What we have heard: moving towards development of a National Autism Strategy

Discussion paper

**Table of Contents**

[Acknowledgement of Country 3](#_Toc144453451)

[Statement on Language 3](#_Toc144453452)

[Trigger warning 3](#_Toc144453453)

[Introduction 5](#_Toc144453454)

[Development of the National Autism Strategy 5](#_Toc144453455)

[Purpose of this paper 6](#_Toc144453456)

[How we will develop the National Autism Strategy 9](#_Toc144453457)

[National Autism Strategy consultation and engagement process 12](#_Toc144453458)

[Consultation timeframe and contact information 12](#_Toc144453459)

[The case for a National Autism Strategy 13](#_Toc144453460)

[The evidence 13](#_Toc144453461)

[Your views 14](#_Toc144453462)

[Overarching key discussion questions 15](#_Toc144453463)

[Key Theme 1: Social Inclusion 16](#_Toc144453464)

[Key issues relating to social inclusion 16](#_Toc144453465)

[Potential areas of action to improve social inclusion outcomes 19](#_Toc144453466)

[Discussion Questions – Social Inclusion 21](#_Toc144453467)

[Key Theme 2: Economic Inclusion 22](#_Toc144453468)

[Key issues relating to economic inclusion 22](#_Toc144453469)

[Potential areas for action to improve economic inclusion outcomes 24](#_Toc144453470)

[Discussion Questions – Economic Inclusion 25](#_Toc144453471)

[Key Theme 3: Diagnosis, Services and Supports 26](#_Toc144453472)

[Key findings relating to diagnosis, services and supports 26](#_Toc144453473)

[Potential actions to improve diagnosis, services and supports outcomes 29](#_Toc144453474)

[Discussion Questions – Diagnosis, Services and Supports 31](#_Toc144453475)

[Key Theme 4: National Roadmap to Improve the Health and Mental Health of Autistic People 32](#_Toc144453476)

[Key findings relating to health and mental health 32](#_Toc144453477)

[Discussion Questions – Health and Mental Health 33](#_Toc144453478)

[Further information about the National Roadmap co-design and consultation process 33](#_Toc144453479)

[Glossary 34](#_Toc144453480)

# Acknowledgement of Country

The Department of Social Services acknowledges 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.

| Statement on Language People use different words to talk about autism, and each person will have their own way of talking about autism and about themselves. Some people in the Autistic community like to use ‘Autistic person’ (identity-first language), some like to say ‘person with autism’ (person-first language), and some are fine with using either. The Australian Government is using identity-first language to talk about the National Autism Strategy. This means that we will usually use the term Autistic person or Autistic people. |
| --- |

## Trigger warning

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

### Beyond Blue Support Service

* Telephone 1300 224 636, 24 hours, 7 days a week.
* Chat online 3pm to 12am AEST, 7 days a week.
* Email for free, short-term counselling, advice and referral services.
* Website: [Beyond](http://www.beyondblue.org.au/get-support/get-immediate-support) Blue Support Service.

### Lifeline Crisis Support

* This confidential service provides support when you are feeling overwhelmed, having difficulty coping or thinking about suicide.
* Speak to a crisis support worker by telephone on 13 11 14, 24 hours, 7 days a week.
* Chat online 7pm to 12pm, 7 nights a week.
* Website: [L](http://www.lifeline.org.au/get-help/get-help-home)ifeline Crisis Support.

### 1800RESPECT

* For support if you are affected by sexual assault or domestic and family violence or abuse.
* Telephone 1800 737 732, 24 hours a day, 7 days a week.
* Chat online 24 hours a day, 7 days a week.
* Website: [1800RESPECT](http://www.1800respect.org.au).

### Autism Connect

* A free, national autism helpline, providing independent and expert autism information over the phone, email and webchat. It supports Autistic people, their families and carers, health professionals, researchers, teachers, employers and the broader community.
* Available from 8am to 7pm, Monday to Friday. Telephone 1300 308 699.
* Website: [A](http://www.amaze.org.au/autismconnect)utism Connect.

### 13 YARN

* Support from First Nations crisis counsellors is available at 13YARN (13 92 76) or by visiting [13 YARN](http://www.13yarn.org.au/).
* Available 24 hours a day, 7 days a week.

### Trauma informed approach

The Department of Social Services (DSS) is committed to adopting a trauma-informed approach to the national engagement and consultation process.

# Introduction

## Development of the National Autism Strategy

In 2021, Australia’s Disability Strategy 2021-31 (the ADS)[[1]](#footnote-2), Australia’s national policy framework for disability, was launched. All governments are committed to working together alongside people with disability, communities, businesses and the non‑government sector to implement the ADS and realise its vision for an inclusive Australian society that ensures people with disability can fulfil their potential, as equal members of the community.

On 27 November 2019, the Senate established a Select Committee on Autism[[2]](#footnote-3) (the Committee) to inquire into and report on the services, support, and life outcomes for Autistic people. The Committee delivered its final report on 25 March 2022.

A key recommendation of the Committee’s report is to develop a person and family-centred National Autism Strategy (the Strategy). The Committee recommends the Strategy should be person and family-centred, address whole-of-life needs for Autistic people and align with other national strategies, and be informed by the recommendations of the Committee’s inquiry, and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

The Australian Government committed funding in the October 2022-23 and May 2023-24 Federal Budgets towards the development of the Strategy and a National Roadmap to Improve the Health and Mental Health of Autistic People (the National Roadmap).

The focus of the Strategy will be on areas of Australian Government responsibility. The Australian Government will refer to states and territories on issues raised in the development process that relate to responsibilities of states and territories, or local government. Areas of shared responsibility will be referred to Disability Reform Ministers[[3]](#footnote-4) to consider shared approaches, where relevant.

Development of the Strategy is being led by the Department of Social Services (DSS), reporting to the Minister for Social Services, the Hon Amanda Rishworth MP. Development of the National Roadmap is being led through a separate, but connected process, by the Department of Health and Aged Care, reporting to the Minister for Health and Aged Care, the Hon Mark Butler MP.

In line with Australia’s commitments under the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), the Strategy will play an important role in protecting, promoting and realising the human rights of Autistic people.

The Strategy will include a focus on intersectional (overlapping) disadvantage or discrimination experienced by Autistic people, based on attributes such as Aboriginality; age; disability; ethnicity; gender identity; race; religion; and sexual orientation.

### Key message

| **The** **Strategy will be a whole-of-life plan for Autistic Australians of all ages, and not just those eligible for the National Disability Insurance Scheme (NDIS).**  The Strategy is expected to:   * Build on the understanding and recognition of autism within key professions and the wider community. * Support improved service coordination between all levels of government. * Consider ways to make education, employment, community, diagnosis, mental health, health and disability services and supports for Autistic people more inclusive and accessible. * Provide better support for families and carers of Autistic people. * Establish a national autism research agenda.   Initiatives under the Strategy will focus on areas of Australian Government responsibility. Issues raised relating to other governments will be advised to them for consideration. |
| --- |

## Purpose of this paper

We want the Strategy to be informed by Autistic Australians and other stakeholders. Listening carefully to the community is an important step to deciding what goes in the Strategy. Public consultation and engagement on this paper is an opportunity to hear what is important to you.

**The paper is intended to provide information about:**

* Why a National Autism Strategy is important and how we will develop it.
* Other inquiries and consultations on autism.
* What we have heard from the Autistic community and other stakeholders already.
* Some of the key issues and barriers Autistic people face.
* Questions that point to areas where we want to hear further from you to help inform the development of the Strategy.
* Areas for potential action.

**This paper is a discussion paper, it is not Australian Government policy.**

This paper aims to:

* Help avoid or reduce the need to ask the Autistic community to retell their stories.
* Invite those who have not yet had their say to take the opportunity to do so if they wish to.
* Test the evidence already available and identify gaps.
* Help guide consultation discussions and the focus of submissions.

The national consultation, engagement, and submission process will shape the way the Australian Government understands:

* What the Autistic community want and think is important (a vision and principles).
* Areas the Autistic community think need to improve (outcomes).
* Where effort should be prioritised to ensure the best outcomes for all Autistic Australians (objectives and priority reform areas).
* How to best engage and consult with the Autistic community in future consultations and processes.

This paper focuses on the role of the Australian Government in supporting Autistic people. While everyone has a role to play in supporting better outcomes for Autistic people, and their families, and carers, we want to hear your thoughts about a national approach that would benefit all Autistic Australians across the country.

Outcomes from the national consultation process will be provided to the National Autism Strategy Oversight Council (the Oversight Council) and will inform the development of the draft Strategy.

### Key message

| This paper explains how we will develop the Strategy. It outlines what the Autistic community, the autism and disability sector, researchers and professionals, and the broader community have already shared. It highlights the key issues raised in public submissions to recent inquiries and consultations regarding the experiences and life journeys of Autistic Australians and their families and carers, including:   * The Senate Select Committee on Autism. * Consultations to inform development of Australia’s Disability Strategy.[[4]](#footnote-5) * The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission).[[5]](#footnote-6) * The Joint Standing Committee on the National Disability Insurance Scheme.[[6]](#footnote-7) * Autism CRC[[7]](#footnote-8) research, evidence, policy and landscape mapping commissioned by DSS and undertaken in 2023. * The South Australian Government First Autism Strategy Discussion Paper – Consultation Report 2023.[[8]](#footnote-9) * The Victorian Government Autism Plan.[[9]](#footnote-10) * The NDIS Review interim report, ‘What we have heard – Moving from defining problems to designing solutions to build a better NDIS’ [[10]](#footnote-11)delivered 30 June 2023. * The Senate Education and Employment References Committee report – the National Trend of School Refusal and Related Matters delivered August 2023.[[11]](#footnote-12)   It also asks questions on topics where we want to hear from you to help inform the development of the Strategy. |
| --- |

# How we will develop the National Autism Strategy

**Australia’s Disability Strategy 2021-31** (the ADS) is Australia’s national policy framework for disability. The ADS is driving action at all levels of government and across the community to improve the lives of all people with disability.

The **National Autism Strategy** will align with the ADS and seek to drive action to improve the lives of Autistic Australians.

Some Autistic people identify as having a disability, and some don’t. The Strategy will reflect the experiences of all Autistic Australians, not just those who identify as having a disability.

| Review what we've heard | **1. We’ve reviewed what we have heard already so people don’t have to retell their stories**.  This included the Senate Committee’s report, gathering and analysing current research, data and evidence, early consultations with some key sector stakeholders, and establishing governance arrangements for the Strategy from October 2022 to July 2023. There is a lot of information from inquiries and previous consultations so we have a lot of information already. This will also consider other relevant Commonwealth, State and Territory Government strategies – both current and in development. |
| --- | --- |
| Test and consult | **2. We want to test what we have heard to ensure we understand gaps, and want to further hear the voices of Autistic people and the wider community** and encourage those who haven’t had the opportunity to be heard.  This process will involve consultation and engagement with Autistic people and their families and carers, the autism and broader disability sector, and researchers and professionals between September 2023 and October 2023. DSS and the Oversight Council will ensure people consulted through this process will be informed of what happens with their feedback, and the outcomes from the consultation process. The draft Strategy is expected to be released for further public consultation later this year. |
| Agree and launch Strategy | **3. Once we have consulted, we want to seek agreement to finalise, launch and implement the Strategy**.  The Australian Government will consider all of the information received through this process and will decide on the final Strategy. At this stage, it is expected the Strategy will be finalised and launched by June 2024. |

### Governance

In May 2023, the Minister for Social Services announced the establishment of the Oversight Council with an Autistic co‑chair and a majority of Autistic members, to guide and inform development of the Strategy, taking account of the information received through the national consultation and engagement, and what is already known. The Oversight Council will help the government make sure that the ideas, thoughts, and experiences of Autistic people, their families and carers play a strong role in informing the vision and objectives of the Strategy.

The Oversight Council includes:

* Eight Autistic community and sector members.
* Two research and professional sector members.
* Six Australian Government members.

The Oversight Council, supported by working groups, will consider the following four key outcome areas:

* Social inclusion.
* Economic inclusion.
* Diagnosis, services and supports.
* Health and mental health (including the National Roadmap).

Each key outcome areas will cover a broader range of issues experienced by Autistic people related to that outcome area.

DSS, the Oversight Council and working groups will consider the diversity of autism and the intersectional**[[12]](#footnote-13)** experiences and needs of all Autistic people and their parents and carers in the Strategy development process, including:

* Autistic infants, children and young adults.
* Autistic girls and women.
* Autistic people diagnosed as adults.
* Older Autistic people.
* Autistic people with high support needs.
* Autistic people with co-occurring disability and/or other conditions, including (but not limited to) Attention Deficit Hyperactivity Disorder (ADHD), and Dyslexia.
* First Nations Autistic people.
* Autistic people from culturally and linguistically diverse backgrounds.
* Autistic people from the LGBTQIA+ community.
* Autistic people who have experienced incarceration.
* Autistic people living in segregated accommodation, group homes and institutions.

We encourage a focus on the diversity of the Autistic community and diversity of needs when providing submissions and feedback.

### Key message

| The National Autism Strategy will sit under and be aligned with Australia’s Disability Strategy.  In developing the Strategy, we will:   * Review what has been heard already. * Test what we know and consult widely. * Focus on the four key outcome areas of social inclusion; economic inclusion; diagnosis, services and supports; and health and mental health. * Take an intersectional approach.   There is an opportunity between September and October 2023 to respond to this paper and have your say as part of the process for developing the Strategy. We want to make sure the process for engaging and consulting on the development of the Strategy will enable the diversity of the Autistic community to have their say.  Following on from this consultation process, the draft Strategy, incorporating feedback gathered from the community through this process, will be released for public comment later this year. |
| --- |

Further information about development of the Strategy and the Oversight Council is available here: [www.dss.gov.au/National-Autism-Strategy](http://www.dss.gov.au/National-Autism-Strategy).

# National Autism Strategy consultation and engagement process

DSS has engaged The Social Deck to undertake the national consultation and engagement process to inform development of the Strategy. This process will involve a broad range of engagement activities, including:

* Release of this paper for public consultation.
* An online discussion wall / ideas wall allowing people to join conversations at a time suitable to them.
* Online workshops.
* Community consultations.
* Small stakeholder workshops.
* Targeted focus groups.

Further information about the consultation activities is available at [www.dss.gov.au/National-Autism-Strategy](http://www.dss.gov.au/National-Autism-Strategy).

In addition to these activities, The Social Deck will be holding a small number of one‑on‑one conversations with individuals to provide their input into development of the Strategy.

We worked with the Autism CRC to develop a co-design and consultation model for community participation in the development of the Strategy.

We have **prepared this paper to help guide key consultation** discussion at public community consultations, and targeted stakeholder meetings and focus groups.

You can **choose to read and respond to the questions** in the whole paper, **the chapters which interest you, or the summary information at the end of each chapter**. You do not have to answer all the questions, unless you would like to, or just answer the ones that are relevant to you. You also don’t need to answer any of the questions. **You can provide your response in any format you like.**

## Consultation timeframe and contact information

**Opening date for submissions:** Monday, 4 September 2023.

**Closing date for submissions:** Monday, 30 October 2023.

**To provide a submission please visit**: [www.dss.gov.au/National-Autism-Strategy](http://www.dss.gov.au/National-Autism-Strategy).

### Key message

| If you would like to provide a response in terms of what we have heard, if you think we have missed anything, or if you would like to respond to the questions outlined in this paper please provide your submission by Monday, 30 October 2023.  You can provide your response in any format you like. |
| --- |

# The case for a National Autism Strategy

## The evidence

### Senate Select Committee on Autism

The Senate Select Committee on Autism (the Committee) was established on 27 November 2019 to inquire into services, support and life outcomes for Autistic people in Australia. The Committee received 168 submissions, as well as additional information, and held nine public hearings across the country.

The Committee delivered its final report on 25 March 2022. The report includes 81 recommendations, and 5 dissenting report recommendations. DSS led coordination and preparation of the Australian Government response to the Committee’s report which was tabled on 8 December 2022.[[13]](#footnote-14)

A key recommendation of the Committee’s report is to develop a person and family-centred National Autism Strategy.

Key findings of the Committee include:

* Life outcomes for Autistic Australians are unacceptably poor and this comes at a personal, social and economic cost.
* Meaningful systemic changes would have an enormous impact.
* Drivers of poor outcomes for Autistic people are complex and interrelated.
* Poor understanding of autism within the community and among service providers.
* Workforce capacity constraints.
* Delays in early identification and family education and support services.
* Complex and poor integrated service environment.
* Generic disability strategies have proven ineffective at improving life outcomes for Autistic people.

Key priorities identified include:

* Building understanding of autism within key professions and the wider community.
* Improving access to early diagnosis and supports.
* Improving service integration and coordination.
* Improving education, employment and health services for Autistic people.
* Supporting parents and carers.
* Establishing a national autism research agenda.

The Committee’s report also recommended the effectiveness of the NDIS for Autistic Australians should be the focus of a separate inquiry.

# Your views

Many Autistic people, their families and carers, the autism and broader disability sector, researchers, professionals, and public officials have previously expressed views in recent inquiries and public consultations. DSS has sought to summarise at a high-level, examples of some of these views. This includes summarising some of the key issues identified by selected Disability and Autistic Representative Organisations’[[14]](#footnote-15) in research papers commissioned by DSS as part of the process for developing the Strategy, including:

* Key issues facing First Nations Autistic people, prepared by First Peoples Disability Network (FPDN).
* The experiences of Autistic women and girls, prepared by Women with Disabilities Australia (WWDA).
* Engaging with Autistic people with an intellectual disability, prepared by Inclusion Australia.[[15]](#footnote-16)
* Lessons learnt for a National Autism Strategy, prepared by Autism Aspergers Advocacy Australia (A4).

If these organisations decide to make their papers public, links will be provided.

DSS acknowledges there are many different views beyond those included in this paper.

DSS have included in this paper a series of overarching questions, and questions against key themes. These are designed to help to guide you on what we would like feedback on.

### Key Message

| A range of previous reviews and consultation processes have sought the views of the Autistic community. DSS has summarised in this paper some themed examples of these views. This also includes input provided by selected Disability and Autistic Representative Organisations, and the Autism CRC.  **DSS invites you to further contribute to improving our understanding by answering the key questions in this paper, or by providing any other feedback you think is relevant to the Strategy.** DSS would like you to respond in the way that works best for you, this will ensure the Strategy incorporates as many voices as possible.  **To provide a submission please visit**: [www.dss.gov.au/National-Autism-Strategy](http://www.dss.gov.au/National-Autism-Strategy). |
| --- |

| Overarching key discussion questions  1. What does a National Autism Strategy need to achieve? 2. How do you think the Strategy can support the rights, autonomy, and diversity of the Autistic community? 3. What needs to improve so Autistic people are better supported across their whole life? 4. What can be done to better support Autistic people from different population groups, including:  * First Nations Autistic people? * Autistic people from culturally and linguistically diverse communities – including those from multicultural, immigrant, and refugee backgrounds? * Autistic women and girls? * Autistic people that identify as LGBTQIA+? * Autistic infants, children, and young adults? * Older Autistic people? * Autistic people who also have an intellectual disability?  1. What might help to improve people’s understanding of Autism? 2. Are there any areas missing from this discussion paper that should be a priority in the Strategy? |
| --- |

# Key Theme 1: Social Inclusion

## Key issues relating to social inclusion

Life outcomes for Autistic Australians are unacceptably poor. This comes at a personal, social, and economic cost for Autistic people. Drivers of poor outcomes for Autistic people are complex and interrelated. Meaningful systemic changes would have an enormous impact *(Committee report).*

### Access to supports, services and information

* Autistic people often experience social isolation and exclusion from mainstream activities, and limited access to personal and community services and supports *(inquiries and consultations).*
* Available information about autism is often too technical and difficult to understand, and needs to be available in a variety of ways. This has particular impacts on First Nations people and those from culturally and linguistically diverse backgrounds *(South Australian (SA) Government consultation paper, and inquiries and consultations).*
* A First Peoples cultural model of disability based on enhancing wellbeing by fostering social inclusion, through the active participation of people with disability in community and cultural activities, is important *(FPDN paper).*
* There is a need for more supports and services to resolve sensory and social difficulties experienced by some Autistic people in community spaces, workplaces, and schools *(SA Government consultation paper, and inquiries and consultations).*
* There are capacity constraints (i.e. barriers and limitations) in regard to the disability workforce *(Committee report).*
* The intersection of autism and intellectual disability is a multifaceted experience with compounding impacts, meaning supports can vary widely depending on the ‘primary’ diagnosis and the order in which they received their diagnosis *(Inclusion Australia paper)*.

### Autism awareness and acceptance

* There is a poor understanding of autism within the community, among service providers, and in essential government services *(Committee report, and SA Government consultation paper).*
* A better understanding of autism is required among NDIS planners, local area coordinators, and frontline services including nurses, teachers, and emergency responders *(inquiries and consultations).*
* Media representation of autism is absent, with terminology often referring to disabilities and autism in a negative context or as a deficit *(inquiries and consultations).*
* Many Autistic people feel they are encouraged to ‘mask’ or ‘camouflage’ their autism in order to fit in. This impacts Autistic girls and women in particular *(inquiries and consultations, and WWDA paper).*
* Autistic people who are non-verbal struggle to communicate due to not having other communication options *(SA Government consultation paper).*
* A lack of understanding and acceptance of autism in the community can make it hard for people to participate in everyday activities including: school; training; work; family; health and community services; public events; and sport and recreation *(Victorian (Vic) Government Autism Plan).*
* Barriers to inclusive communities are reported to be greater for First Nations Autistic people, Autistic people from culturally and linguistically diverse communities, and LGBTQIA+ communities *(inquiries and consultations)*.
* Cultural safety is of high importance to families with Autistic children. Cultural safety can include competency training for service providers, which can mitigate racism, and provide affirmation, cultural acceptance and belonging *(FPDN paper)*.
* There is a need to recognise the inherent intersectionality of racism and ableism[[16]](#footnote-17) experienced by First Nations people. In addition, stigma and shame can contribute to social exclusion and reduced access to supports for First Nations Autistic people *(FPDN paper)*.

### Housing and accommodation

* There is a lack of affordable social and public housing suitable to sensory and spatial design needs to enable many Autistic people to live independently *(Autism CRC mapping)*.
* Some Autistic people face discrimination in the private rental market *(Committee report).*
* Insecure housing contributes to poorer outcomes across health, education and employment domains. It is also a predictor of ongoing engagement with the justice system and has been cited as a factor in decisions families have made to place their children in state care *(Committee report).*
* Given the poor health, education and employment experiences of many Autistic people, they may be more likely than the general population to experience housing stress, insecure housing and homelessness. The link between employment and the ability to afford housing is particularly critical *(Committee report).*
* There is the potential for abuse in shared supported accommodation settings resulting from a combination of complex support needs and a one-size-fits-all approach – which can lead to share homes becoming violent places *(Committee report).*

### Safety, rights and justice

* Autistic people are at greater risk of involvement with the justice system and are believed to be overrepresented in detention settings *(Committee report).*
* Autistic people are more likely to be victims and witnesses of crime than offenders. When they come into contact with the justice system, they can face significant challenges. There is a need to recognise the additional disadvantage of vulnerable Autistic people in the justice system *(Vic Government Autism Plan).*
* People with disability may be subject to many forms of violence, abuse, neglect and exploitation in the criminal justice system as victims, accused people or witnesses and research suggests there is a strong causal link between disability and contact with the criminal justice system *(inquiries and consultations).*
* Prejudicial attitudes can make it more difficult for First Nations people with disability to access justice and receive fair treatment in their engagement with the criminal justice system *(inquiries and consultations).*
* Women, children and young people with disability have a heightened risk of violence, abuse, neglect and exploitation. Research shows First Nations women are the fastest growing group in the Australian prison system *(inquiries and consultations).*
* Restrictive practices can be used across Australia, as a last resort, to prevent or protect people from harm. This includes a perceived risk of harm. This may include preventing or protecting an individual or others from behaviours referred to as ‘challenging behaviours’ or ‘behaviours of concern’ *(inquiries and consultations).*
* People with disability in detention settings, which includes a high number of First Nations people with disability, are at a high risk of restrictive practices, including solitary confinement for long periods of time *(inquiries and consultations).*
* People with disability are also at higher risk of restrictive practices after their release from prison, which can contribute to a cycle of criminalisation and re-incarceration *(inquiries and consultations).*
* A lack of autism awareness and knowledge within the justice system can mean staff misinterpret Autistic characteristics, such as social and communication difficulties, as being law breaking or demonstrative behaviours. This in turn, can lead to an increase in the likelihood of arrest, discrimination, longer sentences, and greater difficulties for Autistic people within detention settings *(Committee report, and Autism CRC mapping).*
* Incarcerated Autistic people do not have adequate access to appropriate supports and services *(inquiries and consultations)*.
* The move from a detention setting into the community can be a high-risk transition point for Autistic people. The risk of re-offending and the increased risk to a person’s mental health, may lead to risk-taking behaviours and even suicide. This can be linked to 'a failure to organise wrap-around supports at a time when individuals are rebuilding their lives' *(Committee report).*
* Some Autistic people find it difficult to report incidents due to trauma and fear of victimisation *(inquiries and consultations).* Autistic people who also have an intellectual disability can have a ‘deep sense of mistrust’ of government systems *(Inclusion Australia paper).* This can lead to people missing out on assistance or can increase the stress and trauma when in the justice system.
* Support through the justice system is often focussed on violence and abuse, or carer abuse, there is little support for Autistic victims of hate crime *(inquiries and consultations).*
* First Nations people and Autistic people are over-represented in the justice system. First Nations Autistic people feel a cultural lack of trust with the police, and there is a need for better support, and understanding of people with disability in the justice system *(FPDN paper)*.
* There has been a call for autism-specific legal services *(inquiries and consultations)*.
* Some Autistic people, particularly younger people, don’t pick up on signs that a situation or environment may not be safe. This is often associated with their processing of sensory information and understanding of social cues *(Vic Government Autism Plan).*

## Potential areas of action to improve social inclusion outcomes

**Access to supports and services and information**

* Adjustments, accommodations, and supports need to be provided to enable Autistic people equitable access to services, including autism specific or autism-tailored pathways within services. *(Autism CRC mapping)*.
* Physical environments (e.g.: schools, hospitals, court rooms), need to be sensory considerate (e.g.: by reducing sensory stimuli in environments) *(Autism CRC mapping)*.
* More options and choice is needed about services or settings that will best support Autistic people, according to their needs and preferences *(Autism CRC mapping)*.
* The idea of creating a central website for autism services and supports has been suggested so people can easily access and navigate information and supports *(SA Government consultation paper)*.

**Autism awareness and acceptance**

* Greater understanding about autism, and all the diversity of its presentation, as well as acceptance, is required within health and government, services, professionals, workplaces, and the community *(Autism CRC paper, and Committee report)*.
* The private sector workforce, and health and government services, need greater training on autism to improve the knowledge, understanding and acceptance of autism *(SA Government consultation paper)*.
* There is strong support for public autism awareness and acceptance campaigns aimed at employers, schools and the broader community *(inquiries and consultations)*.
* More neurodiversity affirming[[17]](#footnote-18) approaches and acceptance of autism and neurodiversity is needed *(Autism CRC mapping)*.

**Housing and accommodation**

* Autistic people need choice and control over where they live and better availability of accessible and affordable housing options, and people in the sector need to increase their knowledge of autism *(Autism CRC mapping, and inquiries and consultations).*

**Safety, rights and justice**

* Increase the understanding of autism within the justice system to improve the experiences for Autistic people, including: provide better education and autism awareness training for justice system personnel; a greater emphasis on community policing approaches; autism-specific legal services and embedding autism as part of initial education courses and professional development for justice system personnel *(Committee report, inquiries and consultations).*
* Further education needs to be provided for all service providers around autism. For example, educating police officers on how to engage with an Autistic person could provide tools to allow for de-escalation of emotions and behaviours that are due to autism *(FPDN paper)*.
* Few justice system policies make specific reference to autism. Policies that do make reference highlight a person’s autism diagnosis should be considered when interpreting their behaviour within a justice setting, and the physical environment should support accessibility *(Autism CRC mapping)*.
* There is a need for appropriate supports and accommodations to be provided to assist with the development of an accessible and inclusive system, and to reduce discrimination within the justice system *(Autism CRC mapping)*.
* Further research is needed into why Autistic people enter the justice system, and the efficacy and use of specialist diversionary pathways[[18]](#footnote-19) *(Autism CRC mapping)*.
* Develop nationally consistent guidance on the type of adjustments that should be made available to Autistic people in justice settings. This should include: the provision of autism-friendly information resources; involvement of disability advocates as standard practice in police interviews; and adjustments to physical environments, policy and court interview processes *(Committee report).*

**Intersectionality (cross cutting all themes)**

* First Nations culture, grounded in the cultural model of disability, based on enhancing wellbeing by fostering social inclusion through the active participation of people with disability in community and cultural activities, and First Nations understandings of neurodivergence, is to be embedded in each aspect of life for First Nations Autistic people. *(FPDN paper).*

| Discussion Questions – Social Inclusion We have heard improved information, awareness and understanding of autism are key to improving social inclusion. There also needs to be an awareness of culture and intersectionality when developing services and supports, and changes made to remove barriers to access to services.   1. Are there any other issues experienced by Autistic people and their families and carers that prevent their inclusion in the community?  * To answer this question you might like to tell us what has prevented you from being included in your community?  1. How do you think we can better support the social inclusion of Autistic people?  * To answer this question you might like to tell us how services and supports could be improved to help you live the life you want.  1. How do you think we can improve community attitudes towards Autistic people? 2. How would you describe better social inclusion for Autistic people? |
| --- |

# Key Theme 2: Economic Inclusion

## Key issues relating to economic inclusion

### Education

* There is a lack of autism knowledge held by education professionals and students, which can lead to:
  + Insufficient provision of adjustments, accommodations, and supports for Autistic students in educational settings *(Autism CRC mapping)*.
  + Impacts are greater for students with behaviours of concern, as they are sometimes disciplined, excluded or suspended from school *(inquiries and consultations)*.
* There is a need to improve knowledge, understanding, and support of autism in each level of education, and additional support for Autistic school students is needed *(SA Government consultation paper)*.
* Schools focus on neurotypical learning approaches and school environments can make it difficult for Autistic students to attend, feel comfortable, or achieve good learning outcomes *(Autism CRC mapping)*.
* Many Autistic students require reasonable adaptive personalised adjustments to support active participation, and schools need to be better resourced to provide adequate supports for Autistic students *(inquiries and consultations)*.
* Sensory issues are not adequately considered in many schools *(inquiries and consultations)*.
* The individual risk factors for school refusal include disability (including autism, ADHD and learning disorders) and mental health challenges (including anxiety and depression) *(Senate School Refusal report).*
* There is a need for better awareness and understanding of school refusal, and support for a coordinated national approach to school refusal given the roles the Australian and state and territory governments have in delivering education. This includes a lack of a national approach to data collection and reporting which hinders the understanding of the prevalence of school refusal *(Senate School Refusal report).*
* Many Autistic students are unlikely to receive the necessary supports to finish secondary school *(inquiries and consultations)*.
* Financial barriers to home schooling (e.g: loss of family income, the cost of purchasing resources, and other costs associated with home-schooling), need to be removed so families who are prepared to put their careers and incomes on hold to educate their child can do so *(inquiries and consultations)*.
* Many Autistic students can experience bullying and abuse *(inquiries and consultations)*.
* There are differences in the levels of support for Autistic students between jurisdictions *(inquiries and consultations)*.
* Education for teachers of First Nations Autistic students is needed, this is particularly important as late diagnosis of autism can occur due to cultural differences from non‑Indigenous groups *(FPDN paper)*.
* Limited self-advocacy skills can make it difficult for Autistic postsecondary students to access available supports and programs (e.g: peer mentoring programs; mental health; and sensory interventions) impacting on Autistic students’ outcomes *(Autism CRC)*.
* Late diagnosis of Autistic women and girls has significant impacts upon their life outcomes in relation to education due to not receiving supports. Many girls diagnosed with autism do not meet the criteria for school-based funding, because they exhibit lower levels of disruptive behaviour and may have developmentally appropriate language skills *(WWDA paper)*.
* It is unclear who is responsible for ensuring inclusive education standards are being met, particularly in regional and remote areas *(inquiries and consultations).*

### Employment

* A disproportionate number of Autistic people are unemployed or underemployed due to limited opportunities and barriers to employment, and lack of support to transition from education to employment *(inquiries and consultations)*.
* Common barriers to employment include: the lack of clarity about the application process; issues with interviews; challenging environments; a lack of flexible working arrangements; and lack of autism awareness among employers *(inquiries and consultations, Autism CRC mapping, and SA Government consultation paper)*.
* There is a lack of awareness among employers and workforces of the importance of diversity, and the value that can be offered by Autistic employees, this can also potentially lead to bullying and discrimination in the workplace *(inquiries and consultations, and Autism CRC mapping)*.
* Ableism, racism and bullying are experienced by First Nations Autistic people. Employers need to focus on strengths, and the benefits Autistic employees bring to the workplace *(FPDN paper)*.
* There is a relatively high proportion of Autistic people working in Australian Disability Enterprises. This suggests an under-utilisation of Autistic people’s skills *(Committee report).*

### Transport

* Many Autistic people feel public transport is inaccessible and unsafe, and experience anxiety with driving, this can impact their ability to travel for work and to access health and other supports *(inquiries and consultations, and Committee report).*
* To take part in social, economic and cultural life, people need to be able to travel around the community. Many Autistic people choose not to, or are not able to operate a vehicle, and rely on public transport. Autistic people often have negative experiences using public transport, resulting from the sensory environment, changes in routine, and encounters with staff who have limited understanding of their preferences and behaviours *(Vic Government Autism Plan).*

## Potential areas for action to improve economic inclusion outcomes

**Education**

* Improve the level of autism knowledge and understanding of educators, schools, and tertiary institutions *(Autism CRC mapping)*.
* Additional teaching support is needed for Autistic students, and appropriate adjustments and accommodations are required to support neurodiversity *(inquiries and consultations)*.
* Structured support for Autistic high school students, and greater support for children moving from primary to high school is needed *(SA Government consultation paper)*.
* Promote autism‑friendly campuses and information, and adopt autism inclusion and peer mentoring programs *(Autism CRC mapping)*.
* Consideration of sensory environments is needed in educational settings *(Autism CRC mapping)*.
* More data is needed on Autistic people in educational settings as the number of Autistic students is rising and better support to transition from primary school to secondary school, and tertiary education is required *(inquiries and consultations)*.

**Employment**

* Greater awareness and understanding of autism among employers and interviewers is needed, including the benefit of inclusivity and diversity in their workplace *(inquiries and consultations, and Autism CRC mapping).*
* Effective employment supports may include: autism awareness in the workplace; career guidance; reasonable adjustments in the workplace; flexible working arrangements; and access to employment services (*inquiries and consultations)*.
* Recruitment adjustments are needed, including: providing relevant information before interview; carers attending alongside in interview; paid employment trials; board experience; employment support services, including support to transition from education to employment; and support with application and interview processes *(Autism CRC, and SA Government consultation paper)*.
* More volunteering, internship programs, small business grants, start-up courses, and mentoring opportunities could create more pathways into employment *(inquiries and consultations)*.
* Greater employment of Autistic people could also be achieved by government-funded trainees, quotas and autism entry programs, or incentivising employers to hire Autistic people and match job roles with Autistic peoples’ strengths *(Autism CRC mapping, and SA Government consultation paper)*.
* Further research is needed on the experiences and needs of Autistic people in the workplace, and on what effective neurodiversity framed supports, and neurodivergent focussed programs may work to increase employment and employment related skills *(Autism CRC mapping)*.
* Expand safe sensory friendly spaces and areas for Autistic people in the workplace *(SA Government consultation paper, and Autism CRC mapping)*.

**Transport**

* There is a need to make transport more autism-inclusive *(Committee report).*
* There is a need to provide training for transport workers and improvements in accessibility, including: clear signage; verbal announcements; and the same driver and the same seat *(inquiries and consultations).*

| Discussion Questions – Economic Inclusion We have heard there is a need to improve knowledge, understanding, and support for autism in education, and additional support for Autistic students is needed. More is needed in terms of helping employers understand autism, and what physical and flexible workplace considerations they could make to support Autistic staff. Increased pathways into employment are needed as well, as support to assist Autistic people apply for jobs are key to improving economic inclusion.   1. Are there any other issues experienced by Autistic people that affect their economic inclusion?  * To answer this question you might like to tell us what has prevented you from being able to fully participate in education, employment, or getting access to transport?  1. How do you think we can better support the economic inclusion of Autistic people?  * To answer this question you might like to tell us how services and supports could be improved to help you participate in education or work, have a career or your own business?  1. How do you think we can better support Autistic people in education, employment and the workforce? 2. How would you describe better economic inclusion for autistic people? |
| --- |

# Key Theme 3: Diagnosis, Services and Supports

## Key findings relating to diagnosis, services and supports

### Assessment and diagnosis

* Difficulties are experienced by Autistic people at all stages of the diagnosis process. The diagnostic process can be long, confusing, deficit-based, and expensive, and there are a lack of professionals who follow the National Guideline for the Assessment and Diagnosis of Autism (currently being updated to reflect the latest evidence base) or who use a neurodiversity affirming approach *(Autism CRC mapping)*.
* Timely diagnosis is necessary for early support and the age of diagnosis is often too late *(Autism CRC mapping)*.
* There are long wait times for diagnosis with public assessments, which can result in families being driven to costly private assessments while others miss out as they cannot afford alternate supports *(inquiries and consultations, and Autism CRC mapping)*.
* Wait lists can be exacerbated by complex referrals, dismissive doctors or teachers, and misdiagnosis *(inquiries and consultations)*.
* Having an autism diagnosis could potentially mitigate risk factors around suicide. The vulnerability of Autistic women can potentially be mitigated if the individual is aware of Autistic traits and potential risk factors for victimisation *(FPDN paper)*.
* There are limited public resources about autism assessment and diagnosis, which impacts on the timeliness of diagnosis *(inquiries and consultations)*.
* It is clear that Autistic women and girls remain undiagnosed at the age of 18. Historically, there have been significant levels of misdiagnosis or under‑diagnosis and gender bias in diagnosis. The impact of late diagnosis is great, especially for women and girls, or people with co-occurring conditions *(inquiries and consultations, and WWDA paper)*.
* Key professionals are not equipped with adequate knowledge about autism and are less likely to identify Autistic traits in women and girls due to a belief that autism is primarily a male condition *(WWDA paper).*
* Misdiagnosis is prevalent, especially in remote communities, due to delays, co‑occurring conditions, or the lack of culturally appropriate diagnostic tools *(FPDN paper)*.
* People with a dual diagnosis of autism and intellectual disability may experience differences to people with an autism, or intellectual disability diagnoses alone. The intersection of autism and intellectual disability is a multifaceted experience with compounding impacts *(Inclusion Australia).*
* Maternal and child health nurses, general practitioners, early childhood education and care professionals and teachers play an important role in assessing whether a child, young person or adult may need further screening and referral for an autism assessment. Professionals often need greater capability in recognising characteristics or behaviours associated with autism *(Vic Government Autism Plan).*

### Early supports and services

* There are delays in early identification and family education and support services *(Committee report)*.
* Early support for children is frequently not based on best practice. There is not enough focus on supporting children and families in their everyday environments – in the home, in early childhood education and services, and in the community. The increasing reliance on therapy delivered in clinical settings has got in the way of children living ordinary and inclusive childhoods *(NDIS Review: what we have heard)*.
* Frontline workers including General Practitioners, nurses, childcare, teachers, and psychologists need to be trained in early detection and supports *(inquiries and consultations)*.
* Families need guidance through pathways, especially early childhood early intervention programs. The role of local area coordinators could be better promoted along with the supports that Autistic people can access *(inquiries and consultations)*.
* Some families do not have the financial or emotional capacity to support their Autistic children *(inquiries and consultations)*.
* The lack of early support can result in patterns emerging of depression and anxiety, and other mental health issues as children become adults *(inquiries and consultations)*.
* Early childhood early intervention resourcing limits consistency and accessibility *(inquiries and consultations)*.
* As the child grows, the need for services and supports can grow and adequate supports are often not available *(inquiries and consultations)*.

### Accessing supports and services

* Autistic people find the current service environment complex and poorly integrated, which is a key factor contributing to poor outcomes for Autistic people accessing supports and services *(Committee report)*.
* A lack of timely access to support services is linked to long waitlists, the high cost of accessing services, and the lack of quality health professionals and trained staff who are competent and have an understanding of neurodivergence *(Autism CRC mapping)*.
* Autistic people and their families and carers experience difficulties navigating the support system, and there is a lack of respite care for families and carers *(inquiries and consultations)*.
* Autism is a lifelong disability and support must continue into adulthood *(inquiries and consultations)*.
* There is a lack of services for Autistic people and their families and carers who live in regional areas *(inquiries and consultations)*.
* Many services need culturally safe practices for First Nations and culturally and linguistically diverse communities *(inquiries and consultations, and FPDN paper)*.
* Improvements are needed in proactive prevention for Autistic girls and women who may be susceptible to abuse *(inquiries and consultations, and WWDA paper)*.
* Updated information on autism awareness programs, timely diagnosis and diagnostic tools for under-represented groups, and reproductive and sexual health is needed *(inquiries and reviews)*.
* The high cost of services are an issue and services are often restricted to urban areas *(FPDN paper)*.
* Late diagnosis has significant impacts on access to support for Autistic women and girls *(WWDA paper)*.
* Due to barriers they face in accessing services, some Autistic people do not seek support unless they are ‘absolutely desperate’ *(WWDA paper)*.
* There are concerns about giving feedback regarding service providers being resolved in an appropriate manner or provoking retaliation *(Inclusion Australia)*.
* The role of behaviour science in services and supports for Autistic people is the most challenging and contentious *(A4 paper)*.
* There is a need to recognise autism as a distinct neurology that needs specific services that are different from other disability services *(A4 paper)*.
* Allied Health professionals have a lack of understanding, knowledge and awareness of co-existing medical conditions with autism *(SA Government consultation paper)*.
* Support can vary widely depending on the ‘primary’ diagnosis *(Inclusion Australia paper)*.

### Advocacy

* There is a need to consult with Autistic-led groups that represent all perspectives, especially co-occurring conditions, and not just general disability peak organisations *(inquiries and consultations)*.
* Parents and carers of Autistic children and relatives struggle with a lack of support and a constant need to provide advocacy *(SA Government consultation paper)*.
* There is a need to understand and accommodate the critical voice of families and independent advocates in supporting people with complex support needs, and sharing their experiences *(Inclusion Australia paper)*.
* There is a risk that Autistic people who need substantial and constant support can be forgotten as they may be unable to speak for themselves *(A4 paper)*.

### Research and data

* New or updated research is needed in specific areas, for example, under-represented groups *(inquiries and consultations)*.
* Data is needed on the effectiveness of therapies, primarily for early supports for infants and adults in the long-term *(inquiries and consultations)*.

## Potential actions to improve diagnosis, services and supports outcomes

| **Assessment and diagnosis**   * Build the understanding of autism within key professions and the wider community *(Committee report)*. * There is a need for improvements across the diagnosis process, including: increasing the number of professionals with knowledge of autism able to diagnose; reducing financial barriers to diagnosis; ensuring an clear and equitable approach to diagnosis; and using a neurodiversity affirming approach *(Autism CRC mapping, and SA Government consultation paper)*. * The National Guideline for Assessment and Diagnosis of Autism (currently being updated to reflect the latest evidence base) outlines guiding principles and recommendations for the early supports process that speaks to the child and family‑centred supports, that are individualised, strength-based and neurodivergent affirming *(Autism CRC mapping)*. * Better access to assessment and diagnosis is required for First Nations people. Have autism assessments fully subsidised by Medicare to enable equity in access *(FPDN paper)*. * A cultural model of support with regard to assessment and diagnosis is needed for First Nations people *(FPDN paper)*. * To remedy gender bias in the diagnostic process, clinicians should seek to obtain an in‑depth understanding of a person’s behaviours and experiences across a variety of contexts, rather than relying on whether or not a person has met relevant score thresholds *(WWDA paper)*. |
| --- |

| **Early supports and services**   * Need to improve access to a range of affordable early support services and supports, with professionals who have an increased level of autism knowledge and understanding *(Autism CRC mapping, and Committee report)*. * Need more consideration of the effect of the supports on caregivers, the influence and method of delivery had on outcomes, or the influence of the individual characteristics of the child (e.g.: age, co-occurring conditions) *(Autism CRC mapping)*. |
| --- |

| **Accessing supports and services**   * Improve supports for parents and carers and service integration and coordination *(Committee report)*. * Further education needs to be provided for all service providers around autism. The autism spectrum is broad and fluid, meaning that support needs for an individual on a particular day may change on subsequent days depending on stressors, the environment, and general health *(FPDN paper)*. * Autism and the accompanying supports need to be viewed through a strengths-based lens – not seen as a deficit. Supports are to be flexible and tailored based on individual, family and community need *(FPDN paper)*. * Have an inclusive approach that integrates services and support within the mainstream *(A4 paper)*. * Creation of a central website for autism services and supports *(SA Government consultation paper)*. * Need to consult with Autistic people and Autistic-led organisations on service integration, coordination and pathway issues, and public services need coordination across the whole-of-life of the condition *(inquiries and consultations).* |
| --- |

| **Advocacy**   * Families should be provided with clear and correct information to support and advocate for their Autistic family members *(Autism CRC mapping)*. * Advocacy organisations support investment into peer networks and post‑diagnosis support groups to strengthen community control by Autistic people *(inquiries and consultations)*. * Listening to Autistic voices and ongoing collaboration and consultation with the Autistic and autism communities is needed *(SA Government consultation paper)*. * People who access advocacy services receive better supports *(inquiries and consultations)*. |
| --- |

| **Research and data**   * Establish a national autism research agenda *(Committee report)*. * Ongoing research and continual evaluation is required to ensure diagnoses are made with the best available tools and processes, and to understand the diagnostic experiences and priorities of Autistic people and their supporters, particularly those from marginalised groups *(Autism CRC mapping).* |
| --- |

| Discussion Questions – Diagnosis, Services and Supports We have heard that we need to build the understanding of autism of professionals and the broader community, and there is a need for improvements across the diagnostic process. The cost and time it takes to undergo the assessment and diagnosis process has great impacts on individuals, and their families and carers, receiving the supports they need. Supports and services need to be evidence-based. Additionally, improvements to service and supports pathways and coordination are needed.   1. Are there other issues about diagnosis, services and supports experienced by Autistic people that you would like to add?  * To answer this question you might like to tell us what has prevented you from getting a diagnosis, or accessing services and supports that would help you live the life you want?  1. How could we improve access to diagnosis, services and supports for Autistic people?  * To answer this question you might like to tell us what has helped you to access a diagnosis, services or supports.  1. How can we better support access to neurodiversity-affirming, person-centred services and supports for Autistic people? 2. How can we better make sure that diagnosis, services and supports for Autistic people are strengths-based, culturally responsive and trauma-informed? 3. How would you describe what better access to diagnosis, services and supports looks like for Autistic people? |
| --- |

# Key Theme 4: National Roadmap to Improve the Health and Mental Health of Autistic People

### Key message

| The **National Roadmap is being developed through a separate process by the Department of Health and Aged Care.** If you choose to address any issues that fall within the remit of the National Roadmap in your response, DSS will provide this to the Department of Health and Aged Care for consideration in their development of the Roadmap.  The **Department of Health and Aged Care will be undertaking a separate co-design and consultation process** to inform development of the National Roadmap. If you would like further information about their consultation process and how you can participate please visit: [Department](http://www.health.gov.au/our-work/national-roadmap-to-improve-the-health-and-mental-health-of-autistic-people) of Health and Aged Care. |
| --- |

## Key findings relating to health and mental health

### Physical health

* Many physical healthcare providers do not have sufficient knowledge of autism, do not know how to tailor their approaches to Autistic clients, or do not provide the accommodations or supports that would enable Autistic people to access their service *(Autism CRC mapping, and inquiries and consultations)*.
* The environment (sensory experience) of physical healthcare settings, and the communication demands and logistics of making appointments, reduces the accessibility of healthcare services for Autistic people. This can result in people avoiding accessing physical healthcare, even when necessary *(Autism CRC mapping, and inquiries and consultations)*.
* Some Autistic people feel they are dismissed or not believed by healthcare providers *(Autism CRC mapping)*.
* Problems with accessing physical healthcare are in addition to broader issues of long wait lists, high costs, and limited availability of providers *(Autism CRC mapping)*.
* Autistic women, girls and non-binary people experience various co-occurring health conditions which can have a significant impact on their wellbeing. This can be exacerbated by late or delayed diagnosis *(WWDA paper)*.

### Mental health

* Many mental health providers do not have sufficient knowledge of autism or its inter‑relationship with mental health problems or other diagnosis *(Autism CRC mapping)*.
* Many providers do not know how to tailor their approaches to Autistic clients or do not provide the accommodations or supports that would enable Autistic people to access their services *(Autism CRC mapping)*.
* Limited availability of providers, long wait lists and prohibitive costs lead to many Autistic people not accessing supports, or having to wait a long time to access supports *(Autism CRC mapping)*.
* Lack of services is particularly impactful for the Autistic community given research showing significantly more Autistic people than non-Autistic people experience mental health challenges *(Autism CRC mapping)*.
* Autistic women, girls and non-binary people experience various co-occurring health conditions which can have a significant impact on their wellbeing *(WWDA paper)*.
* There are links to ‘masking’ autism with poor mental health outcomes *(WWDA paper)*.
* Late diagnosis has significant impacts upon life outcomes in relation to health and access to support *(WWDA paper)*.
* There are many experiences of Autistic burnout[[19]](#footnote-20) among First Nations Autistic people, and First Nations people face healthcare and cultural disadvantages *(FPDN paper).*

### Access to supports, services and information

* There is a lack of available appropriate supports increasing the risk of co-occurring conditions for Autistic people *(inquiries and consultations)*.
* There is a lack of flexibility and rescheduling of appointments in rural and regional areas *(inquiries and consultations)*.
* There is a lack of culturally appropriate information for First Nations and culturally and linguistically diverse communities *(inquiries and consultations)*.
* Government services and information are fragmented, with Autistic people falling through gaps between supports provided by different levels of government *(inquiries and consultations)*.

| Discussion Questions – Health and Mental Health  1. Are there other health and mental health issues experienced by Autistic people that the National Autism Strategy should help to address? 2. How can we better support health and mental health outcomes for Autistic people?  * To answer this question you might like to tell us what needs to improve about health and mental health services and supports? |
| --- |

## Further information about the National Roadmap co-design and consultation process

The Department of Health and Aged Care will be undertaking a separate co-design and consultation process to inform development of the Roadmap. If you would like further information about their consultation process and how you can participate please visit: [Department](http://www.health.gov.au/our-work/national-roadmap-to-improve-the-health-and-mental-health-of-autistic-people) of Health and Aged Care.

# Glossary

| **Term** | **Definition** |
| --- | --- |
| ADS | Australia’s Disability Strategy 2021-31. |
| Autistic burnout | Autistic burnout results from chronic life stress and a mismatch of expectations and abilities without adequate supports. It is characterised by pervasive, long-term (typically 3+ months) exhaustion, loss of function, and reduced tolerance to stimulus. |
| Autism CRC | Autism CRC is an independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum. |
| Committee | Senate Select Committee on Autism. |
| DSS | Department of Social Services. |
| Intersectionality | Intersectionality refers to ways in which different aspects of a person’s identity can expose them to overlapping forms of discrimination and marginalisation based on attributes such as: age; disability; ethnicity; gender identity; race; religion; and sexual orientation. |
| LGBTQIA+ | Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex, Asexual. |
| Masking | Hiding or controlling behaviours associated with autism that could be viewed as inappropriate in order to be socially accepted. |
| National Roadmap | The National Roadmap to Improve Health and Mental Health of Autistic People. |
| NDIS | National Disability Insurance Scheme. |
| Oversight Council | The National Autism Strategy Oversight Council. |
| UN CRPD | United Nations Convention on the Rights of Persons with Disabilities. |

1. [www.disabilitygateway.gov.au/ads](http://www.disabilitygateway.gov.au/ads) [↑](#footnote-ref-2)
2. [www.aph.gov.au/select\_autism](http://www.aph.gov.au/select_autism) [↑](#footnote-ref-3)
3. [www.dss.gov.au/our-responsibilities/disability-and-carers/programmes-services/government-international/disability-reform-ministers-meeting](http://www.dss.gov.au/our-responsibilities/disability-and-carers/programmes-services/government-international/disability-reform-ministers-meeting) [↑](#footnote-ref-4)
4. [www.dss.gov.au/how-we-consulted-on-the-development-of-australias-disability-strategy-2021-2031](http://www.dss.gov.au/how-we-consulted-on-the-development-of-australias-disability-strategy-2021-2031) [↑](#footnote-ref-5)
5. [www.disability.royalcommission.gov.au](http://www.disability.royalcommission.gov.au) [↑](#footnote-ref-6)
6. [www.aph.gov.au/parliamentary\_business/committees/joint/national\_disability\_insurance\_scheme](http://www.aph.gov.au/parliamentary_business/committees/joint/national_disability_insurance_scheme) [↑](#footnote-ref-7)
7. [www.autismcrc.com.au](http://www.autismcrc.com.au) [↑](#footnote-ref-8)
8. [www.yoursay.sa.gov.au/state-autism-strategy](http://www.yoursay.sa.gov.au/state-autism-strategy) [↑](#footnote-ref-9)
9. [www.statedisabilityplan.vic.gov.au/victoria-autism-plan](http://www.statedisabilityplan.vic.gov.au/victoria-autism-plan) [↑](#footnote-ref-10)
10. [www.ndisreview.gov.au/resources/reports/what-we-have-heard-report](http://www.ndisreview.gov.au/resources/reports/what-we-have-heard-report) [↑](#footnote-ref-11)
11. [www.aph.gov.au/Parliamentary\_Business/Committees/Senate/Education\_and\_Employment/SchoolRefusal](http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Education_and_Employment/SchoolRefusal) [↑](#footnote-ref-12)
12. ‘Intersectionality’ refers to ways in which different aspects of a person’s identity can expose them to overlapping forms of discrimination and marginalisation based on attributes such as: age; disability; ethnicity; gender identity; race; religion; and sexual orientation. [↑](#footnote-ref-13)
13. [www.dss.gov.au/publications-articles-responses-to-government-inquiries/australian-government-response-to-the-senate-select-committee-on-autism](http://www.dss.gov.au/publications-articles-responses-to-government-inquiries/australian-government-response-to-the-senate-select-committee-on-autism) [↑](#footnote-ref-14)
14. [www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/consultation-and-advocacy/national-disability-peak-bodies](http://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/consultation-and-advocacy/national-disability-peak-bodies) [↑](#footnote-ref-15)
15. [www.inclusionaustralia.org.au/submission/engaging-with-autistic-people-with-an-intellectual-disability](http://www.inclusionaustralia.org.au/submission/engaging-with-autistic-people-with-an-intellectual-disability) [↑](#footnote-ref-16)
16. [↑](#footnote-ref-17)
17. ‘Neurodiversity affirming approaches’ seek to affirm the person’s neurodivergent identity. In the context of autism, this refers to providing supports that embrace each person’s unique understanding of other people and the world around them. [↑](#footnote-ref-18)
18. ‘Diversionary pathways’ consider reasons behind a person’s offending behaviour and provide treatment and support options to eligible people facing criminal charges. [↑](#footnote-ref-19)
19. [www.spectrumnews.org/news/autistic-burnout-explained/](http://www.spectrumnews.org/news/autistic-burnout-explained/) [↑](#footnote-ref-20)