

31 May 2024

Autism Policy Team

Department of Social Services.

By email: AutismPolicy@dss.gov.au

Dear Autism Policy Team,

Amaze submission to Draft National Autism Strategy.

Amaze works to build acceptance and understanding of autism in communities, educational settings, organisations and businesses, and wider society. Informed by evidence, experts and lived experience, we influence policy change for Autistic people and provide independent, credible information and resources to individuals, families, professionals, government, and the wider community. We are closely connected with the community through our national Autism Connect helpline, peer support networks and capacity building initiatives.

We are pleased to provide the attached submission to your Draft National Autism Strategy consultation.

Please contact me by email at <u>jim.mullan@amaze.org.au</u> or by phone on <u>03 9657 1600</u> if we can assist by providing further information or answering any questions you may have.

Yours sincerely,

Jim Mullan

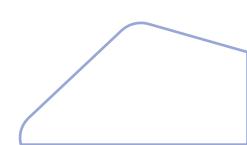
Chief Executive Officer

A National Autism Strategy to improve the experiences and outcomes of <u>all</u> Autistic people and close the gaps between Autistic and non-Autistic Australians.

Amaze submission to Draft National Autism Strategy.

31 May 2024.





Executive Summary

We congratulate the Australian Government on its commitment to developing a National Autism Strategy (Strategy) and acknowledge the work that has been undertaken to date by the Department of Social Services, Oversight Council and Working Groups, in co-design and consultation with the Autistic and broader Australian community.

The Strategy provides an exciting and long overdue opportunity to address the whole of life needs of all Autistic people and improve their life outcomes. It also provides an opportunity to reduce the ongoing gaps between Autistic and non-Autistic Australians. We welcome the release of the draft Strategy as a further opportunity for our community to engage with the Strategy's development and ensure their diverse voices and perspectives are heard.

In principle we support the draft Strategy's vison, goals and commitments to strengthen social and economic inclusion, and improve access to quality service provision and assessment and diagnosis. However, we are concerned that the Strategy lacks specificity, timeframes and the accountability measures that will be needed to evaluate its success and inform future learnings. We are also concerned that the commitments in the draft Strategy contain some significant gaps (including in relation to people with complex and high support needs and their parents and carers, vulnerable intersectional cohorts and across housing, justice, the NDIS, education, employment, and research) and that it may not have been adequately informed by a diversity of lived experience, particularly from vulnerable Autistic cohorts.

We therefore recommend that the final Strategy:

- 1. Include a comprehensive and accountable goal: to improve the daily experiences and life outcomes of all Autistic people and close the gaps between Autistic and non-Autistic Australians.
- 2. Provide specific and measurable actions, targets and timeframes, with a robust Outcomes Framework.
- 3. Address gaps in the draft Strategy, including by committing to targeted actions for people with complex and high support needs and their parents and carers, and vulnerable intersectional cohorts.
- 4. Be informed by Ensure a diversity of Autistic voices and perspectives, and those of parents and carers, are informing the Strategy's development.

We also ask that you advocate for the Strategy to become a whole of governments initiative (as per the Australian Disability Strategy) to drive national consistency and collaboration, as well as State and Territory autism commitments and the development of State and Territory autism plans.





Summary of Recommendations

- 1. Create a comprehensive and accountable whole of Strategy goal.
 - Amend the Strategy's Goal to state: The goal of the Strategy is to improve the daily experiences and life outcomes of all Autistic people and close the gaps between Autistic and non-Autistic Australians.
- 2. Provide specific and measurable actions, targets and timeframes, with a robust Outcomes Framework.
 - Include specific targets and milestones across each of the Strategy's outcome areas.
 - Review the Strategy's Commitments and consider how they may be strengthened to ensure greater accountability and transparency, with accompanying timeframes.
 - Include timeframes for developing each aspect of the Evidence Framework and Evaluation Plan.
 - Prioritise data collection and the early co-design of a robust and detailed Outcomes Framework.
 - Build into the Strategy, timeframes for reviewing and renewing the strategy.
- 3. Address gaps in the draft Strategy, including by committing to targeted actions for people with complex and high support needs and their parents and carers, and vulnerable intersectional cohorts.
 - (a) People with complex and high support needs and vulnerable intersectional cohorts.
 - Create specific commitments and commit to identifying targeted actions for Autistic people with complex and high support needs and their parents and carers, and vulnerable intersectional cohorts.
 - In the Guiding Principles, recognise that Autistic people with complex and high support needs face unique and daily risks of harm, disadvantage, isolation and poor life outcomes.
 - In the Guiding Principles, 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.
 - Define 'complex and high support needs' in the Strategy's glossary.

(b) Housing

- Commit to:
 - > supporting Autistic people to live as independently as possible.
 - improving equal access to, and choice and control over, safe and accessible housing options.
 - > creating nationally consistent autism accessibility guideline for all housing types.

(c) Justice

 Commit to co-designing a national strategy or framework to reduce the disproportionate numbers of Autistic people involved in the justice system, improve their experiences and outcomes, drive better communication and collaboration across sectors, and promote national consistency.

(d) Employment and economic inclusion.

- Commit to:
 - > co-designing a National Autism Employment Framework.
 - > understanding and meeting the employment support needs of people with complex and high support needs, and vulnerable intersectional cohorts.

- meeting the immediate and long-term support needs of Autistic people who are unable to work.
- meeting the support needs of parents and carers who are unable to work.

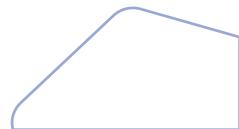
(e) Research

 Commit to developing a National Autism Research Framework to drive best practice research, address gaps in research (particularly for vulnerable cohorts), improve research coordination and collaboration, and promote neuro-affirming and ethical research.

(f) Other gaps

- Commit to:
 - ensuring consideration of the diverse needs of Autistic people in future sector wide reforms, including NDIS review and Disability Royal Commission (DRC) related reforms.
 - measuring the effectiveness of disability sector wide reforms, legislation, standards and strategies for Autistic people (such as the *Disability Discrimination Act* 1992 and *Disability* Standards for Education).
 - > increasing student access to Autistic led peer support and mentoring, including across all Australian schools.
 - increasing services and supports at key transition points in the school years, and upon leaving school to access employment or further learning.
 - establishing National user-led, autism specific advocacy services (individual and systemic), to operate in parallel with generalist disability advocacy services.
 - increasing access to 'one stop shops' for quality, holistic and timely autism assessment and diagnosis.
 - providing post diagnosis supports and resources to assist Autistic people, and their families/ carers, to connect to therapies, peers and community.
 - > tailoring best practice resources for autism assessment and diagnosis to the needs of vulnerable intersectional cohorts.
 - improving the wellbeing and social and economic inclusion of parents and carers. and meeting the unique support needs of Autistic parents.
- 4. Ensure a diversity of Autistic voices and perspectives, and those of parents and carers, are informing the Strategy's development.
 - Increase the diversity of Autistic voices and perspectives, and those of their parents and carers, informing the Strategy's development (including a diverse representation of Autistic people with varying lived experiences, support needs, co-occurring conditions and cultural backgrounds).
 - Attach a transparent and accessible co-design framework to the Strategy.
 - Commit to driving co-designed research into best practice approaches for reaching the most at-risk and hard to reach Autistic cohorts, including making participation accessible.
- 5. Advocate for a whole of governments commitment to the National Autism Strategy, including to drive state and territory commitments and autism plans.





Introduction

We thank the Australian Government for its ongoing commitment to a National Autism Strategy that can address the needs of all Autistic people and improve their life outcomes. The draft Strategy recognises that actions and supports to improve the lives of all people with disability have not always met the needs of Autistic people, and that a targeted, autism specific approach is required. The Strategy also recognises autism as a form of neurodivergence, however it is important to emphasise that this Strategy is about autism and does not purport to address the needs of all neurodivergent people. Given that the needs of different neurodivergent cohorts can differ significantly, it is important that their unique and specific needs are addressed in co-design and collaboration with these cohorts.

The draft Strategy provides a solid foundation for a framework capable of improving the lives of Autistic Australians and their parents and carers, as well as reducing social inequalities. Our submission provides recommendations to strengthen the Strategy's transparency and accountability and increase its capacity to address the diverse needs of all Autistic Australians, including those with complex and high support needs. We also recommend the creation of a transparent Co-design Framework (to be attached to the final Strategy) to ensure the Strategy's ongoing development, implementation and evaluation is informed by a diverse representation of Autistic people with varying lived experiences, support needs, co-occurring conditions and cultural backgrounds.

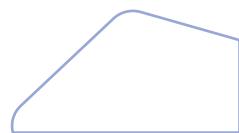
1. Create a comprehensive and accountable whole of Strategy goal.

In principle we support the draft Strategy's Vision Statement and Goal, to improve life outcomes for all Autistic people. However, we recommend broadening the goal to be clear that the Strategy is also aimed at improving the day-to-day experiences and wellbeing of Autistic people and achieving the social and economic outcome of closing the gaps between Autistic and non-Autistic Australians.

As recognised in the Strategy and by the Senate Select Committee on Autism, Autistic people continue to experience discrimination, bullying, a lack of inclusion and inclusive spaces, and some of the worst disparities in life outcomes compared to other people with disability and people without disability. For example, 32% of Autistic students do not make it past Year 10 (compared to 35% of all people with disability and 15% of people without a disability). The unemployment rate of Autistic people is 34% which is three times the rate of people with disability generally, and almost eight times the rate of people without disability. The Senate Select Committee also highlighted that while parent and carer wellbeing is critical to the experiences and outcomes of Autistic people, support for parents and carers is grossly inadequate.

A key goal of the Strategy should be to address these poor experiences, discrepancies and inequities with accountability measures built into the Strategy to assess its success against these indicators (i.e. in reducing the unemployment rate for Autistic people, increasing the number of Autistic students making it past Year 10).





Amend the Strategy's Goal to state: The goal of the Strategy is to improve the daily experiences and life outcomes of all Autistic people and close the gaps between Autistic and non-Autistic Australians.

2. Provide specific and measurable actions, targets and timeframes, with a robust Outcomes Framework.

The draft Strategy provides welcome commitments to enhance social and economic inclusion and improve service provision and access to timely and quality autism assessment and diagnosis. However, these commitments lack timeframes, many are very general and high level in nature, and their achievement will be difficult to measure. While we understand specific and measurable actions to fulfil these commitments are to be provided via detailed action plans and a Governance Framework (and that an Evidence Framework and Evaluation Framework and Evaluation Plan will be developed to help measure success and inform change), more specific, time-bound and accountable measures are required in the Strategy itself.

Where these measures are to be provided in supporting documents, these must be created as early as possible and released for consultation to ensure the Strategy's targets, specific actions and accountability measures are transparent and informed by our community.

A robust Outcomes Framework will be essential to identify progressive indicators and measures to assess the Strategy's progress and impact. Supported by the Victorian Government, Amaze is currently developing a best practice Outcomes Framework to measure and report upon outcomes from the refreshed Victorian Autism Plan. We strongly encourage the Australian government and Oversight Council to take learnings from the Victorian Government's Victorian Autism Plan (2019), and the work that is now being undertaken to ensure transparency, learnings and the measurement of success going forward. We would be very pleased to share our Autism Connect data and in house expertise from our Evidence and Impact team to help develop an Outcomes Framework for the NAS.

Early attention must also be given to the **data** that will be required to enable monitoring and measurement, including baseline data, and ensuring that all relevant data across sectors is capable of measuring autism specific outcomes. We strongly encourage you to review the Senate Select Committee on Autism's recommendations 27 and 28 regarding data collection, including to consider a National Autism Register and ensure the needs of Autistic people are adequately represented in national disability data.

Finally, the draft Strategy does not specify timeframes for conducting a co-designed review and renewal of the Strategy. These timeframes must be built into the Strategy, as per the recommendations of the Senate Select Committee on Autism (see pg. 67 of Final Report), to ensure that it remains current, is suited to the local context and changes occurring across the disability ecosystem, and that it is strengthened by ongoing learnings.





- Review the Strategy's Commitments and consider how they may be strengthened to ensure greater accountability and transparency, with accompanying timeframes.
- Include specific targets and milestones across each of the Strategy's outcome areas.
- Include timeframes for developing each aspect of the Evidence Framework.
- Prioritise data collection and the early co-design of a robust and detailed Outcomes Framework.
- Build into the Strategy, timeframes for reviewing and renewing the strategy.
- Address gaps in the draft Strategy, including by committing to targeted actions for people
 with complex and high support needs and their parents and carers, and vulnerable
 intersectional cohorts.
 - (a) People with complex and high support needs and vulnerable intersectional cohorts.

The Strategy highlights **intersectionality**, the multiple and overlapping forms of disadvantage and discrimination experienced by Autistic people from vulnerable intersectional cohorts, and their poorer life outcomes. It also recognises a **lack of research and evidence** relating to the life experiences, needs and views of many of these intersectional groups, and the impact this has on policies and support services meeting their needs.

However, we are concerned that the draft Strategy includes **no commitments to create targeted actions for many of these cohorts**. For example, there are no specific commitments or commitments to create targeted actions for Autistic First Nations people, older Autistic people, young Autistic children or Autistic people from culturally and linguistically diverse backgrounds. The disadvantage, poor outcomes and barriers to accessing assessment and diagnosis and disability services across these groups is well known and captured by the Senate Select Committee on Autism in its <u>Final Report</u>. Nor are there any specific or measurable targets or milestones to be met across each outcome area for these groups.

We are particularly concerned that the vulnerability of **Autistic people with complex and high support needs** is barely acknowledged, and that this cohort is included only in the Strategy's discussion on intersectionality. There is no meaningful recognition of, or adequate commitments to, addressing their unique and disproportionately high levels of risk or disadvantage. Nor are there any commitments to meeting the support needs of their parents/carers and families.

As recognised by the Senate Select Committee on Autism in its <u>Final Report</u>, many Autistic people, diagnosed with Level 3 autism (also referred to by some as profound or severe autism), have very **complex and high-level communication and behaviour support** needs related to their autism. This cohort and their families can experience **unique challenges** contributing to daily distress and **risks** to their safety and the safety of others. They can also experience unique and debilitating forms of **discrimination** (particularly across education, employment and health), social isolation and have particularly poor life outcomes. Many Autistic people with complex and high support needs utilise a range of **communication devices and methods**, these can include from low and high tech augmentative and alternative communication devices



and gestures. However, there remains a lack of respect for, and understanding of these devices and methods across the community, including poor capabilities and understanding by schools and disability support services. The families of Autistic people with complex and high supports can also have **higher support needs**, **including for economic inclusion** (as discussed in further detail below).

While Autistic people with complex and high support needs may also be part of **vulnerable intersectional cohorts**, i.e. they may also be a First Nations Autistic person and/or they may also have a co-occurring condition, such as an intellectual disability, they are not part of an intersectional cohort simply because they are an Autistic person with complex and high support needs.

The Senate Select Committee on autism recognised that Autistic people with complex and high support needs are more vulnerable to discrimination and poor outcomes, and that actions and supports targeted towards all Autistic people can often fail to meet their needs. It therefore recommended a range of **targeted actions** to support this cohort, including across the areas of education, disability services, housing and advocacy. For similar reasons, with more general actions often failing to meet their needs or be culturally appropriate, the Senate Select Committee also identified targeted actions for other vulnerable intersectional cohorts, including those discussed above.

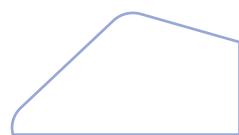
If the Strategy is to meet the needs of all Autistic people, its **guiding principles** must recognise the unique disadvantage and poor outcomes experienced by people with complex and high support needs, as well as vulnerable intersectional cohorts. These principles should also recognise the different and varying communication methods used by many Autistic people, and the rights of Autistic people to choice and control over the communication methods they use. The Strategy must also include **commitments to targeted actions** for Autistic people with complex and high support needs, and vulnerable intersectional cohorts, with **timeframes and specific and measurable targets** across each outcome area to measure success.

Furthermore, we would recommend that the term 'complex and high support needs' be defined in the Strategy's glossary to be clear about the cohort this term refers to. It is our understanding that it refers to Autistic people diagnosed with Level 3 autism, who have complex communication and behaviour support needs, require daily support across multiple domains, and who are more vulnerable or at a greater risk of harm or disadvantage than the broader Autistic community. Many in this cohort will also have co-occurring conditions, such as intellectual disability and/or psychosocial disability.

Recommendations:

- Create specific commitments and commit to identifying targeted actions for Autistic people with complex and high support needs and their parents and carers, as well as vulnerable intersectional cohorts (in co-design with a diverse representation of those groups) across each outcome area, supported by specific and measurable targets, milestones and timeframes.
- In the Guiding Principles, recognise that Autistic people with complex and high support needs face unique and daily risks of harm, disadvantage, isolation and poor life outcomes.





- In the Guiding Principles, 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, with a commitment to improving community understanding, respect and capabilities (including in schools).
- Define 'complex and high support needs' in the Strategy's glossary.

(b) Housing

The Strategy identifies 'equal opportunities for Autistic people to access housing' within its key themes of what the Strategy should achieve (p.16). However, the Strategy contains no further discussion or commitments to improve access to housing for Autistic people. This is surprising given that the public consultation discussion paper to inform the Strategy's development, released in 2023, identified housing and accommodation as a key issue relating to social inclusion (p.17). It indicated that the Strategy was likely to highlight the poor experiences and outcomes of Autistic people in housing and guide autism specific reforms, particularly in relation to housing affordability, design and safety, as well as discrimination and choice and control over housing options (consistent with the recommendations of the Senate Select Committee on autism in Chapter 15 of its Final report).

While we recognise housing reforms are likely to flow from the Disability Royal Commission's recommendations, an autism specific approach and lens to housing is urgently needed.

As highlighted in the Senate Select Committee's Final Report and the Strategy's public consultation discussion paper, autism specific commitments are required under the Strategy to:

- Understand the unique barriers experienced by Autistic people that are impacting their access to, and choice and control over, safe housing options (including across private housing, Specialist Disability Accommodation (SDA) and social housing).
- > Provide the **supports** required for Autistic people to live independently and reduce the disproportionately high numbers of Autistic people having to remain living at home with their families.
- Address discrimination experienced by Autistic people in the private rental market.
- Improve housing accessibility, including by creating a nationally consistent autism accessibility guidelines for all housing types.
- Increase the **availability of housing stock**, particularly robust SDA housing stock that meets the individual needs of Autistic people that may require it.

Recommendations:

Commit to:

- supporting Autistic people to live as independently as possible.
- improving equal access to, and choice and control over, safe and accessible housing options.
- creating nationally consistent autism accessibility guideline for all housing types.



(c) Justice

The Strategy identifies 'equal opportunities for Autistic people to access justice services' within its key themes of what the Strategy should achieve (p.16). However, it only **includes one high-level commitment relating to justice** – 'Greater public education and awareness including a better understanding of autism within...the criminal justice system' (Commitment 1(a)).

While autism training is needed across the justice system to improve understanding, significant improvements to a range of systems and services are also needed to reduce the **disproportionate numbers of Autistic people represented in the justice system, ensure equal access to justice and ensure the justice system is able to meet the diverse needs of all Autistic people** (as victims and alleged offenders). The Disability Royal Commission identified numerous systems and service-related reforms required to improve the experiences and outcomes of people with cognitive disability, including autism. These included co-designed national practice guidelines and policies relating to screening for disability and identification of support needs in custody, revision of the National Statement of Principles Relating to Persons Unfit to Plead or Not Guilty by reason of Cognitive or Mental Health Impairment (including to prohibit indefinite detention), and a review diversion programs. While these reforms would no doubt benefit Autistic people, an autism specific approach to improving the justice system is also needed.

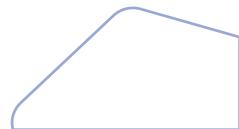
To further understand the systems and service needs of Autistic people in particular, we strongly commend the systematic review, led by the Global Autism and Criminal Justice System Consortium (GACJSC), funded by the International Society of Autism Research, Policy gaps and opportunities: A systematic review of autism spectrum disorder and criminal justice intersections. This review recommends autism specific reforms to reduce this cohorts contact with law enforcement (including the introduction of alternative responder models), create autism appropriate police interview strategies, create autism accessible courtrooms, provide safe custodial settings and diversions to appropriate community settings, and improve access to supports post prison to reduce recidivism. While some of these reforms require action by States and Territories, a co-designed national strategy nationally consistent action is urgently needed.

For further information and evidence regarding the experiences of Autistic victims and alleged offenders, their poor outcomes in Australia and reform needs, we are also pleased to share our submissions to the <u>Victorian Inquiry into the criminal justice system (September-2021)</u> and the <u>Disability Royal Commission (November 2021)</u>, with <u>addendum (May 2022)</u>.

Recommendation:

Commit to co-designing a national strategy or framework to reduce the disproportionate numbers of Autistic people involved in the justice system, improve their experiences and outcomes, drive better communication and collaboration across sectors, and promote national consistency.





(d) Employment and economic inclusion.

The Senate Select Committee on Autism recommended that a National Autism Employment Framework be developed under the auspices of the Strategy (Recommendation 58).

While the draft Strategy includes some welcome commitments to improve employment, there does not appear to be any plan to proceed with a National Autism Employment Framework. This is disappointing given comprehensive and well-co-ordinated reforms are urgently needed to improve the experiences of Autistic people and reduce their disproportionate rate of unemployment.

As recommended by the Senate Select Committee, a Framework could:

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

A Framework could also drive research, particularly into understanding and meeting the needs of vulnerable intersectional cohorts.

A commitment is also needed in the Strategy to understanding and meeting the employment support needs of **people with complex and high support needs**. As highlighted in evidence to the Senate Select Committee on Autism, the needs of this cohort are not well understood, and employment initiatives most commonly target Autistic people with lower support needs (or without intellectual disability). The abilities of this cohort are too frequently **underestimated** or supports are deemed too hard. Actions are urgently needed to raise the profile of this cohort's rights and abilities to work, build the understanding and capabilities of employers to meet their needs, ensure they can access the employment supports they need, and ensure they have meaningful **choice and control** over their employment options.

Ensuring that the needs of Autistic people with complex and high support needs are met will be particularly important as changes are made to the operations of Australian Disability Enterprises and Disability Employment Services over the coming years. **Any actions towards building mainstream inclusion must meet the needs of this cohort,** with investment in innovative employment models, to ensure they are not left behind or further locked out of employment.

It must also be recognised that **not all Autistic people will be able to work**. The Strategy must equally address their needs to ensure they are supported, together with their families and carers, with access to appropriate housing, funding, disability supports and pensions. The Strategy should also promote initiatives and resources to ensure this cohort are protected and well supported, with their rights to choice and control accorded, in cases of emergency and after their parents/families are gone.



Commit to:

- co-designing a National Autism Employment Framework.
- understanding and meeting the employment support needs of people with complex and high support needs, and vulnerable intersectional cohorts.
- meeting the immediate and long-term support needs of Autistic people who are unable to work.
- meeting the support needs of parents and carers who are unable to work.

(e) Research

In its Final Report, the Senate Select Committee on Autism recommended a National Autism Research Framework be developed under the auspices of the strategy (Recommendation 26). However, the draft Strategy only includes **one commitment in relation to research**, 'to explore how autism research can best be fostered and applied to policy and service delivery and underpinned by the Strategy's guiding principles' (Commitment 22).

We are concerned that this commitment fails to address the **broader need for a Framework to identify** and drive future research needs and guide collaboration, co-ordination and transparency. A Framework is also needed to measure progress towards research targets and milestones.

As recognised in the strategy (p.18), there is little research or other evidence available relating to the life experiences, needs or views of vulnerable cohorts, including First Nations Autistic people, culturally and linguistically diverse Autistic people, older Autistic people, Autistic people in child protection and justice systems and Autistic people with complex and high support needs. A Framework is urgently needed to drive research for these cohorts and guide future policy and supports.

A Framework could also provide guidance for **best practice neuro-affirming and ethical research** for autism and highlight the importance of supporting **autistic research led by Autistic researchers**.

Recommendation:

Commit to developing a National Autism Research Framework to drive best practice research, address gaps in research (particularly for vulnerable cohorts), improve research coordination and collaboration, and promote neuro-affirming and ethical research.

(f) Other gaps

NDIS reform and early intervention: The draft Strategy includes very little on early intervention and the NDIS (or NDIS reforms), two areas of great significance for Autistic people and their families and carers. Further to the high-level commitments (commitments 16 to 20) to improve access to services and supports, further information is needed on how the strategy will intersect with the NDIS review and ensure that the needs of Autistic people (including to access to best practice early intervention and Foundational Supports) are met through the reform process.



- Education: The draft Strategy includes only three very high-level commitments on education. We encourage you to also consider including commitments to increasing student access to peer support and mentoring across all Australian schools. There is considerable evidence regarding the benefits of peer support and mentoring in schools and we would encourage engagement with the I CAN Network to hear more about the successes of their peer support and mentoring program. We would also encourage you to commit to improving services and supports at key transition points in the school years, and upon leaving school to access employment or further learning. Further information is also required on how the Strategy will ensure the needs of Autistic students are carefully considered in any response to the Disability Royal Commission's recommendations on education, particularly regarding inclusive education and the development of a National Roadmap to Inclusive Education. We welcome Commitment 4, ensuring the needs of Autistic people are considered in any future amendments to or reviews of the Disability Discrimination Act 1992 and associated disability Standards. However, a commitment to assessing the effectiveness of the Act and associated Standards for Autistic students is also required.
- Assessment and Diagnosis We welcome the commitments to improve access to timely and quality autism assessment and diagnosis. To further inform your commitments in the Final Strategy, upon request we will be pleased to share the evaluation of an autism assessment service model, created by Amaze and IPC Health, and supported by WAVE design, piloted in 2022-23. The evaluation highlights the importance of support for Autistic people and their families not only through the identification, assessment and diagnosis process, but also post diagnosis to set families up for supports beyond therapies, including connections to peers and community. It also highlights that effective diagnosis support models include timely assessments (including where appropriate, access to multiple assessments on one day), affordable rates, co-ordination and practical support, emotional preparation for families, a balanced approach that highlights strengths, supports tailored to the unique family context and validation of parents' knowledge, efforts, skills and concerns. We would also emphasise the importance of ensuring Australians of all ages, gender, race and identity can access a timely and quality assessment and diagnosis. As recognised by the Senate Select Committee on Autism, different cohorts can face very different barriers to accessing diagnostic services. For example, older Autistic Australians were historically not supported to seek an assessment and diagnosis or understand their support needs. Specific commitments to improve access to assessment and diagnosis, and services and supports for these cohorts are urgently needed. Commitment 13 should also be amended to recognise that best practice resources to support Autistic people and their supporters through the assessment and diagnosis process should be tailored to the specific needs of vulnerable intersectional cohorts.
- Advocacy We welcome the commitment to 'increase the capability of advocates and advocacy organisations to challenge and reduce stigma of autism (Commitment 1(d)), however the capacity of advocacy and autism organisations needs to be increased for far wider purposes. National user-led, autism specific advocacy services (individual and systemic) are needed, to operate in parallel with generalist disability advocacy services. Specialist services are also required to support the unique advocacy needs of Autistic people with complex and high support needs, and those of their parents and carers. Adequate funding would need to be attached to ensure these services could maintain pace with



- increasing demand for advocacy services caused by the NDIS, and increased demand that is likely to flow from NDIS and DRC related reforms. For more information and evidence, please see Amaze's submission to the DRC Amplifying the voices of Autistic people through advocacy (December 2021).
- Parents and carers The Strategy fails to address the support needs of parents and carers of Autistic children, or the unique support needs of Autistic parents. As recognised by the Senate Select Committee on Autism, despite the wellbeing of parents and carers being critical to the experiences and outcomes of Autistic people, there is overwhelming evidence that support for parents and carers is grossly inadequate. The Senate Select Committee highlighted that this includes a lack of respite care and other services that are family-centred and offer wrap around supports. As discussed above, carers can also require extensive support for economic inclusion, particularly those caring for Autistic people with complex and high support needs. The Senate Select Committee recommended that supports for parents be improved, including through access to respite services, NDIS supports and supports for economic inclusion. Commitments are also needed to increase understanding and meet the unique supports needs of Autistic parents.

Commit to:

- ensuring the consideration of the diverse needs of Autistic people in future sector wide reforms,
 including NDIS review and DRC related reforms.
- measuring the effectiveness of disability sector wide reforms, legislation, standards and strategies for Autistic people (such as the Disability Discrimination Act 1992 and Disability Standards for Education).
- increasing student access to Autistic led peer support and mentoring, including across all Australian schools.
- increasing services and supports at key transition points in the school years, and upon leaving school to access employment or further learning.
- establishing National user-led, autism specific advocacy services (individual and systemic), to operate in parallel with generalist disability advocacy services.
- increasing access to 'one stop shops' for quality, holistic and timely assessment and diagnosis.
- providing post diagnosis supports and resources to assist Autistic people, and their parents/ carers, to connect to therapies, peers and community.
- tailoring best practice resources for assessment and diagnosis to the needs of vulnerable intersectional cohorts.
- improving the wellbeing and social and economic inclusion of parents and carers, and meeting the unique support needs of Autistic parents.





4. Ensure a diversity of Autistic voices and perspectives, and those of parents and carers, are informing the Strategy's development.

We remain concerned that the Strategy's development may not be being adequately informed by a **diversity** of Autistic voices and perspectives (including a diverse representation of Autistic people with varying lived experiences, support needs, co-occurring conditions and cultural backgrounds) or their families and carers. It is vital that these voices and perspectives are heard through the Oversight Council and working groups, as well as when reaching out to the community.

Best practice co-design of public policy impacting Autistic people involves the coordinated participation and shared decision-making of policy makers and a diversity of stakeholders (including Autistic people and their families and carers) in the process of policy development, implementation, and evaluation. It must genuinely and actively engage a diversity of lived experiences and expertise, including from cohorts that can be most at-risk and/or hard to reach. The process must involve Autistic participants (and their families and carers) from different backgrounds and with varying conditions and support needs, together with broad sector representation, to ensure that the multidimensional insights captured lead to multidimensional solutions that meet the needs of the widest group possible.

Best practice co-design requires the early mapping out of an accessible and transparent co-design framework with stakeholders. A co-design framework should be attached to the final Strategy and create a clear mutual understanding of the objective, process and role of participants, and ensure that participation in each step (i.e. development, implementation and evaluation) is accessible, involving as many ways as possible for participants to engage and share their experiences, expertise, ideas and concerns. It should also ensure the process is respectful, equitable, accountable and transparent, providing open channels for communication and visibility regarding the inclusion or consideration of all contributions and ideas. Best practice co-design promotes ownership and trust and ensures the needs and priorities of all stakeholders are addressed.

We appreciate that some particularly vulnerable Autistic cohorts, including people with complex and high support needs and many vulnerable intersectional cohorts, can be difficult to reach. We are eager to assist in any way we can to continue to help you engage these cohorts (and their families and carers) and/or support the provision of autism accessible information on the Strategy and consultation process/co-design opportunities.

We would also recommend that the Strategy include a commitment to co-designed research into best practice approaches for reaching hard to reach Autistic cohorts and making participation accessible for all. This will be valuable not only for informing your ongoing approach to the Strategy's co-design, but indeed the co-design of all future government policy and initiatives impacting Autistic people.





Commit to:

- increasing the diversity of Autistic voices and perspectives, and those of their parents and carers, informing the Strategy's development (including a diverse representation of Autistic people with varying lived experiences, support needs, co-occurring conditions and cultural backgrounds).
- attaching a transparent and accessible co-design framework to the Strategy.
- driving co-designed research into best practice approaches for reaching the most at risk and hard to reach Autistic cohorts, including making participation accessible.

5. Advocate for a whole of governments commitment to the National Autism Strategy.

To promote national **consistency** to the greatest extent possible, stronger **collaboration** and a more comprehensive and effective response to the needs of Autistic people across **all levels of government**, we encourage you to **advocate**, including to the Disability Reform Ministerial Council, **for a whole of governments commitment to the NAS** (as per the Australian Disability Strategy).

A whole of governments approach could also **drive the development of state and territory autism plans** in each state and territory, building on the refreshed Victorian Autism Plan, and the South Australia Autism Strategy currently under development. It could drive plans tailored to regional needs, leveraging local expertise and resources while maintaining a unified national direction to the extent possible and appropriate.

Recommendation:

Advocate for a whole of governments commitment to the NAS, including to drive state and territory commitments and autism plans.



