DRAFT FOR CONSULTATION

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

Please note that this is provided for comment only.

All content is subject to decisions of Government.

Foreword from the Minister for Health and Aged Care

[placeholder - to be inserted following public consultation]

Contents

Acknowledgement of Country

The Department of Health and Aged Care acknowledges and pays respect to the Traditional Owners and Custodians of the lands throughout Australia. We recognise the strength and resilience of Aboriginal and Torres Strait Islander peoples, and their continuing connections to land, sea, and community. We pay our respects to Elders past, present and emerging.

Acknowledgement of the autism sector’s leadership

The Australian Government acknowledges the Autistic people, their families, carers and support networks, representative organisations and the Autistic and autism community members who advocated for the Department of Health and Aged Care to act on issues which impact the health and mental health of Autistic people. This advocacy culminated in the establishment of the National Roadmap to Improve the Health and Mental Health of Autistic People (the Autism Health Roadmap). In particular, the Department of Health and Aged Care acknowledges the stakeholders who worked collaboratively to shape the initial stages of the Autism Health Roadmap and the Autistic and autism community members who have contributed to the development of the Autism Health Roadmap.

Statement on Language

The Department of Health and Aged Care recognises that when referring to individuals on the autism spectrum, there is no one term that suits all people and that language is an individual and highly personal choice. Some people in the Autistic and autism communities like to use ‘Autistic person’ (identity-first language), some like to say, ‘person with autism’ (person-first language), and some are fine with using either.

The Department of Health and Aged Care uses identity-first language, ‘Autistic person’ or ‘Autistic people’, and capitalises the term Autistic. Identity first language reflects the belief that being Autistic is a core part of a person's identity which cannot, and should not, be treated as separate.[1] The use of a proper noun further emphasises that being Autistic is a robust, shared, and valued identity.[2]

Content warning

The Autism Health Roadmap contains information that may be distressing to some readers. It includes information about the experiences of Autistic people, their families and carers, and the barriers they face. If you need support the following free services are available to help you.

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: Autism Connect.

Beyond Blue Support Service

A free telephone and online service available to everyone for brief counselling.

- 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: Beyond Blue Support Service.

Lifeline Crisis Support

A confidential service providing 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.

eheadspace

A free online and telephone support and counselling to young people between ages 12-25 every day from 9am–1am AEDT.

- Call 1800 650 890
- Chat online through webchat to speak to a clinician.
- Send an email for a response within 2 days.
- More information, including how to create a headspace account, can be accessed at: Connect with a mental health clinician 1-on-1 | headspace.

13 YARN

A free and confidential one on one crisis support service available for Aboriginal and Torres Strait Islander peoples.

- 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.

Qlife

An anonymous and free LGBTIQ+ peer support and referral service for people in Australia wanting to talk about sexuality, gender, bodies, feelings or relationships.

- Call: 1800 184 527
- Website: https://www.qlife.org.au.

Overview

The Autism Health Roadmap outlines a vision for addressing the breadth of issues faced by Autistic people in the health care system and outlines actions to improve health and mental health outcomes for the growing population of Autistic people in Australia.

This vision will shape improvements to general and autism-specialised health care services and build the capacity of the people who work in health and mental health services, to better serve and support Autistic people, their families, and carers.

The Autism Health Roadmap has six Guiding Principles. These principles articulate overarching core concepts that are inherent to all focus areas, actions and outcomes considered in the Autism Health Roadmap.

Guiding Principles

- Understand and promote the individualised and intersecting needs of Autistic individuals in health and mental health services
- Recognise mental health as integral to all health
- Ensure partnership and inclusion by involving Autistic individuals, their families and carers in decisions that affect them
- Services for Autistic people, their families and carers should be universally accessible
- Uphold human rights, self-determination, and autonomy of Autistic people
- Acknowledge and cater to the specific needs of Autistic people as a priority population in all health services

The Autism Health Roadmap is focused on six key areas of health and mental health, referred to as Focus Areas.

Focus areas

- Focus Area A – Improving support for Autistic people, their families and carers, in health and mental health services
- Focus Area B – Improving the quality, safety and availability of Autism Affirming health and mental health care across their lifespan
- Focus Area C – Building better connections between health, mental health, and other service sectors, including the NDIS
- Focus Area D – Improving autism education and training for health and disability professionals
- Focus Area E – Strengthening research and data on health and mental health of Autistic people and their families and carers
- Focus Area F – Arrangements for oversight, monitoring, and implementation of the Autism Health Roadmap

Related to the Focus Areas are specific outcomes and actions. **Outcomes** are the changes envisioned to be achieved in the 10-year span of the Autism Health Roadmap. They are the ideal ‘future state’. **Actions** are concrete steps that can enable progression toward intended outcomes.

The Autism Health Roadmap is an Australian Government strategy, led by the Department of Health and Aged Care. It is intended to provide national leadership on what might be explored through more specific or localised jurisdictional or industry autism strategies, plans, programs, agreements, and initiatives. The Department of Health and Aged Care is committed to working with state and territory governments, the community sector, and the health provider industry to achieve the vision and outcomes of the Autism Health Roadmap.

The content of the Autism Health Roadmap is the culmination of a consultative development process, including a series of co-design engagements with a broad range of Autistic and autism community stakeholders during 2023 and 2024.

Timeframe

The Autism Health Roadmap will span 10 years, 2025–2035.

Please note that Australia’s Disability Strategy (ADS 2021–2031) is due for review in 2031. Actions remaining and future directions for the Autism Health Roadmap will be considered as part of that review.

Background

On 27 November 2019, the Senate established a Select Committee on Autism (the Senate Select Committee) to inquire into and report on services, support, and life outcomes for Autistic people.

The Senate Select Committee delivered its final report on 25 March 2022.[3] A key recommendation of the Committee’s report was to develop both a National Autism Strategy and a National Roadmap to Improve the Health and Mental Health of Autistic People.

Following the Senate Select Committee, several Autistic and autism community members, including health advisors and representatives from Autism Aspergers Advocacy Australia (A4), AMAZE and the Australian Autism Alliance worked with the Department of Health and Aged Care prior to the formal establishment of the Autism Health Roadmap Working Group. These members helped shape the initial direction of the Autism Health Roadmap and allowed for a full co-design process to be established.

The Australian Government committed funding in the October 2022–23 and May 2023–24 Federal Budgets to develop the National Autism Strategy and Autism Health Roadmap.

Concurrent Australian Government reforms and reviews

Please note this section may be updated or changed for the final version of the Autism Health Roadmap.

The National Autism Strategy

The Australian Department of Social Services has led the development of the National Autism Strategy, which sets out a framework for improving the life outcomes for Autistic people in the years ahead.

The National Autism Strategy is focused on four key outcome areas:

- social inclusion
- economic inclusion
- diagnosis, services and support
- health and mental health (the Autism Health Roadmap).

The Autism Health Roadmap encompasses the health and mental health aspects of the broader National Autism Strategy.

National Health Reform Agreement

The National Health Reform Agreement (the NHRA) is an agreement between the Australian and state and territory governments. It sets out the terms under which the Commonwealth and states and territories would work together to improve health outcomes for all Australians. A key function of the NHRA is to set out how much and the details of how the Australian government provides funding to states and territories for public hospital services and community health services.

The first NHRA was created in 2011. The 2020–25 Addendum to NHRA amends the Agreement for the period 1 July 2020 to 30 June 2025.

Reforms to Strengthen Medicare

Medicare is Australia’s universal health insurance scheme, subsidising the costs of health care (hospital services, medical services, and tests, imaging and scans) for all Australians. The 2023–24 and 2024–25 Commonwealth Budgets included funding for several measures to strengthen Medicare. These measures include:

- making it cheaper for people to see a general practitioner, through tripling of the bulk billing incentive for general practices
- expanding the age eligibility from under 13 years to under 25 years for Medicare rebates for assessment and development of a treatment and management plan for individuals diagnosed with complex neurodevelopmental disorders, such as Autism.

- making health care more affordable and available for women, including a review of services subsidised by Medicare and an extension of the Medicare Benefits Schedule (MBS) item for telehealth for sexual and reproductive health
- implementing a voluntary patient registration system intended to strengthen the relationship between patients and their general practitioner and other Primary Health practitioners – known as MyMedicare
- ‘wrap around’ primary care for frequent hospital users, giving improved access to comprehensive clinical care and supporting self-management for people with chronic conditions
- Primary Health Network commissioning of multidisciplinary teams in general, and mental health services in particular.

The Final report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission)

The Disability Royal Commission final report was tabled in the Australian Parliament on 29 September 2023. The final report includes 222 recommendations. Addressing these recommendations requires a coordinated national effort. All governments are committed to working closely together to support and implement the Disability Royal Commission’s vision for an inclusive Australia, and to ensure reform will implement meaningful and lasting change.

The Australian Government released its initial response to the Disability Royal Commission on 31 July 2024. Following careful consideration and community consultation, the Australian Government accepted or accepted in principle 130 of the 172 recommendations that were fully or partially the responsibility of the Commonwealth. This response is the first stage of the broader program of reform to address the Disability Royal Commission’s recommendations alongside related disability reforms. Phasing the implementation of reforms allows for immediate change in key areas, while enabling collaboration and consultation over a longer period on more complex reform.

The Australian Government response to the Disability Royal Commission final report is available at http://www.dss.gov.au/disability-and-carers/australian-government-response-to-the-disability-royal-commission

The Independent Review into the National Disability Insurance Scheme (NDIS Review)

The Australian Government released the final report of the NDIS Review on 7 December 2023. 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.

Addressing the NDIS Review's recommendations to make a positive change for people with disability requires a whole-of-country effort. This includes all levels of government and the entire community – including businesses, non-government organisations, service providers and workers that support people with disability.

The Australian Government is carefully considering the recommendations in the final reports of both the NDIS Review and the Disability Royal Commission before providing its full response. Careful sequencing of any changes will be needed to ensure the most important foundations are in place before broader reforms occur.

Australia's Disability Strategy

Australia's Disability Strategy 2021–2031 (ADS) is the national policy framework for disability. 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. Actions to implement the ADS are included in Action Plans on specific topics.

National Mental Health and Suicide Prevention agreement

The Commonwealth and all states and territories entered into the National Mental Health and Suicide Prevention Agreement (National Agreement) in March 2022.

The National Agreement aims to achieve systemic, whole-of-government reform to deliver a comprehensive, coordinated, consumer-focused mental health and suicide prevention system with joint accountability across all governments.

The National Agreement key priority areas include regional planning and commissioning, priority populations, stigma reduction, safety and quality, gaps in the system of care, suicide prevention and response, psychosocial supports outside the National Disability Insurance Scheme, national consistency for initial assessment and referral, workforce, and data and evaluation.

Autistic and autism community involvement in developing this Autism Health Roadmap

The Department of Health and Aged Care has produced the Autism Health Roadmap in close collaboration with many Autistic people and autism community members. This has been done through the Autism Health Roadmap Working Group (the Working Group), extensive co-design consultations with key groups, and a public consultation process. A summary is outlined below, with further detail in Appendix A.

The Working Group was the lead stakeholder group that supported and guided development of the Autism Health Roadmap. Membership includes Autistic individuals, their families and carers, and representatives of stakeholder organisations, including advocacy bodies, relevant peak bodies, researchers, clinicians, and representatives from Commonwealth and state and territory health and disability agencies. Working Group chairs included two Autistic members.

The Working Group has supported the development of the Autism Health Roadmap by:

- ensuring the Autism Health Roadmap is developed with inclusivity and transparency
- identifying topics of relevance and defining priority areas for the Autism Health Roadmap
- fostering connection to other key stakeholders essential to the process
- advising the Department of Health and Aged Care regarding the wording of the Autism Health Roadmap.

The goals of the Autism Health Roadmap were informed by a national co-design process with Autistic co-leadership at each step. Autistic members of the Working Group were involved in developing co-design principles to ensure that the process was appropriate for the Autistic and autism community. The process was then conducted by an external expert organisation, the Autism Cooperative Research Centre (Autism CRC).

The Autism CRC consulted with Autistic people, their families and carers, health and mental health practitioners and representative organisations. The Autism CRC ensured engagement with people from the key priority populations as identified by the Working Group (described later in this document). Consultation was conducted through a range of activities, including focus group interviews. In addition, the Autism CRC performed an analysis of data from almost 5000 Autistic people, families, carers and professionals.

In February 2024, the Autism CRC hosted the National Health and Mental Health Services Community Co-design Summit (the Summit). The Summit was attended by Autistic people, families and carers of Autistic people, professionals in health, mental health, allied health and disability fields including Autistic and non-Autistic practitioners. The Summit resulted in the identification of key priorities and recommendations for consideration in the development of the Autism Health Roadmap. The final report, including detailed appendices and an Easy English version, is available on the Department of Health and Aged Care's website: National Roadmap to Improve the Health and Mental Health of Autistic People | Australian Government Department of Health and Aged Care.

About autism and Autistic health

What is autism?

Every Autistic person is unique, and Autistic people have different cultural and linguistic backgrounds, individual identities and often other disabilities and co-occurring conditions. There is no one universally accepted definition of autism that is able to capture the diversity of Autistic experiences.

The Autism Health Roadmap adopts a biopsychosocial model of disability to understand the experiences of Autistic people. Autism is considered primarily as a neurodevelopmental condition.[4] In line with the social model of disability, the Autism Health Roadmap takes the approach of recognising that attitudes, practices and structures in a neurotypical world can create barriers for Autistic people to participate fully and equally in the community.

As a condition, autism is lifelong, and influences how people process information, communicate and interact with others. It is diagnosed by trained clinicians, who observe certain characteristics within social communication, behaviours and intense or focused interests, as well as assessing the person‘s developmental history. There are two sets of diagnostic criteria commonly used throughout Australia and the world: the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders and the World Health Organization’s International Classification of Diseases.[5]

In 2018 there were 205,200 Autistic Australians, an increase from 164,000 in 2015.[6] More people under 25 are diagnosed as Autistic than older age groups, with the highest prevalence being in those people aged 10 to 14.[7]

Autistic people all display differences in the way they communicate and socialise, and process information and think, when compared to the non-Autistic population. For some Autistic people, this may present as intense interests, a preference for order and certainty in their environment, strong attention to detail, and sensory processing differences. These traits vary in how they present in different individuals and Autistic people may have different support needs throughout their lifetime.[8]

Some Autistic people may communicate directly and literally, and may interpret sarcasm, jokes or small talk differently to non-Autistic people. Others may be non-speaking and use Augmentative and Alternative Communication (AAC) with a device or other technology or unaided (e.g., gestures and manual sign) to communicate. Some Autistic people may use different communication strategies (e.g., speech or communication technology) as their support needs change depending on their energy, stress or life circumstances. Autistic people may use and understand nonverbal communication, such as facial expressions and tone of voice differently to non-Autistic people.

Autistic people may also experience increased or decreased sensitivity and awareness to the sensations of sound, light, smells, tastes and touch and experience differences in interoception, proprioception and vestibular processing, compared to non-Autistic people.

They may avoid fluorescent or bright lights, remove tags from clothing, use noise cancelling headphones or avoid certain textures and experience differences in their awareness of balance, sense of movement and internal sensations. Alternatively, they may seek sensations relating to motion, light, odours or other sensory experiences for pleasure or self-regulation. A difference in sensory processing can cause difficulties with experiencing environments which cause sensory overwhelm or trigger sensory sensitivities and may lead to a meltdown or shutdown.

Further to these experiences, and expanded on in detail below, is the fact that many Autistic people experience co-occurring conditions such as language and learning difficulties, and a range of medical conditions. Many of these challenges can be overcome with appropriate support, knowledge and understanding from professionals and society as a whole. The Autism Roadmap aims to propose concrete steps which can be taken to reduce some of these challenges.

Physical, mental health and experiences of suicide of Autistic people

In general, Autistic people suffer poorer health than the general population, including greater risks of co-existing conditions and premature death. However, detailed knowledge of these issues is restricted due to a limited focus on Autistic health research. This is likely because traditionally autism was considered a behavioural and neuropsychiatric condition, rather than a different neurotype which coexists with a range of other health conditions.[9]

Autistic people experience an increased incidence of a wide range of co-existing physical conditions including epilepsy, gastrointestinal disorders, central nervous system anomalies, diabetes, muscular dystrophy, sleep disorders, autoimmune conditions, allergies, hypertension, obesity and thyroid disease.[10,11]

A recent review of literature found that the most common co-existing conditions associated with autism were epilepsy and immune, gastrointestinal, and sleep disorders.[12] Research suggests that the overall occurrence of at least some co-existing conditions with autism is common. In one study from the United States, the median number of co-existing conditions experienced by Autistic people was 11.[13]

Risks of particular conditions are not spread evenly across the population of Autistic people, and it appears that co-existing conditions affecting some Autistic people are quite different to those affecting others. For example, in an investigation of health care service use data, clusters of Autistic children were found, characterised by either (1) high rates of co-existing conditions, (2) diagnoses of developmental delay, or (3) low rates of co-existing conditions.[14] Differing incidences of co-existing conditions among different members of the Autistic population are not well understood.[15]

Increased incidence of a wide range of mental health conditions has also been found in Autistic people. Common co-existing conditions include anxiety, depression, bipolar and mood disorders, schizophrenia and other psychoses, eating disorders, substance use disorders and obsessive-compulsive and related disorders.[16] Similarly to co-existing physical conditions, incidence of co-existing mental health conditions is not shared equally among the Autistic population, which is presently also poorly understood.[17]

A significant factor that impacts Autistic people's health and mental health is their negative experiences of interpersonal interactions and social situations. Autistic people also often experience higher rates of bullying, discrimination and isolation,[18] as well as higher rates of abuse and domestic violence.[19,20]

Studies consistently show a two to three-fold increase in the premature mortality rate in Autistic people over that of the general population.[21] In a study of Australian mortality data, Autistic people died at twice the rate of the general population.[22] This is thought to be because of increased rates of co-existing health and mental health conditions, including completed suicides.

Suicidal thoughts and behaviours are more prevalent among Autistic people compared with the general population.[23] It appears that suicidal attempts are associated most strongly with co-occurring depression, and that other factors such as schizophrenia, adjustment disorders, anxiety disorders, and mood disorders may also be associated.

Barriers to accessing health services for Autistic people

The incidences of co-existing physical and mental health conditions underscore the need for effective health and mental health services for Autistic people. However, Autistic people and their families and carers report significant barriers to accessing, navigating, and receiving safe, respectful, appropriate, and connected health and mental health services. These barriers include:

- the sensory environment of health services
- low levels of health literacy
- financial costs related to attending services
- past negative experiences and trauma, including stigma
- diagnostic overshadowing
- being unable to access health services due to a lack of communication support
- health professionals' lack of awareness or stigma towards Autistic people.

Autistic people often experience stigma related to their autism diagnosis or Autistic traits.[24] Autism stigma is primarily influenced by a poor understanding of autism in combination with a negative view of Autistic traits. This stigma can mean Autistic people face ignorance, prejudice and discrimination. It can also affect the quality and appropriateness of health care received, leading to reduced access and efficacy of care.[25] This can all have negative consequences for Autistic people's physical and mental health.

Parents and carers of Autistic children face difficulties navigating assessment and treatment supports and health professionals for children and young people, as well as age restrictions limiting eligibility for services. These difficulties underscore the need for strong advocacy in accessing services.

Priority populations

First Nations peoples

Due to non-Indigenous cultural biases in diagnostic tools, First Nations Autistic peoples are more likely to be misdiagnosed and/or not diagnosed to that of non-Indigenous Autistic people. This means that prevalence rates appear to be lower in First Nations peoples despite not actually being so.[26] First Nations Autistic peoples, their families and carers also face additional barriers to accessing health care, such as racism and culturally unsafe services.

In line with the Australian Government's commitments to the National Agreement on Closing the Gap, the actions outlined in the Autism Health Roadmap seek to embed the four priority reforms. That is, Aboriginal Community Controlled Health Organisations should be prioritised as service providers wherever possible; any improvements to health care settings need to be culturally safe; any research priorities should look at options that improve data sovereignty; and all efforts should explore opportunities for shared decision making.

Culturally and linguistically diverse (CaLD) people

Current diagnostic frameworks for autism involve assessing communication methods, social and behavioural differences against specific cultural norms. This can be a barrier to identifying autism in people who are not from majority cultural groups.[27] As a result, CaLD Autistic people may be more likely to have delayed and/or missed autism diagnoses.[28,29] CaLD Autistic people may also face extra barriers to health care, including experiences of racism, communication and language differences, and cultural influences which may mean their behaviours are not what a majority-culture doctor would expect. These differences may in turn impact the likelihood that they are diagnosed or offered treatment, because they do not adhere to the expected cultural norm.[30]

Women and girls

Although boys and men are statistically 3.5 times more likely than women to be diagnosed as Autistic,[31] this does not (necessarily) mean more boys and men have autism. Historically, there has been a greater understanding of autism in the male population. Although some diagnostic tools and support services have improved for recognising autism in women, many continue to cater to the needs of men. Current research shows that Autistic women are more likely to be misdiagnosed with affective disorders and/or personality disorders.[32] There is limited data in relation to non-binary gendered Autistic people.

Autistic women and girls can experience complex medical support needs which in turn can affect puberty and sexuality development. Despite these additional needs, research shows that Autistic individuals are less likely to receive basic reproductive and sexual health care, such as cervical cancer screenings and gynaecology visits, compared with non-Autistic individuals.[33] In pregnancy, Autistic individuals also experience higher rates of various pregnancy complications and related health issues: preterm birth, caesarean delivery, pre-eclampsia and pre- and post-natal depression.[34]

Recognising non-binary people can experience similar reproductive and sexual health matters to that of individuals identifying as women, the above information is applicable to all Autistic people with female sex characteristics regardless of their gender identity.

LGBTQIA+ people

Autistic people are much more likely to identify as LGBTQIA+ than non -Autistic people.[35] Additional barriers faced by LGBTQIA+ people include experiences of discrimination and additional stressors in health care settings, which can lead to higher rates of suicide and suicide attempts as well as diagnosis of mental health conditions.[36] Autistic people may also be denied gender affirming care because of a presumption that they are unable to understand their gender identity. Where they are able to access gender affirming care, this may take into consideration their additional sensory and communication needs.

People who live in rural and remote areas

People who live in rural and remote areas have limited access to diagnostic services and ongoing supports for autism.[37] Specific barriers can include appointment wait times, travel times and lack of choice in specialist services. People in rural and remote areas have poorer health outcomes, including higher rates of injury, potentially preventable hospitalisations, and suicide.[38]

People with co-occurring intellectual, psychological, cognitive, physical or developmental health conditions

Autistic people are more likely than non-Autistic people to have a range of other conditions, such as intellectual disability, attention deficit hyperactivity disorder (ADHD), epilepsy, depression, anxiety, eating disorders, cardiovascular disease and diabetes.[39,40,41]

Autistic people experience a range of support needs, from low support to high support needs, which can shape their experiences with the health system. Support needs can affect aspects of health and mental health care such as providing informed consent, an increased need for services to be coordinated, and greater challenges finding a suitable health professional or service.

These additional conditions may mean that some Autistic people need more support or different adaptations in order to access services. Poorer health and mental health outcomes for Autistic people with co-occurring conditions frequently occur due to diagnostic overshadowing, misdiagnosis and service refusal on the basis that an autism diagnosis is beyond the capabilities of the service provider.[42]

People in residential settings

Autistic people who live in residential care such as aged care facilities, disability group homes, rehabilitation care, respite care facilities, boarding houses and out-of-home care settings can face barriers to individualised health care and autonomy in health care, and health impacts from the sensory environment. Autistic people in these settings are more likely to have their physical and mental health conditions overlooked.[43]

Autistic people in correctional settings

Autistic people who are incarcerated in correctional settings such as prisons and detention centres can also face barriers to individualised health care and autonomy in health care, and health impacts from the sensory environment. Autistic people in correctional settings can face a range of impacts to their health, including lack of Medicare or most Pharmaceutical Benefits Scheme access for health or mental health treatment,[44] missed diagnoses, limited state funded justice health services, and complexities navigating the system due to differing social communication methods, behaviours, and experiencing under or over sensory stimulation.[45,46]

People who are from low socio-economic backgrounds

Financial costs can be a barrier to accessing diagnoses and ongoing health care. However, these needs are particularly acute for Autistic people from low socio-economic backgrounds. This can compound the challenges of getting a diagnosis and accessing treatment, resulting in people being more likely to be under-diagnosed compared to people from higher socio-economic backgrounds.[47] Specific barriers include the costs of health care, transport and organising care for other family members, and awareness of autism by providers.

Neurodiversity

Neurodiversity is a term that is used to describe the natural range of diversity that exists in human neurodevelopment and human cognitive neuroscience. Although all people process and perceive the world differently, some differences are grouped and named.[48]

Autism is one form of neurodivergence (that is, a neurocognitive difference that has been grouped and named). Other forms include attention deficit hyperactivity disorder (ADHD) and learning differences (such as dyslexia). Many people also have more than one different neurotype, for example: autism and ADHD.

In the Autism Health Roadmap, the Department of Health and Aged Care recognises that autism is only one of many neurodivergences. The focus in the Autism Health Roadmap is on autism, rather than on all possible neurodivergences. Key outcomes and actions outlined in the Autism Health Roadmap aim to build on the existing work in the emerging field of neurodiversity-affirming care, but with a specific focus on the needs of Autistic people. Because of this, the term ‘Autism Affirming care’ has been adopted for the Autism Health Roadmap.

Autism Affirming care

An important part of acknowledging neurodiversity is ensuring that health care undertakes adjustments to meet the needs of neurodivergent people, including Autistic people. For many Autistic people and specialised practitioners, it is seen as good practice to provide health and mental health care which is tailored to the particular neurotype and needs of Autistic people. This is currently referred to by a range of terms, including ‘Autism Affirming’ and ‘neurodiversity affirming care’. It is an example of person-centred care.

While the recognition of the need for this type of specialised care is a promising development, it is important to acknowledge that ‘neurodiversity affirming care’ is intended to cater to the needs of all neurodivergent populations, beyond the specific needs of Autistic people. ‘Autism Affirming care’ therefore captures the specific and limited focus on meeting the needs of Autistic individuals. It is not intended to exclude people who experience more than one type of neurodivergence (e.g., people who are both Autistic and have ADHD). It is important to note that there is currently no clear set of standards or consensus on workforce capabilities amongst health practitioners about what constitutes best practice in this type of care.

Due to this wide variance in terms and how they are used, the Autism Health Roadmap uses ‘Autism Affirming care’ to mean specialised care and practice for Autistic people. The outcomes and actions described in this Roadmap propose specific steps intended to help establish a consensus about these skills and capabilities. Reaching consensus on what Autism Affirming care is and how it should be practised will involve considering the intersections with and people’s understanding of other forms of practice such as neurodiversity affirming care and trauma informed care.

Guiding Principles of the Autism Health Roadmap

There are overarching principles that guide all aspects of the Autism Health Roadmap, referred to as Guiding Principles. The intent is that these principles are inherent to everything expressed in the Autism Health Roadmap.

The Guiding Principles were developed in close consultation with the Working Group, which included Autistic people, their families and carers, members of Autistic organisations, health practitioners, researchers, and other sector stakeholders.

Understand and promote the individualised and intersecting needs of Autistic individuals in health and mental health services

Aspects of a person's identity can overlap to create unique experiences of discrimination, disadvantage, and inequality. For one person, autism could be one facet of an intersectional experience with a variety of other aspects of their identity that might also lend to further discrimination or complexity. For example, an Autistic person who may also be gender diverse, or a person of colour, a victim of gender-based violence or have a co-existing physical disability, will likely experience compounded disadvantage. The Autistic person's interactions with the world will need to be relational and intersectional rather than compartmentalised or siloed transactions on isolated aspects of their identity.

Because of this, every aspect of improving the health and mental health of Autistic people needs to be founded within this recognition. All priorities put forward within the Autism Health Roadmap recognise that there is no one size fits all approach that will work. Rather, people's experiences of health and mental health services are influenced by their intersectional identities. As articulated throughout the Autism Health Roadmap, health and mental health services should make efforts to consider these experiences when providing services.

Recognise mental health and suicide prevention as integral to good health

Mental health is a key aspect of general health and wellbeing. Autistic people experience poorer mental health, including higher rates of co-occurring mental health conditions than non-Autistic people. They are also more at risk of experiences that can contribute to poor mental health, including bullying and social isolation. Noting that suicidality is not necessarily linked to a mental health condition, but often considered to be related to mental health, there is growing evidence that Autistic people are up to 3 times more likely to die by suicide than the general population. Additionally, Autistic people are at a higher risk of self-harm behaviours, such as in the context of repetitive behaviours. Autistic people are also significantly more likely to die by self-harm.[49]

These inequities are perpetuated when mental health is considered to be separate to, or separately from, physical health. To acknowledge that mental health is integral to, not separate from, a person's overall health, the Autism Health Roadmap considers outcomes and actions that relate to mental health throughout, not separately from other areas of health.

Ensure partnership and inclusion by involving Autistic individuals, their families and carers in decisions that affect them

Co-design is an investigative and creative process that brings together people who are impacted by the product, service, or resource (also known as 'outputs') and people with knowledge and technical skills to jointly create that output. Co-design aims to empower and put people with lived experience at the centre of the design process, recognising that people with lived experience are the people who know best. This is particularly important when the people who will be the recipients, or users, of a service may think and perceive the world differently to those who would otherwise lead it.

The Autism Health Roadmap has been co-designed, co-reviewed and will be co-delivered with Autistic people, their families and carers and support networks. It is critical that any initiative stemming from the outcomes and actions outlined in the Autism Health Roadmap should embed the fundamental principle of engaging with Autistic people, their families and carers in the planning, design, governance, implementation and evaluation of the Roadmap.

Services for Autistic people, their families and carers should be universally accessible

Universal design involves ensuring that policies, programs, and services are accessible to as many people as possible inclusive of age, ability, gender identity, culture, language, and any other social characteristics.

Uphold human rights, self-determination, and autonomy of Autistic people

Autistic people have the right to be respected and safe from all forms of discrimination, vilification, violence, and abuse throughout their lives. This is in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), to which Australia is a signatory.[50] Specific articles which are key to this include: Article 25 (right to the highest attainable standard of health) and Article 3 (freedom to make choices).

There should be freedom of choice, control and support for Autistic people to make their own (individual) decisions across their lifespan, about all aspects of their health and health care.

Acknowledge and cater to the specific needs of specific priority groups of Autistic people

As a result of many historical and cultural factors, particular groups of people in our society experience higher rates of disadvantage, greater barriers accessing services or other forms of inequities than others. Groups which are focused on in the Autism Health Roadmap are as follows:

- people with high or complex disability needs, including:
    - complex communication needs
    - complex behaviour support needs
    - people in residential settings
    - people in institutional settings
    - people with intellectual disability
- First Nations peoples
- culturally and linguistically diverse people
- LGBTIQA+ people
- women and girls
- people who live in rural and remote areas
- people who are from low socio-economic backgrounds.

Any efforts to improve the health and mental health of Autistic people should consider specific ways to target and improve the lives of these groups of people. Where evidence demonstrates the benefit of specific interventions for different priority groups, those interventions should be supported.

Diagnosis, Services and Supports

The National Autism Strategy and the Autism Health Roadmap are being developed in parallel by the Department of Social Services and the Department of Health and Aged Care respectively.

While the process of diagnosis is an inherently clinical component of health practice, the pre-diagnosis steps of screening, identification, assessment and referral of autism should be occurring across sectors and human service systems. In acknowledgement of this, the areas of obtaining a diagnosis, coordinating services and ensuring there is support across systems is being addressed in the *Diagnosis, Services and Supports* implementation stream of the National Autism Strategy.

The National Autism Strategy is scheduled to be completed before the end of 2024. When it is finalised its actions related to diagnosis and service coordination will be aligned with the work of the Autism Health Roadmap.

Public feedback and advice was sought at multiple stages in the development of the National Autism Strategy. Feedback relating to health and mental health advice obtained during consultations was passed to the Department of Health and Aged Care and considered as part of the development of the Autism Health Roadmap.

Similarly, public feedback received during consultation on the Autism Health Roadmap that is more relevant to the cross-sector *Diagnosis, Services and Supports* work plan will be referred to the National Autism Strategy team.

Further information: https://www.dss.gov.au/disability-and-carers/national-autism-strategy

Focus Area A

Improving support for Autistic people, their families and carers, in health and mental health services

Why this is important

Appropriate support for Autistic people within the health and mental health care landscape is not currently consistent or universal. This extends to the limited support and engagement in health settings of and for families and carers of Autistic people. As a result, Autistic people can experience more barriers to timely and effective healthcare than the general population. This can have long-term and profound impacts.

These barriers can mean Autistic people are more likely to experience distress when using health and mental health services, and ultimately, they may avoid seeking health care altogether. Many Autistic individuals report distressing and violating experiences when accessing health services. Through the Autism CRC consultations, one individual shared:

> *I had to have an endoscopy and I went to go to the hospital … the Anaesthetist saw on my records that I was Autistic and automatically assumed I was incompetent and gave me a sedative without my knowledge or permission, to knock me out before going into, you know, before getting administered the anaesthetic. (Autism CRC Report, p.27).*

The sensory environment can have a significant impact on Autistic individuals' experiences in health and hospital settings. Features which may be inconsequential to non-Autistic people such as noise, lighting and proximity to others can have major negative impacts on Autistic people. While these barriers can be prevented through the provision of reasonable accommodations, data provided both through research and in consultations suggest that health services currently do not consistently provide appropriate accommodations for Autistic people, their families and carers.[51,52]

> *I just went [to the] medical centre because they bulk-billed at the time. But that is not a nice place, that is not a nice place at all, because the waiting room [is] so big, and even through COVID, even with every second chair, they [are] still too close together. And it's too busy and it's too bright, and it's really overwhelming and people are calling people and yelling, and it's very hard to actually know what's going on. It's just overwhelming. So, I had to, I stopped going there ... (Autism CRC Report, p.39).*

Autistic people have said that information provided by health services is at times inaccessible and unclear, such as when medical terminology is used without explanation, which worsens other issues with health literacy.

> *There's enough information out there, but ... the format how it's presented and how it's provided isn't always as neurodiverse friendly ... People like my daughter [who also has an intellectual disability] and people with more profound autism are going to need help ... to access those services … (Autism CRC Report, p.32).*

This means that Autistic people don't access the right type of health care and delay seeking it when in need. Ultimately, these delays can result in increased co-existing health conditions and mortality.[53,54,55,56] Autistic people have the right to access health care and they also have the right to make their own individual decisions across the lifespan, about all aspects of health and health care. This is backed by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).[57]

There are various aspects that can impact whether an Autistic person is given full autonomy in decision making and/or provided support in health decision processes. Regardless of a person's capacity and communication methods, appropriate medical consent should be sought from all Autistic people as required, through individual consent or using appropriate supported decision making processes.

Understanding communication differences is particularly important when seeking appropriate medical consent. Many Autistic people may feel that their preferences for treatment are doubted or disregarded, and ultimately that their needs go unheard.

> *The affordability of health care services can also pose a significant barrier to health and mental health care. (Autism CRC Report, p.22).*

A scarcity of bulk billing and expenses associated with transport to appointments, particularly for those living in rural or remote areas, can also be a barrier to Autistic people accessing healthcare. Some Autistic people have experienced that they either *… can buy groceries this week or can talk to [their] psychologist (Autism CRC Report, p.22).*

Another reported barrier is that some Autistic people find it challenging to recognise if and when they need to seek professional healthcare. This can extend to difficulties in describing what they are experiencing, or difficulty perceiving internal bodily sensations and symptoms accurately. These are related to people's experiences of interoception. Alexithymia (or the inability to recognise and label emotions in self and others) is also a persistent challenge for many Autistic people seeking care, especially mental health care. One individual reported:

> *I have alexithymia so I can't express what I'm feeling a lot of the time, so being able to communicate what I need to a doctor is really challenging (Autism CRC Report, p.36).*

What the future could look like (outcomes)

A1. Health and mental health facilities are able to accommodate the sensory, communication and accessibility needs of Autistic people.

A2. Information and resources about health and mental health services are more accessible for Autistic people and autism community members. Information is provided in appropriate alternative formats for different communication and cultural contexts.

A3. Autistic people, their families and carers are actively supported to participate as equal partners in care. They are provided with support and information so that they can be aware of and understand the information they are provided, their health rights and what it is to give informed consent if they so choose.

A4. Autistic people's interoceptive differences, including experiences of symptoms, emotions, and pain are identified, supported, and accommodated in all health and mental health services.

A5. Autistic people and their appointed decision maker at times when and where they do not have capacity, are supported to make informed decisions about their health care.

A6. Financial and administrative barriers to accessing health and mental health services are reduced for Autistic people across primary and specialist care.

Steps to get to an improved future

Government has heard from Autistic people, autism community members and other subject matter experts about what could be implemented to drive change and improve supports for Autistic people, their families and carers in the health and mental health care system. Possible actions for consideration include:

Possible actions for Focus Area A

- Review, collate and investigate the best examples of health, mental health and suicide literacy resources for Autistic people, their families, and carers in partnership with Autistic and autism community members. These resources would provide examples for the further development of literacy resources.
- Review existing, or if needed develop and promote, tools for best practice models of care for supporting autonomy, facilitating support for decision-making, obtaining informed consent for treatment, and ensuring adequate and ethical safeguards for those that lack capacity to provide informed consent. These models should also consider the role of parents, carers, and guardians.
- Regularly review existing Australian Government health and mental health information and resources for consumers and health practitioners, to ensure Autistic people's needs are explicitly addressed.

- Develop information in areas identified as key gaps in the review of health literacy resources for Autistic people. Key topics could include:
    - when you might need to see a professional
    - how different kinds of professionals can help
    - how to navigate services, including making appointments
    - the traits/characteristics and varied presentations of autism
    - pain expression, interoception, emotions and alexithymia.
- Establish requirements for autism friendly spaces and other autism adjustments in the Australasian Health Facility Guidelines and related building and accessibility standards. Updates to these guidelines should include consultation with Autistic people to ensure these revisions are appropriate for the needs of Autistic people, families and carers.
- Develop resources for health and mental health professionals and service staff to improve their understanding and competency regarding Autistic traits, interoception, distress and pain expression in autism in partnership with Autistic people, autism community members and health practitioners. Ensure that these resources refer to or build on existing tools or instruments that support practice.
- As a priority action, consider how to improve access to and affordability of primary care services, including general practice, to address the health and mental health needs of Autistic people. This could include considering:
    - different funding models to allow for more timely and affordable diagnosis pathways for Autistic people of all ages.
    - exploring innovative models of diagnosis, treatment and care coordination in primary care and community-based specialist services.
    - longer consultations to accommodate different cognitive processing and communication needs, and complex mental health needs
    - otherwise increasing affordability and ways that health professionals can provide additional health and mental health supports to Autistic people, including referring Autistic people to free publicly available services if appropriate and/or peer support services.
- The Australian Commission on Safety and Quality in Health Care could:
    - develop and promote guidance for health service organisations and clinicians in line with the Autism Affirming Framework such as fact sheets, evidence briefs and webinars
    - develop information for priority groups, including Autistic people, to raise awareness of the Australian Charter of Health Care Rights including development of an Easy Read version
    - consider Autistic people’s needs in ongoing work related to health literacy (see Focus Area B).

Focus Area B

Improving the quality, safety and availability of Autism Affirming health and mental health care for Autistic people across their lifespan

Why this is important

Health services are often designed to meet the needs of non-Autistic people. Health professionals and services may be under equipped to meet the complex and often unique needs of Autistic people.[58] This can result in challenging and traumatising experiences, and inequity of outcomes for Autistic people. The Disability Royal Commission, found that "there has been, and continues to be, systemic neglect of people with cognitive disability in the Australian health system".[59] The Disability Royal Commission also found that people with cognitive disabilities (including some Autistic people who experience autism either as a cognitive disability or as a co-occurring disability) can experience trauma and distress when they undergo health procedures or treatment, whether in clinics, the community or hospital.[60]

> *So-called 'challenging' behaviour induced by stress can be extremely detrimental to good health care, for example if treatment has to be postponed or abandoned. Repeated distressing experiences can intensify this stress and can lead people with disability and their families to lose trust in the health system and fear further interactions.*[61]

A significant quality and safety issue is the use of harmful restrictive practices and misuse of restrictive practices on Autistic people. Restrictive practices include a range of actions, including physical, mechanical, chemical and environmental restraints.

Restrictive practices can cause significant harm to Autistic people, including trauma and physical health impacts. Any restrictive practice used unnecessarily or inappropriately can break trust between Autistic people (and their carers and family) and the health worker who undertook the restrictive practice. It is critical that restrictive practices are reduced and eliminated in health and mental health services through strategies that include the use of Autism Affirming care (including neurodiversity affirming and trauma-informed care).

Diagnostic overshadowing is also common for Autistic people with co-existing mental illnesses or neurological disorders. That is, symptoms of mental illness or neurological disorder are dismissed, or the person's or carer's reports of symptoms are not trusted, or people are less likely to be recognised as Autistic if they have a diagnosis of a different condition. Instead, the person's experience is incorrectly attributed to the autism diagnosis. In these scenarios, an Autistic person will miss out on evidence-based effective therapeutic intervention for their co-existing diagnoses.

One carer shared their experience:

> *they say [my daughter] has autism, but she also has brain injury. It is likely that we would get turned away, regardless of the service … We feel sorry for your situation, but we can't help you … (Autism CRC Report, p.48).*

Another key issue in this area is the common experience for Autistic people and their families and carers in difficulty finding suitable non-crisis mental health services. There is limited availability of autism-specific mental health services, and most mental health services don't provide the level of complex support required.

Complaints and grievance processes can often be unclear or not properly implemented, leaving people without proper recourse for addressing substandard care.

What the future could look like (outcomes)

B1. There are clear definitions and practice capabilities for Autism Affirming health care for Autistic people, co-designed with Autistic people and members of autism communities, and including approaches for different life stages and the intersecting needs for priority populations.

B2. Integrated models of health and mental health care, including suicide prevention, for Autistic people are developed, implemented and available, with specialisation corresponding to complexity of need.

B3. Autistic people are welcomed and accommodated for in all health and mental health service settings. Autistic people are not dismissed or refused service simply because of their autism diagnosis without an assessment of the condition they presented for.

B4. Health services reduce all restrictive practices and eliminate all harmful restrictive practices used with Autistic people, including mechanical restraint, physical restraint, and chemical restraint. Alternative interventions are available and used as routine practice.

B5. Health practitioners are skilled and proactive in upholding Autistic people's rights, including being able to support them to make decisions when they may not have the capacity to communicate their needs or provide consent.

B6. Health practitioners are capable of identifying and protecting against the Autistic experience of chemical restraint, and are well-informed of the evidence and harms associated with using medicines to control the behaviour of Autistic people.

B7. Health and mental health services take proactive steps to avoid diagnostic overshadowing.

Steps to get to an improved future

Government has heard from Autistic people, autism community members and other subject matter experts about what could be implemented to deliver on change and improve quality and safety for Autistic people, their families and carers in the health and mental health care system. Possible actions for consideration include:

Possible actions for Focus Area B

- Co-design and develop a national theory and practice framework for Autism Affirming care (Autism Affirming Framework). This could include individual and organisational definitions and descriptors of autism practice approaches (trauma informed care) and be mapped to existing health, mental health and suicide prevention practice guidelines and service models.
- Review existing health and mental health initiatives that include Autistic people as a focus cohort and align them with the definitions and practice descriptions of an Autism Affirming Framework.
- Align efforts to support general practitioners with current reforms in Primary Health Care, particularly actions around integrated person-centred care. Promote understanding of autism within existing sector reform efforts, including exploring further provisions that enable general practitioners to spend more time with Autistic patients and consideration of the communication needs and diverse abilities of Autistic people, including those with co-occurring conditions and complex disability support needs.
- Promote best practice care of Autistic people within existing sector reform efforts based on an Autism Affirming Framework. This could include further provisions that enable health practitioners to spend more time with Autistic patients. Further, that there is more consideration of the communication needs and abilities of Autistic people, including those with co-occurring conditions and complex or high disability support needs.
- Consider options for a national practice recognition initiative to make it easier for Autistic people to identify health professionals who, within their scope of practice and aligned with an Autism Affirming Framework, specialise in services for Autistic people.
- Pilot and promote best practice models of Autism Affirming care, as defined by an Autism Affirming Framework. Ensure that the specialised needs of the priority populations are considered in selection of the pilots.
- As part of an upcoming review of the National Safety and Quality Health Services (NSQHS) Standards, consider how they may be able to be more applicable to autism and alignment to an Autism Affirming Framework. This should include self-harm, suicide risk mitigation, and the reduction of all and elimination of harmful restrictive practices.
- Co-develop practice guidance and education material on the use of psychotropic medicines for Autistic people and Autistic experiences of chemical restraint, with reference to:
    - an Autism Affirming Framework

  - the Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard
  - existing evidence and practice guidance on the use of medicines to address behaviours with Autistic peoples, including systematic reviews of pharmacological interventions, alternatives to prescribing medicines, and deprescribing practices.

- Promote pathways for Autistic people, their families and carers to raise complaints with health services and practitioners, and to escalate complaints where required.
- Consider evidence from the Autism Affirming Framework as part of the upcoming review of the National Safety and Quality Health Services (NSQHS) Standards.
- Review the safety and quality aspects of health service practice guidance and education material on the use of psychotropic medicines to consider the needs and experiences of Autistic people.

Focus Area C

Building better connections between health, mental health, and other service sectors, including the NDIS

Why this is important

The Australian health care system can be complex and fragmented, making it difficult to navigate for Autistic people, their families and carers. A cohesive national approach, including integration of services and supports within the health system and supporting sectors, is vital. This approach will allow funding and access for appropriate and inclusive health services and activities that facilitate effective treatment, recovery and support.

Improved connectivity is required between health, mental health and other service sectors including the NDIS. Improving connections between these sectors could include:

- better coordination of service delivery for wrap around care
- policy and program development linkages
- information sharing culture, practice and enabling legislation
- flexible and tailored service interfaces for seamless continuum of care
- support to navigate the complexities of the service system.

If connections between services are not improved, Autistic people will continue to experience barriers to health services. These barriers are likely to result in inadequate diagnosis and treatment, poor health outcomes, and the risk of cycling through hospitals, health care services, homeless services and/or correctional or forensic services. This is particularly important for Autistic people who are managing co-occurring health and mental health conditions and/or disabilities in the community.

> *Consideration of care coordinators could be an action, which is often needed. Most practitioners end up case managing and supporting which adds to clinicians' times. (Autism CRC Report, page 59).*

Disconnects between service systems can also make it difficult to transition between services such as across states, child/adult services, and hospital/community supports, including the intersection of health and NDIS supports. The transition from child/young adult to adult services can also be particularly challenging.

Efficient information sharing between services is (also) a crucial part of quality connected care. It can be frustrating and sometimes traumatising for Autistic people when they are required to repeat their medical and mental health history when attending different services. Related to this, health practitioners have shared their challenges working with inconsistent information systems. Data security and privacy also remain significant concerns, particularly in light of the stigma around autism diagnoses. With any information sharing improvements, there is a need for robust safeguards to protect sensitive information including consideration of the ability for Autistic people to opt-out of data collection.

Self or parent advocacy plays a critical role for Autistic people engaging with health care services. Advocacy facilitates dialogue about health service experiences and needs. Advocacy is also a mechanism that encourages active participation of Autistic people as health care consumers. Unfortunately, inconsistent or unreliable service coordination and delivery can reduce avenues for advocacy.

What the future could look like (outcomes)

C1. Health and mental health services are better able to support Autistic people during transitions between different settings (e.g., admitted to non-admitted) and life stages (e.g., transition from child and youth to adult services). Services are funded and equipped to provide transition support that is personalised to account for Autistic people's varying and intersecting needs.

C2. Models of integrated care are used to facilitate Autistic people's journeys between health and mental health services and other services, including community services, the NDIS, foundational supports, education, disability, employment, early childhood, justice, and social services.

C3. Autistic people, families and carers, advocates and Autism organisations are provided with targeted, timely, specialised, accurate and relevant health and mainstream service linkage information to assist with recognising and connecting to related service systems.

Steps to get to an improved future

Government has heard from Autistic people and other subject matter experts, what could be implemented to deliver on change and improve connectivity of services for Autistic people, their families and carers in the health and mental health care system. Possible actions for consideration include:

Possible actions for Focus Area C

- Develop and publicise an 'autism passport' which is an accessible and practical tool for Autistic people to share information with health services. The passport should contain information on an individual's sensory, cognitive, communication, co-occurring conditions, and treatment preferences. Opportunities for digital integration could also be explored.
- Establish or build upon existing primary health communities of practice to connect and support health and mainstream sector professionals to improve regional coordination and responsiveness to health, mental health, suicide prevention and mainstream support needs of Autistic people.
- Consider potential models for Autistic and autism-proficient service navigators/liaison officers in health and mental health services. Consider whether

disability health navigators (recommended in the NDIS Review and Disability Royal Commission) could be equipped to play this role.

- Work in partnership with states and territories on specialised multi-disciplinary health and mental health care service options, either improving existing services or establishing new services. These centres could provide comprehensive, physical, and mental health care planning and services, including telehealth, tailored to Autistic people and capable of working with people with highly complex conditions.
- Consider ways to support Autism organisations to ensure that they can assist Autistic people, their families and carers with engaging health, mental health, suicide prevention and connected service systems.

Focus Area D

Improving autism education and training for health and disability professionals

Why this is important

Health care professionals play a critical role in the recognition, diagnosis, and ongoing support of Autistic people. To do this effectively, they need to have an adequate understanding of autism, confidence in their skills to work with Autistic people and an appropriate attitude towards autism.[62] This competency currently varies considerably across the health care sector, with some health professionals reporting only moderate levels of knowledge and self-efficacy in their practice. Health practitioners often lack autism-specific training in their professional education.[63] This can have significant impacts on Autistic people's health-related quality of life, including:[64]

- Autistic people having poorer communication experiences with health care providers,[65] and health care providers not understanding differences in communication methods and sensory experiences in autism
- health care providers misinterpreting or making assumptions about Autistic people's behaviours and/or communication, leading to potential misdiagnosis
- Autistic people, their families and carers perceiving that health professionals are unwilling to make needed accommodations for Autistic patients
- Autistic people, their families and carers perceiving that health professionals hold stigma towards autism
- lack of continuity of care/collaboration between health care professionals, for an Autistic person's health care journey.[66]

Autistic people consistently highlighted the importance of improving autism education and training for health and disability professionals. This includes training and education to improve understanding of:

- autism and intersectionality
- health standards and regulations
- how to obtain consent and assent
- how to provide trauma informed care
- how to better respond to distress and suicidal ideation
- appropriate ways to adapt treatment and care so that it is accessible.

Opportunities to develop training through co-design with Autistic people, as well as health and mental health practitioners, would be vital to its success. Autistic co-delivery of training, including involving Autistic practitioners, should be used where possible.

Further structural improvements would be supported by embedding autism competency in professional standards and registration.

Introducing education and training about autism in a way that is productive for all health professionals and appropriately involves Autistic people and autism communities is something that will require further work and consideration. Many health and mental health practitioners face genuine pressures and constraints in relation to balancing professional development with service delivery capacity.

The training curriculum is crowded, and practitioners often do not have time to undertake professional development beyond their specific specialty and regulatory compliance.

A subgroup of currently practicing health and mental health professionals identify as Autistic. Exact rates are not known because many health professionals do not disclose their diagnosis. This is for a range of reasons, with a major one being a perception that Autistic health professionals may not be supported to continue practicing because of their diagnosis.

Some Autistic individuals may prefer Autistic health professionals, as they are seen to have a more sophisticated understanding of the diverse presentations of autism and adopt a strength-based approach in their practice. Additionally, many Autistic people have reported feeling dismissed or humiliated when seeking health services (from generally non-Autistic professionals) and this may contribute to a stronger desire to access services from professionals with lived experience. With this in mind, Autistic health professionals need to feel safe disclosing that they are Autistic to their colleagues and clients or patients. This includes ensuring that they are protected against any long-term negative repercussions that might be based on misconceptions about their ability to practice. Additionally, Autistic health professionals may be over-consulted to inform health and mental health autism initiatives and may also have personal traumatic experiences in health and mental health service contexts. As a consequence, they may be more vulnerable to experiencing burnout when working in the autism field and may require additional support to manage their workload and mental health.

What the future could look like (outcomes)

D1. Co-designed and co-delivered education and training about autism is accessible to all health professionals, including pre-registration education, vocational training, formal qualifications, and professional development.

D2. Health, mental health, and disability professionals are capable of effectively communicating and engaging with Autistic people in ways that lead to Autistic people's health and mental health needs being better met.

D3. Health and mental health professionals are more capable of meeting the health and mental health care needs of Autistic people, including appropriate to different life stages and the intersecting needs of priority populations.

D4. Autistic people are supported to train and thrive as health and mental health professionals and peer support workers, by:

- understanding the rates of Autistic health and mental health professionals and peer support workers

- working with professional bodies to address barriers to Autistic people accessing and training and openly identifying in their workplaces
- improving understanding of reasonable adjustments in health and mental health service workplaces for Autistic practitioners.

Steps to get to an improved future

Government has heard from Autistic people and other subject matter experts, what could be implemented to deliver on change and improve education and training for health and disability professionals. Possible actions for consideration include:

Possible actions for Focus Area D

- Enhance existing resources and/or establish additional resources or services, for health and mental health practitioners in primary care supporting Autistic patients who need care beyond the practitioner's direct expertise. Examples might include:
    - an extension of Health Pathways
    - hotline to a specialised health practitioner
    - Primary Health Network resources provided to local practitioners
- The Department of Health and Aged Care to improve how other Government areas work with Autistic people (e.g. Social Services, Education, NDIA, NDIS Commission) and how they can improve their health and mental health.
- Consider options for a competency-based national program of professional development to improve health, mental health and suicide prevention workforce in the following areas (could be aligned with an Autism Affirming Framework):
    - autism, including diverse presentations, communication, interoception, alexithymia and pain expression
    - intersectionality and complexity
    - National Standards of care and how they apply to autism
    - relevant legislative frameworks, adjustments, and accommodations
    - informed consent and assent for all Autistic people, with a specific focus on people who do not have the capacity to give informed consent
    - supporting people with very high and complex disability needs
    - supporting Autistic people when they are in crisis situations or expressing suicidal ideation
    - trauma-informed care.

Focus Area E

Strengthening research and data on the health and mental health of Autistic people and their families and carers

Why this is important

Research and data are fundamental to recording, understanding, and monitoring the health progression and health outcomes of Autistic people. There are currently significant gaps in research and data regarding the health and mental health of Autistic Australians. One reason for these gaps is that there is no routine data collection or reporting on health outcomes for Autistic people at a national level and limited data collection and reporting from states and territories. National data collection is also a challenge across the health system, with a lack of disaggregated data making it difficult to identify outcomes for Autistic people. Data that captures the inequities of Autistic people moving through the health and mental health system is needed:

> *There is currently a very problematic lack of disaggregated data in the health care system – we currently don't identify the group that is disabled people in hospitals so we can't identify the data that shows which sites are performing well. (Autism CRC Report, p68).*

Collecting current, reliable, and consistent national data and reporting routinely would provide insights into the prevalence of autism in Australia and co-occurring health and mental health conditions, which could lead to better understanding of how best to address health care needs. Additionally, national data would support the need for and opportunities for further meaningful research about Australia's Autistic and autism community.

New data collection and new research is important as it would contribute to appropriate health services being made available to all Autistic people.[67] Some specific areas of research and data that are particularly lacking include: understanding the mental health of Autistic people; information on the health inequities that Autistic people face; and the experiences of Autistic people from priority population groups.

> *… we need to capture data on the inequities of Autistic people moving through the health and mental health system. If we can't show the costs and poor outcomes of Autistic people in health care, it makes it very difficult to justify and target any increases in capacity. (Autism CRC Report, p68).*

Future research and data need to be routinely co-designed and co-produced with the Autistic and autism community, to generate more appropriate, productive, and Autistic-led health strategies.[68] Research and data collection should also consider that many Autistic people may self-identify, and that many people in the Autism community consider self-identification to be as valid as a formal diagnosis.

Co-produced research would align future health care opportunities with the priorities of the Autistic and autism community. A critical area for innovation would be putting the lived experience of Autistic people at the centre of research, including Autistic-led and participatory research. It will also be important to embed intersectional experiences in research, including people with high and complex support needs, LGBTIQA+, cultural and linguistically diversity and First Nations-led research.

What the future could look like (outcomes)

E1. Health and mental health services, and relevant national data sets, routinely collect data in a way that accurately identifies Autistic people, and report nationally. This should include:

- autism diagnosis (including self-identified diagnosis)
- service usage
- co-existing health and mental health conditions and disabilities
- satisfaction with services
- restrictive practices
- clinical and individual recovery mental health outcomes.

E2. Health and mental health services have access to a comprehensive range of evidence and research translation materials, communities of practice, research partnerships and insights specific to Australian Autistic populations and systemic needs.

E3. Health and mental health research about Autistic people is conducted in partnership with Autistic people (including with co-leadership where appropriate), their families and carers and autism community members, and is focused on priorities that will reduce the health inequities experienced.

Steps to get to an improved future

Government has heard from Autistic people, autism community members and other subject matter experts about what could be implemented to deliver on change and improve research and data on health and mental health outcomes of Autistic people, their families and carers. Possible actions for consideration include:

Possible actions for Focus Area E

- Consider funding and prioritising research which identifies strategies to improve Autistic people's overall health and healthcare.
- Priority areas and population groups may include:
  - child and adolescent health and mental health
  - addresses diagnostic overshadowing
  - suicide prevention and reducing self-harm
  - intersections of autism health with intellectual and cognitive disabilities
  - women's and reproductive health

- Conduct a set of systematic reviews to address current research and practice gaps, such as considerations relating to understanding of health, mental health and suicide prevention outcomes for Autistic people, including:
    - existing health and mental health data
    - unmet health, mental health, and crisis response needs
    - referrals
    - mandatory reporting of adverse outcomes, and other relevant metrics.
- Leverage existing and upcoming data and reporting reforms, where disability identifiers in data sets are being improved to develop a comprehensive and consistent set of autism identifiers. This would be required for an ongoing basis of national health and mental health data collections and reporting.
- Develop and establish national evidence-based standards in pain measurement for Autistic people. This should have applicability across diverse settings such as primary care, bedside care, ambulance transport and childbirth, plus across all ages, abilities and intersectional experiences.
- Review the current measurement tools and practice guidelines used to identify co-occurring health and mental health conditions for Autistic people. The review should identify options for further development of existing or new tools and guidelines that are appropriate for Autistic people. The options should be valid for Autistic people with co-existing conditions and for priority populations.

Focus Area F

Arrangements for oversight, monitoring, and implementation of the Autism Health Roadmap

Why this is important

Effective governance that brings together Autistic people, the autism community, health providers and governments will be essential to improving the health and mental health of Autistic people.

Robust, transparent, and inclusive oversight and monitoring arrangements are needed, to ensure that governments and service system stakeholders are held to account for improving the health and mental health of Autistic people.

What the future could look like (outcomes)

F1. A program of work to improve the health and mental health of Autistic people is overseen by a diverse group of stakeholders and incorporates high quality engagement with Autistic people and autism communities. Key groups include:

- Autistic people, including Autistic people from all priority populations
- families and carers of Autistic people
- representatives from the health, mental health and disability sectors
- representatives of universities, professional colleges, accreditation, and registration bodies
- cross-government representation.

F2. Autistic people, families and carers, autism community members and other stakeholders have access to accessible, co-designed and relevant information about work towards improving the health and mental health of Autistic people. This should include a way to provide feedback about implementation of the Autism Health Roadmap.

F3. Work towards improving the health and mental health of Autistic people is underpinned by clear implementation timeframes and a robust monitoring, evaluation, and reporting framework.

Steps to get to an improved future

Government has heard from Autistic people and other subject matter experts about what could be implemented to deliver on arrangements for oversight, monitoring, and implementation of the Autism Health Roadmap. Possible actions for consideration include:

Possible actions for Focus Area F

- Establish a Governance Group to oversee and monitor work to improve the health and mental health of Autistic people. This should include Autistic and autism representatives, practitioners and their representative bodies, and government representatives.
- Report annually on implementation of the Autism Health Roadmap and progress of work to improve the health and mental health of Autistic people.
- Consider development of an Outcomes, Monitoring and Evaluation Framework. Critical data gaps should be identified and addressed.

Appendices

Appendix A – Development of the Autism Health Roadmap

Overview

The Autism Health Roadmap presents the first nation-wide opportunity to coherently articulate the change that Autistic people and autism community members want to see. This includes having the directions and actions that will help move us there; the data, measures and evaluative efforts needed to monitor what progress is being made; and the governance and oversight to keep this multi-level reform project on track. Furthermore each organisation or group of people will be held to account for their part in its delivery.

The Autism Health Roadmap was developed across 2023–2024 in partnership with Autistic people and autism community members. A broad range of stakeholders were engaged throughout the process, including Autistic people, research organisations, medical professionals, community organisations, and organisations specific to some of the Autism Health Roadmap's priority populations.

An important part of this was the engagement of the Autism Health Roadmap Working Group (the Working Group) as the lead stakeholder group engaged throughout the Roadmap's development.

The Department of Health and Aged Care engaged an external expert organisation, the Autism Cooperative Research Centre (Autism CRC) to design, arrange, facilitate, manage, and report on community consultations for the Autism Health Roadmap. Autism CRC is the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum. There was a strong focus on using appropriate co-design methodology and meaningful engagement.

Autism Health Roadmap Working Group

The Autism Health Roadmap Working Group (the Working Group) was the primary stakeholder group which supported and guided the development of the Autism Health Roadmap. The responsibilities of the Working Group were to support the Department of Health and Aged Care by providing input on the development of the Autism Health Roadmap, including:

- ensuring the development was conducted in an inclusive and transparent manner
- identifying topics and defining priority areas for targeted short-, medium- and long-term action
- providing linkages to other key stakeholders essential to development and future implementation of the Autism Health Roadmap
- disseminating information and requests for input to their networks
- reviewing meeting papers, including draft versions of the Autism Health Roadmap.

The Working Group was chaired by the First Assistant Secretary of the Primary Care Division at the Department of Health and Aged Care in 2023, and the Assistant Secretary for Allied Health and Service Integration Branch in 2024. Four deputy co-chairs assisted with each meeting – Dr Melanie Heyworth, Ms Geraldine Robertson, Mr Andrew Davis and Professor Nick Lennox.

The full membership of the Working Group was:

Name	**Organisation being represented**
Ms Hayley Clapham	*Autistic individual member*
Dr Jac den Houting	*Autistic individual member*
Ms Julianne Higgins	*Autistic individual member*
Dr Lionel G. Evans	*Autistic individual member*
Ms Monique Blakemore	*Autistic individual member*
Dr Wenn B. Lawson	*Autistic individual member*
Ms Genevieve Brookman	Autistic Self Advocacy Network of Australia and New Zealand
Ms Jenny Karavolos	Australian Autism Alliance
Mr Bob Buckley	Autism Aspergers Advocacy Australia (A4)
Dr Jodi Lamanna	First Peoples Disability Network (FPDN)
Ms Thea Dunkley	National Aboriginal Community Controlled Health Organisation (NACCHO)
Mr Dwayne Cranfield	National Ethnic Disability Alliance (NEDA)
Ms Donna Blanchard	Australian Advisory Board on Autism
Mr Bill Gye (OAM)	Community Mental Health Australia
Professor Julian Trollor	Department of Developmental Disability Neuropsychiatry (3DN) at UNSW
Associate Professor Darren Hedley	Olga Tennison Autism Research Centre (OTARC)
Professor Dawn Adams	Australasian Society for Autism Research (ASfAR)
Dr Catherine Marraffa	Royal Australasian College of Physicians (RACP)
Dr James Best	Royal Australian College of General Practitioners (RACGP)
Dr Emma Radford	Royal Australian and New Zealand College of Psychiatrists (RANZCP)
Ms Nicole Pates	Allied Health Professionals Australia (AHPA)
Dr Catriona Davis-McCabe	Australian Psychological Society (APS)
Commonwealth Government Representative	Mental Health and Suicide Prevention Division, Department of Health and Aged Care
Commonwealth Government Representative	Disability Support Branch, Department of Social Services
Commonwealth Government Representative	National Disability Insurance Agency
Commonwealth Government Representative	National Disability Insurance Scheme (NDIS) Quality and Safeguards Commission

State/Territory Government Representative	ACT Health Directorate, ACT Government
State/Territory Government Representative	Ministry of Health, NSW Government
State/Territory Government Representative	NT Health, Northern Territory Government
State/Territory Government Representative	Children's Health Queensland Hospital and Health Service, Queensland Government
State/Territory Government Representative	Queensland Health, Queensland Government
State/Territory Government Representative	Department for Health and Wellbeing, Government of South Australia
State/Territory Government Representative	Department of Health, Victoria State Government
State/Territory Government Representative	Department of Health, Tasmanian Government
State/Territory Government Representative	WA Department of Health, Government of Western Australia

Community consultations

The Department of Health and Aged Care prioritised ensuring consultations were accessible, inclusive, and appropriate for Autistic people and autism community members. To help execute this, the Department of Health and Aged Care engaged Autism CRC via a competitive limited tender.

In partnership with the Department of Health and Aged Care, Autism CRC undertook consultations with the key priority populations identified for the Autism Health Roadmap:

- people with high or complex disability needs, including:
  - high communication needs
  - high behaviour support needs
  - people in residential settings
  - people with intellectual disability
  - non-speaking Autistics
- First Nations people
- culturally and linguistically diverse people
- LGBTIQA+ people
- women and girls
- people in rural and remote areas
- people from low socio-economic backgrounds.

Co-design methodology and meaningful engagement

The Department of Health and Aged Care and Autism CRC were committed to addressing the breadth of issues faced by Autistic people in the health care system and outlining actions to improve the health and mental health outcomes for the growing population of Autistic people in Australia. The Department of Health and Aged Care worked in a transparent manner which was inclusive and supported Autistic people to engage with as few barriers as possible.

The consultations were designed to be:

- evidence based, appropriate using co-design methodology which was able to reach and accommodate Autistic people and the autism community
- inclusive, meaningful, and transparent. A key aspect of this was a ‘no surprises’ approach for participants – they were made fully aware of what they will be experiencing before consultations, what happened during them, and how their data or information was used/will be used
- trauma-informed, safe, and respectful.

Autism CRC undertook the following streams of activity as part of the co-design process:

- establishment of a Stakeholder Reference Group, which included people with lived experience, as well as health and mental health practitioners. This group provided strategic advice on how the co-design and community engagement process should occur and commented on analysis and findings
- secondary analysis of several existing national data sets, containing information from over 5,000 Autistic people, families, carers and professionals
- in-depth focus groups and interviews with 107 people
- ‘Reimagining health care services’ co-design workshops with 48 stakeholders
- hosting the National Health and Mental Health Services Community Co-design Summit held on 2 February 2024, which engaged 69 Autistic people, professionals in health, mental health, allied health and disability fields including Autistic and non-Autistic practitioners
- engaging a further 159 stakeholders in the co-design and community engagement activities including workshops, focus groups and interviews.

Key findings from the co-design:

Autism CRC ultimately delivered 25 recommendations to the Department of Health and Aged Care for consideration in the Autism Health Roadmap. Key ideas included:

- improving access to primary care including through optional annual health care checks and an extended mental health care plan
- enhancing information and support to equip Autistic people to understand options and rights, make informed decisions, and advocate for themselves or access advocacy supports

- creating targeted information and resources addressing widespread Autistic health and mental health issues such as interoception; sensory adjustments in health care environments; diagnostic overshadowing; and eating disorders
- establishing a network of Autistic and autism-proficient systems navigators (with the potential for this to be interlinked with local navigators proposed through the NDIS review)
- identifying and developing best practice and neuro-affirming approaches, including through assessing what has already been done and what can be learnt from it, and priority projects in critical areas such as mental health and pregnancy, birth and post-natal care
- strengthening workforce capability through training, tools, and recognising and connecting practitioners with autism proficiency and peer workers.

Appendix B – Glossary of Terms Used in the Autism Health Roadmap

Accessible	Environments, facilities, services, products and information that people are able to use and interact with in a way that suits their needs.
Alexithymia	Refers to the experience of disrupted emotional awareness. It impacts a person's ability to recognise, identify, and describe feelings or emotions.
Augmentative and alternative communication	Methods of communication personalised to enable the participation of a person who may experience barriers to spoken communication. Methods can include no, low or high levels of technology. Some examples are gestures and/or signing, pointing to visuals, and the use of an IPad or tablet app.
Autistic people and autism community members	Refers to the collective communities 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 Autism Health Roadmap, best practice is: • strengths-based, trauma-informed and autism 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 focused, with robust monitoring and evaluation.
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 people who are involved 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	A process through which 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 Autistic people identify as members of a cultural minority.
Diagnostic overshadowing	A tendency for clinicians to presume that physical or mental health symptoms are due to an overarching diagnosis (e.g.,, autism), rather than other co-occurring conditions.
Evidence Based	The definition of evidence-based is comprised of three pillars: 1. research evidence (science)

	2. clinical practice (trauma-informed, culturally responsive, LGBTQIA+ inclusive) 3. 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 peoples	Aboriginal and Torres Strait Islander peoples, otherwise known as First Nations, 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.
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.
Neurodivergent and Neurodiverse	**Neurodivergent –** A person or people whose brain development or functioning falls outside of (or diverges from) the range usually considered 'typical'. **Neurodiverse –** A collective term for groups including mixed neurotypes, 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.
Neurodiversity-affirming	A strengths and rights-based approach to developmental differences that aims to provide support and adaptations that affirm neurodivergent identity.
Neurotype	A type of brain, in terms of how a person interprets and responds.
Neurotypical	A label for people who are not neurodivergent.
Primary Health Network (PHN)	Independent organisations funded by the Department of Health and Aged Care to manage primary health care across 31 regions. PHNs commission health services according to identified need in their region, build workforce capacity and improve service quality, and connect services for patients.

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 *Disability Discrimination Act 1992* (Cth) s4(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	Differences in experiences of the senses, such as acute awareness of light, sound, texture, touch, taste and/or smell, vestibular sensations, proprioception and interoception commonly experienced by 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 formal or 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.
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.

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