropriate legislation and policy and for better protections to be enforced.
d. the importance of respectful and safe guardianship and trusteeship legislation

Recommendation 35:

Guiding Principle 6 Rights be amended to be stronger than “uphold” and instead reflect “taking explicit and transparent steps to defend the rights of...”

Recommendation 36:

Guiding Principle 6 Rights be amended to incorporate in the following paragraph suitable wording to capture “safe” includes a supported decision-making paradigm and protections to safeguard individuals including financially, particularly when they no longer have family support network available.

Individualised and Holistic

This Strategy recognises that there are different aspects of a person's identity[i] that can overlap and shape their diverse needs, abilities and experiences, and that other factors such as geography, socio-economic status, where they live, income, education, and the extent of support networks can also have an impact. This Strategy promotes an individualised and neurodiversity-affirming, holistic person and family-centred approach to meeting these needs and diverse communities across the whole life.

The critical factor of severity of impairment is omitted.

It was identified that the guiding principles needed to reflect:

a) the inclusion of older Autistic people stronger than just 'across the whole life' as a deeply unrepresented group with significant disadvantage, extremely high underdiagnosis rates and specific challenges.
b) the complexity of Autistic people with profound autism (aka requiring very substantial support), including complex communication needs and also Autistic parents

Recommendation 37:

Guiding Principle 7 Individualised and Holistic be amended to reflect:

a. the inclusion of older Autistic people stronger than just 'across the whole life' as a deeply unrepresented group with significant disadvantage, extremely high underdiagnosis rates and specific challenges.
b. the complexity of Autistic people requiring very substantial support (aka profound autism), including complex communication needs and also Autistic parents
c. severity of autism so that Autistic people requiring very substantial support (aka profound autism) are not at the risk of being marginalised or being categorised as an intersectional attribute.
d. Remove reference to neurodiversity-affirming, as this is applied too broadly in this context.

e.

Social Inclusion Commitments

Social Inclusion continued

1. Improve understanding of, and change attitudes towards, Autistic people across all of society, through:
    a. Greater public education and awareness including a better understanding of autism within workplaces, and with a focus on health, education and the criminal justice system.
    b. Increasing visibility and representation of Autistic people in the media, sports and the arts.
    c. Increasing accessible and sensory-friendly public and online spaces.
    d. Increasing the capability of advocates and advocacy organisations to challenge and reduce stigma of autism.

National Autism Strategy | Help shape the change

Social Inclusion continued

2. Increase opportunities for social connections and peer support.

3. Improve Australian Government service delivery, communication, and information to meet the needs of Autistic people.

4. Ensure consideration of the needs of Autistic people in future amendments to or reviews of the *Disability Discrimination Act 1992* (Cth) and associated disability standards.

5. Improve the safety and welfare of Autistic people through the reduction of all forms of discrimination, violence, abuse, bullying, vilification, and exploitation.

National Autism Strategy | Help shape the change

Social Inclusion Feedback

While the commitments in social inclusion were agreed in principle the feedback was that the commitments required more work to reflect people requiring very substantial support (aka profound autism) and their families and carers. Much of the additional specific feedback has been captured in the recommendations below but some key highlights of specific feedback were that:

a) it was critical that it was essential that a better understanding of the diversity of autism to result in a more autism informed Australia required:
    i. that it was more than just workplaces referred to in 1a);
    ii. understanding of the true extent of individual diversity and capacity of autism with each individual having their own set of unique experiences, capabilities and preferences. This in as in particular what is considered “social inclusion” by Autistic people can be very different to neurotypical people.
    iii. there is a special focus to increase understanding and reduce stigma in First Nations and CALD communities.
    iv. there is focus on complex communication needs.

> *“We need to have profound autism recognised with all of its challenges. And then that comes with different educational programs and different employment settings and doctors and diagnosis and all those things”.*
>
> *“You know, I would love to be able to take my kids out, and these are the things that the government can do. There's an inclusive park that's in Broadbeach the tourist capital, and every child goes there and it's not safe for disabled people to go there, let alone Autistic people. And it's right on the beach. These decisions that were made by State Council, and we weren't included in these conversations.”*

> *I am East Asian, and in my culture, autism is so stigmatised that we are discouraged from speaking about the condition and how it affects our children. We must also change the attitudes of immigrant communities towards Autistic people, I believe, to assist parents in accessing supports.*
>
> *I just can't explain to people anymore how I can function so well and then suddenly barely speak and need to spend a week in bed. I am tired of trying to explain and also of defending myself.*
>
> *trying to infiltrate business advisory services is a joke. we get told we're not innovative enough and innovation really is a kid cleaning wheelie bins as much as someone in an acceleration program.*

It was also identified that important elements of safety and welfare include financial abuse and the increased risk profile of individuals who do not have family and carer support networks and need to rely on guardianship and trustee arrangements.

Recommendation 38:

Review Commitment 1a) under Social Inclusion so that it better reflects that a better understanding of autism is not specifically called out only for workplaces (as it currently reads)

Recommendation 39:

Ensure that the action plan for Commitment 1a) captures that a better understanding of autism includes:

a. a representation and understanding of the full diversity of presentations of autism;
b. a better understanding across all of society (including businesses, transport, community locations, shopping centres, first responders etc) and government bodies and agencies.
c. the impact social isolation from the community has including adversely impacting mental health, education, social and economic outcomes.
d. an understanding of complex communication needs and respecting choice and control of communication styles across all aspects within society
e. the range of barriers that prevent Autistic people from full and equal participation in the community and society.
f. the impact of unaccommodating built environments and the low levels of supported independent living.[14];
g. the lack of services designed specifically to cater for Autistic people with Autistic people often having to 'make do' with generic services or services designed for people with intellectual and cognitive disabilities.[15];

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[14] Senate Select Committee on Autism (2022) 'Services, Support and Life Outcomes for Autistic Australians,' *Australian Government*, Canberra, pp. 34.

[15] Senate Select Committee on Autism (2022) 'Services, Support and Life Outcomes for Autistic Australians,' *Australian Government*, Canberra, p 92.

h. the experience and barriers of intersectional discrimination
i. the experience and additional barriers of people with autism requiring very substantial supports (aka profound autism), including on individuals, and families/ carers. This includes additional considerations of safety, health, and well-being in the home and in public places (including absconding, water, fire and other hazards both to the individual and also the family/ carers).
j. increase understanding and reduce stigma in First Nations and CALD communities.
k. how to support Autistic people, including the serious risks related to online safety and mental health.
l. unnecessary restrictive practices like over medication and physical restraints.
m. the role of families and carers and advocacy organisations as advocates
n. how society can support individuals, families, carers and advocacy organisations to feel empowered to raise their need for support
o. the many interests and talents that Autistic people have that are not limited to IT.

Recommendation 40:

For Social Inclusion Commitment 1b) be qualified so the representation be "increasing visibility and representation of different Autistic people in the media according to Autistic people and families and carers so that the community views Autistic people according to how they have been chosen to be viewed".

Recommendation 41:

For Social Inclusion Commitment 1c) to capture that "increasing accessible and -sensory friendly public and online spaces need to be free access and/or affordable to ensure that it is inclusive of those individuals and families who do not have economic privilege/ are facing financial hardship.

Recommendation 42:

For Social Inclusion Commitment 1d) to
a. be expanded to include Autistic people, their families and support networks.
b. replace "increasing capability" with "resourcing"; and
c. capture the education of Autistic people and their families and carers in their rights.

Recommendation 43:

For Social Inclusion Commitment 2 to be clear that:
a. increasing social connections and peer supports is for all Autistic people (as may imply currently only related to NDIS);
b. this needs to include families and carers;
c. this should include a special focus on First Nations and CALD communities; and
d. social connections and peer supports are Autistic and Non-Autistic

Recommendation 44:

For Social Inclusion Commitment 3 to be expanded to include for all of government to be demonstrably the exemplar organisation for autism inclusion practice through investment in a change in narrative and culture including mandatory training capturing organisation-wide knowledge, skills, and confidence in engaging with and including Autistic people, their families, and carers.

Recommendation 45:

Add an overarching commitment under the Social Inclusion Commitments to address the significant levels of social isolation and discrimination faced by parents and carers to improve their wellbeing and meet the unique support needs of people with profound autism (aka requiring very substantial supports).

Recommendation 46:

For Social Inclusion Commitment 4 to be expanded to reflect that the Australian Government ensures that all existing and future policies, strategies, programs, interventions, and research relating to Autistic people have an “autism-lens” applied, the National Autism Strategy is referenced where relevant and there is appropriate representation of Autistic people, their families and autism community, as relevant, on reference groups.

Recommendation 47:

For Social Inclusion Commitment 5 to be expanded to reflect:

a. that the reduction of all forms of discrimination, violence, abuse, bullying, vilification, and exploitation should not rely on the Autistic person, their families and support networks to enable this to have effect but there are independent mechanisms to safeguard the effective operation.
b. other forms of “safety and welfare” include chemical and physical restraints, public areas such as beach, parks etc, mouthing unsafe items, household poisons, unsanitary practices etc.
c. financial abuse and the increased risk profile of individuals who do not have family and carer support networks and need to rely on guardianship and trustee arrangements.

Recommendation 48:

For a specific commitment to be introduced for National Standards for Autism Friendly Environments and Services Across Government Business and Community Organisations.

Economic Inclusion Commitments

Economic Inclusion

6. Increase meaningful employment opportunities (including business ownership, self-employment, entrepreneurship and social enterprise) for Autistic people.

7. Support employers to hire and retain Autistic employees through improving the accessibility ofrecruitment processes and fostering workplace environments that are safe and inclusive for all Autistic people

8. Improve the supports and services available to Autistic people to ensure they have choice and control over their education and careers.

National Autism Strategy | Help shape the change

Economic Inclusion continued

9. Increase representation of Autistic people in senior and board positions to promote people asvisible role models.

10. Improve inclusive practices and the quality and accessibility of advocacy resources for Autistic students across all education settings, and their families, carers and support networks.

11. Build on commitment 5 *Improve the safety and welfare of Autistic people through the reduction of all forms of discrimination, violence, abuse, bullying, vilification and exploitation* to specifically focus on Autistic students in all levels of education.

National Autism Strategy | Help shape the change

Employment Feedback

Feedback highlighted that Economic Inclusion made little provision specifically for people with profound autism (aka requiring very substantial supports) and their families and carers although they often face more barriers to achieve economic inclusion.

There are further barriers for those who are First Nations and CaLD background, applying to both individuals and carers. Additional barriers are faced by those who are single parents and/or Autistic parents, who are also First Nations or CALD. Please note that additional commitment has been proposed under the Section titled Gaps below under Carers.

While there is limited data on the specific employment rates of each sub-group of the, there is evidence to suggest that the workforce participation goes down with each layer of intersectional disadvantage.

There was also no strategy to meet the immediate and long-term support needs of Autistic people who are unable to work or to meet the support needs of parents and carers who are unable to work.

It was also identified that the Strategy makes no specific reference to supported employment, despite the significant reference in the Disability Royal Commission, which included a call for award wages.

Furthermore, the Senate Select Committee on Autism reported under Recommendation 58 that a National Autism Employment Framework be developed under a National Autism Strategy. This would be welcomed to ensure the diverse range of Autistic people are captured in a structured, well-governed, innovative, and measurable way. It will also provide for longevity with strategies across the lifespan particularly for those who will never achieve employment and parent/ carers find themselves no longer available to continue to support their children.

Economic Inclusion Commitment 10 makes reference to improve quality and accessibility to advocacy resources for students. This is also required with employment, often regarding supported decision-making, bridging complex communication needs and to address employer discrimination.

Recommendation 49:

Create a separate commitment that develops a National Autism Employment Framework (possibly relabelled as a National Autism Economic Framework) and includes:

d) understanding and meeting the employment support needs of people with profound autism (aka requiring very substantial support), and vulnerable intersectional cohorts (choice and opportunities in all environments). This includes complex communication needs.
e) protection/ safeguard mechanisms for significantly disadvantaged due to very substantial support needs; and
f) economic inclusion options for Autistic people who may never be in a position to be gainfully employed to meet immediate and long-term support needs. This may include:
    v) a sustainable disability support pension,
    vi) Medicare to be expanded in coverage for age and the reduction in payment gaps,
    vii) ability to loan/lease/sell back equipment and communication devices.
    viii) volunteering opportunities

Recommendation 50:

Create a similar commitment as under Commitment 10 for Education Inclusion for Economic Inclusion referencing quality and accessibility to advocacy services, as well as resources, for employees. This is to address shortfalls in supported decision-making, complex communication needs and employer discrimination, among other things.

Recommendation 51:

Interface with relevant DRC Recommendations that government endorses regarding Supported Employment to ensure an autism lens and the codesign, co-production and co-implementation with people with autism across the full diversity and their families and carers.

Education Feedback

The feedback was that similar to employment there was little provision specifically for people requiring very substantial supports (aka profound autism) although they often face more barriers to achieve education inclusion.

Lack of Inclusive Education including Complex Communication Needs

When it comes to education participation, research suggests that there are similarly a range of factors which challenge the full and equal participation of students with autism. Except for some schools across Australia that have made a distinctive effort to provide an inclusive education, the majority of schools and educators provide very few accommodations for Autistic students, even when there is a clear benefit.[16] For example, while many Autistic students experience auditory processing delays, have complex communication needs or are non-verbal; classroom communication is mostly verbal and instructions or information on topics is rarely provided in alternative visual formats

Intersectional Disadvantage

Furthermore, for Autistic students who face intersectional disadvantages, the schooling and education system can present an array of additional disadvantages. For example, First Nations and CaLD Autistic students face added disadvantages associated with language and cultural barriers,[17] the education system curriculum being centred around a white colonial history[18] and a risk of experiencing racism from their educators and peers.[19] LGBTIQA+ students often have to navigate, at best a lack of understanding of their experiences, and at worst, blatant discrimination and school expulsion based on their gender or sexual identification.[20] Autistic students living in rural or remote areas or who experience socio-economic disadvantage are more likely to attend public, under-resourced schools with even more limited ability to offer support and accommodations;[21] and Autistic women and girls are less likely to even receive recognition of their support requirements, due to barriers to diagnosis and pressures around compliance and social assimilation.[22] And this is just some of the issues.

Suspension, Exclusion and Restrictive Practices

High rates of suspensions and exclusions for Autistic students and the use of restrictive practices remain a live issue (as highlighted by the Disability Royal Commission). There

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[16] Australian Autism Alliance (2020) ‘The Autism Dividend: Unleashing the skills, talent and opportunity of Australia’s autistic community,’ p. 31.

[17] See for example: Foundation House and Multicultural Youth Advocacy Network (2021) *National Education Roundtable. Briefing Paper: Education and students from refugee and migrant backgrounds,* Viewed 8 June 2023, p. 6 <https://myan.org.au/wp-content/uploads/2020/11/education_issue_05.pdf>; Prior, M (2013) ‘Language and Literacy Challenges for Indigenous Children in Australia,’ Australian Journal of Learning Difficulties, Vol. 18, no. 2, pp. 123-137 <https://eric.ed.gov/?id=EJ1024454>.

[18] See for example Moore, R (2017) 'History textbooks still imply that Australians are white,' The *Conversation*, Viewed 8 June 2023 <https://theconversation.com/history-textbooks-still-imply-that-australians-are-white-72796>.

[19] See for example Pirest, N and Biddle, N (2015) 'Racism hits Indigenous students' attendance and grades,' *Australian National University*, Viewed 8 June 2023 <https://www.anu.edu.au/news/all-news/racism-hits-indigenous-students-attendance-and-grades>;

[20] See for example: Elphick, L (2023) ‘Religious schools can still expel LGBTQ kids. That needs to change,’ *Sydney Morning Herald,* Viewed 8 June 2023 <https://www.smh.com.au/national/religious-schools-can-still-expel-lgbtq-kids-that-needs-to-change-20230221-p5cm5l.html>.

[21] See for example: Cobbold, T (2020) ‘Low SES Schools Have Far Less Resources than High SES Schools,’ *Save Our Schools Australia*, Viewed 8 June 2023 <https://saveourschools.com.au/equity-in-education/low-ses-schools-have-far-less-resources-than-high-ses-schools/>.

[22] See for example: Yellow Lady Bugs and the Department of Education and Training Victoria (2008) ‘Spotlight on Girls with Autism.’ <https://yellowladybugs.com.au/School/Download>.

is no agreed and consistent approach to positive behaviour management across education and learning settings, which further disenfranchises Autistic learners.

Parent/ Carer Economic Disadvantage

Research indicates that once children were of schooling age, mothers of children with autism spectrum disorder had up to two times the odds of being not in the labour force compared to other mothers, after adjusting for confounders.[23] The increased number of school-age Autistic children is not matched by increased services to meet their needs. Parents/carers are expected to put Autistic children in mainstream schools and out-of-school care, settings that lacked skilled staff or adequate resources.

So, families – typically mothers – are required to provide the support safety net for their Autistic child. Many parents of Autistic children must work reduced hours because they need to provide care for their Autistic child. Or they are often required to collect their child early from school, or from childcare, because the settings cannot support the child when the child is distressed. Autistic children are much more likely to be bullied; and when they are they are often blamed and mistreated for their consequent behaviour. This can lead to school refusal and/or home-schooling. And the mother is unable to work.

Many students with profound autism (aka requiring very substantial supports) whether funnelled into special school settings, or if in mainstream are frequently part time. and are regularly sent home or unable to attend school due to the environment or safety issues. Hence the demands on parents of Autistic students, often surpass those of parents of non-Autistic students (e.g., demands to collect their children early, attend school meetings or to home-school their children). This means that parents of Autistic students often have reduced opportunities to engage in paid employment which adversely impacts parental wellbeing and financial security. Even if the mother can continue working, the imposition on her career is substantial. She works reduced hours, is considered less reliable, and has fewer opportunities and promotions. It is also difficult to kick start a career after being absent from paid employment for a significant period.

In a national survey with over 3000 respondents that the Australian Autism Alliance commissioned in 2020 undertaken by the ACU Engagement (ACU 2020 Survey) more than one-third of Autistic adults (42.1%) and about a third of parents/carers (31.5%) have lost their job due to their or the person they care for’s autism. Many parents end up feel invisible, undervalued, irrelevant and lonely.

Furthermore, many migrant and refugee women, especially those on temporary VISAs are not eligible for government support payments such as Paid Parental Leave, the

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[23] Callander EJ, Lindsay DB. The impact of childhood autism spectrum disorder on parent’s labour force participation: Can parents be expected to be able to re-join the labour force? Autism. 2018;22(5):542-548. doi:10.1177/1362361316688331

Family Tax Benefit (FTB) and the Childcare Care Subsidy (CCS).[24] The immigration system is also not autism-friendly, and many immigrant parents are hesitant to reveal their child's autism out of fear of deportation.

Safety and Welfare

It was also identified that Economic Inclusion Commitment 11 makes specific reference to improving the safety and welfare of Autistic people through the reduction of all forms of discrimination, violence, abuse, bullying, vilification, and exploitation to specifically focus on Autistic students at all levels of education. While the Disability Standards for Education (DSE) specify a number of obligations for educational providers to prevent discrimination against disabled and Autistic students, evidence suggests that disability discrimination is still rife across all levels of education. According to statistics from the Australian Human Rights Commission, the majority (38 per cent) of all complaints are lodged under the protections of the Disability Discrimination Act, with approximately 8-10 per cent of those complaints being specific to education.

Among a number of other recommendations related to the provision of support for Autistic students and training for educators, the need to strengthen accountability mechanisms for education providers was specifically recommended in the yet-to-be-implemented final report on the 2020 review of the DSE.

Tertiary Education

It was also highlighted that of those students who manage to attend Tafes and Universities there is a need to invest more to enable the attraction, and retention of autism students. Although most research about the barriers that face Autistic students is focused on primary and sometimes high school, there is evidence that these barriers persist and often worsen throughout all levels of education, including at universities and TAFEs.[25]

Given Tertiary education is covered by the Federal government and is a significant stepping stone to achieving employment, particularly to enable graduate entry to Australian Public Service roles a specific stand-alone Commitment regarding Tertiary Education should exist that addresses a Tertiary Education Roadmap inclusive of the safety and wellbeing of Autistic Tertiary students. This is particularly relevant here as outlined above that those with complex communication needs are often underestimated.

Furthermore, many parents, particularly CALD and First Nations parents often feel helpless and powerless to help their children in the education system, especially universities and TAFE. Once their children become adults, education institutions shut out parents from discussions as they are not autism-friendly or understanding of disability. Many feel overwhelmed and unable to help their children to graduate and get jobs.

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[24] ASRC (2020) 'Income support and Centrelink entitlements for temporary visa holders,' *Asylum Seeker Resource Centre*, Viewed 7 June 2023 <https://asrc.org.au/wp-content/uploads/2013/04/HRLP-Infosheet-COVID19-Jobkeeper-and-Jobseeker-updated-August-2020.pdf>.

[25] Ibid.

Pathways

It was identified that early investment in the development of employment readiness skill would be of benefit rather than the current practice of 1-2 years prior to leaving school or after leaving school. The age of employment in most states is 14yrs, and part time work as a teenage is linked to better employment outcomes in early adulthood.

Life readiness skills were also identified to be of benefit, particularly for financial security and safety with succession planning. This includes investment in building money management skills, budgeting, avoiding fraud / scams, and learning to understand and navigate things like tax, utility bills, renting, etc.

Recommendation 52:

Add in a Commitment under the Economic Inclusion section which addresses the economic disadvantage experienced by parents and carers. This includes:

h) provision for increasing accessibility and flexible work options available to carers. This could be supporting fully remote and / or work from home options, job sharing employment opportunities.
i) business / government grants that are accessible for self-employment.
j) funded education to kickstart career or investigate and build employment capacity.
k) funding to support building a business such as accounting and tax advice, legal advice and website establishment.
l) mentor / peer support to support into the employment world.
m) addressing the superannuation gap
n) meeting the support needs of parents and carers who are unable to work.

Recommendation 53:

Expand Economic Inclusion Commitment 10 to capture specifically “ accommodations and complex communications needs” and make reference to capture people with autism requiring very substantial support (aka profound autism) and vulnerable intersectional students.

Recommendation 54:

Introduce a specific Tertiary Education commitment that addresses a Tertiary Education roadmap inclusive of the safety and well-being of Autistic Tertiary students and capture of lead indicator data such as dropouts and transfers. This should include consideration of the CCN Framework

Recommendation 55:

Expand Economic Inclusion Commitment 6 to include a restoration channel and strategy to close the gap for those students who have disengaged, past and present.

Recommendation 56:

Expand Economic Inclusion Commitment 11, that makes specific reference to improving the safety and welfare of Autistic people, to have:

c) a restoration channel and strategy to close the gap for those students who have school refusal, and/or have been unfairly victimised so as to re-engage disengaged students, past and present.

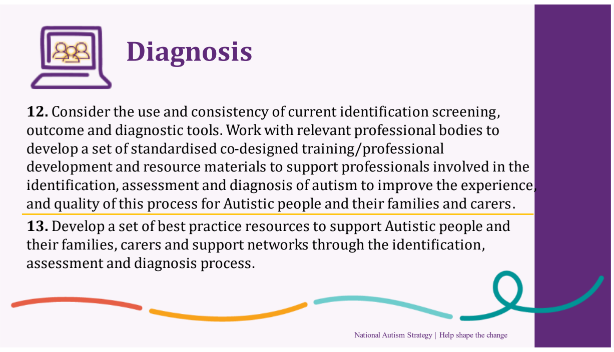
d) a review of the Disability Standards for Education with an autism lens in the short-term action plan with a view to addressing strategies to
  iii) enable choice and opportunities -mainstream, special school, hybrid etc.
  iv) suspension and expulsion

Recommendation 57:

Expand Economic Inclusion Commitment 6 to include career pathways and better school transition supports and captures early investment in the development of:

a) employment readiness skills in readiness for employment at eligibility age (14-15yrs); and
b) Life readiness skills such as money management skills, budgeting, avoiding fraud / scams, and learning to understand and navigate things like tax, utility bills, renting, etc.

Diagnosis, Services & Supports Commitments

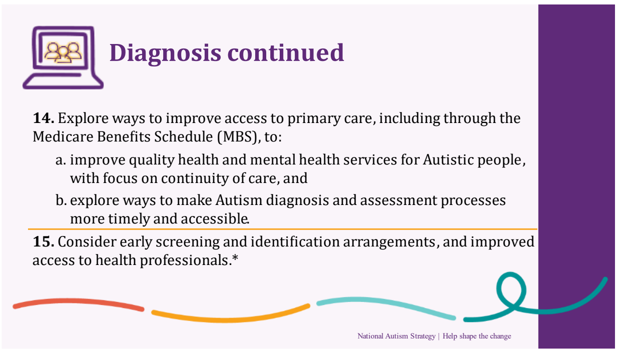


Diagnosis

12. Consider the use and consistency of current identification screening, outcome and diagnostic tools. Work with relevant professional bodies to develop a set of standardised co-designed training/professional development and resource materials to support professionals involved in the identification, assessment and diagnosis of autism to improve the experience, and quality of this process for Autistic people and their families and carers.

13. Develop a set of best practice resources to support Autistic people and their families, carers and support networks through the identification, assessment and diagnosis process.

National Autism Strategy | Help shape the change



Diagnosis continued

14. Explore ways to improve access to primary care, including through the Medicare Benefits Schedule (MBS), to:

a. improve quality health and mental health services for Autistic people, with focus on continuity of care, and

b. explore ways to make Autism diagnosis and assessment processes more timely and accessible.

15. Consider early screening and identification arrangements, and improved access to health professionals.*

National Autism Strategy | Help shape the change

Services & Supports

16 . Improve access to quality, timely, neurodiversity-affirming and equitable supports and services for Autistic people, including for people living in rural, regional and remote areas.

17. Encourage greater representation of people with lived experience in delivering supports and services to Autistic people.

18. Develop a set of best practice training and resource materials for people providing services and supports to Autistic people.

19. Explore the feasibility of a decision-making tool to empower Autistic people to make informed decisions about all areas of their life.

20. Work with states and territories to improve service integration between the NDIS, foundational supports and mainstream services.

National Autism Strategy | Help shape the change

Diagnosis, Service and Supports Feedback

Feedback highlighted that Diagnosis, Service and Supports requires a number of additions to incorporate people requiring very substantial supports (aka profound autism) and their families and carers.

Diagnosis Complexities Due to Intersectionality

While it is also common for Autistic people to have psychosocial disabilities as co-occurring conditions, biases in assessment processes mean that Autistic women and gender-diverse people in particular often experience misdiagnoses which create further barriers to being diagnosed Autistic. While it is impossible to identify the exact number of misdiagnoses that occur, estimates suggest that approximately 80 per cent of Autistic women are misdiagnosed – often with conditions such as borderline personality disorder (BPD) eating disorders, bipolar disorder, and anxiety.[26]

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[26] See for example Gesi, C et a. (2021) 'Gender Differences in Misdiagnosis and Delayed Diagnosis among Adults with Autism Spectrum Disorder with No Language or Intellectual Disability,' *Brain Sci,* Vol. 11, no. 7, p. 912 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8306851/>; Rudra, A (2022) 'Why many women with autism and ADHD aren't diagnosed until adulthood – and what to do if you think you're one of them,' The Conversation, Viewed 13 June 2023 <https://theconversation.com/why-many-women-with-autism-and-adhd-arent-diagnosed-until-adulthood-and-what-to-do-if-you-think-youre-one-of-them-179970>

> *"I had electro convulsive therapy because I was misdiagnosed and now live with a short-term memory impairment".*

National Autism Core Capabilities Framework

It was highlighted how inappropriate and unskilled care for Autistic individuals can put health at serious risk, cause unnecessary restrictive practices like over medication and restraints, and lasting mental trauma. These experiences seem to occur predominately with the people with profound autism (aka requiring very substantial supports). The Strategy therefore needs to be inclusive of all Autistic people and their experiences.

> *"The need for specialised training for supporting SPA individuals needs to be acknowledged in the strategies."*
>
> *I had a really really poor experience over 10 years of admissions …….. when I had a missed diagnosis of depression and was spending weeks in in this hospital and my psychiatrist……, had zero understanding of neurodivergence easy and zero understanding of emotional dysregulation and all these things are actually were what I was experiencing from asking for my whole life.*
>
> *You are allowed to have strong emotions and not be seen as a crazy person, but when you speak to a psychiatrist you know you withhold those strong emotions.*
>
> *the other gap I think is around the education of health professionals broadly across the entire health system, which is what is autism, how does it affect my patient and how can I help my patient? If that person that's helping them medically doesn't understand autism, then it creates an absolute nightmare.*

High-quality information and training are a key enabler for implementation. An example is the UK has developed a national autism core capabilities framework.[27] 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.

Targeted support for parents in the pre-and post-natal period

Post-birth and into parenting, Autistic mothers and parents of Autistic children also report experiencing higher rates of depression, social isolation, selective mutism, and prolonged stress about the various responsibilities associated with caregiving. While there is some support available in the form of postnatal midwifery, child health centres, playgroups and early childhood education centres, these options are often inaccessible for Autistic children and parents due to heightened sensory sensitivities, communication difficulties and a workforce that is not aware of the Autistic experience. Additionally, many disabled and Autistic parents avoid seeking formal support due to a fear of the

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[27] https://www.autismhampshire.org.uk/assets/uploads/Autism_Capabilities_F0ramework_Oct_2019_1.pdf

involvement of child protection. As was cited in the Senate Select Committee Inquiry on Autism, there is evidence that many Autistic mothers have had their children removed for 'no other reason than their disability;'[28] an issue which is even more common for Autistic women who are First Nations or have had prior contact with the justice system.

> “recognise the psychosocial issues of Autistic people and support them to access counselling services”
>
> “Preconceived beliefs and how to make sure that there's the right pathways ……
> and not to let their preconceived biases impact.”

Medicare Benefits (to access Diagnosis Assessments)

A key driver to assessments is affordability. Rebates for autism assessments and diagnosis under the Medicare Benefits Schedule (MBS) are only available for children and adults under 25 years of age and do not cover the total cost of the assessments.

Given the evidence that Autism is often not identified among particular cohorts (such as women and gender-diverse people) until adulthood and that Autistic people are more likely than the general population to experience economic disadvantage, the MBS rebate restrictions mean that many individuals simply cannot afford a diagnosis.

> *“Fix the discrimination in the Medicare rebate against Autistic people. GP referral for autism diagnostic assessment - the same as all other disabilities. The requirement of paediatrician / psychiatrist referral is a huge barrier”.*
>
> *“there's a four year wait time and the Medicare rebate for diagnostic assessment of all disability types need to be expanded throughout the lifespan”*

Information and Supports dedicated to Autistic people and families.

A straightforward way to improve the accessibility of services and supports to Autistic people and their families is to publish information specifically tailored to their needs. Development of such resources needs to occur through co-design with Autistic people, families, and the autism community with a particular focus on various communication formats and channels, considering supported decision making, dignity of risk and substitute decision making.

It was also identified that there are insufficient supports available to people post-diagnosis.

> *“There are cultural reasons why Asian communities don't talk about autism. Aboriginal and Torres Strait Islanders have different views on disability as well, as do Middle Eastern cultures. It's so important to allow for the different perspectives such as collective rather than individualistic ideals and how to accommodate them.”*

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[28] Blakemore, M et al. (date not available) ‘Multiple and Intersecting Forms of Discrimination Against Autistic Women. For The Attention of the Special Rapporteur on Violence Against Women,’ *The Coalition of Autistic Women.* <http://www.australianautismalliance.org.au/wp-content/uploads/2017/03/Autistic-Women.pdf>.

> *"We need to support CALD families to access services as they are unfamiliar with the services network here."*
>
> *"diagnosis involves the abstraction of manifested traits and behaviour and can be challenging as the process is reductionistic and does not look at a person's strengths or a person as a whole. So, it's important for those seeking a diagnosis/parent or carer to be provided with what options and support are there, and applicable, reviews so they don't feel isolated or let down."*
>
> *"Diagnosis is very difficult for immigrant parents like me to pursue for our children. Since there is so much stigma among doctors within Asian communities, many diagnosticians from immigrant backgrounds don't really understand autism. In my community, we often view autism and NDIS as a "white person's domain".*
>
> *"Asian cultures like our own have always viewed disability and mental health issues with fear and misconceptions".*
>
> *"The gap for me is that after you get diagnosed, you fall off a Cliff......OK, I'm diagnosed now. What? Who am I? What do I do? Who do I need to connect to? How do I get help? How do I even learn about what the hell just happened?"*

.Recommendation 58:

Commitments 12 and 13 make specific reference to "all Autistic people" and vulnerable intersectional cohorts which includes Autistic people with profound autism (aka requiring very substantial supports) and First Nations/ CALD (CARM) etc.

Recommendation 59: Amend the Best Practice definition in the Glossary to capture that all three elements are equal.

Recommendation 60:

The Australian Government support the National Autism Strategy by implementing a national autism core capabilities framework to identify key capabilities for those working with and for supporting Autistic people including those requiring very substantial supports (aka profound autism).:

- values and behaviours that underpin all the capabilities in the framework.
- evaluation methodology:
  - individual assessment of knowledge and/or competence
  - impact on practice
  - impact on quality of service (e.g., measuring service user outcomes and/or levels of satisfaction from Autistic people and their families).
- continuous monitoring and annual reporting requirements.
- built-in timelines for review of the framework (every 3 years).

Recommendation 61:

That Recommendation 60 is also to apply to:

a) professional bodies hence supporting current issues highlighted regarding diagnosis, behaviour support practitioners and other existing and emerging roles due to the NDIS and DRC Review. For example, the staff or experts need to have to undergone specific behaviour management courses or psychology specialisations before they are assigned to be responsible for the care of Autistic individuals requiring these areas of expertise.

b) Building capability in universal service platforms, particularly maternal and child health services and General Practitioners to detect warning signs and refer young children for assessment.

Recommendation 62:

Professionals to make available Autistic-affirming parental supports, as an alternative to mainstream parent support options, during the pre-and post-natal period to support Autistic parents in developing necessary skills.

Recommendation 63:

Remove the age limit and remove (or as a minimum reduce) the rebate restriction on diagnostic assessments under the Medicare Benefits Schedule. (for Health Roadmap)

Recommendation 64:

Create and publish information tailored to the needs of Autistic people and their families with a particular focus on addressing, complex communication needs, supported decision-making, dignity of risk and substitute decision-making.

Recommendation 65:

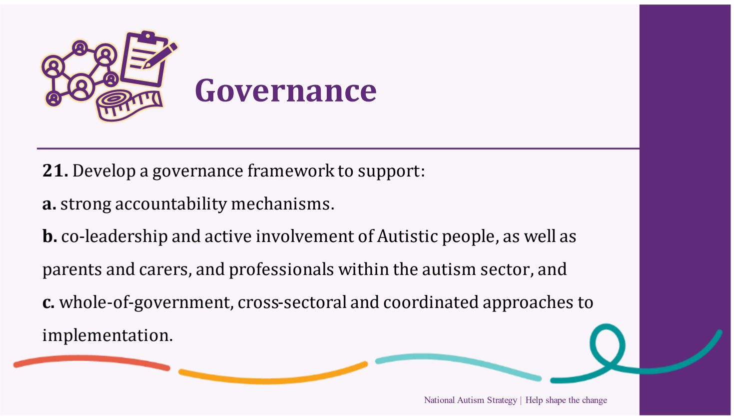
Provide post diagnosis supports and resources to assist Autistic people particularly those with profound autism (aka requiring very substantial supports), and their families/ carers, to connect to therapies, peers and community.

Recommendation 66:

Ensure the definition of “Best Practice” captures for it to be culturally safe to Autistic people, including people requiring very substantial supports (aka profound autism) and their families/carers. Also, for the term “Best Practice” in the Glossary to reflect that the three elements are equal.

Governance, Research & Reporting

Governance Commitments Feedback



Governance

21. Develop a governance framework to support:

a. strong accountability mechanisms.

b. co-leadership and active involvement of Autistic people, as well as parents and carers, and professionals within the autism sector, and

c. whole-of-government, cross-sectoral and coordinated approaches to implementation.

National Autism Strategy | Help shape the change

Feedback highlighted that it was identified that Commitment 21 refers to the development of a framework to support co-leadership rightly including Autistic people but implicitly relegating parents and carers to a secondary level. This is perceived as demonstrating the marginalisation of the family members and carers of people requiring very substantial support (aka profound autism) who themselves may not be able to participate directly in such processes.

People also said it needs action and funding and must be upheld, with ‘measures that mean something to Autistic people” and where there are “consequences for failures to uphold the Strategy.’ Funding and incentives particularly applies to regional and remote areas.

People also raised that paid governance roles should exist for Autistic people including with complex communication needs and their families and carers. To this end it has been raised in all the consultations that there is concern that real change occurs given a lack of legislation with material consequences, and government commitment at all levels.

> “these are all nice words on paper but will there be real change – that is accountabilities and measures. How will this really be measured?”

> “….. even if you've got an advocate and there's smacking on the door, pounding on the doors and nothing opens, that's not, that's not a solution, …… I think they attributed in a federal budget last night think 1.2 million to the complaints line.”

> My son is 14 years old. He's had over 40 carers in his life. As I said, he requires substantial support. It is a very, very difficult job to support my son and as a result we have a big turnover of staff in his life which reduces the quality of his life and if we're going to improve access to quality, timely, neurodiversity, affirming and equitable supports for

> autistic people ……..including, in regional and remote areas, we need to be looking at programs, funding tax laws anyway possible to for a small business owner right through it to a large, not for profit.

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

- clear and measurable actions, targets, and milestones;
- an implementation plan with clearly defined responsibilities;
- ongoing monitoring and reporting requirements; and
- built in timelines for review and renewal of the strategy [29]

Recommendation 67:

Commitment 21 further captures the following for clarity and consistency:

d. underpinned by the Guiding Principle
e. 21a) is expanded to include "to measure and ensure that each of our commitments and actions are achieved'.
f. a suitable statement reflecting page 18 of the Draft National Autism Strategy. That is establishing a governance framework:
    v. that is representative of the diversity within the Autistic and autism community,
    vi. that adopts an inclusive process for consultations,
    vii. that designs actions with people with profound autism (aka requiring very substantial supports) and their families and carers and support networks to address the multiple and overlapping structural barriers they experience; and
    viii. provides ways for Autistic people and their families and carers and support networks to communicate with the Australian Government in a way that suits them.

Recommendation 68:

Commitment 21 captures a suitable statement reflecting pages 28-29 of the Draft Autism Strategy Plan including proposed timelines, three action plan periods and the length of the National Autism Strategy.

Recommendation 69:

Commitment 21 captures that the detailed strong accountability and governance structures outlined in each of the three Action Plans will include an evaluation of the existing accountability and governance structures supporting change where evidence

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[29] Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [xi]

supports that these have not been successful to date, and outcomes are poor. This includes reviewing contemporary policies so that legislation and policy are aligned and consistent Nationally.

Recommendation 70:

That the Strategy is viewed alongside any other policy initiatives (including NDIS review and Disability Royal Commission (DRC)) and supported by adequate, ongoing funding.

Recommendation 71:

Existing legislation and policies are reviewed to identify their effectiveness and where there are shortfalls address to support the rights of Autistic people.

Recommendation 72:

Appoint an oversight taskforce with paid governance roles that includes Autistic people including those with complex communication needs and families and carers of those Autistic people requiring very substantial support (aka profound autism).

Commitments –Research

Research

22. Explore how autism research can best be fostered and applied to policy and service delivery and underpinned by the Strategy's Guiding Principles.

National Autism Strategy | Help shape the change

Research Commitments Feedback

Feedback included the need to commit to developing a National Autism Research Framework to drive best practice research, address gaps in research, improve research coordination and collaboration, and promote ethical research as recommended in the Senate Select Committee on Autism (Recommendation 26).

It was also identified that it is acknowledged by researchers that profound autism (aka requiring very substantial supports) is dramatically underserved by research. It was highlighted that highly relevant and important research and recommendations presented by the Lancet Commission (2021) [30] seem to have been overlooked.

Furthermore, it was highlighted that current autism research in Australia is not adequately inclusive of Autistic persons requiring very substantial supports (aka profound autism), including those with complex communication needs, their families and carers and vulnerable cohorts (CALD and First Nations). This includes emphasising the importance of families and carers involvement, particularly for this important cohort.

For example, recent studies have found Autistic people have a reduction in life expectancy between 6.14 and 14.59 years less than the average population, for those with co-occurring intellectual disability[31].

There was concern that this cohort would be marginalised unless explicitly referenced. It was also recognised that this research typically costs more and takes longer so funding needs to be specifically identified for this cohort to ensure adequate attention is provided (Refer Appendix 1 Dr Matthew Siegel). A first step would be to fund for the identification of the size of the Australian autism population, development of a consensus definition to advance and improve the lives of people requiring very substantial supports (aka profound autism) needs and identify how to best research, measure and collect for this cohort.

It was also highlighted that too much of the research is focused on early childhood and heavily east coast focused.

> *"We need a real investment in research on improving health outcomes, economic participation, supporting non-speaking Autistics to have better outcomes, support options for regional and remote (real geographic isolation), and supported decision-making that works in meaningful ways for Autistic people (e.g., a lot of traditional supported decision-making strategies are heavily speech based)".*
>
> *"So how do you capture what is profound, severe and lifelong in a child so that these people aren't put on pathways that are problematic or their parents are treated as if this is a short-term problem that is your responsibility".*
>
> *To me, the outcomes framework should be measuring the targets within the strategy itself.*

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[30] The Lancet Commission on the future of care and clinical research in autism, 2021 Lancet Commission report

[31] O'Nions et al 2024 - https://www.thelancet.com/journals/lanepe/article/PIIS2666-7762(23)00195-3/fulltext)

Recommendation 73:

Commitment 22 is amended to capture the following:

c. As well as Develop, “Design and Implement” autism research that can best be fostered and applied to policy and service delivery; and
d. this research is linked to the National Autism Strategy Commitments, Evidence Framework and Evaluation and Reporting.

Recommendation 74:

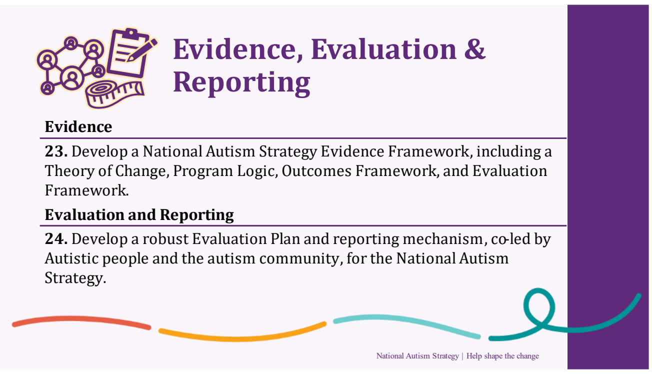
Commit to developing a National Autism Research Framework as recommended in the Senate Select Committee on Autism Recommendation 26. The Framework should:

c. commit to best practice approaches to ensure the involvement of the diversity of the Autistic and autism community, including often overlooked cohorts such as people requiring very substantial support (aka profound autism), complex communication needs, supported decision making, vulnerable cohorts including older Autistics, families/carers and Autistic researchers.
d. identify how to connect with and learn from research that's happening globally so that actions which underpin the strategy are evidence-led and aligned.

Recommendation 75:

Fund autism research to realise the National Autism Research Framework. Fund as a first project for the identification of the size of the Australian autism population, development of a consensus definition to advance and improve the lives of people requiring very substantial supports (aka profound autism) needs and identify how to best research, measure and collect for this cohort.

Commitments – Evidence, Evaluation and Reporting Framework



Evidence, Evaluation & Reporting

Evidence

23. Develop a National Autism Strategy Evidence Framework, including a Theory of Change, Program Logic, Outcomes Framework, and Evaluation Framework.

Evaluation and Reporting

24. Develop a robust Evaluation Plan and reporting mechanism, co-led by Autistic people and the autism community, for the National Autism Strategy.

National Autism Strategy | Help shape the change

Evidence Commitments Feedback

Feedback was provided as to how to provide clarity and consistency which has been incorporated in the recommendations below.

It was also highlighted that there is a need to prioritise data collection and ensure consistency of collection and ensure a focus on systems change and interdependence, beyond cause-and-effect logic.

Recommendation 76:

Commitment 23 is amended to capture the following:

3. “and underpinned by the Strategy’s Guiding Principles”;

4. the National Autism Strategy Framework developed with the National Autism Strategy Oversight Council will form the baseline for the development of the National Autism Strategy Evidence Framework;

Recommendation 77:

Commitment 21 captures accountability measures that will include:

f. **clear** and **measurable** outcomes, goals, actions, targets, milestones, and data requirements;

g. an **implementation plan** with clearly defined responsibilities;

h. **continuous monitoring, adjustment of actions as relevant** and **annual reporting requirements**;

i. **evaluation reports** through re-engagement with the **Autistic and autism community no less frequently than every 3 years**;

j. **built-in timelines** for **review** and **renewal** of the strategy (every 5 years) based on the aforementioned monitoring and re-engagement process. This should include a review of contemporary lessons learnt Internationally, Nationally and State/Territory Jurisdictions regarding relevant Strategy.

Recommendation 78:

Commit to undertake a review and incorporate as relevant the Senate Select Committee on Autism’s Recommendations regarding data collection, including for a National Autism Register.

Commitments – Evaluation and Reporting

Feedback was provided as to how to provide clarity and consistency which has been incorporated in the recommendations below.

It was also highlighted that there is a need for a robust evaluation plan and reporting mechanism, that includes Autistic people with profound autism (aka requiring very substantial support) and their families and carers.

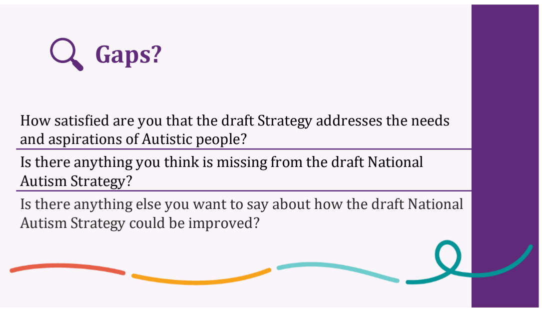
Recommendation 79:

Commitment 24 is amended to capture the following:
a. “and underpinned by the Strategy’s Guiding Principles”
b. inclusion of family and carers, Autistic community
c. that is representative of the diversity within the Autistic and autism community, including Autistic people with profound autism (aka requiring very substantial support).

Recommendation 80:

A definition of co-led is added to the Glossary and includes reference to representation for Autistic people with profound autism (aka requiring very substantial support).

Gaps



Gaps?

How satisfied are you that the draft Strategy addresses the needs and aspirations of Autistic people?

Is there anything you think is missing from the draft National Autism Strategy?

Is there anything else you want to say about how the draft National Autism Strategy could be improved?

There were a number of gaps identified in the draft Strategy.

Strategy Gaps – Housing

Due to factors such as low employment rates, high rates of poverty and limited support for independent living, many Autistic people experience high rates of housing insecurity, homelessness and reliance on their family and caregivers for permanent and or temporary accommodation.[32]

This is particularly true for people with profound autism (aka requiring very substantial support). When Autistic people requiring very substantial support (aka profound autism) are unable to stay with or rely on family for monetary support and accessible accommodation, it is common for them to be placed in institutional living environments in group homes, healthcare, and even aged care facilities. While it has been broadly recognised that people with disability have a right to right to choose where they live and whom they live with, a lack of accessible housing and support for independent living means that in reality, Autistic people with profound autism (aka requiring very substantial support) often have little choice but to remain in segregated living.

For First Nations Autistic people, Autistic women, the risk of housing insecurity is even more significant due to the high likelihood of experiencing domestic and family violence, family breakdown and caregiving responsibilities.

Hence it was identified that there was a need to commit to supporting Autistic people to live as independently as possible and improving equal access to, and choice and control over, safe and accessible housing options including for vulnerable intersectional cohorts.

It was also identified that there was a need to creating nationally consistent autism accessibility guideline for all housing types.

> *"We would like to see robust housing at affordable prices in the rental market across the community in society and not just isolated in remote areas with limited or no access to services. More of such houses are needed also in Public Housing to reduce the lengthy waiting list. Otherwise, this cohort of Autistic persons are marginalized, isolated, and put at great risk. They often find themselves homeless as landlords aren't prepared to rent to*

---

[32] Senate Select Committee on Autism (2022) 'Services, Support and Life Outcomes for Autistic Australians,' *Australian Government*, Canberra, pp. 32.

> *them. Families struggle to maintain and repair the homes at their own costs so as not to breach leases. All of this adds to the deterioration of the mental health of the person themselves, their families and carers. It perpetuates the revolving door of homelessness in an already overstretched and burdened public housing situation".*
>
> *"We would like to see incentives for the private rental market to build accessible and robust housing such as overseas".*

Recommendation 81:

Include a Commitment in the National Autism Strategy under the Social Inclusion Commitments to Develop and Implement a Strategy to support Autistic People to have choice and control of Affordable, Accessible and Safe Housing Options in populated areas as well as regional. This includes Supported Independent Living, Homelessness, Effective Emergency Accommodation and transitioning from service or institutional settings as a priority for Autistic people in alignment with any National Strategies.

This should include a specific commitment to:

e. supporting Autistic people to live as independently as possible, including people requiring very substantial support (aka profound autism) and vulnerable intersectional cohorts.
f. improving equal access to, and choice and control over, safe and accessible housing options including public housing, rental, owner occupied with the potential for incentives [33]for the private rental market.
g. creating nationally consistent autism accessibility guideline for all housing types, including "robust" housing.
h. integrate the need to accommodate supported independent living into the early stages of all urban planning & development. This should include a mandate that a age of diverse living options to be included in the planning like essential services - public transport hubs, retail areas, parks & open spaces.

Strategy Gaps – Justice and Child Protection

It was identified that there was a need to commit to co-designing a national strategy or framework to reduce the disproportionate numbers of Autistic people involved in the justice system and child protection, improve their experiences and outcomes, drive better communication and collaboration across sectors, and promote national consistency.

Due to social and economic disadvantage, combined with entrenched ableism, intersectional discrimination, and limited access to supports, Autistic people of all ages are overrepresented in the justice system and child protection in all Australian states

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[33] UK Autism Research Charity Autistica (https://www.autistica.org.uk)

and territories. Much of this relates to people with profound autism (aka requiring very substantial support) due to behaviours of concern, complex communication needs and guardianship arrangements. Often finding themselves being denied decision-making and representation in criminal proceedings through guardianship arrangements.

For Autistic women, the issues associated with reporting domestic and family violence are also exacerbated. When proceeding to family court for family violence or related issues, they experience high rates of discrimination and face heightened risk of losing custody battles over their children.

Recommendation 82:
Include a Commitment in the National Autism Strategy under the Social Inclusion Commitments to Develop and Implement a Strategy to Arrest the Overrepresentation of Autistic people dealing with the Justice System and Child Protection issues and Achieve Effective Informed Interactions. This includes:

a. Co-designed Autism training, including the diversity of autism, complex communication needs, positive behaviour responses, restrictive practices and supported decision making for the Justice System Workforce including first responders, correctional services, and Child Protection workforce including Family and Child Commission.
b. Diversion programs, including to therapeutic approaches and settings.
c. Prison-to-community transitions.
d. Improvement of Child Protection processes.
e. Medicare benefit scheme access remains active while incarcerated.
f. NDIS Plans reactivation before release from incarceration.
g. Incorporation of DRC Recommendations 8.4, 8.12, 8.14, 8.16, 8.21 and page 286 Collect and publish data relating to people found unfit to plead, or not guilty by reason of cognitive or mental health impairment, broken down by disability type, sex and First Nations Status.

Recommendation 83:
Provide support for the implementation of a Disability Rights Act (DRA), as per the recommendation in the Disability Royal Commission final report.

Strategy Gaps – Transportation and Accessible Supports

It was identified that transportation is a key enabler of economic and social inclusion. This includes all forms of transportation - road, rail and air and should extend to assistance animal accessibility on transportation. Important elements are accessibility, availability, and affordability.

Recommendation 84:
Include a Commitment in the National Autism Strategy to Develop and Implement a Strategy to Address Transport Accessibility, Availability, Safety and Affordability Challenges, in consultation with Autistic people, including people requiring very substantial support (aka profound autism) and their families and carers. Safety includes undoing seat belts in the back seat, behavioural challenges in the car and public transport.

Strategy Gaps – Carers

There is a need to build a sustainable care economy, including interaction with NDIS as this is an important element of a successful ecosystem. Modelling[34] suggests …

> that informal carers of people with intellectual disability and/or ASD in Australia had aggregated lost income of AU$310 million, lost taxation of AU$100 million and increased welfare payments of AU$204 million in 2015. These are projected to increase to AU$432 million, AU$129 million and AU$254 million for income, taxation, and welfare respectively by 2030.

It was highlighted that despite the important role of parents and carers there is very little supports.

It was also identified that there is very little legislation, policies or framework regarding succession care or capability and capacity of organisations to create and administer, particularly for Autistic people requiring very substantial support (aka profound autism).

> *“The legal aspects of care of autistics persons needing care to manage their lives beyond the lifetime of their family members/parents has always been of great concern”.*
>
> *“financial management and effective guardianship safeguarding an autistic person's financial and other safety is an area that needs special attention”*
>
> *“There is a need to find safer alternatives to being under guardianship trustee “*
>
> *“Lack of reference to guardianship and succession care are gaps in the strategy. This sits with the needs of people with 'profound' autism. Resourcing and enforcing supported decision making also need to be receive mention in the Strategy”.*
>
> *“I need some respite and supports to do simple things like cleaning”.*

Recommendation 85:

Include a Commitment in the National Autism Strategy to Develop and Implement a Strategy to Build a Sustainable Carer Economy including:

d. access to peer parent networks;
e. parenting support needs (well-being); and
f. respite which may include expanding this within existing systems such as Care2Serve and the NDIS

Recommendation 86:

Government endorsement and funding for the development of a framework for safeguarding and maintaining long-term care of Autistic children (legal and other formal arrangements) to ensure succession of care planning. This should include the development and implementation of succession of care disability standards and build capacity and capability to create and administer succession case plans. This also needs to make reference to a supported decision-making protocol.

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[34] Deborah Schofield, D., Zeppel M.J.B., et. al. (2019*) Intellectual disability and autism: socioeconomic impacts of informal caring, projected to 2030,* BJP 215, 654–660. doi: 10.1192/bjp.2019.204.

Refer to Recommendation 52 Economic Inclusion to address the economic disadvantage experienced by parents and carers.

Strategy Gaps – Workforce

Currently, disability needs an increased workforce but there has been a national shortage for a number of years. This is coupled with a high rate of burnout, due to the nature of disability involving complex human-to-human interactions, and lower productivity due to the nature of the work.

Recommendation 87:

Include a Commitment in the National Autism Strategy to Develop and Implement a Workforce and Innovation Strategy that results in a productive, skilled, resilient, value-based workforce and optimises the human capability of Autistic people with a particular recognition of the unique needs and challenges of people requiring very substantial support (aka profound autism).

Strategy Gaps – Autism Specific Independent Advocacy

Feedback captured during the group forums was that while independent advocacy is critical for to ensure that the best interests of and with the Autistic person and their families and carers with disability, without conflict of interest with Government, public and private service providers, the NDIA, or disability service providers are being upheld there is insufficient supports accessible often many with closed waitlists.

It was highlighted that adding to this was that there were only pockets of independent advocates who have a knowledge of autism and no advocacy organisations specific to complex communication needs (CCN).

> *“There is currently no advocacy organisation specific for CCN, this autistic subgroup has huge need for individual advocacy.”*
>
> *“Individuals who are severely impacted by autism need more targeted attention in order to ensure that the improvement in quality of life is achieved for them under the Strategy”*
>
> *“Strong advocacy networks with a special focus on the non-speaking and people having no families is currently an unmet need. The lack of citizen advocacy services and poor advocacy resources for autistic adults is concerning and needs to be addressed.”*
>
> *“Your feelings of helplessness and hopelessness at times that it almost consumes me, and I don't know what to do. You know, you go to advocate advocacy organizations, and they're all at capacity.”*

This often leaves families and carers needing to take on another role - advocacy and attempting to understand all their appropriate rights and navigate complex systems while time constrained as the primary carer.

Recommendation 88:

Include a Commitment in the National Autism Strategy to Develop a Model and Fund Independent Specialised Autism Advocacy delivered locally in the changing environment. This is to include specialised services to support complex communication needs (CCN).

Strategy Gaps – Early Investment (Intervention)

It was noted that the draft Strategy appeared to have sparse mention of early investment (intervention). Given the importance of early investment in services and supports in the context of Autism a specific commitment to early investment in services and supports should exist particularly in the context of the NDIS Review recommendations for Foundational Supports and the Federal commitment to Early Years.

> *"There is an absence of early intervention anywhere…….. appropriate, early intervention for autistic people."*
>
> *"profound, severe and lifelong is not being recognised and we're seeing just in the last month a lot of children with autism who have very low development scores and no language being told that it's not permanent, that it will go away and that you should have a bit of speech therapy and go to mainstream childcare rather than a proper earlier invention program".*

Recommendation 89:

A further commitment be added to Diagnosis, Services and Supports that captures the development of a strategy regarding Early Investment (Intervention) and how this will interface with the NDIS Review regarding foundational supports and the Federal Early Years strategy to ensure the needs of Autistic people and their families are met. This is to include ensuring an autism lens and co-design and implementation with the full diversity of Autistic people and parents and carers.

Other Comments

The group participants expressed concern and disappointment of their submissions appearing largely ignored in the reflection of the draft Strategy.

Recommendation 90:

Enable this draft report regarding Families and Carers of Autistic People to be a working paper with feedback to be incorporated up until 9th August 2024, where differences will be summarised by J Karavolos, NASOC member for the Oversight Council's consideration of the 14th August 2024.

Appendix 1 Consensus Definition

Recommendation 1 as a result of the consultations with families and carers of Autistic people is to Develop a consensus definition for profound autism (aka requiring very substantial support for the purpose of the National Autism strategy. Include this definition on the Glossary.

As outlined in the Section titled "Statement on Autism" a number of key elements were agreed for inclusion. A number of key elements were identified NOT to be included. These are as follows:

Critical Elements for a Consensus Definition

Some of the critical elements that were raised to support a consensus definition:

- adaptive functioning (as identified by Dr Matthew Siegel) "requiring 24-hour access to an adult who can care for them if concerns arise, being unable to be left completely alone in a residence, and not being able to take care of basic daily adaptive needs"

  or in the words of Judith Ursitti "Can I leave this person alone and go to my neighbours house and borrow a cup of sugar"

- significant person-to-person care and support with daily living skills and personal care;

- complex communication needs which include being nonverbal, minimally verbal or unreliable speakers with complex representations;

- constant or significant monitoring due to safety concerns such as self-injurious behaviours, pica, and absconding. This includes as adults.

- life-long/permanent

Some of the elements that were identified should NOT be considered as critical elements:

- IQ (decouple from autism);
- behavioural support needs/ behaviours of concern;
- complex;
- severe as severe has been more closely associated with IQ

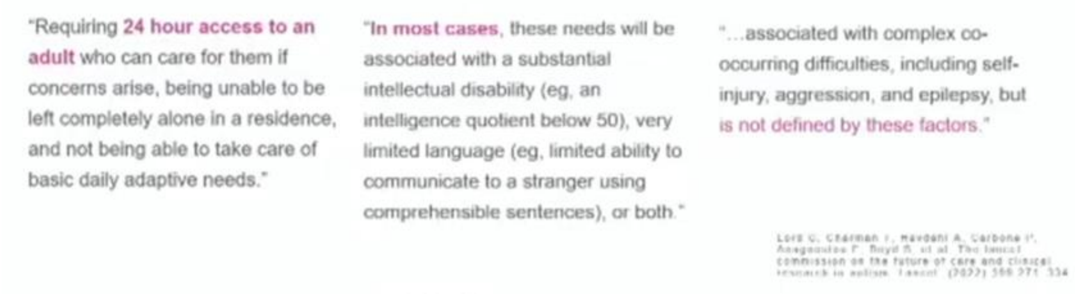
There were a number of references provided to support the discussions. These are provided below with some summary points.

1. Dr Matthew Siegel –2024 International Society for Autism Research Annual Meeting.

In summary, it is emphasised that people with profound autism consistently experience unique, devastating, and often unseen challenges that require solutions, not only for them but for their caregivers. Research indicates that the proportion of studies that included those with profound autism has decreased significantly over time. The continuing recognition of profound autism will open the doors to more inclusive research. Only then can targeted advocacy increase access to critically needed supports and services for this marginalized population.

Key notes:

- Intellectual Disability (ID) was redefined, and a major shift was made from IQ based to being IQ PLUS Adaptive Behaviour. The diagnosis can't be made without adaptive behaviour measure. Adaptive behaviour looked at three areas:
    - Conceptual skills
    - Social Skills
    - Practical Skills
- Lancet Commission on the Future of Care and Clinical Research in Autism brought together stakeholders from six continents and a range of perspectives, including clinicians and other health-care providers, researchers, advocates, self-advocates and parents.
- The A priority definition or criteria about profound autism was about adaptive functioning – the key criteria "only required piece" that was necessary is **"requiring 24 hours access to an adult"** (refer first block on left). The middle box fills out the picture in most cases and right-hand box can be associated but definitive.



"Requiring **24 hour access to an adult** who can care for them if concerns arise, being unable to be left completely alone in a residence, and not being able to take care of basic daily adaptive needs."

"**In most cases**, these needs will be associated with a substantial intellectual disability (eg, an intelligence quotient below 50), very limited language (eg, limited ability to communicate to a stranger using comprehensible sentences), or both."

"…associated with complex co-occurring difficulties, including self-injury, aggression, and epilepsy, but **is not defined by these factors**."

- Most if not all studies have focused on this and language.
- What captured it well was Judith Ursitti's definition, mother of a young adult "Can I leave this person alone and go to my neighbour's house and borrow a cup of sugar and meaning they will be safe and can take care of themselves and if the answer is not then that is definition of profound autism for the person to have their needs met.
- The question was asked "why does this group need attention? Some of the key points were the families themselves can have greater social isolation and

experiences of stigma. Another reason to focus on this group is that the outcomes for this group can be dramatically different from other people who are on the autism spectrum – in employment, in friendship, in living outside of the family home etc.…**so this suggests if the outcomes are very different that probably is because the supports needed are differently.**

- An example was given how behavioural challenges bend the development trajectory. The real problem is that wherever this child ends up is different to what their potential was and this matters.
- There is also a big disparity in global research. In research now there is very little study in people with autism and ID.
- A research study was done - what was the inclusion in treatment literature in “severe autism which might now be called “profound” and how is this concept “severe/ profound even defined?
- The variability of measures was very concerning. This created a disparity in who participates in research and how individuals, family and society can benefit from that research.
- The conclusion was:
  - that this group has great need but receives markedly little research attention
  - Adaptive function captures a critical feature of this group.
  - a consensus definition of complex presentations/ profound autism does not exists which really impedes progress as speaking about different this - need to come together more on a consensus as this will advance/ improve their needs.

2. **‘**Luke Beardon[35] argues that ‘autism plus environment equals outcomes. That outcome might be positive or negative, but the person who is autistic remains the same; it is the environment that leads to the outcome. So, if you want a successful outcome, and you recognise that an autistic person cannot change their brain, then the only thing you can change is the environment. And that often, but not always, means the people within that environment.’

   https://www.researchgate.net/profile/Luke-Beardon-2

3. From deficits to a spectrum, thinking around autism has changed. Now there are calls for a ‘profound autism’ diagnosis [36]

   https://theconversation.com/from-deficits-to-a-spectrum-thinking-around-autism-has-changed-now-there-are-calls-for-a-profound-autism-diagnosis-194049.

   A key source of debate has been whether broadening the diagnosis of autism has made the diagnostic label no longer entirely fit-for-purpose.

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[35] https://www.researchgate.net/profile/Luke-Beardon-2, Sheffield Hallam University | SHU · The Autism Centre

[36] https://theconversation.com/from-deficits-to-a-spectrum-thinking-around-autism-has-changed-now-there-are-calls-for-a-profound-autism-diagnosis-194049, November 9, 2022

A key criticism is that, after the significant gains of the past few decades in recognising the broad spectrum of autistic people, dividing autistic people into two groups using relatively arbitrary criteria would represent a retrograde step.

It is clear there is a large group of people who do not feel well served by the broad nature of the current autism diagnosis. There is a clinical and moral responsibility to acknowledge and value this perspective and explore it further. To do so would be entirely consistent with the history of our changing understanding of autism over time.

Whether or not “profound autism” is eventually seen as an appropriate diagnostic term, it is important to acknowledge that this debate touches on deeply personal issues of identity and understanding.

The voice of autistic people must be central in this discussion. The voices of families who care for autistic people must also be valued.

4.Key points from a number of sources indicate that the term "profound autism" may lead to the following:

a. **Diagnostic overshadowing**: This occurs when one experience (such as challenging behaviour) is attributed solely to an existing diagnosis (e.g., autism), ignoring other co-occurring conditions. For instance, an autistic person's gastrointestinal distress might be dismissed as merely part of their autism, rather than investigating other potential conditions like Ehlers-Danlos Syndrome.
b. **Lack of Biomarker Evidence**: The socially constructed categories provided by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) lack biomarker evidence. These categories should be considered "transiently useful fictions" rather than rigid descriptors. Using terms like "profound" or "severe" perpetuates this flawed framework and hinders accurate research.
c. **Oversimplification**: Labelling autism as "profound" or "severe" oversimplifies its multifaceted nature. Autistic individuals have unique strengths and challenges, and such labels fail to capture this complexity.
d. **Overlooking Individualised Support**: Autistic individuals have diverse support needs. By using broad labels, we risk overlooking specific requirements. For example, an individual that was inaccurately labelled with "severe" autism may excel in certain areas while struggling in others. Focusing on individualised support is crucial for enhancing quality of life.
e. **Diagnostic Tunnel Vision:** When clinicians attribute all difficulties to autism, they may miss co-occurring conditions. This leads to inadequate support. Instead of assuming that every challenge is due to autism severity, we should explore other possibilities.
f. **Inadequate Services**: Relying on severity labels can lead to cookie-cutter interventions. Autistic individuals deserve tailored services that address their unique needs. A one-size-fits-all approach fails to provide meaningful support.
g. **Stigma and Low Expectations**: Describing autism as "profound" or "severe" perpetuates negative stereotypes. It fosters low expectations and undermines efforts to empower autistic individuals. Quality service provision requires recognising their potential and strengths.

h. **Psychological Impact**: Being labelled as "profoundly autistic" can affect an individual's self-esteem and mental health. It reinforces a deficit-based view, hindering their sense of agency and well-being.
i. **Social Isolation**: When society views autism through a lens of severity, it isolates autistic individuals. They face barriers to inclusion, education, and employment. A more nuanced understanding would promote acceptance and social integration.

Shannon Des Roches Rosa, *Grave Concerns About Profound Autism and Diagnostic Overshadowing by from Thinking Person's Guide to Autism*

https://thinkingautismguide.com/2023/09/grave-concerns-about-profound-autism-and-diagnostic-overshadowing.html

Steven K. Kapp *Profound Concerns about "Profound Autism": Dangers of Severity Scales and Functioning Labels for Support Needs*
Department of Psychology, University of Portsmouth, King Henry Building, King Henry I Street, Portsmouth PO1 2DY, UK, Published: 19 January 2023

https://www.mdpi.com/2227-7102/13/2/106

5. WHY THE TERM PROFOUND AUTISM IS NEEDED

HTTPS://WWW.PROFOUNDAUTISM.ORG/RESEARCH/PROFOUND-AUTISM-FACTS/

AUTISTIC PEOPLE WHO REQUIRE 24/7 CARE THROUGHOUT THEIR LIVES HAVE PROFOUND AUTISM

The use of the term profound autism is about clarity, not competition.

People with profound autism consistently experience unique, devastating, and often unseen challenges that require solutions, not only for them but for their caregivers.

WHAT IS PROFOUND AUTISM?

Simply stated, people with profound autism require lifetime, 24/7 care.

The definition of autism has evolved over the years, creating an increasingly heterogeneous spectrum. While the entire spectrum deserves recognition and support, profound autism is a term intended to provide clarification about autistic people who:

- Require 24/7 care from an adult caregiver throughout their lives;

And also:

- Present with an IQ below 50;
- or have minimal or no language.

Based on previous work by the Lancet Commission[1] published in 2021, the Centers for Disease Control released their first prevalence study[2] on profound autism in April 2023.

The research concluded that:

- The percentage of 8-year-old children with profound autism among those with autism was 26.7%. This means that 1 in 4 children with autism have profound autism.
- Compared with children with non–profound autism, children with profound autism were more likely to be:
  - female;
  - from racial and ethnic minority groups;
  - of low socioeconomic status;
  - born preterm or with low birth weight;
  - have self-injurious behaviours;
  - have seizure disorders;
  - and have lower adaptive scores.

WHY THE NEED FOR THE TERM PROFOUND AUTISM?

- People with profound autism consistently experience unique, devastating, and often unseen challenges that require solutions, not only for them but for their caregivers.
- Research indicates that the proportion of studies that included those with profound autism has decreased significantly over time.[3] The continuing recognition of profound autism will open the doors to more inclusive research. Only then can targeted advocacy increase access to critically needed supports and services for this marginalized population.

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[1] *Lord C, Charman T, Havdahl A, Carbone P, Anagnostou E, Boyd B, Carr T, de Vries PJ, Dissanayake C, Divan G, Freitag CM, Gotelli MM, Kasari C, Knapp M, Mundy P, Plank A, Scahill L, Servili C, Shattuck P, Simonoff E, Singer AT, Slonims V, Wang PP, Ysrraelit MC, Jellett R, Pickles A, Cusack J, Howlin P, Szatmari P, Holbrook A, Toolan C, McCauley JB. The Lancet Commission on the future of care and clinical research in autism. Lancet. 2022 Jan 15;399(10321):271-334. doi: 10.1016/S0140-6736(21)01541-5. Epub 2021 Dec 6. Erratum in: Lancet. 2022 Dec 3;400(10367):1926. PMID: 34883054.*

[2] *Hughes MM, Shaw KA, DiRienzo M, et al. The Prevalence and Characteristics of Children With Profound Autism, 15 Sites, United States, 2000-2016. Public Health Reports. 2023;0(0). doi:10.1177/00333549231163551*

[3] *Stedman, Amy & Taylor, Briana & Erard, Michael & Peura, Christine & Siegel, Matthew. (2019). Are Children Severely Affected by Autism Spectrum Disorder Underrepresented in Treatment Studies? An Analysis of the Literature. Journal of Autism and Developmental Disorders. 49. 10.1007/s10803-018-3844-y.*

6. James Morton – email dated 24th July 2024

The group struggled with definition of P/S and whilst there is no perfect definition we feel this can be done 3 ways:

1. The old DSM IV criteria for autistic disorder.
2. DSM level 3 (however this is very descriptive and subjective).
3. Objectively assessable which would be of value in providing guidelines for future research
   a. Adults: IQ < 70 severe, IQ < 50 profound
   b. Children:

	Profound	Severe	Moderate
VABS	<50	50-<70	70-<85
PLS SS	<50	50-<70	70-<85
MSEL SS	<20	20-<30	30-<40
ADOS SS	>10	10->6	6->3

Defined by most severe score on any one of the scores
VABS: Vinelands Adaptive Behaviour Score, PLS Preschool Language Scale, MSEL Mullens Scales of Early Learning, ADOS Calibrated Severity Score

7. Media Misstep: Non-Profound Autism Definitely Does Not Mean Mild

https://www.ncsautism.org/blog//the-problem-with-profound-autism, April 24, 2023

While we embrace the progress of the profound autism label, we must be vigilant to ensure the term does not obscure the broader population clearly and often severely disabled by autism but who do not meet criteria for "profound" — or be used to trivialize the skyrocketing rates of autism.

While the field works to improve autism categorization, let's be sure the vast middle of autism does not get passed over as "mild" as we increase our overdue efforts to bring a higher resolution to the autism discourse.

8. John Elder Robison, Reflections on "Profound Autism"

https://www.psychologytoday.com/au/blog/my-life-aspergers/202112/reflections-profound-autism, December 8, 2021

Whether you agree with this or not, I hope you will agree there is a subset of the population with significant support needs due to their level of disability, and that they are currently underserved. If you don’t like the idea of this term, what would you do to start us on a path toward better outcomes for that group?

Appendix 2 Statement on Autism

Recommendation 3 is to Create a “Statement on Autism” in the draft Strategy before the Statement on Language to capture what autism means and reflect the full diversity of Autistic people.

Some of the themes identified during the focus groups to be addressed include:

a. Autism is a distinct disability and not based on intersectional aspects.
b. autism as a spectrum that needs to be individualised, multiple perspectives (with no one dominant view) and multiple solutions;
c. Ensure this includes a clear statement of the meaning of autism and that it is decoupled from “co-occurring conditions”.
d. Co-occurring conditions are to be referenced in a clear statement about the complexities, challenges and barriers that Autistic people face as well as acknowledgement of the strengths of Autistic people.
e. Add a statement recognising that Autism is a disability.
f. There is specific reference to Autistic people requiring very substantial support (aka profound autism) and complex communication needs.

The below includes an extract of the Autistic Society UK version as an example.

The National Autistic Society recognises the varying needs of autism.

Varying Needs of Autism

Autism is a spectrum disorder which means Autistic people can have varying support needs. One third of autistic people also have a learning disability. The autism spectrum isn't linear, and many people talk about the 'spiky profile.' This means an autistic person could be a leading expert on nuclear physics but unable to remember to brush their teeth or clean their clothes.

Some Autistic people will require very substantial support (aka profound needs), which may mean that they require full time care and support. Some people may need a bit of support with day-to-day activities, while others live fully independent lives.

With the right support in place, all Autistic people should be able to live the life they choose.

Learning disabilities

Autistic people can have different 'degrees' of learning disability, which can affect all aspects of their life, from studying in school to learning how to wash themselves or make a meal. Some people will be able to live fairly independently - although they may need a degree of support to achieve this - while others may require lifelong, specialist support. Some autistic people do not have accompanying learning disabilities, but may still have specific learning difficulties, such as dyslexia.

Non-verbal communication

Some Autistic people are non-verbal, or selectively mute, meaning that they do not speak. Although a person may not use spoken word, there are plenty of other ways to communicate.

Appendix 3 Detailed recommendations regarding Complex Communication Needs (CCN)

Recommendation 12 is for a section regarding communications to be captured in the National Autism Strategy similar to the Statement on Language. This is to outline reference to a sub-strategy capturing a co-design protocol, and communication framework that support the diversity, rights, and autonomy of Autistic people who have complex communication needs (CCN). Items identified are:

a. identification of CCN subgroups;
b. the range of communication devices and methods that Autistic people use
c. supported decision making.

The below strategies provided are to be considered for inclusion in the Strategy or Action Plans or as part of the resulting Co-design protocol and Communication Framework.

1. Provide access to AAC for people with CCN, including in mainstream, and community environments.
2. Provide input of professional expertise and skills in teaching AAC to the CCN community.
3. Provide training of professionals in education, allied health, legal domains, and other fields, as well as service providers to utilise AAC with their clients with CCN.
4. Provide systemic guidelines in the use of AAC across all institutions that service Autistic people.
5. Provide individual advocacy for people with CCN, their parents/carers and support network for inclusion.
6. Research to develop AAA devices that meet the needs of Autistic people and understand various aspects of AAC such as motor related barriers, needs for assistance in using AAC devices.
7. People to learn supported decision and effective ways to assist Autistic people to understand the question and respond.
8. The ability of services to help autistics to use their strengths to develop skills better to get independent which is the primary goal of intervention has to be improved. Services such as assessment, school and therapy services need to be updated.
9. Research to understand various aspects of AAC such as motor related barriers, needs for assistance in using AAC devices.

Appendix 4 Vision and Goal

Our Vision and Goal

The National Autism Strategy’s **vision** is for a **safe** and **inclusive society**, where all Autistic people can fully participate in all aspects of life, in line with international human rights.

The **goal** of the National Autism Strategy’s is to **improve life outcomes** for all Autistic people.

National Autism Strategy | Help shape the change

Feedback on the Vision

The majority of the group thought it was good that the Vision remained broad. Suggestions for improvement included:

e. encapsulating words such as “thrive” and/or “live their best lives”.
f. recognition of an accessible society
g. the need for the right individualised supports to enable Autistic people to live their best lives.
h. the terminology needs to recognise and respect the diversity of Autistic people, including those who have different goals. There are concerns in particular that “fully participate in all aspects of life” is not achievable for some and also not desirable.

The Recommendation is for the Vision be reviewed to be more ambitious, recognise the need for an accessible society and the need for the right individualised supports. There may also be value in defining “safe” if the word remains in the Vision.

Options identified incorporating feedback and suggestions are:

1. *“The National Autism Strategy’s vision is for a safe, **accessible and** inclusive society where all Autistic people are empowered **with the right individual supports** to ~~fully participate~~ **thrive** in all aspects of life, in line with international human rights.”*

OR

2. *“ The National Autism Strategy’s vision is for a safe, **accessible and** inclusive society where all Autistic people are empowered **with the right individual supports** to ~~fully participate~~ **live their best lives**. line with international human rights.”*

The feedback received was:

1. the options proposed were much better (note this will be put as a survey to the group for final feedback in this paper)

2. “live their best lives” was more reflective and better than “thrive”
3. the word safe was liked but had different connotations for different people – safe as in free from abuse, exploitation, vilification versus safe as in banning all vehicles.

> *“I think safe life is OK, but just 'safe' cannot be achieved”.*
>
> *“Our son has been excluded from so many things based on safety grounds - it needs to be more holistic - e.g., fulfilling”.*

4. that ”equity” was not realistic.

5. a whole different version proposed by a participant in the forum considering the feedback:

Option 3. “The National Autism Strategy envisions a safe, inclusive society where all Autistic people have the opportunity to live their best lives, recognising their diverse needs and abilities, and participating meaningfully in various aspects of life with the necessary supports and accessibility”.

Feedback on the Goal

Suggestions for improvement included:

a. it was not ambitious enough, particularly “improve” as this does not mean on par with other people in society.
b. reference to just “improving life outcomes” did not speak to people. There needed to be reference to more such as agency, autonomy, self-determination or a definition of “improving life outcomes”.
c. it reads like something you would find on a provider’s website.
d. it was unclear how this would be measured to recognise if it’s been realised. Suggestions made were for the following words to be used:
   i. “social equity” to achieve human rights
   ii. “thrive” to replace “improve”
   iii. reference to “experiences” as well as “outcomes” as it’s the day to day lives of Autistic people that need to be improved as well.
e. several people commented on having one goal was not sufficient and that it was vague. It was suggested that rather than a single goal that there be a list of more specific goals that captured concrete concepts that are meaningful, measurable and achievable. The concern was also that the goal was open ended and could be interpreted according to the narrative at the time. It was also suggested and

endorsed that a more concrete and measurable goal is to “close the gap” with other Australians.

Overall, the sentiment was to have more clear achievable goals that are measurable that works toward either an aspirational goal or aspirational vision.

The resulting Recommendation x is:

The Goal be reviewed to be:

a. more accountable by being more measurable, with the possibility of more than one goal leading to one aspirational goal or vision,

b. more ambitious - replace word ‘improve’ in the Goal with something more ambitious like thrive; and

c. captures the sentiment for Autistic people to have the rights, choices, and experiences in life that every other Australian enjoys to close the gap.

OPTIONS

Options that were preliminary tested with the Family and Carer forum participants based on their feedback is as follows:

1. “The goal of the Strategy is for all Autistic people to thrive”.

OR

2.“The goal of the Strategy is to improve life experiences and outcomes for all Autistic people to thrive”.

OR

3.“The goal of the Strategy is to improve life experiences and outcomes for all Autistic people to thrive and achieve social equity.

OR

4. *“The goal of the Strategy is to improve life experiences and outcomes for EACH Autistic person to thrive and achieve social equity.* (the word “each” recognising each person is different)

OR

5. *“ The goal of the Strategy is to improve life experiences and outcomes for all Autistic people to thrive across the life span, and achieve social equity, choice and there are no gaps with other Australians."*

OR

6. *“ The goal of the Strategy is to improve life experiences and outcomes for all Autistic people to thrive across the life span, where social justice, equality and choice exist and there are no gaps with other Australians."*

The feedback received was:

a. the options proposed were much better (note this will be put as a survey to the group for final feedback in this paper). Specific feedback was:
    - *like No1 as it simple*
    - *No 5 is unrealistic*
    - *No 6 is the most ambitious and should be aiming high*
    - *“No gaps” is a pipe dream but apart from that No 6 is good**
    - *If ”No gaps” is unrealistic this takes the discussion back to equity to achieve equal opportunity and/or “levelling the playing field”

b. it was imperative that whatever the goal or goals are that they are translated from words on a page to measurable actions.

c. whatever the end goal was it needed to be relatable from each Autistic person’s lens as if each individual had defined it as not all Autistic people have the same goals and their own preferences need to be recognised and respected.