



Developing a National Autism Strategy

Summary discussion paper

This is a summary of the discussion paper about developing a National Autism Strategy (the Strategy). In this document, we talk about:

- Why we need a National Autism Strategy
- How it will be developed
- How you can get involved
- Four discussion areas:
 - [social inclusion](#)
 - [economic inclusion](#)
 - [diagnosis, services and supports](#)
 - [National Roadmap to Improve the Health and Mental Health of Autistic People](#).

Each area has questions that will help us learn what should be in the National Autism Strategy.

The need for a National Autism Strategy

A new National Autism Strategy will provide a coordinated, national approach to governments and services giving better support to Autistic people and their families.

Life outcomes for Autistic people are worse than they should be. For example, Autistic people have a lower life expectancy than other Australians.

It can be harder for Autistic people and their families to get the help they need. This includes getting:

- the right healthcare
- support at school or university
- job opportunities
- secure housing.

How the National Autism Strategy is being developed

An [Oversight Council](#) has been set up to help develop the National Autism Strategy. It includes an Autistic co-chair and majority Autistic members.

The Autism CRC co-designed an inclusive community engagement and consultation process. This process will inform the National Autism Strategy.

Now we want Autistic people, families and carers, and community members to have their say.

Have your say

This round of public engagement will run until **30 October 2023**. Visit the [Department of Social Services website](#) to find ways you can get involved.

You can:

- Make a [submission](#) or answer the guided questions online
- Share your ideas on an [online ideas wall](#)
- Register for an [online workshop](#)
- Come to a [community](#) engagement event in one of 15 locations around Australia.

Key discussion questions

- What does a National Autism Strategy need to achieve?
- How can the Strategy support the rights, autonomy, and diversity of Autistic people?
- What needs to improve so Autistic people are better supported for their whole life?
- What can we do to better support Autistic people from different population groups? This includes:
 - 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.
- What might help to improve people's understanding of Autism?
- Are there any areas missing from this discussion paper that should be a priority in the Strategy?

Help and support

Please be aware that this paper contains 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.

[Lifeline Crisis Support](#): Telephone 13 11 14, 24 hours, 7 days a week.

Autism Connect is a free, national helpline providing independent and expert Autism information that you can trust over phone, email and webchat. Call **1300 308 699** to speak with an Autism Connect Advisor or visit [Autism Connect](#) to find out more or connect via email or webchat.

[13YARN](#) provides support from First Nations crisis counsellors. **Telephone 13YARN (13 92 76), 24 hours, 7 days a week.**

We will take a trauma-informed approach to all consultation activities.

Discussion areas

1. Social inclusion

The problem

There are lots of reasons why Autistic people are not able to live the lives they want and deserve. This can include:

- Autistic people can **experience social isolation** or exclusion from activities.
- **Autism is not well understood** in the community. This includes among front line services (nurses, doctors, teachers, and emergency responders) and in essential government services.
- **Information about Autism and the supports available is often difficult to understand.** Particularly for diverse communities including First Nations people and people from culturally and linguistically diverse backgrounds.
- It is likely that Autistic people are at higher risk of experiencing **housing stress**. There is a lack of **appropriate, safe and affordable housing** options for Autistic people to live independently. Some Autistic people face discrimination in the private rental market.
- Autistic people are more likely to be victims and witnesses of crime than offenders. Autistic people are at **greater risk of involvement with the justice system**. A lack of awareness and understanding means increased chances of arrest and discrimination. It can impact sentencing and can cause difficulty in detention settings.
- **Intersectional communities face extra barriers.** For example, First Nations Autistic people, Autistic people from multicultural backgrounds and LGBTIQ+ communities. These groups can lack culturally safe supports. They can also experience racism, ableism, stigma and shame.
- Many Autistic people feel like others want them to **hide or mask their Autism to fit in**. This is a particular problem for Autistic women and girls.

Potential areas of action

Areas that a National Autism Strategy might need to focus on to help address these issues:

- **Better access to supports, services and information** that help Autistic people and their families to understand Autism.
- **Improve understanding of Autism**, and its diversity, in the community. This is especially important within health, government services, professionals and workplaces.
- Make sure Autistic people have choice and control over where they live. This includes better availability of accessible and affordable housing options.
- Sensory considerate physical environments (e.g. schools, hospitals, court rooms).
- **A better understanding of Autism and specific policies in the justice system** to improve the experiences of Autistic people and the prevent over-representation of Autistic people. This could include **Autism-specific legal services**.
- Cultural model of disability and First Nations understandings of neurodivergence to be embedded in each aspect of life for First Nations Autistic people.

Discussion questions

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

2. Economic inclusion

The problem

There are barriers for Autistic people to participate in education and employment. These can include:

- **A lack of understanding of Autism** amongst educational professionals (like teachers) and students. This can leave Autistic students unsupported or excluded from school. It can include bullying or abuse.
- Autistic students may **need reasonable adjustments** to take part in schooling. Schools need to be better resourced to provide these adjustments.
- There needs to be a better awareness and understanding of school refusal in Autistic students.
- Autistic post-secondary students can have **limited self-advocacy skills**. This can stop them from asking for things that would help in their studies making it more difficult to get supports and therefore impacting outcomes.
- **Late diagnosis of Autistic women and girls** can impact their life outcomes. Especially in relation to education because they didn't get supports they may have needed during school years.
- More Autistic people are **unemployed or under employed**. There is a high proportion of Autistic people working in Australian Disability Enterprises. This suggests Autistic people's skills are under-utilised.
- Barriers to employment can include:
 - the application process
 - challenging environments
 - lack of flexibility.
 - low Autism awareness among employers.
- First Nations Autistic people experience **ableism, racism, and bullying**.
- People need to be able to travel around the community to take part in social and economic life. However, many Autistic people have negative experiences. They feel **public transport is inaccessible and unsafe**. This can make it difficult to travel to school or work.

Potential areas of action

Areas that a National Autism Strategy might need to focus on to help address these issues:

- Increase Autism knowledge and understanding in educators, schools and institutions.
- Extra teaching support and appropriate adjustments and accommodations – including consideration of sensory environments.
- **Greater understanding of Autism among employers** and in workplaces. This should include the benefits of inclusivity and diversity.
- **More pathways to employment** for Autistic people. This could include volunteering, internship, small business grants, start-up courses and mentoring opportunities.
- **Transport should be more Autism-inclusive**. Training should be provided to transport workers and improvements made in transport accessibility.

Discussion questions

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

3. Diagnosis, services and supports

The problem

Autistic people can experience difficulties at all stages of the diagnosis process. It can also be hard to find and access appropriate services and supports. This can include:

- The **diagnosis process** is long, confusing and expensive. It can make Autistic people feel like they do things wrong or are a problem. If diagnosis takes too long, people can miss out on support they need early in life.
- **Misdiagnosis and underdiagnosis** is very common, particularly amongst women and girls. It can also be common in remote communities. This can be because of delays or co-occurring conditions. There may also be a lack of culturally appropriate diagnostic tools.
- **Families need help** to understand what support is available. Some families don't have the money or emotional strength to support their Autistic children. There is a lack of respite care for families and carers.
- **Early intervention** is often not focused on supporting children in their everyday environments. For example, home, childcare, school and community. Relying on therapies in clinical settings can stop children from living ordinary, inclusive childhoods.
- **Services and supports are not connected.** This makes it difficult for Autistic people to ask for and get the help they need. People need balanced information so they can make informed choices.
- **Long waitlists, high costs and a lack of safe** supports and services can be barriers to getting help.
- Allied Health professionals **lack understanding, knowledge,** and awareness of co-existing medical conditions.
- There is a need for **new or updated research.** Including in areas like under-represented groups and effectiveness of therapies.

Potential areas of action

Areas that a National Autism Strategy might need to focus on to help address these issues:

- **Improve the diagnosis process.** This includes more professionals with the knowledge and ability to diagnose Autism.
- Build the understanding of Autism within key professions (e.g. nurses, doctors, teachers).
- Improve access to affordable early intervention services and supports.
- Make sure First Nations people have better access to assessment and diagnosis.
- Creation of a central website for Autism services and supports.
- Have an inclusive approach that integrates services and support within the mainstream
- Establishing a national Autism research agenda.

Discussion questions

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

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

The National Roadmap is being developed through a separate process by the Department of Health and Aged Care.

The problem

- Many healthcare providers don't have enough **knowledge of Autism**. They don't know how to tailor their approach for Autistic clients.
- Autistic people can **avoid getting healthcare** because of the sensory experience. This includes communication demands and the logistics of making appointments.
- Some Autistic people feel **dismissed or not believed** by healthcare providers.
- Providers can have **limited availability, long wait lists** and **high costs**. This means many Autistic people don't get mental health support.
- A **lack of available supports** increases the risk of co-occurring conditions.
- There is a **lack of culturally appropriate information** for First Nations and culturally and linguistically diverse communities
- **Government services and information are fragmented**. This means Autistic people fall through gaps between supports.

Insights from this consultation process about health and mental health will be shared with the Department of Health and Aged Care to help in the development of the Roadmap.

Visit the [Department of Health and Aged Care website](#) for more information about how you can be involved.

Discussion questions

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

Contact

For more information about the National Autism Strategy visit www.dss.gov.au/national-autism-strategy

For queries about the National Autism Strategy, please contact the Department of Social Services at AutismPolicy@dss.gov.au

For queries about how to get involved in the consultations, including support to register for a consultation activity please contact The Social Deck at engage@thesocialdeck.com or on 0458 228 142.