Help shape the change.

Draft National Autism Strategy

This is a draft Strategy which has not yet been agreed by Government. Following feedback through the public consultation process the draft Strategy will be further refined and it is expected the final Strategy will be presented to Government by the end of 2024.

The National Autism Strategy is an Australian Government strategy and relates to areas of Commonwealth responsibility to improve life outcomes for Autistic people.

Feedback from the community on issues relating to states and territories has been shared with state and territory governments.

In any areas of joint responsibility between the Commonwealth and state and territory governments, the Strategy will guide the Australian Government's engagement with jurisdictions.

Table of Contents

Acknowledgement of Country	4
Acknowledgement of Autistic people and their families and the autism community	4
Statement on Language	4
Statement on Neurodiversity	4
Content warning	5
Introduction	6
Background	6
Vision Statement	8
Goal	8
Guiding Principles	8
Commitments	
About Autism	12
Employment	12
Education	
Safety, health and wellbeing	13
National Consultation	14
What should a National Autism Strategy achieve?	16
Strategy Foundations	17
Outcome Areas and Commitments	20
Social Inclusion	20
Economic Inclusion	22
Diagnosis, supports and services	24
Health and Mental Health	27
Implementation – Delivering on the Outcome Areas	28
Implementing the National Autism Strategy	28
Governance	28
Research	29
Evidence Framework	30
Evaluation and Reporting	32
Acronyms	33
Glossary	34
Appendices	39
Appendix A - Roles and Responsibilities of Governments	40
Appendix B - How the National Autism Strategy was developed	44

	Appendix C - Connection to other Australian Government Action	45
	Appendix D – Common co-occurring neurotypes, disabilities and medical health conditions	49
	Appendix E – Theory of Change diagram	50
Εı	ndnotes	51



Acknowledgement of Country

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

Acknowledgement of Autistic people and their families and the autism community

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

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 and autism 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. Some Autistic people identify as having a disability, while others do not.

The Australian Government uses identity-first language, Autistic person or Autistic people. This approach is supported by current research.

Statement on Neurodiversity

Neurodiversity is a term that is used to describe the natural range of diversity that exists in human neurodevelopment. Although all people process the world differently, some differences are grouped and named.

The neurodiversity of a community arises from the presence of different brain types (also known as 'neurotypes'). There is a majority neurotype (known as 'neurotypical') and there are minority neurotypes (known as 'neurodivergent').

Neurodivergent brains process the world in a way that differs from **neurotypical** brains. Well-known forms of **neurodivergence** include autism, Attention Deficit Hyperactivity Disorder (ADHD), and learning differences (such as dyslexia). Many people are also '**multiply divergent**' (that is, they have more than one different neurotype, for example: autism and ADHD).

Many neurodivergent people (including Autistic people) believe that there is no "normal" or "healthy" type of brain or mind, or one "right" style of neurocognitive functioning.

Overall, the **Neurodiversity Paradigm** — which centres the lived experience of neurodivergent people, including Autistic people — implements a **strengths-based**, **rights-based**, and **neurodiversity-affirming** approach, which seeks to embrace individuality.



Content warning

Please be aware that this Strategy 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 the Strategy, there are free services available to help you.

Beyond Blue Support Service

- Telephone 1300 224 636, 24 hours a day, 7 days a week.
- Chat online 24 hours a day, 7 days a week.
- Email for free, short-term counselling, advice and referral services.
- Website: <u>Beyond Blue Support Service</u>.

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 a day, 7 days a week.
- Chat online 24 hours a day, 7 days a week.
- Website: Lifeline Crisis Support.

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

- 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: <u>1800RESPECT</u>.

13 YARN

- Support from First Nations crisis counsellors is available at 13YARN (13 92 76) or by visiting: 13
 YARN.
- Available 24 hours a day, 7 days a week.

Autism Connect

- A free, national autism helpline, providing independent and expert information about autism over the phone, email and webchat. It supports Autistic people, their families and carers and support networks, health professionals, researchers, teachers, employers and the broader community.
- Available from 8am to 7pm, Monday to Friday. Telephone 1300 308 699.
- Website: <u>Autism Connect</u>.

5 - National Autism Strategy

Trauma-informed approach

The Department of Social Services is committed to adopting a trauma-informed approach to the development of this Strategy, including the national engagement and consultation process, and implementation of the Strategy.



Introduction

This Strategy sets out a framework for improving the life outcomes for Autistic people in the years ahead. It includes a vision, goal and guiding principles which frame the scope of effort.

This Strategy is focussed on four key outcome areas:

- social inclusion
- economic inclusion
- diagnosis, services and support, and
- health and mental health (the National Roadmap to Improve the Health and Mental Health of Autistic People).

Each outcome area covers a broad range of issues and this draft Strategy includes commitments for three of the key outcome areas: social inclusion; economic inclusion; and diagnosis, services and supports. Actions to improve health and mental health are being developed through the National Roadmap. The specific actions to achieve the commitments will be detailed in Action Plans, which will be co-designed with Autistic people and their families and carers, researchers, policy makers and the broader autism community. These stakeholders will also be involved in implementation, monitoring and reporting on the Strategy.

This is an Australian Government strategy and is intended to operate alongside state and territory autism strategies, where they exist.

Australian, state, territory, and local governments all play a part in supporting Autistic people. Sometimes, more than one government is involved in funding or delivering a service system. In most circumstances, one level of government has the main responsibility for service delivery.

See **Appendix A** for roles and responsibilities of governments.

Background

In 2021, Australia's Disability Strategy 2021-31 (ADS), 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 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 (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 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).

6 - National Autism Strategy



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 to consider shared approaches, where relevant.

Development of the Strategy is being led by the Department of Social Services, reporting to the Minister for Social Services. 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.

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.

See Appendix B for further information on how the National Autism Strategy was developed.

See Appendix C for further information on the connection to other Australian Government action.



Vision Statement

The National Autism Strategy's vision is for a safe, inclusive society. All Autistic people are able to fully participate in all aspects of life, in line with international human rights.

Goal

The goal of the Strategy is to improve life outcomes for all Autistic people.

Guiding Principles

The Guiding Principles set out how the Strategy foundations will be put into practice. The Strategy foundations include the UN CRPD, the biopsychosocial model of disability, strengths-based and neurodiversity-affirming approach, and intersectionality.

In partnership - Nothing about us, without us

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

Accessible based on Universal Design

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

Self Determination and Autonomy

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

Aligned and Accountable Outcomes

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

Acceptance and Inclusivity

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

Rights

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

Individualised and Holistic

8 - National Autism Strategy

This Strategy recognises that there are different aspects of a person's identity¹ that can overlap and shape their diverse needs, abilities and experiences, and that other factors such as geography, socio-economic status, where they live, income, education, and the extent of support networks can also have an impact. This Strategy promotes an individualised and neurodiversity-affirming, holistic person and family-centred approach to meeting these needs and diverse communities across the whole life.



Commitments

The commitments relate to areas of Australian Government responsibility. Feedback from the community on issues relating to states and territories has been shared with state and territory governments. In any areas of joint responsibility between the Commonwealth and state and territory governments, the Strategy will guide the Australian Government's engagement with jurisdictions.

Social Inclusion

- Improve understanding of, and change attitudes towards, Autistic people across all of society, through:
 - a. Greater public education and awareness including a better understanding of autism within workplaces, and with a focus on health, education and the criminal justice system.
 - b. Increasing visibility and representation of Autistic people in the media, sports and the arts.
 - c. Increasing accessible and sensory-friendly public and online spaces.
 - d. Increasing the capability of advocates and advocacy organisations to challenge and reduce stigma of autism.
- 2. Increase opportunities for social connections and peer support.
- 3. Improve Australian Government service delivery, communication, and information to meet the needs of Autistic people.
- 4. Ensure consideration of the needs of Autistic people in future amendments to or reviews of the *Disability Discrimination Act 1992* (Cth) and associated disability standards.
- 5. Improve the safety and welfare of Autistic people through the reduction of all forms of discrimination, violence, abuse, bullying, vilification and exploitation.

Economic Inclusion

- 6. Increase meaningful employment opportunities (including business ownership, self-employment, entrepreneurship and social enterprise) for Autistic people.
- 7. Support employers to hire and retain Autistic employees through improving the accessibility of recruitment processes and fostering workplace environments that are safe and inclusive for all Autistic people.
- 8. Improve the supports and services available to Autistic people to ensure they have choice and control over their education and careers.
- 9. Increase representation of Autistic people in senior and board positions to promote people as visible role models.
- 10. Improve inclusive practices and the quality and accessibility of advocacy resources for Autistic students across all education settings, and their families, carers and support networks.
- 11. Build on commitment 5 *Improve the safety and welfare of Autistic people through the reduction of all forms of discrimination, violence, abuse, bullying, vilification and exploitation* to specifically focus on Autistic students in all levels of education.
- 9 National Autism Strategy

Diagnosis, Services and Supports

- 12. Consider the use and consistency of current identification screening, outcome and diagnostic tools. Work with relevant professional bodies to develop a set of standardised co-designed training/professional development and resource materials to support professionals involved in the identification, assessment and diagnosis of autism to improve the experience, and quality of this process for Autistic people and their families and carers.
- 13. Develop a set of best practice resources to support Autistic people and their families, carers and support networks through the identification, assessment and diagnosis process.
- 14. Explore ways to improve access to primary care, including through the Medicare Benefits Schedule (MBS), to:
 - a. improve quality health and mental health services for Autistic people, with a focus on continuity of care, and
 - b. explore ways to make Autism diagnosis and assessment processes more timely and accessible.
- 15. Consider early screening and identification arrangements, and improved access to health professionals.*
 - * Consideration is to be given to how this commitment links with joint work being undertaken by the Australian and state and territory governments as part of Australia's Disability Strategy 2021-31 and in response to the Independent Review of the NDIS. Details on work to meet this commitment will be developed in Action Plan/s.
- 16. Improve access to quality, timely, neurodiversity-affirming and equitable supports and services for Autistic people, including for people living in rural, regional and remote areas.
- 17. Encourage greater representation of people with lived experience in delivering supports and services to Autistic people.
- 18. Develop a set of best practice training and resource materials for people providing services and supports to Autistic people.
- 19. Explore the feasibility of a decision-making tool to empower Autistic people to make informed decisions about all areas of their life.
- 20. Work with states and territories to improve service integration between the NDIS, foundational supports and mainstream services.

Governance

- 21. Develop a governance framework to support:
 - a. strong accountability mechanisms,
 - b. co-leadership and active involvement of Autistic people, as well as parents and carers, and professionals within the autism sector, and
 - c. whole-of-government, cross-sectoral and coordinated approaches to implementation.



Research

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

Evidence

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

Evaluation and Reporting

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



About Autism

"If you've met one person with autism, you've met one person with autism."

Dr Stephen Shore

There is not one universally accepted definition of autism that captures everyone's experience.

Autism is a lifelong neurodevelopmental difference. Autistic people share common traits that present differently in each Autistic person. Every Autistic person is unique, and their experiences of day-to-day life are dynamic based on the systemic, environmental, and interpersonal barriers that each individual experiences at the time. As such, the support needs for each person differs and may change, particularly around big life transitions, or in certain situations or environments.

Autistic people often excel in some areas and contexts (particularly areas of interest), and thrive in contexts that match their needs and abilities, yet they may also face considerable challenges in other areas without appropriate and timely supports in place.

Over 95% of Autistic people are multiply neurodivergent and have co-occurring disabilities and / or medical health conditions, many of which overlap in diagnostic criteria. This can make it difficult to identify and support Autistic people with multiple differences if people are not aware of them.

Many of these common co-occurring neurotypes, disabilities, and medical health conditions have been listed at **Appendix D**.

More than **200,000** Australians have a diagnosis of autism.³ However, the number of Autistic people living in Australia is likely to be substantially higher. This can be for different reasons. For example, historical approaches to diagnosis, cost or wait times to receive a diagnosis, or people may feel that diagnosis is not the right path for them.

'Even after getting a formal diagnosis, people often question whether I'm really Autistic or how much it actually impacts my life'. - Autistic person, 35, Brisbane

Employment

Autistic people are almost **8 times more likely** to be **unemployed** than the general population.⁴ Furthermore, the unemployment rate of Autistic people in Australia is **34.1%**, which is **three times** that of people with other disabilities.⁵

'I have experience of being unemployed and underemployed. I have two bachelor degrees, yet, I worked in a supermarket on the checkouts for 15.5 years.' – Autistic person, 51, Perth



Education

At least 3.2% of Australian school aged children are Autistic, and autism is a lifelong condition.⁶

77% of Autistic 5-20 year olds attending school or an education institution experienced difficulty at their place of learning.⁷

Only **8.1%** of Autistic people had a bachelor degree or higher, compared with **31.2%** of non-Autistic people.⁸

Safety, health and wellbeing

Autistic adults experience more barriers to healthcare than non-Autistic people.⁹

Autistic people have a life expectancy of more than **20 years** shorter than the general population and are **9 times** more likely to die of suicide than the general population.¹⁰

Autistic people are 2.5 times more likely to experience depression than the general population. 11

'It's hard to ask for help (with mental health), when half of the times you have, have been really negative.' – Autistic person, Canberra

Compared to the general population, Autistic adults experience higher rates of physical and sexual violence and are more likely to be subject to cyclical or repeated instances of violence.¹² They are experiencing **ostracisation** and **social exclusion** at higher rates than the general population.¹³

Autistic people are experiencing **discrimination** and are at higher risk of **homelessness** than the general population.¹⁴

Autistic people are overrepresented in the **criminal justice system** and are likely experience significant barriers in **accessing justice services**. ¹⁵



National Consultation

Autistic people, their families and carers and support networks, advocates, researchers and other stakeholders were asked what needs to be done through a Strategy to help improve outcomes for Autistic people across all stages of life.

A multi-method engagement process was led by engagement specialists, The Social Deck, between 4 September 2023 and mid-November 2023. Community engagement was designed with consideration of the Autism CRC co-design and community insights report. ¹⁶ This approach aimed to support as many people as possible to contribute in a variety of ways and to choose the methods that best suited them. This included the opportunity to contribute no matter where they lived in Australia.

There were more than 2,000 participations with people and organisations from all states and territories. Autistic people were the largest contributor to these consultations, followed by families. More than 100 separate engagement activities were held and this included over 20 different targeted discussions with people from intersectional population groups.

Key themes emerging from the consultation process

The consultation covered vast areas of discussion, with important issues and ideas raised across all stages of a person's life.

Rights, autonomy and safety

- Ensuring equal opportunities is a right that needs to be supported by legislation and systems, and anti-discrimination protections should be better enforced.
- Promoting and supporting self-advocacy and supported decision making to uphold the rights and dignity of Autistic people, including families and carers.
- Recognising and nurturing leadership of Autistic individuals.
- Ensuring clear accountability and strong governance in implementing and monitoring the Strategy.
- Person-centred and individualised, particularly when it comes to supporting the rights, autonomy and diversity of the Autistic and autism community.

Understanding autism

- Improving community understanding and acceptance of autism.
- Implementing national awareness and public education campaigns.
- Understanding autism training for consumer-facing services.
- Supporting advocacy to challenge and reduce the stigma often faced by Autistic individuals.
- Educating people about autism from a young age.
- Ensuring positive representation in media, and in sports and the arts.
- Understanding Autistic people with a Pathological Demand Avoidance (PDA) profile.

Social inclusion

- Sensory-friendly public, physical and online spaces.
- Supporting social connections and peer support.
- Improving access to legal support and a more inclusive justice system.
- Improving and adapting communication and information.
- Having access to accessible transport.
- Neurodiversity-affirming spaces and support systems.



Education and learning

- Autism training for teachers and schools.
- Improving and creating pathways and transitions from schooling to further education and work.
- More supports for Autistic students.
- Inclusive higher education.
- Inclusive educational practices.

Employment and income support

- Employment support and training for Autistic people.
- Autism-friendly workplaces.
- Adequacy of income support.
- Removing hiring biases.

Diagnosis, services and supports

- Ensuring affordable, accessible and safe services.
- Providing safe and inclusive diagnosis.
- Supporting families and carers.
- Addressing issues with NDIS access and use.
- Ensuring affordable and timely diagnosis.
- Improving diagnostic tools and processes.
- Ensuring continuity of support services.
- Providing respite services for caregivers.

Health and mental health

- Providing autism-friendly health and mental healthcare.
- Training for health and mental healthcare professionals.
- Caring for people with co-occurring neurotypes, disabilities, mental health conditions and medical health conditions.
- Addressing high rates of mental illness and suicide.
- Ensuring adequate support for people with a PDA profile.

Research

• Improving the research and evidence base around the experiences and needs of Autistic people and their families and carers.

Governance, accountability, monitoring and evaluation

- Ensuring commitments and actions are designed with Autistic people and are funded and embedded.
- Ensuring appropriate Autistic co-led, co-design and co-production implementation to ensure clear accountability.
- Provide mechanisms for continual feedback to ensure the Strategy is flexible and adapts to changes in community needs and expectations.
- Evaluation and reporting processes to be co-led by Autistic people and options available to align actions based on ongoing feedback and evaluation.

Communication

- Put voices of Autistic people at the centre of the Strategy's implementation.
- Provide regular updates on the implementation and evaluation of the Strategy, using accessible and easy to understand communication.

15 - National Autism Strategy



What should a National Autism Strategy achieve?

The Autistic and autism community want to see an ambitious national strategy for Australia. A Strategy that sees Autistic people have the same level of access as other people in the community and that 'levels the playing field for Autistic people and their families.'

People said the Strategy needs to be underpinned by action and must be upheld, with 'measures that mean something to Autistic people' and where there are 'consequences for failures to uphold the Strategy.'

Five consistent themes emerged about what a National Autism Strategy should achieve:



Inclusion: systemic, societal and attitudinal change across all four outcome areas of the National Autism Strategy discussion paper.¹⁷



Acceptance: a better understanding of autism across all parts of the community to create a more autism-informed Australia, and a sense of belonging for all Autistic people.



Recognising Autistic strengths where Autistic people have a strong voice: strength-based and neurodiversity-affirming practices are the norm.



Recognition of individual diversity and capacity: acknowledgement that every Autistic person has their own experiences and aspirations, and can participate freely and equally in all areas of life.



Better quality of life and improved living standards: systems and supports in place to provide for basic needs, to ensure access to health and mental health services to stay well, and equal opportunities for Autistic people to: participate in society; access housing; access justice services; and thrive in education and employment.

To achieve these themes, it is essential that the Strategy includes arrangements to measure progress and ensure accountability for actions and outcomes.



Strategy Foundations

The following references provide the foundation for the Strategy's Guiding Principles and form the basis for the Strategy.

United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)¹⁸

The UN CRPD came into force in 2008 and charges signatory countries, including Australia, with the responsibility to ensure people with disability enjoy their inherent right to life on an equal basis with others (Article 10).

This Strategy's person-centred, rights-based approach aligns with the UN CRPD's guiding principles:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.
- Non-discrimination.
- Full and effective participation and inclusion in society.
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity.
- Equality of opportunity.
- Accessibility.
- Equality between men and women and all genders.
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Biopsychosocial model of disability

The UN CRPD describes people with disability as people who have long-term physical, mental, intellectual or sensory differences that, when interacting with inaccessible communities and environments, prevent full and equal community participation.

This Strategy adopts this model of disability to understand the experiences of Autistic people. Under the model, the sense of being "disabled" because of autism comes from experiencing attitudes, practices and structures that make it more difficult to participate equally in a neurotypical world.

This Strategy aims to address those attitudinal, behavioural and structural barriers, and create change in society which enables Autistic people to experience more independence, inclusion and control.

Strengths-based and neurodiversity-affirming approach

Rather than looking for ways to help Autistic people "fit in" in a neurotypical world, this Strategy takes a neurodiversity-affirming approach, valuing and respecting all neurotypes. It seeks to promote understanding and acceptance of neurodiversity. The need for change sits with society as a whole.



Intersectionality

"Intersectionality is just a metaphor for understanding the ways that multiple forms of inequality or disadvantage sometimes compound themselves, and they create obstacles that are not often understood within conventional ways of thinking."

Professor Kimberlé Crenshaw, 1989

The way people experience the world is shaped by the way their individual circumstances and characteristics interact with attitudes, systems and structures in society. People's experiences differ according to factors such as their gender, sexuality, race, culture, ethnicity, religion, citizenship, socio-economic status, geographical location, and body shape/size. This interaction results in individual people experiencing differing levels of outcomes or discrimination.

Taking an intersectional approach to this Strategy recognises, and seeks to address, the structural barriers and hidden biases that have a negative impact on the life experiences of individual Autistic people who face multiple and overlapping forms of disadvantage and discrimination. This Strategy will drive greater respect for, and acceptance of, the Autistic and autism community in its full diversity.

This approach recognises there is very little research and other evidence available relating to the life experiences, needs or views of certain cohorts of Autistic people, including:

- First Nations people,
- culturally and linguistically diverse (CALD) people, including those from migrant and refugee backgrounds,
- infants and toddlers,
- young people (12 to 30 years of age noting there are subgroups within this age range),
- women, girls, and gender-diverse people,
- older people,
- people who have co-occurring neurotypes, disabilities and medical health conditions,
- people who identify as a member of the LGBTQIA+ community,
- people in regional, rural, and remote areas,
- people who use alternative or augmentative communication or are non-speaking or minimally-speaking,
- people with intellectual disability,
- people with complex and high support needs,
- people living in supported independent living,
- people living in segregated accommodation, group homes and institutions,
- people with experience of trauma and violence,
- people in child protection and justice systems, and
- health professionals, and researchers.

As a result, policies and support services often fail to adequately support Autistic people who are members of these intersectional groups.



This Strategy aims to address this representation issue by:

- establishing a governance framework that is representative of the diversity within the Autistic and autism community,
- adopting an inclusive process for consultations,
- designing actions with Autistic people and their families and carers and support networks to address the multiple and overlapping structural barriers they experience, and
- providing ways for Autistic people and their families and carers and support networks to communicate with the Australian Government in a way that suits them.



Outcome Areas and Commitments

Social Inclusion

Social inclusion is about ensuring everyone has the opportunity to participate fully in our society. Social inclusion allows the equal opportunity for people to learn, work, connect and collaborate with others, and have a voice, including those who are non-speaking or minimally-speaking. When people are equally included they can participate.

Full participation in social, recreational, sporting, religious and cultural life is central to Autistic people living an accessible and connected life within their communities. This requires accessibility to be an integral part of the design of services and systems. It requires going beyond just physical accessibility. Providing easily accessible information about community services, events and facilities, and providing low sensory spaces, supports the inclusion of Autistic people in their communities.

Why it is important

Everyone should have the opportunity to participate in all aspects of life and society, free from all forms of discrimination. Without social inclusion, people are more likely to experience poor mental health, isolation, discrimination, abuse and violence. Social inclusion, and feeling connected, respected and valued in society is important for an individual's health, safety and wellbeing.

How it applies to Autistic people

Autistic people and their families and carers and support networks experience disproportionately high rates of social isolation, discrimination, abuse and violence. Factors contributing to low rates of social inclusion include the intersection with poor employment rates, a lack of community understanding of autism, limited opportunities to participate in the community and build social connections, unaccommodating built environments, issues with access to transport, and low levels of independent living.



Commitments

- 1. Improve understanding of, and change attitudes towards, Autistic people across all of society, through:
 - a. Greater public education and awareness including a better understanding of autism within workplaces, with a focus on health, education and the criminal justice system.
 - b. Increasing visibility and representation of Autistic people in the media, sports and the arts.
 - c. Increasing accessible and sensory-friendly public and online spaces.
 - d. Increasing the capability of advocates and advocacy organisations to challenge and reduce stigma of autism.
- 2. Increase opportunities for social connections and peer support.
- 3. Improve Australian Government service delivery, communication, and information to meet the needs of Autistic people.
- 4. Ensure consideration of the needs of Autistic people in future amendments to or reviews of the *Disability Discrimination Act 1992* (Cth) and associated disability standards.
- 5. Improve the safety and welfare of Autistic people through the reduction all forms of discrimination, violence, abuse, bullying, vilification and exploitation.



Economic Inclusion

An inclusive economy ensures all parts of society, especially poor or socially disadvantaged groups, have full, fair, and equitable access to market opportunities as employees, leaders, consumers, entrepreneurs, and community members.

Employment and financial security is central to improving outcomes for Autistic people, including providing jobs and career opportunities, and having adequate income for people to meet their needs.

Employment supports Autistic people to have more control over their lives, be financially independent and have a better standard of living. Increasing employment opportunities for Autistic people includes encouraging business ownership and development, self-employment and entrepreneurship.

Additionally, evidence shows preparing young people for employment can have long-term benefits for their employment prospects and careers.

Adequate income provides increased financial security, economic independence and an appropriate standard of living, giving people more choice and control over their lives, and enabling their participation in community life. The income support system provides an important safety net for people with disability who are unable to work or cannot find employment.

Why it is important

Everyone should be able to access safe, secure and equitable education and employment opportunities. Economic inclusion has many benefits, including having an adequate income and stable employment, contributing to a person's wellbeing and financial security, as well as contributing to society and the economy on the whole. Educational settings and workplaces can also benefit from having people with a diversity of views, skills and experiences. Income support is an important support to help people with disability to gain employment and contribute to their economic independence.

For the first time in 2023, the Australian Public Service Employee Census captured data on neurodivergence. Results showed 7.7% of respondents considered themselves to be neurodivergent, and a further 11.5% indicated they were not sure.¹⁹

How it applies to Autistic people

School education outcomes for Autistic people are poorer than those of the general population. Many people have reported experiences of discrimination and bullying in schools, and that school environments can pose multiple challenges for Autistic students. The unique learning styles of Autistic students can create barriers to accessing the curriculum, and some students may need a high level of support to participate in education. There were also numerous reports of school's failures to make adjustments and provide appropriate supports for Autistic students. Supporting Autistic students to transition from school to further education and employment is critical.



Stakeholders have reported poor employment outcomes for Autistic people in Australia as well as identifying underemployment as a significant issue. Autistic people often work below their potential and capacity, resulting in reliance on families, carers and other support networks, and government funded services and benefits. Barriers to employment range from low education attainment and limited work experience, social and communication difficulties, sensory issues, and anxiety with accessing public transport in order to get to work. Unsuitable recruitment practices, a lack of appropriate workplace supports, and discrimination and bullying also contribute to poor employment outcomes for Autistic people.

Commitments

- 6. Increase meaningful employment opportunities (including business ownership, self-employment, and entrepreneurship and social enterprises) for Autistic people.
- 7. Support employers to hire and retain Autistic employees through improving the accessibility of recruitment processes and fostering workplace environments that are safe and inclusive for all Autistic people.
- 8. Improve the supports and services available to Autistic people to ensure they have choice and control over their education and careers.
- 9. Increase representation of Autistic people in senior and board positions to promote people as visible role models.
- 10. Improve inclusive practices and the quality and accessibility of advocacy resources for Autistic students across all education settings, and their families, carers and support networks.
- 11. Build on commitment 5 Improve the safety and welfare of Autistic people through the reduction of all forms of discrimination, violence, abuse, bullying, vilification and exploitation to specifically focus on Autistic students in all levels of education.



Diagnosis, supports and services

Autism is diagnosed by health professionals who observe an individual's characteristics such as social communication, behaviours and focused interests. Some people who do not have a formal diagnosis also self-identify as Autistic.

Primary healthcare providers, for example General Practitioners, are often the first point of contact who will begin the process by referring an individual to a health professional with experience in assessing neurodevelopmental disabilities.

Once referred for an assessment, individuals and their families and carers and support networks should expect a timely and comprehensive assessment and referral to support services based on the individual's needs.

Autistic people and their families and carers and support networks can experience difficulties at all stages of the identification, assessment, diagnosis and decision process, in particular the time it can take to receive a diagnosis, and the associated cost. It can also be hard to find, access and navigate appropriate supports and services once a person has an autism diagnosis.

Personal and community supports, including both specialist supports and mainstream services available to the general public, are fundamental to improving overall outcomes for Autistic people.

Why is it important

Access to neurodiversity-affirming early screening and supports, and timely and comprehensive autism identification assessment and diagnosis, means an individual will be better able to access supports and services, improving long-term outcomes and reducing risk of developing mental health concerns.

How it applies to Autistic people

The average age of diagnosis in children in Australia is about 3-4 years of age, with the most frequent age for diagnosis being 5.9 years. This is despite research showing that identification is possible in infancy (from 0 to 12-months of age), and diagnosis is possible as early as 18-24 months of age. ²⁰ Early identification and diagnosis leads to better education, social and economic outcomes for Autistic people. It also leads to better mental health in adulthood, and less feelings of stigma and shame about being Autistic.

Early diagnosis reduces the ongoing support required by school age children, as well as lowering overall support costs for families and carers and the wider community.

Diagnosis is likely to occur later for girls, women, and gender diverse people, those with less overt or 'internalised' presentations, those living in regional, rural and remote areas, and those who have co-occurring neurotypes, disabilities and medical health conditions with overlapping diagnostic criteria. Without timely identification and diagnosis, individuals may not be able to access appropriate supports, including through the NDIS.

Multiple stakeholders reported significant delays in obtaining an autism diagnosis, with the optimal waiting period of 3 months, and the median wait time for an assessment in the public system being 16 weeks, with some stakeholders advising the wait period could be longer, for example: 6 months to 2 years or more.

Other barriers include: the complexity involved in providing an autism diagnosis; the reliance on the expertise of the professionals involved; inconsistent approaches to diagnosis; availability of diagnostic services; the cost of diagnostic services; and awareness and understanding of autism.

24 - National Autism Strategy



Support for Autistic people can be provided through an often complex mix of disability supports funded by the NDIS, non NDIS-funded mainstream and community services and supports, as well as informal supports provided by families, carers and support networks.

There are high levels of unmet demand, and service gaps and inadequacies. The cost of services is also a concern for many, as well as the lack of information and support when navigating services, including the NDIS. The lack of service integration across sectors, and poor understanding of autism in both community and professional settings, and workforce shortages, were also commonly identified barriers.



Commitments

Diagnosis

- 12. Consider the use and consistency of current identification screening, outcome and diagnostic tools. Work with relevant professional bodies to develop a set of standardised co-designed training/professional development and resource materials to support professionals involved in the identification, assessment and diagnosis of autism to improve the experience, and quality of this process for Autistic people and their families and carers.
- 13. Develop a set of best practice resources to support Autistic people and their families, carers and support networks through the identification, assessment and diagnosis process.
- 14. Explore ways to improve access to primary care, including through the Medicare Benefits Schedule (MBS), to:
 - a. improve quality health and mental health services for Autistic people, with a focus on continuity of care, and
 - b. explore ways to make autism diagnosis and assessment processes more timely and accessible.
- 15. Consider early screening and identification arrangements, and improved access to health professionals.*
- * Consideration is to be given to how this commitment links with joint work being undertaken by the Australian and state and territory governments as part of Australia's Disability Strategy 2021-31 and in response to the Independent Review of the NDIS. Details on work to meet this commitment will be developed in Action Plan/s.

Services and Supports

- 16. Improve access to quality, timely, neurodiversity-affirming and equitable supports and services for Autistic people, including for people living in rural, regional and remote areas.
- 17. Encourage greater representation of people with lived experience in delivering supports and services to Autistic people.
- 18. Develop a set of best practice training and resource materials to for people providing services and supports to Autistic people.
- 19. Explore the feasibility of a decision-making tool to empower Autistic people to make informed decisions about all areas of their life.
- 20. Work with states and territories to improve service integration between the NDIS, foundational supports and mainstream services.

Actions delivered under these commitments will take into account: the differences in presentation by different cohorts (for example: girls, women and gender diverse people); intersectionality; and the need for tools, supports and services to be tailored for different cohorts and to be neuro-diversity affirming. The development and delivery of actions will seek to be co-designed or involve Autistic community/academics as appropriate.



Health and Mental Health

Actions to improve health and mental health are being developed through the development of the National Roadmap to Improve the Health and Mental Health of Autistic people in Australia (the National Roadmap), which is being led by the Department of Health and Aged Care (DoHAC).

Outcome Statement: Enhance the physical health, mental health and wellbeing for all Autistic people across the lifespan.

The National Roadmap is being developed separately to the Strategy, in order to address health and mental health needs in greater detail. The National Roadmap will include specific actions and outcomes to improve the health and mental health of Autistic people and their families and carers.

The National Roadmap is being driven by the Autistic and autism community, through:

- guidance from a cross-stakeholder Working Group,
- co-design work, which DoHAC has engaged the Autism CRC to undertake, and
- consultation with the National Autism Strategy Oversight Council.

The Roadmap will consider key outcome areas such as:

- Best practice models of care.
- Support to navigate the health and mental health systems.
- Education and training of health professionals.
- Improved coordination of health, mental health supports and sectors.
- Research, data and measurement to support continuing improvement.
- Accessibility integrated across the entire health and mental health systems.



Implementation – Delivering on the Outcome Areas Implementing the National Autism Strategy

Three Action Plans will support implementation of the Strategy:

- First Action Plan: short-term (the first year),
- Second Action Plan: medium-term (the next few years), and
- Third Action Plan: long-term (longer term actions).

The first Action Plan will be informed by the work of the National Autism Strategy Oversight Council and Working Groups, the national consultations undertaken during the development of this Strategy, and a range of reports commissioned by the Australian Government. The first Action Plan will include ongoing governance arrangements and an Evidence Framework comprising a Theory of Change, an Outcomes Framework, and Evaluation Framework developed with the Autistic community and autism sector.

Governance

The development of this Strategy was supported by governance arrangements and the implementation of this Strategy will also be supported by governance that ensures continued deep engagement, trust and accountability over the delivery of commitments and achievement of intended outcomes.

A governance framework will be developed as part of implementation planning. Key features will include:

- Ministerial oversight arrangements in relation to the implementation of the Strategy.
- A continuing role for a representative group of Autistic people and their families and carers, researchers and professionals.
- Continuing collaboration across the Australian Government.
- In any areas of joint responsibility between the Commonwealth and state and territory governments, the Strategy will guide the Australian Government's engagement with jurisdictions.

The governance framework will be enhanced to include:

- A truly whole-of-government approach, recognising coordinated effort is required across all areas of government and sectors including health, education, disability, and employment.
- Ongoing ways to listen to and respond to the voices of Autistic people and their families and carers, support networks, and communities.
- A review and evaluation of the Strategy involving Autistic people and their families and carers.

Detailed accountability and governance structures will be outlined in each of the three Action Plans which allows the structure to best respond to the specific priorities/actions identified.

Why is it important

The governance framework will set out a visible and robust accountability structure to drive implementation and decision-making under the Strategy.



How it applies to Autistic People

The governance framework will identify and prioritise areas of focus, drive change across these areas, and report on progress made to improve the lives of Autistic people.

Commitment

- 21. Develop a governance framework to support:
 - a. strong accountability mechanisms,
 - b. co-leadership and active involvement of Autistic people, as well as parents and carers, and professionals within the autism sector, and
 - c. whole-of-government, cross-sectoral and coordinated approaches to implementation.

Research

The National Disability Research Partnership (NDRP) has been established under ADS. The NDRP will facilitate collaborative and inclusive disability research, providing a stronger evidence foundation for policy and service delivery.

There are also a number of organisations and research bodies already working hard to build our understanding of the lived experience of autism and identify the types of supports that deliver the best outcomes for Autistic people of all ages.

Commitment

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



Evidence Framework

A robust Evidence Framework that aligns data, research and evaluation is integral to the development, implementation and impact of the Strategy. It will advance the vision of the Strategy by measuring what matters to Autistic people and driving the use of data and evidence to inform effective, practical change.

The core components of the Strategy's Evidence Framework include: a Theory of Change (underpinned by related logic chains); an outcomes framework; and a monitoring and evaluation framework. These can form the single comprehensive Strategy Evidence Framework or exist as separate interrelated pieces.

Core component	Contribution to Strategy Evidence Framework
Theory of Change and logic chains	Sets out the evidence, assumptions and theories about the investments, initiatives and mechanisms that will drive the Strategy to achieve good outcomes.
Outcomes Framework	Specifies the progressive indicators and outcome measures to enable assessment of the progress and impact of the Strategy.
Evaluation Framework	Assesses what, why, how and for whom the Strategy is making a difference. What has been implemented? How is it working? Why? Under what conditions? For what people? What difference has been produced?

A Theory of Change explains the conditions and, underpinned by an evidence-base, why certain activities or actions will lead to a particular outcome.

This is a way to make sure there is a solid rationale, based on the best research and evidence, and have confidence the Strategy can achieve the outcomes wanted from the actions proposed in the Action Plans under this Strategy.

See Appendix E for a Theory of Change diagram example.

The Theory of Change responds to key problems identified by Autistic people and their families and carers and support networks, and the organisations who work with them. It explains how and why Strategy initiatives and actions should lead to improved life outcomes for Autistic people and their families and carers.

It reflects the evidence, research and findings about the nature of the problems, issues and concerns experienced by Autistic people and their families and carers, and outlines what will be effective in creating positive change.

Importantly the Strategy's Theory of Change is also informed by the broader evidence relating to the effective implementation of policy and systems change initiatives.

Because Australia's first-ever National Autism Strategy is an initiative of the Australian Government (rather than a whole of governments initiative like ADS), the Theory of Change will focus on relevant national policies, programs and responsibilities.



The Theory of Change is underpinned by a series of Outcomes logic chains which trace the link between major actions under the Strategy, and the related outputs and the outcomes these are expected to create over the short, medium, and longer term.

Together these components identify the outcomes being sought, the indicators and measures of success, why, what, how and when actions, investments and initiatives related to the Strategy are assessed and reported on. Underpinned by strong governance and effective leadership, these components also ensure there is strong transparency and accountability for outcomes across the life of the Strategy.

Objectives of the Evidence Framework

Major objectives of the Evidence Framework are to:

- 1. **Provide national leadership** to develop strategic, robust data and evidence that continuously informs policies and practices that are inclusive and responsive to Autistic people and their families and carers and support networks.
- 2. Address significant data gaps that exist in relation to the needs, experiences and outcomes of Autistic people and their families and carers and support networks.
- 3. **Build capacity to measure relevant experiences and outcomes for Autistic people** of different ages and circumstances, including intersectional groups identified in the Strategy.
- 4. Understand how place impacts on outcomes and experiences of Autistic people living in different locations and parts of Australia.
- 5. **Support the development of evidence informed approaches to policy and practices** by establishing indicators, outcome measures and data sets for the life of the Strategy.
- 6. **Provide for national independent monitoring and reporting** on identified outcomes in the Strategy.
- 7. Drive co-produced research that builds capability and understanding of the experience of Autistic people in relation to the Strategy's key themes.
- 8. **Inform the effective, efficient and thoughtful application of funding** and resources to advance the vision, purpose and priorities of the Strategy, and continuous quality improvement over the life of the Strategy.

Commitment

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



Evaluation and Reporting

An Evaluation Plan will be developed as part of the first Action Plan. It will outline how we will measure the impact of actions under the Strategy on achieving the Strategy's goal of improving life outcomes for all Autistic people.

The Evaluation Good Practice Guide Checklist developed under ADS will underpin the approach to evaluation activities.²¹

Evaluation activities will be both quantitative (for example: measuring changes in the labour force participation rate for Autistic people) and qualitative (for example: documenting the positive changes experienced by individual Autistic people and their families and carers). Consistent with the commitment to accountability, evaluation reports will be publicly available.

Commitment

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



Acronyms

ADS	Australia's Disability Strategy 2021-2031
Autism CRC	Autism CRC is an independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum.
CALD	Culturally and Linguistically Diverse
Committee	Senate Select Committee on Autism
DDA	Disability Discrimination Act 1992 (Cth)
DRC	Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023)
DSM-5 TR	DSM-5 American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders, 5th edition
DSS	Department of Social Services
LGBTQIA+	Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex, Asexual. The + stands for all other identities not encompassed in the short acronym.
National Roadmap	The National Roadmap to Improve Health and Mental Health of Autistic People
NDIA	National Disability Insurance Agency – the agency responsible for the National Disability Insurance Scheme.
NDIS	National Disability Insurance Scheme
NGO	Non-Government Organisation
Oversight Council	National Autism Strategy Oversight Council
TSD	The Social Deck – the organisation engaged to undertake the national consultation process to inform development of the Strategy.
UN	United Nations
UN CRPD	United Nations Convention on the Rights of Persons with Disabilities

dss.gov.au/National-Autism-Strategy

Glossary

Ableism	Ableism refers to attitudes and behaviours that label people with disability as different, less than or inferior to people without disability, incapable of exercising choice and control and a burden on society. Ableism, like other forms of discrimination, can manifest both personally and structurally.
Accessible	Environments, facilities, services, products and information that people are able to use and interact with in a way that suits their needs.
Assistive devices and technologies	Devices and technologies designed, made, or adapted to assist people with disability to participate in activities more independently.
Augmented and alternative communication	Methods of communication personalised to enable the participation of a person who may experience barriers to spoken communication.
Autistic and autism community	Refers to the collective community of Autistic people, their families and carers, friends and support networks, advocacy groups, researchers, and other people in their lives.
Autism	Autism is a lifelong neurodevelopmental difference. Autistic people experience differences in the way they process information and interact with their environment compared to non-Autistic people. This means the way that Autistic people communicate, connect with others, and engage with aspects of day-to-day life are different to those of non-Autistic people.
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 or more months) exhaustion, loss of function, and reduced tolerance to stimulus.
Autonomy	A person's right and freedom to make decisions, control their life and exercise choice.
Best Practice	 In the context of the National Autism Strategy, best practice is: Strengths-based, trauma-informed and neurodiversity-affirming. Embracing safety, choice, collaboration, empowerment, and respect for diversity. Co-leadership between government and the Autistic and autism community. Informed and guided by lived experience, expertise and insights. Evidence-based decision making. Data-driven, outcomes focussed, with robust monitoring and evaluation.

Camouflaging	An overarching term with 3 categories:
	Compensation - Strategies used to actively compensate for difficulties in social situations. Examples include: copying body language and facial expressions and learning social cues from movies and books.
	Masking - Strategies used to hide Autistic characteristics or portray a non-Autistic persona. Examples include: adjusting face and body to appear confident and/or relaxed and forcing eye contact.
	Assimilation - Strategies used to try to fit in with others in social situations. Examples include: putting on an act and avoiding or forcing interactions with others.
Carer	Someone who provides supports to a person with disability on an unpaid basis, often a family member. These family members can include young people and carers. Some legislation refers to 'carers' and some people with disability prefer the term over 'support person'.
Co-delivery	The process of collaborating with stakeholders and end-users to apply and maintain aspects of the completed project, products, services, systems, policies, laws and research.
Co-design	A design process where stakeholders are equal partners and take leadership roles in the design of products, services, systems, policies, laws and research.
Co-occurring conditions	The occurrence of more than one neurotype, disability, or medical health condition at the same time.
Co-production	An extension of 'co-design', where stakeholders are involved in the development and design, decision-making, implementation and evaluation of products, services, systems, policies, laws and research.
Cultural safety	An outcome that respects, supports and empowers the cultural rights, identity, values, beliefs and expectations of a particular culture while providing quality services that meet their needs.
Culturally and linguistically diverse	This broad term describes communities with diverse languages, ethnic backgrounds, nationalities, traditions, societal structures and religions. This includes people with a different heritage or linguistic background than dominant Australian culture and language, people with dual heritage, and people who are migrants and refugees. Some members of the Deaf community and Auslan users also identify as members of a cultural minority.
Disability Representative Organisation (DRO)	A peak organisation providing systemic advocacy and representation for people with disability.

Evidence Based	The definition of evidence-based is comprised of three pillars:
	 Research evidence (science). Clinical practice (trauma-informed, culturally responsive, LGBTQIA+ inclusive). Clients' values and preferences.
	These pillars should be underpinned by lived experience and none of the pillars are to be valued higher than the other, they must all work together to be considered evidence-based.
First Nations person or people	First Nations or Aboriginal and Torres Strait Islander people are the first peoples of Australia. They are not one group, but comprise hundreds of groups that have their own distinct set of languages,
	histories and cultural traditions.
Human rights model of disability	Disability is a natural part of human diversity that must be respected and supported in all its forms. People with disability have the same rights as everyone else in society, including: the right to dignity and respect; to live free from violence, abuse, neglect and exploitation; and to participate fully in the community.
Informal supports	The social support networks that provide protection for people with disability by increasing connections, relationships and visibility in the wider community.
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.
Medical model of disability	A deficit approach that views impairment or disability as an individual inadequacy that must be fixed or remediated.
Meltdown	Externalised response to an overwhelming situation. A meltdown is not a tantrum or something that can be controlled.
Multiply Neurodivergent	People who have two or more neurodivergent neurotypes, for example: autism and ADHD.
Neurodiversity-affirming	Is a strengths and rights-based approach to developmental differences and aim to provide support and adaptations that affirm neurodivergent identity.
Neurodivergent and Neurodiverse	Neurodivergent - A person or people whose neurodevelopment falls outside of (or diverges from) the range usually considered "typical".
	Neurodiverse - A collective term for groups including mixed neurodevelopment, for example: this may be a group of Autistic and non-Autistic people or neurodivergent and neurotypical people.

Neurodiversity	A term used to describe the natural variation and development in human neurocognition and within communities. Although all people process the world differently, some differences are grouped and named. The neurodiversity of a community arises from the presence of both neurodivergent and neurotypical people.
Neuronormativity	A set of standards, expectations and norms that centre certain ways of functioning as the right way.
Neurotype	A type of brain, in terms of how a person interprets and responds.
Neurotypical	A label for people who are not neurodivergent.
Pathological Demand Avoidance	Pathological Demand Avoidance, or Persistent Drive for Autonomy (PDA), is considered a profile or subtype of autism. It is characterised by an extreme need for control and autonomy driven by high levels of anxiety or an automatic nervous system threat response, which results in demand avoidance, emotional regulation difficulties and a heightened reaction to stress. Although PDA is not captured within the current DSM5-TR, the PDA Society United Kingdom have developed guidelines to identify a PDA profile. ²²
	PDA is considered significantly impactful.
Reasonable accommodation	Article 2 of the Convention on the Rights of Persons with Disabilities defines reasonable accommodation as 'necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms'.
Reasonable adjustment	The <i>Disability Discrimination Act 1992</i> (Cth) s 4(1) defines an adjustment to be made by a person as a reasonable adjustment 'unless making the adjustment would impose an unjustifiable hardship on the person'.
Restrictive practice	Any action, approach or intervention that has the effect of limiting the rights or freedom of movement of a person. Restrictive practices include physical restraints, chemical restraints, mechanical restraints, environmental restraints and seclusion.
Sensory differences	Acute awareness of light, sound, texture, touch, taste and/or smell, commonly experienced by Autistic people.
Shutdown	An internalised response to an overwhelming situation.
Social model of disability	The social model of disability recognises attitudes, practices and structures can be disabling and act as barriers preventing people

	from fulfilling their potential and exercising their rights as equal members of the community. The social model seeks to change society in order to accommodate people with disability. It does not seek to change people with disability to accommodate society. It supports the view that people with disability have the right to be fully participating on an equal basis with others.
Stimming	Behaviour that many Autistic people engage in to calm, comfort, soothe and regulate themselves. Stimming behaviours can also provide enjoyment to Autistic people.
Supports and services	Actions, practices, strategies or resources that promote the participation and inclusion of a person or people with disability in society.
Support network	These networks refer to the informal relationships people have with family, friends, neighbours, work colleagues and other members of their community, that help them achieve their personal goals.
Trauma	The lasting adverse impacts that may arise when a person has lived through an event, series of events, or set of circumstances that is experienced as physically or psychologically harmful or life threatening.
Trauma-informed	Frameworks and strategies to ensure that the practices, policies and culture of an organisation and its staff understand, recognise and respond to the effects of trauma and minimise, as far as possible, the risk that people may be re-traumatised.
Triggers	Every Autistic person is different, but sensory differences, changes in routine, anxiety, and communication differences are common triggers that may result in certain behaviours.
Universal Design	Universal design is the design of buildings, products or environments to make them accessible to most people, regardless of age, disability, background or any other factors.
Whole-of-government framework	Joint activities performed by a range of agencies in order to provide a common solution to particular issues.

Appendices

Appendix A - Roles and Responsibilities of Governments

Appendix B – How we developed the National Autism Strategy

Appendix C – Connection to other Australian Government action

Appendix D – Co-occurring neurotypes, disabilities, and medical health conditions

Appendix E – Theory of Change diagram



Appendix A - Roles and Responsibilities of Governments

This Strategy is focused on actions related to the roles and responsibilities of the Australian Government.

Listing key government roles and responsibilities helps everyone understand which level of government is responsible for the systems that may be used by people with disability.

In many cases, more than one level of government has some responsibility for a support, service or system. For example, the Australian Government and state and territory governments are all involved in funding, delivering and/or regulating systems like education, community housing, and the NDIS.

The table on government roles and responsibilities that is included in this Appendix is from ADS and shows where one level of government holds primary responsibility for the delivery of a system. There is also a section in the table showing systems where responsibilities are shared to an extent that primary responsibility for delivery cannot be assigned to one level of government.

More detailed information about roles and responsibilities, as well as some of the key systems outside of government, can be accessed through ADS Hub²³. This information includes:

- points of contact for people to identify and contact the agency responsible for delivering the service they want to access or to handle a specific issue they are experiencing,
- legislation and agreements outlining the funding, regulation and operational responsibility for those services and systems, and
- the NDIS Applied Principles and Tables of Support setting out responsibilities between the NDIS and other service systems.

People who do not have access to the internet can contact the National Disability Information Gateway telephone helpline on 1800 643 787.

The table on government roles and responsibilities is high-level and does not include every support, service or system. The table also does not include all systems provided by governments.



Government Roles and Responsibilities

Primary responsibility for delivery lies with the Australian Government

- NDIS* (administration)
- Information, Linkages and Capacity Building (ILC)
- NDIS Quality and Safeguards Commission
- Employment services
- Income support payments
- Federal justice system
- Australian Federal Police
- Child Care Subsidy
- Medicare Benefits Schedule
- General practitioners
- Pharmaceutical Benefits Scheme
- Aboriginal Community Controlled Health Organisations
- Aged Care system
- My Aged Care
- Veterans' Care system
- Universities
- Hearing Services Program
- Commonwealth Ombudsman
- Australian Human Rights Commission

Primary responsibility for delivery lies with state and territory governments

- Public, social and community housing
- Public hospitals
- Community health services
- Home and Community Care programs for under 65s
- Public transport services
- Public primary and secondary schools
- TAFE/Vocational Education and Training (VET)
- Kindergartens and pre-schools
- Jurisdictional court systems and correctional centres
- State and territory Police
- Guardianship, Public trustees and Ombudsman
- Child protection
- Community visitors programs for disability**
- Domestic and family violence services
- Major sporting facilities
- State and territory human rights/anti-discrimination bodies



Primary responsibility for delivery lies with local governments***

- Urban planning/design of the built environment
- Accessible buildings
- Local development planning
- Local roads, bikeways and footpaths
- Local parks and recreational facilities
- Local sports grounds
- Public toilets
- Playgrounds
- Council-run childcare and aged care centres
- Municipal services
- Parking regulation
- Public libraries and community halls

Responsibility for delivery is substantially shared across levels of government

- NDIS* (funding and shared governance)
- Mental health supports and services
- Disability advocacy services individual and systemic
- Concessions for government services
- Community infrastructure
- Arts and cultural funding and support
- Public museums, galleries and performance facilities

Note: This listing of roles and responsibilities is not comprehensive and some responsibilities may change over time.

- * The National Disability Insurance Scheme (NDIS) is a nationally based scheme jointly governed and funded by the Australian, state and territory governments. Delivery of the NDIS is the responsibility of the National Disability Insurance Agency, a Commonwealth Corporate Entity.
- ** Not all states have community visitors programs for disability (e.g. Tasmania, Western Australia).
- *** Local governments are established by state and territory governments (except the ACT) to deliver a range of municipal services and infrastructure, which is determined by each state and territory government. Listed examples of key responsibilities of most local governments are not representative of the responsibilities of all local governments.



42 - National Autism Strategy

The Australian, state and territory, and local governments make and uphold laws, rules and regulations, and agreements that play a role in supporting people with disability and upholding their rights. Examples include:

- The Disability Discrimination Act 1992 (Cth) and the Standards made under this Act.
- The National Disability Insurance Scheme Act 2013 (Cth) and NDIS Rules.
- Bilateral Agreements on the NDIS.
- NDIS Applied Principles and Tables of Support.
- National guidelines for safety, employment, and disability access.
- Agreements between the Australian Government and state and territory governments under the Intergovernmental Agreement on Federal Financial Relations.
- State and territory disability services Acts and disability inclusion Acts.
- State regulations on planning, development and management of state-based infrastructure and resources.
- Local government planning and regulation.

There is also a range of international instruments that establish normative standards and principles for the treatment of people with disability. Examples include:

- The UN CRPD
- Convention on the Rights of the Child, Convention on the Elimination of all Forms of Discrimination
 Against Women, International Convention on the Elimination of All Forms of Racial Discrimination,
 International Covenant on Civil and Political Rights, International Covenant on Economic,
 Social and Cultural Rights, and the Declaration on the Rights of Indigenous Peoples.



Appendix B - How the National Autism Strategy was developed Phases of Strategy development

1. Reviewing what the Australian Government has already heard so people didn't have to retell their stories.

Review what we've heard 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 had a lot of information already. Other relevant Australian, state and territory government strategies – both current and in development – were also considered. Findings from recent inquiries and reviews, including the Disability Royal Commission and the NDIS Review, were also considered.

Test and consult 2. Testing what the Australian Government had heard to ensure gaps were understood, and to hear further from Autistic people and the wider community and encourage those who haven't had the opportunity to be heard.

This process involved consultation and engagement with Autistic people and their families and carers and support networks, the autism and broader disability sector, and researchers and professionals between September 2023 and November 2023. The draft Strategy is now being tested with the Autistic and autism community and wider community.

Agree & launch the Strategy 3. Once consultation with the Autistic and autism community and wider community is finished, agreement will be sought to finalise, launch and implement the Strategy. The Australian Government will consider all of the information received through the consultation process and will decide on the final Strategy. At this stage, it is expected the Strategy will be finalised and launched by the Minister for Social Services in 2024.

Appendix C - Connection to other Australian Government Action

This Strategy considers and aligns with other relevant Australian, state and territory government strategies, and inquiries and reviews.

Australia's Disability Strategy 2021-31

Australia's Disability Strategy 2021-31²⁴ (ADS) is Australia's national disability policy framework. It drives action at all levels of government to improve the lives of people with disability. ADS's vision is for an inclusive Australian society that ensures people with disability can fulfil their potential, as equal members of the community.

The National Autism Strategy will sit alongside ADS and aims to make ADS vision a reality for Autistic people.

Senate Select Committee on Autism – Government Response

On 27 November 2019, the Senate established a Select Committee on Autism²⁵ (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.

After considering 168 written submissions and holding nine public hearings, the Committee found:

The drivers of poor outcomes for Autistic people are complex and interrelated.

Some of the drivers include:

- Poor understanding of autism within the community and among service providers results in negative experiences of existing services and supports, social and economic exclusion and discrimination.
- A critical shortage of professionals with autism-specific knowledge means there are fewer choices in services, with many having long wait lists.
- Delays in early identification and family and education support services causes children and young people to miss out on vital early support that would improve their longer term life outcomes.
- The complex and poorly integrated service environment creates an undue burden for Autistic people and their families and carers seeking support, particularly for those experiencing intersectional disadvantage or vulnerability.
- Services are not designed to meet the needs of Autistic people, which means that Autistic people
 are expected to accept services which do not account for their specific needs, including sensory and
 communication challenges.

Generic disability strategies have proven ineffective at improving life outcomes for Autistic people.

Concerns raised with the Committee about current approaches to supports for Autistic people included:

- They are often too generic and do not effectively address the specific needs of Autistic people, leading to poorer outcomes compared to those with other disabilities.
- References to autism are often in relation to children only and do not recognise the experience of autism across the life span.
- Autistic people and their families and carers and support networks can be overwhelmed by the fragmented service system delivered through different levels of government.

Additionally, people may or may not identify with their diagnosis, as Autistic or neurodivergent, or as having a disability.

45 – National Autism Strategy



Meaningful systemic changes would have an enormous impact, with instances of good practice demonstrating how this can be achieved.

Inadequate or inappropriate support can have a devastating impact on the lives of Autistic people and their families. Too often, access to adequate support appears to be a matter of chance; relying heavily on the knowledge and skills of individual teachers, support workers, and healthcare professionals who have adjusted their practice to accommodate the needs of Autistic students, clients and patients.

The Committee recommended the development of a person and family-centred Strategy, that addresses whole-of-life needs for all Autistic people, and include targeted actions to support vulnerable cohorts, co-designed with Autistic people and the autism community, which aims to:

- Build understanding of autism within key professions and across the wider community.
- Improve access to early diagnosis and intervention.
- Improve service integration and coordination.
- Improve education, employment and health services.
- Support parents and carers.
- Includes a national autism research agenda.

The Committee also advised that accountability will be critical to delivering genuine change or otherwise stating that without such strong accountability measures, the National Autism Strategy risks becoming another aspirational yet ineffective plan for change.

Therefore, the Committee recommends the Strategy adopt a range of accountability, including:

- clear and measurable actions, targets, and milestones,
- an implementation plan with clearly defined responsibilities,
- ongoing monitoring and reporting requirements, and
- built-in timelines for review and renewal of the Strategy.

Government commitment to develop an Early Years Strategy²⁶

The Australian Government has recognised how critical the early years are for children's development and positive outcomes over their lifetime, and has committed to developing an Early Years Strategy to create a more integrated approach to the early years and better support children's education, wellbeing and development. It will identify ways to reduce program and funding silos across departments, better integrate and coordinate functions and activities across government, and target outcomes to deliver better outcomes for young Australians and their families.

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability²⁷

In September 2023 the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with a Disability (the Royal Commission) made 222 recommendations on how to improve laws, policies, structures and practices to ensure a more inclusive and just society that supports the independence of people with disability and their right to live free from violence, abuse, neglect and exploitation.

This Strategy has considered how the Royal Commission's recommendations are relevant to Autistic people. The commitments under this Strategy align with the Royal Commission's vision for an inclusive Australia, where individuals live with dignity, equality and respect.



Government Response to the National Disability Insurance Scheme (NDIS) Review²⁸

On 7 December 2023, the Australian Government released the final report of the Independent Review into the National Disability Insurance Scheme (NDIS).

The Independent Review panel received almost 4,000 submissions – including from people with disability, NDIS participants, their families and carers, as well as the providers and workers who support them.

The report makes 26 recommendations and 139 supporting actions that aim to restore trust, confidence and pride in the NDIS through:

- Developing a unified system of support for people with disability.
- An NDIS experience centred on the whole person and their support needs.
- Better support for children and adolescents through mainstream services and a significant expansion of services outside the NDIS.
- More active government involvement and stewardship of NDIS markets to make them more efficient and effective.
- Improving service quality and ensuring appropriate safeguards and risk proportionate regulation.

While the full Government response to the NDIS Review will be released in 2024, the Australian Government has committed to working with state and territory governments to deliver reforms to the NDIS.

On 6 December 2023, National Cabinet agreed to implement changes to the NDIS to improve the experience of participants and restore the original intent of the Scheme to support people with permanent and significant disability, within a broader ecosystem of supports.

Additionally, National Cabinet agreed to jointly design additional foundational supports, for which the Government and the states and territories will jointly commission. These supports would offer people with disability a foundation to live a good life and be included in the community, regardless of whether they are in the NDIS or not. Foundational supports would interconnect with existing mainstream services like childcare and schools.

The Joint Standing Committee on the NDIS, Inquiry into the Capability and Culture of the National Disability Insurance Agency (NDIA)²⁹

In November 2023, the Joint Standing Committee on the NDIS released its final report into the capability and culture of the NDIA. In the report, the Committee focuses on the operational processes and procedures of the NDIA, staff employment and workforce matters, and the impact of the NDIA's capability and culture on NDIS applicants and participants. The Committee sought to make the NDIS more accessible for participants, and their families and carers. The report makes 27 recommendations directed at improving the participant experience with the NDIA so that it can provide participants with the support necessary to make and communicate decisions that affect their lives.



Senate Community Affairs References Committee Inquiry: Assessment and support services for people with ADHD³⁰

In November 2023, the Senate Community Affairs References Committee released a report with 15 recommendations for addressing barriers people with ADHD experience when accessing assessment, diagnosis and support services. The report notes ADHD often co-exists with forms of neurodivergence, including autism.

The Australian Public Service Disability Employment Strategy 2020-2025³¹

The Australian Public Service Disability Employment Strategy 2020-2025 aims to increase the employment of people with disability across the Australian Public Service to 7% by 2025. The strategy recommends a number of actions across two focus areas: attract, recruit and retain more people with disability; and accessible and inclusive workplace cultures and environments, and include actions specifically for the Australian Public Service Commission (APSC), departments and agencies, and the Senior Executive Service. The strategy also supports ADS.

Working Future: The Australian Government's White Paper on Jobs and Opportunities (The Employment White Paper)

On 25 September 2023, the Working Future: The Australian Government's White Paper on Jobs and Opportunities (The Employment White Paper) was published. The Employment White Paper lays the foundation for current and future Government policies that will shape the labour market over the years to come. A key focus of the Employment White Paper is to improve economic inclusion and participation in employment for people with barriers to work, including people with disability.

The Employment White Paper includes current and future Government actions to improve economic participation for people with barriers to work.

The Employment White Paper and the strategy both focus on improving employment outcomes and economic participation for people with barriers to employment.



Appendix D – Common co-occurring neurotypes, disabilities and medical health conditions

Common co-occurring neurotypes, disabilities, and medical health conditions include, but are not limited to:

- Attention Deficit Hyperactivity Disorder (ADHD)
- Intellectual Developmental Disorder (Intellectual Disability)
- Pathological Demand Avoidance (PDA)
- Obsessive Compulsive Disorder (OCD)
- Epilepsy
- Sensory processing differences
- Rejection sensitivity dysphoria
- Alexithymia
- Sleep disorders
- · Learning differences such as dyslexia, dyscalculia and dysgraphia
- Speech and language delays, differences and disorders
- Global Developmental Delay
- Developmental Coordination Disorder (also known as Dyspraxia)
- Tic Disorders (such as Tourette's Disorder)
- Chronic migraine
- Anxiety
- Depression
- Eating disorders, such avoidant/restrictive food intake disorder (ARFID), Anorexia Nervosa, and Bulimia
- Fragile X Syndrome
- Rett's Syndrome
- Down Syndrome
- Deafness
- Blindness
- Metabolic conditions
- Medical conditions, such as Crohn's disease, Ehlers-Danlos Syndrome, Mast Cell Activation Syndrome, and Postural Orthostatic Tachycardia Syndrome.

Just like in any other community, there is great diversity within the Autistic and autism community. People may or may not identify with their diagnosis, as Autistic, neurodivergent or as having or not having a disability.

How and when an Autistic person shares information about their identity is a personal decision that can change over time. This may be influenced by factors such as the extent of the functional challenges they experience, the environment they are in.



Appendix E - Theory of Change diagram

Theory of Change

The Problem Statement

Actions to Realise Change

Impact

Issue - What is / are the issues being addressed?

Actions - short, medium and long-term.

Success - what will success look like?

Measures - How will

success be measured?

Who - Who experiences this problem?

What - What is their

experience?

Evidence to support this

Risks and Barriers -What are the associated risks? What funding / resourcing risks or barriers exist?

Enablers and Opportunities - Why, and based on evidence, can we believe the theory of change will achieve the expected results?

How - How will the action drive change?

What - What will the client / customer / participant experience as a result of the change?

Co-design / Engagement - What engagement will be undertaken?

Endnotes

¹ Such as: disability; race; gender; sexuality; culture; age; bodyshape/size and religion.

³ Australian Bureau of Statistic, Survey of Disability, Ageing and Carers 2018: <u>Disability, Ageing and Carers, Australia: Summary of Findings, 2018 | Australian Bureau of Statistics (abs.gov.au)</u>

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⁶ Australian Bureau of Statistic, Survey of Disability, Ageing and Carers 2018: <u>Disability, Ageing and Carers, Australia: Summary of Findings, 2018</u> | Australian Bureau of Statistics (abs.gov.au)

⁷ Australian Bureau of Statistic, Survey of Disability, Ageing and Carers 2018: <u>Disability, Ageing and Carers, Australia: Summary of Findings, 2018</u> | <u>Australian Bureau of Statistics (abs.gov.au)</u>

⁸ Australian Bureau of Statistic, Survey of Disability, Ageing and Carers 2018: <u>Disability, Ageing and Carers, Australia: Summary of Findings, 2018</u> | Australian Bureau of Statistics (abs.gov.au)

⁹ Arnold SR, Bruce G, Weise J, Mills CJ, Trollor JN, Coxon K. Barriers to healthcare for Australia autistic adults. Autism. 2023 May 10:13623613231168444. Doi: 10.1177/13623613231168444. https://pubmed.ncbi.nlm.nih.gov/37161777/

¹⁰ Senate Select Committee on Autism, Parliament of Australia, *Services, support and life outcomes for autistic Australians* (2022) [3.2]: <u>Select Committee on Autism – Parliament of Australia (aph.gov.au)</u>
¹¹ Autism CRC Supporting Mental Health Resource:

https://www.autismcrc.com.au/sites/default/files/resources/SASLA_Supporting-mental-health_Resource.pdf

¹² Vicki Gibbs, Jennie Hudson & Elizabeth Pellicano, 'The Extent and Nature of Autistic People's Violence Experiences During Adulthood: A Cross-sectional Study of Victimisation' (2023) 55(10) *Journal of Autism and Developmental Disorders* 3509. See also Fabienne Cazalis et al, 'Evidence That Nine Autistic Women Out of Ten Have Been Victims of Sexual Violence' (2022) 16 *Frontiers in Behavioral Neuroscience*.

¹³ Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [3.42]: Select Committee on Autism – Parliament of Australia (aph.gov.au)

¹⁴ Senate Select Committee on Autism, Parliament of Australia, Services, support and life outcomes for autistic Australians (2022) [3.38] - [3.39]: Select Committee on Autism – Parliament of Australia (aph.gov.au)

¹⁵ Senate Select Committee on Autism, Parliament of Australia, *Services, support and life outcomes for autistic Australians* (2022) [3.41]: <u>Select Committee on Autism – Parliament of Australia (aph.gov.au)</u>. See also Commonwealth, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, *Final Report* (2023) vol 8, 34-38; 110: <u>Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability</u>

¹⁶ Autism CRC, Community insights and unheard perspectives report (September 2023): <u>Community insights and unheard perspectives</u> | Autism CRC

¹⁷ Developing the National Autism Strategy – Discussion Paper: <u>Developing the National Autism Strategy</u> – <u>Discussion paper | engage.dss.gov.au</u>



² Soke G et al 2018. Prevalence of Co-occurring Medical and Behavioural Conditions/Symptoms Among 4- and 8-Year-Old Children with Autism Spectrum Disorder in Selected Areas of the United States in 2010. J Autism Dev Disord. 2018 Aug; 48(8):2663-2676. Available at https://pubmed.ncbi.nlm.nih.gov/29524016/#:~:text=Overall%2C%20the%20prevalence%20was%20higher,were%20first%20evaluated%20for%20ASD

- ¹⁸ United Nations Convention on the Rights of Persons with Disability: www.social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-crpd
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- ²³ Australia's Disability Strategy Hub | Disability Gateway
- ²⁴ Australia's Disability Strategy 2021-2031, Disability Gateway: <u>Australia's Disability Strategy Hub</u> <u>Disability Gateway</u>
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- www.aph.gov.au/parliamentary business/committees/senate/community affairs/adhd
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