Australian Government
Department of Health
and Aged Care

National Roadmap to Improve the Health and Mental Health of Autistic People 2025–2035

Foreword from the Minister for Health and Aged Care

Throughout the course of our lives, many Australians will be diagnosed with autism or will know a relative, friend, colleague or member of the community who is Autistic. In 2022, 290,000 Australians were diagnosed with autism.

The National Roadmap to Improve the Health and Mental Health of Autistic People 2025–2035 (the Autism Health Roadmap) affirms that Autistic people, their families and carers deserve access to high-quality health and mental health care to lead healthy and fulfilling lives. The Autism Health Roadmap sets out concrete steps that recognise what will make the Australian health and mental health care better for Autistic people. The Autism Health Roadmap sets out six focus areas with specific outcomes and actions. The actions aim to make Australia a country where Autistic people are able to be better understood by health professionals and more comfortable in health care settings.

To develop the Autism Health Roadmap my department consulted Autistic people, families and carers, advocacy organisations, clinicians and researchers, professional colleges and associations, peak bodies, commonwealth agencies and state and territory governments. I extend my thanks to all the individuals and organisations who shared their experience, advice, hopes and priorities for the Autism Health Roadmap.

The Autism Health Roadmap forms part of the National Autism Strategy, which will improve outcomes for all Autistic people in Australia by coordinating a national approach to services and supports, including access to services, health care, education and employment. This Roadmap represents the Australian Government's commitment to improve the health and mental health outcomes of Autistic people.

The Government will use this Roadmap, in conjunction with the National Autism Strategy, to consider future policy settings and how to achieve the actions to improve the lives and experiences of Autistic people, their families, carers and support networks.

The Hon Mark Butler MP
Minister for Health and Aged Care
25 February 2025

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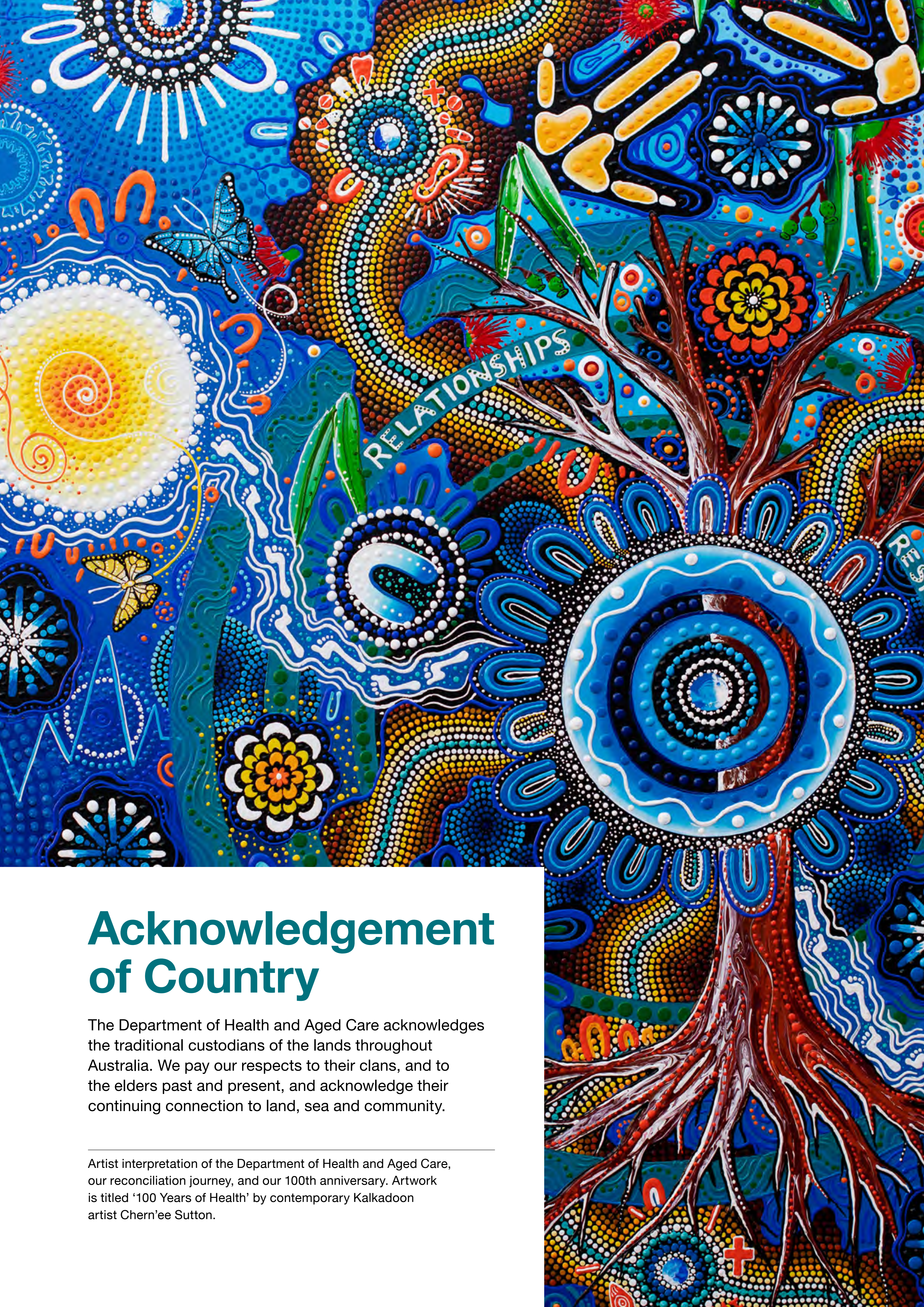


Acknowledgement of Country

The Department of Health and Aged Care acknowledges the traditional custodians of the lands throughout Australia. We pay our respects to their clans, and to the elders past and present, and acknowledge their continuing connection to land, sea and community.

Artist interpretation of the Department of Health and Aged Care, our reconciliation journey, and our 100th anniversary. Artwork is titled ‘100 Years of Health’ by contemporary Kalkadoon artist Chern’ee Sutton.

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 take action to improve the health and mental health of Autistic people. This advocacy culminated in the development of the National Roadmap to Improve the Health and Mental Health of Autistic People (the Autism Health Roadmap). The Department of Health and Aged Care especially 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 Autistic individuals, 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 the term '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. The following free services are available to support you if you need help.

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 short-term 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 in 2 days.
- You can access more information about headspace at: **Connect with a mental health clinician 1-on-1 | headspace**.

13 YARN

A free and confidential one to one crisis support service available for Aboriginal and Torres Strait Islander people.

- Support from Aboriginal and Torres Straight Islander 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: **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. It includes 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 seven 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

- Recognise and support the diversity of Autistic experience
- Understand, respect and promote the individualised and intersecting needs of Autistic individuals and their families and carers in health and mental health services
- Recognise mental health and suicide prevention as integral to good health
- Ensure that Autistic people are included and considered in the design and delivery of health and mental health services that affect them, including through co design and co production
- Services and supports for Autistic people, their families and carers should be universally accessible, affordable and autism affirming
- Uphold human rights, self-determination, and autonomy of Autistic people
- Acknowledge and accommodate the needs of specific priority groups of Autistic people

The Autism Health Roadmap is grouped into six 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

Grouped under each of the Focus Areas are specific outcomes and actions. **Outcomes** are the changes envisioned to be achieved in the 10-year lifespan of the Autism Health Roadmap. They are the ideal 'future state'. **Actions** are concrete steps that can be taken to progress toward intended outcomes, which are grouped into

- **Stage one (years 1 to 3)**
- **Stage two (years 4 to 7)**
- **Stage three (years 8 to 10)**

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 and associated plans. The Department of Health and Aged Care will work with state and territory governments and all sectors of the community, to achieve the vision and outcomes of the Autism Health Roadmap.

The Autism Health Roadmap was developed through 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.

Relationship to the National Autism Strategy

The Autism Health Roadmap is aligned with the National Autism Strategy, which is being led by Australian Government Department of Social Services. Both documents together set out a framework to improve the lives of Autistic people in Australia. The National Autism Strategy covers areas including access to services, health care, education, and employment. It will help to guide a more coordinated, national approach supporting Autistic people at each stage of life.

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).

Whilst the National Autism Strategy describes the commitment for the diagnosis, services and support outcome (in improving systems for Autistic people and their families to access a diagnosis); the practice of diagnosis is inherently the responsibility of the health practitioners and therefore referenced in the Autism Health Roadmap. Work in this area will be strongly coordinated between the National Autism Strategy and Autism Health Roadmap and will involve the extensive engagement of health professionals in making changes to support the diagnostic needs of Autistic people and their families.

Timeframe

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

Noting that Australia's Disability Strategy (ADS 2021–2031) is due for review in 2031, remaining actions and future directions of 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.

Diagnosis, Services and Supports

The National Autism Strategy and the Autism Health Roadmap were 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 and is an area of action in the Autism Health Roadmap, the pre-diagnosis steps of screening, identification, assessment and referral for autism diagnosis occur across sectors and human service systems. In acknowledgement of this, the cross-sector commitments of referring for a diagnosis, coordinating services and ensuring there is support across systems are addressed in the Diagnosis, Services and Supports stream of the National Autism Strategy, with the Department of Health and Aged Care as a contributing agency.

The National Autism Strategy was released on 14 January 2025. Actions related to diagnosis and service coordination have been aligned with the work of the Autism Health Roadmap. Implementation of the Autism Health Roadmap may incorporate parts of the National Autism Strategy, and vice versa.

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 was more relevant to the cross-sector Diagnosis, Services and Supports implementation plan were referred to the National Autism Strategy team at the Australian Government Department of Social Services.

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

Autistic and autism community involvement in developing the 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 supported the development of the Autism Health Roadmap by:

- ensuring the Autism Health Roadmap was 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 outcomes and actions in 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 groups, interviews and surveys. The Autism CRC also analysed the 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: **https://www.health.gov.au/our-work/national-roadmap-to-improve-the-health-and-mental-health-of-autistic-people**

The public consultation was open from Wednesday 14 August to Friday 27 September. The aim of the consultation was to hear from Autistic people, their families and carers, as well as researchers and other individuals who are involved in the lives of Autistic people. The survey was available in three formats:

- the full survey, which used the exact draft wording in the Autism Health Roadmap, using technical language that is more familiar to health professionals and policy makers
- the short survey, which was aimed at people less familiar with technical language, and might be more suitable for people who need support
- the easy read survey, which used simple words and visuals to describe the Autism Health Roadmap
- Individuals and organisations were also able send written or recorded submissions through email.

A total of 313 survey and submission response were received, including 148 from Autistic people.

About autism and Autistic health

What is autism?

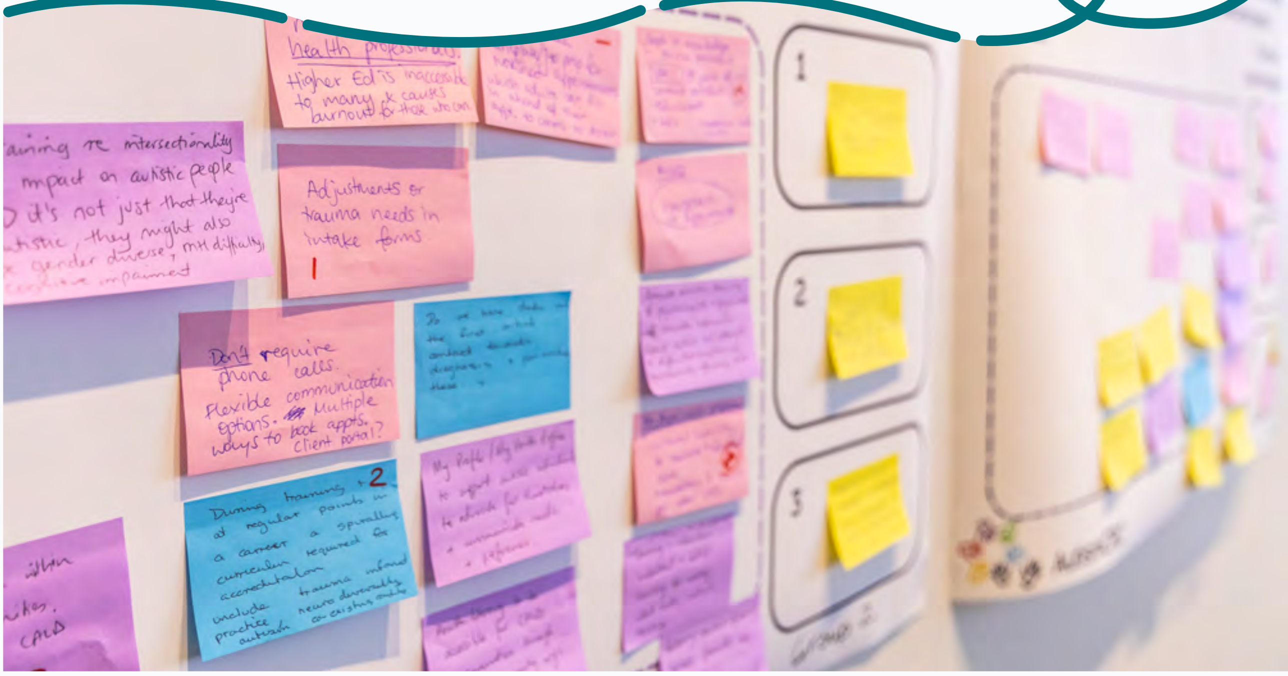
Every Autistic person is unique. Autistic people have different cultural and linguistic backgrounds, individual identities, and often other disabilities and co-occurring conditions. There is no one universally accepted definition that adequately captures the breadth and diversity of Autism.

The Autism Health Roadmap recognises that for many people, Autism is an identity, with some Autistic people choosing to self-identify as Autistic instead of seeking a formal diagnosis. However, Autism is considered in the Autism Health Roadmap primarily as a neurodevelopmental condition[4] and a disability, framed within the biopsychosocial model of disability.[5] The Autism Health Roadmap recognises that attitudes, practices and structures in a neurotypical world can create barriers for Autistic people to participate fully and equally in the community. It also recognises that for many Autistic people, their experience of their Autism can have significant impact on their life, beyond social and attitudinal barriers.

The Autism Health Roadmap is a document of the Department of Health and Aged Care and as such uses terms and clinical definitions that are understood by health and medical practitioners. The use of this language is not intended to diminish or deny Autism as an identity or exclude the inherent strengths of Autism as an identity and set of characteristics.

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 the domains of social communication and behavioural patterns, as well as assessing an individual'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 (DSM-5-TR) and the World Health Organization's International Classification of Diseases (ICD-10/ICD-10-AM).[6]

Autistic people often display differences in the ways they communicate, socialise, 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 characteristics vary in how they present in different individuals and Autistic people may have different support needs throughout their lifetime.[7]



Some Autistic people may communicate very directly, or may interpret sarcasm, jokes or small talk differently to non-Autistic people. Around one-third are non- or minimally speaking;[8] some of this population will use alternative communication with a device, other tools (like picture boards), or 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 (internal sensations), proprioception (bodily sensations), vestibular processing (bodily orientation) and sensorimotor processing (e.g., apraxia), compared to non-Autistic people. For some, their sensory differences have a profound effect on their ability to function, be creative or participate in different contexts.

Autistic people are also more likely to experience strong interests or preferences, which may include dedication to a particular area of skill, and/or a need engage repeatedly in a particular activity or action. Repetitive behaviour might include returning to an area of considerable interest or knowledge, or to an activity that provides sensory relief or pleasure. Engaging in these sensory or known actions or activities can also be a response to an environment that is stressful. For some Autistic people, repetitive behaviours can result in physical harm, and additional support may be required to ensure that repetitive behaviours are adaptive and safe.

Further to these experiences, many Autistic people experience co-occurring health and mental health conditions. Challenges in receiving the health support needed to treat these co-occurring health and mental health conditions can be overcome with appropriate support, knowledge and understanding from professionals and society as a whole. The Autism Health Roadmap aims to provide concrete steps which can be taken to reduce some of these challenges.

Prevalence of autism in Australia

Estimates of the prevalence of autism, including levels of severity, are a point of academic and social contention. As discussed in the priority populations section below, diagnosis of autism is influenced by many social and cultural factors such as societies' evolving understanding of autism, gender and the cultural group a person belongs to.[9]

According to the Australian Bureau of Statistics (ABS) Survey of Disability and Carers (SDAC), which is a survey in which carers or individuals self-report about their own health conditions or the health conditions of someone they care for in, in 2022, 290,000 Australians (1.1% of the population) identified as Autistic. This represents a 41.8% increase since the 2018 SDAC, in which 205,200 Australians (0.8% of the population) identified as Autistic. In the 2022 SDAC, Autism prevalence was higher for people who were assigned male at birth (1.6% of the Australian population) than people who were assigned female at birth (0.7% of the Australian population).

In 2022, more people under 25 self-reported as Autistic than people aged 25 and older (3.1% of Australians under 25 compared to 0.3% of Australians aged over 25).[10] When considering this, it is important to note that previous iterations of the SDAC have also observed lower rates of Autism in older populations. The ABS, who administer and interpret the survey, note that this 'drop' in prevalence is likely to be due to the design of the SDAC, rather than a reflection that the prevalence of Autism reduces after age 25.[11]

As highlighted in Focus Area D, there is a significant lack of data regarding Autistic people's health and disability needs. The 2022 SDAC states that of those identified as Autistic (by self-report or by a caregiver) '73% of respondents reported a profound or severe disability, which was only a slight growth from 68.9% in 2018'.[12] This contrasts with a 2023 meta-analysis of worldwide studies of the prevalence of autism reports that rates for Autistic people with high dependency and/or complex support needs to be approximately 35% of the total Autistic population.[13]

Physical, mental health and suicide among Autistic people

Autistic people suffer poorer physical and mental health than the general population, including greater risks of co-existing conditions, shorter life expectancy and premature death. It is common for Autistic people to experience the following physical health conditions at higher rates as well as others which are not listed:[14,15]

- gastrointestinal conditions
- central nervous system conditions
- epilepsy
- autoimmune conditions
- sleep disorders.

Autistic people are also at higher risk of mental health conditions which may include:[16]

- anxiety and depressive disorders
- bipolar and mood disorders
- eating disorders
- schizophrenia
- obsessive compulsive and related disorders
- substance use disorders.

However, detailed knowledge of these issues is restricted due to a limited focus on Autistic health research, particularly among priority populations. This is likely because traditionally autism was considered a behavioural and neuropsychiatric condition, rather than a different neurotype that coexists with a range of other health conditions.[17,18,19]

While the exact causes of higher rates of co-occurring physical health conditions among Autistic people are unknown, risk factors for developing health conditions may include inadequate access to health care services, services not catering to Autistic needs, and inadequate understanding of co-occurring physical health conditions among health professionals. 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.[20] Differing incidences of co-existing conditions among different members of the Autistic population are not well understood.[21] The presence of these conditions creates challenges in accessing health care services. There is a strong need for integrated health services to provide adequate care to Autistic people and for health professionals.

The higher rates of mental health conditions and completed suicide among Autistic people can be attributed to experiences of social exclusion and isolation, bullying, discrimination, abuse and domestic violence. Autistic people also report that having a co-occurring mental health condition can be a significant barrier to accessing existing health services.[22] Studies consistently show a two to three-fold increase in the premature mortality rate in Autistic people over that of the general population.[23] In a study of Australian mortality data, Autistic people died at twice the rate of the general population.[24] 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.[25] It appears that suicidal attempts are associated most strongly with 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.[26] 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.[27] 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

The priority populations for the Autism Health Roadmap reflect the groups and individuals which need to be better understood and included in research, service access and health professionals' understanding of autism.

Autistic people with high support, dependency and/or complex needs

Autistic people experience a range of support needs, from low support to high support needs, which can shape their experiences within 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.

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.[28,29,30]

These additional conditions may mean that some Autistic people need more support or different adaptations to access services. Poorer health and mental health outcomes for Autistic people with co-occurring disabilities and/or 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.[31]

Autistic people in residential settings

Autistic people who live in residential settings such as aged care facilities, disability group homes, rehabilitation care, respite care facilities, boarding houses and children in 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.[32]

Autistic people in correctional settings

Autistic people in correctional settings such as prisons and detention centres can 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 missed diagnoses, and complexities navigating the system due to differing social communication methods, behaviours, and experiencing under or over sensory stimulation.[33,34]

Aboriginal and Torres Strait Islander people

Due to non-Indigenous cultural biases in diagnostic tools, Aboriginal and Torres Strait Islander people are more likely to be misdiagnosed and/or not diagnosed compared to non-Indigenous Autistic people. This means that autism prevalence rates appear to be lower in Autistic Aboriginal and Torres Strait Islander people despite not actually being so.[35] Aboriginal and Torres Strait Islander people, their families and carers also face additional barriers to accessing health care due to colonisation and systemic racism, social, cultural, behavioural and economic factors which impact individual and community health.

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 Closing the Gap 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. In aligning with the National Aboriginal and Torres Strait Islander Health Plan 2021–2031 (the Health Plan), the actions outlined in the Autism Health Roadmap seek to embed Priority 6 of the Health Plan through:

- placing an emphasis on improving the health care system to ensure that mainstream services must be capable of providing high quality, culturally safe, trauma-aware, healing-informed and responsive care to Aboriginal and Torres Strait Islander people
- seeking to engage with Aboriginal Community Controlled Health Services to provide a comprehensive range of health and social and emotional wellbeing services, such as wraparound support services including for disability.

Culturally and Linguistically Diverse (CaLD) Autistic people

Autistic people from Culturally and Linguistically Diverse (CaLD) communities may encounter additional obstacles in their daily lives. In consultations for the National Autism Strategy, focus groups also identified an alternate term of Culturally and Racially Marginalised (CaRM) people, who experience multifaceted barriers, including experiences of racism, which can further marginalise them and exacerbate the challenges they already face due to being Autistic. The Autism Health Roadmap uses the “CaLD” terminology but acknowledges the impact racial marginalisation has on CaLD communities.

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.[36] As a result, CaLD Autistic people may be more likely to have delayed and/or missed autism diagnoses.[37,38] 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.[39]

In line with Australia's Multicultural Framework Review, the Autism Health Roadmap endorses principles of multiculturalism and, recognising the overlapping impacts of racism and ableism, aims to collaborate with CaLD communities and Autistic people within them.

Autistic people who identify as LGBTQIA+

Autistic people are much more likely to identify as LGBTQIA+ than non-Autistic people.[40] 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.[41] Autistic people may also be denied gender affirming care because of a presumption that they are unable to understand their gender identity. Autistic people may also face sensory and communication barriers when accessing gender affirming care.

Autistic women and girls

Although boys and men are statistically 3.5 times more likely than women to be diagnosed as Autistic,[42] this does not (necessarily) mean more boys and men are Autistic. 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 primarily cater to the needs of boys and men. Current research shows that Autistic women are more likely to be diagnosed late and/or misdiagnosed with affective disorders and/or personality disorders.[43]

Autistic women and girls can experience complex medical support needs associated with a range of factors such as sensory sensitivities, communication support needs and the existence of co-occurring conditions. While research on Autistic experiences during particular periods such as puberty, pregnancy and menopause is limited, emerging research suggests that these life periods can intensify sensory sensitivities, anxiety and social difficulties for Autistic women and girls.[44] Additionally, 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.[45] Despite these additional needs, research shows that Autistic individuals are less likely to receive basic reproductive and sexual health care compared with non-Autistic individuals.[46]

Women with disability are more likely to have experiences of sexual violence than those without disability. One in 25 (4.0%) Australian women aged 18 and over with disability have experienced sexual violence in the last 2 years. This compares to 1 in 40 (2.5%) women without disability.[47] Research on the experiences of Australian Autistic women in this field is limited. However, international evidence suggests that rates of sexual violence are as high, if not higher, than other people with disability for Autistic women.[48] Recent research suggests that as many as 9 out of 10 Autistic women are victims of sexual violence.[49]

There is limited data in relation to non-binary gendered Autistic people. 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.

Autistic people and families 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.[50] 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.[51]

Autistic people and families 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 socioeconomic 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.[52] Specific barriers include the costs of health care, transport and organising care for other family members.

Autistic people who receive a late diagnosis

Autistic people who are diagnosed later in life may be at increased risk of developing co-occurring mental health conditions such as depression, anxiety, obsessive compulsive disorder and related disorders, and eating disorders.[53] This can significantly impact their health, quality of life and provide additional barriers and challenges when seeking and accessing health services.[54]

Autistic older people

Older Autistic people face significant barriers in accessing health and mental health supports that meet their needs. Older Autistic people because of where they are in their lifespan are more likely to require health and mental health services but may find that these services are not tailored to their Autistic needs, including being at a greater risk of overshadowing and/or not receiving care that is able to recognise how their autism may impact other co-occurring conditions. Through the public consultation to the Autism Health Roadmap, older Autistic people shared experiences where entering aged care led to a heightened need for appropriate mental health supports.

Autistic children and young people, especially those in vulnerable situations (e.g. out-of-home care)

Autistic children and young people will have improved health and mental health outcomes if they have access to diagnosis, services and supports early in their lives.[55] Current barriers for children and young people include delays and the financial costs involved in seeking a diagnosis, as well as limited understanding of autism in the community. It is especially important that children and young people in vulnerable situations (e.g. in out-of-home care) receive health and mental health supports that are equitable and meet their individual needs.

Neurodiversity

Neurodiversity is a term which describes the natural range of diversity that exists in human neurodevelopment. Although all people process and perceive the world differently, some differences are grouped and named.[56] 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.

To appropriately address the needs of Autistic people, the Autism Health Roadmap focuses on autism, rather than on other neurodivergences. The Autism Health Roadmap aims to build on existing work focused on the particular 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 that is tailored to the needs of Autistic people. This means ensuring that health environments and the way that health services are delivered are inclusive for neurodivergent people by making active changes in the way that they provide support and health care. Failing to provide such adjustments can be a significant barrier to accessing health care and for Autistic people, and sometimes means that they are not able to access health care at all.

The process of acknowledging the diversity of Autistic needs and providing appropriate adjustments to care is referred to by a range of terms, including 'Autism Affirming' and 'neurodiversity affirming care'. It is an example of person-centred care, which 'affirms' or 'states publicly' that environments and services must adapt for people so that they are able to receive the health services that they require. The term is about having an overarching, shared, view of how health services should be delivered to Autistic people. It is separate to what then occurs in terms of health and mental health assessment and treatment of individuals.

It is important to recognise that 'neurodiversity affirming care' is intended to cater to the needs of all neurodivergent populations, inclusive of rather than specific to the needs of Autistic people. 'Autism Affirming care' is used to describe care that is tailored to 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), in the same way that the needs of Autistic people with other co-occurring conditions are included in Autism Affirming Care.

It is important to note that there is currently no clear set of standards or consensus on workforce capabilities among health practitioners and autism specialists for what constitutes best practice in this type of care for Autistic people.

Due to 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, including when offered in a mainstream service setting. The outcomes and actions described in the Autism Health Roadmap propose specific steps intended to help establish a consensus about what theory, practice, workforce and service capabilities should exist to appropriately support Autistic people to access high quality health care in Australia. A part of this work is to reach consensus on what Autism Affirming care is and how it should be practised, with consideration of the intersections with and people's understanding of other forms of practice such as existing clinical therapeutic approaches, and the broader practices of 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.

Recognise and support the diversity of Autistic experience

Autistic individuals' experiences and interactions with the world can be vastly different depending on how they think, communicate, respond to sensory input, and engage socially.

Impacts can vary across different cognitive and psychosocial domains, as well as over time and in different settings, in ways that are not always consistent with neurotypical measures of impairment. Sometimes this leads to needs not being accommodated, especially if there is a superficial presentation of average or above average functional capacity.

Practices and structures in health service systems can contribute to Autistic people experiencing barriers to service access and equality.

Some Autistic individuals are unable, or need considerable support, to care or advocate for themselves. For these people, it is critical to ensure that a holistic, whole-of-family and autism affirming approach is taken, while remaining evidence informed and therapeutically effective.

Understand, respect and promote the individualised and intersecting needs of Autistic individuals (and their families and carers) in health and mental health services

Aspects of a person's socioeconomic situation, race, sex, culture or identity can often have a compounding effect on their disadvantage, resulting in more complex needs when accessing health and mental health services.

For example, an Autistic person who may also be gender diverse, culturally and linguistically diverse, or have co-occurring physical or mental health conditions, may experience barriers to services due to their complex presentation to health and mental health services. Some Autistic people have also shared instances of being excluded from services due to having co-occurring conditions such as substance addiction or mental illness.

All actions put forward within the Autism Health Roadmap recognise that most Autistic people are experiencing a range of intersecting needs and that there is no one size fits all approach to care that is affirming of the Autistic experience. Health and mental health professionals and services should make efforts to consider and support intersecting needs when providing services.

Recognise mental health and suicide prevention as integral to good health

Autistic people experience higher rates of co-occurring mental health conditions than non-Autistic people, as well as misdiagnosis and diagnostic overshadowing.

Autistic people experience anxiety, depression, eating disorders, obsessive compulsive disorder and self-harm and die by suicide at higher rates than non-Autistic people. This may be because Autistic people are at a higher risk of experiences that can contribute to poor mental health, including bullying, social isolation and discrimination.

Autistic people report that they are frequently misdiagnosed with mental health conditions, leading to unnecessary prescription of medication and other invasive cognitive and behavioural treatments.

Diagnostic overshadowing is also a common experience for Autistic people who do experience a co-occurring mental health condition. Given the similarity between Autistic traits and some mental health conditions, assessment and evaluation of autism may not be considered for many years, sometimes until adolescence or adulthood is reached. Conversely, many Autistic people find that their co-occurring mental health conditions are not diagnosed or treated because health professionals consider that the feelings and behaviours are related to their autism, not a separate mental health condition.

Autistic people continue to experience poor mental health outcomes, misdiagnosis and diagnostic overshadowing when autism and Autistic mental health are not adequately understood or emphasised. The Autism Health Roadmap integrates health and mental health to acknowledge the importance of mental wellness to overall wellbeing outcomes.

Ensure that Autistic people are included and considered in the design and delivery of health and mental health services that affect them, including through co-design and co-production

Including Autistic people in the design and delivery of the health and mental health services that affect them is key to acknowledging their experiences and insights into their own health and wellbeing. This is especially important given the broad diversity of neurotypes and experiences of Autistic people in health services.

The Autism Health Roadmap builds on this understanding and has been co-designed, co-reviewed and will be co-delivered with Autistic people, their families and carers and support networks. Co-design is an investigative and creative way of working with Autistic people to recognise and include lived experience perspectives at the centre of the design process for the Autism Health Roadmap.

This is particularly important as Autistic people; their families and carers will be the primary recipients of the changes made to health and mental health systems. Critically, that the outcomes and actions in the Autism Health Roadmap embed the fundamental principle of engaging with Autistic people, their families and carers in planning, design, governance, implementation and evaluation.

Services and supports for Autistic people, their families and carers should be universally accessible, affordable and autism affirming

To meet the needs of all Autistic people, health and mental health services and supports should be universally accessible, affordable and autism affirming. This means that Autistic people should have access to the full range of quality affordable health services, when and where that they need them, with minimal systemic barriers. This includes the full continuum of essential health and mental health services from prevention, treatment, emergency and crisis intervention to rehabilitation and palliative care. For Autistic people to be able to access these services and supports, accommodations should be made based on a contemporary understanding of autism and Autistic people's needs.

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

Autistic people have the right to be safe from harm and treated equitably in Australian health services. They should be respected for who they are and supported to make decisions about the things that affect them. This is in accordance with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), to which Australia is a signatory. Of relevance is Article 3 (freedom to make choices) and Article 25 (right to the highest attainable standard of health).

The Autism Health Roadmap holds that Autistic people should enjoy the same quality, safety and access to health services as all other Australians. There should be freedom of choice, control and support for Autistic people and their families to make individual or supported decisions across their lifespan, about all aspects of their health and health care.

Acknowledge and accommodate the needs of specific priority groups of Autistic people

As a result of many historical and cultural factors, particular groups of Autistic people experience higher rates of disadvantage, greater barriers accessing services or other forms of inequities than others. Because of the breadth, scope and variety of these experiences it is not possible to identify a complete list of groups that have higher, or more severe, needs than other groups. Key groups which were highlighted during the development of the Autism Health Roadmap are listed below. Work to implement actions from the Autism Health Roadmap will consider these and other priority populations to make health and mental health outcomes more equitable for all Autistic people.

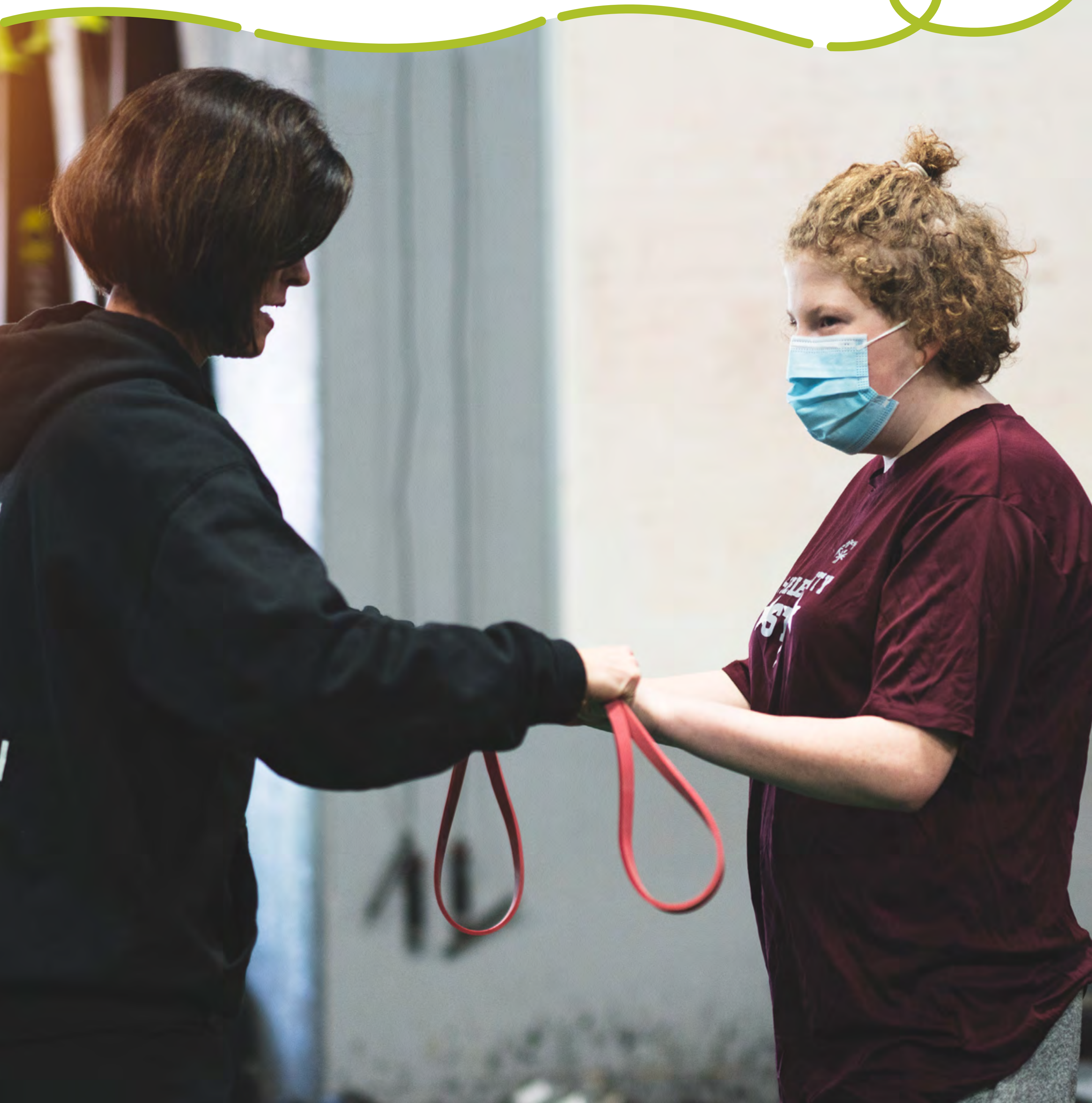
Examples of groups who have been highlighted as being a particular priority include:

- people with high support and dependency and/or complex needs, including:
  - complex communication needs
  - complex behaviour support needs
  - complex mental health needs
  - people with intellectual disability
  - people living in residential, institutional settings or supported accommodation
- Aboriginal and Torres Strait Islander people
- 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
- people who receive a late diagnosis
- older people
- children and young people, especially those in vulnerable situations (e.g. out of home care).

All 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.

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 health care 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.[57,58]

> 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 also impacts people making informed decisions about their health.

> 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 do not 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 higher rates of mortality.[59,60,61,62] All Autistic people have the right to access health and mental health care and to make their own decisions across their lifespan, about all aspects of their health and health and mental health care. This is backed by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).[63]

Autistic people may experience being excluded from making decisions and/or not provided with the support they need to make an informed health decision. 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 the expenses associated with transport to appointments, particularly for those living in rural or remote areas, can also be a barrier to Autistic people accessing health care. 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 care from relevant health and mental health professionals. This can include difficulties in describing what they are experiencing, difficulty perceiving internal bodily sensations and symptoms, or having a different experience of generally expected symptoms such as pain. 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)

Outcome A1. Health and mental health facilities are able to accommodate individual cognitive, communication and sensory needs.

Outcome A2. Information and resources about relevant health and mental health services are more accessible for all Autistic people, their families, carers and support networks. Information is provided in appropriate alternative formats for different communication and cultural contexts and needs.

Outcome A3. All 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 with, their health rights and what it is to give informed consent, if they choose to do so.

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

Outcome 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 and mental health care.

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

Steps to get to an improved future (actions)

Stage one (years 1 to 3)

Action A1. Regularly review existing Australian Government health and mental health information and resources (including digital resources) for consumers and health practitioners, to ensure all Autistic people's needs are explicitly addressed. This will be continued across the life of the Autism Health Roadmap.

Action A2. As a priority action, consider how to improve access to and affordability of primary care services, including general practice, that address the health and mental health needs of all Autistic people across their lifespan. This could include:

- 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 and allied health services
- longer consultations to accommodate different cognitive processing and communication needs, and complex mental health needs
- preventative health support including for co-occurring and emerging chronic conditions through annual health checks for Autistic people
- otherwise increasing affordability and ways that health professionals can provide additional health and mental health supports to all Autistic people, including referring Autistic people to free publicly available services if appropriate and/or peer support services.

This will be continued across the life of the Autism Health Roadmap.

Action A3. 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. This work would provide examples for the further development of literacy resources. Ensure that these resources are in formats accessible to Autistic people, including people with complex and high support communication needs.

Stage two (years 4 to 7)

Action A4. Develop information, resources and education for Autistic people, their families and carers, in areas identified as key gaps in health literacy resources. Ensure that these resources are accessible for all Autistic people and include resources that are accessible and relevant to Autistic people with high support and/or complex needs. Key topics could include:

- the traits/characteristics and varied presentations of autism, including gender and cultural differences
- how Autistic people experience sensations and common experiences differently to non-Autistic people
- common co-occurring health and mental health conditions
- when you might need to see a professional
- how different kinds of professionals can help
- what you should expect from a health care professional
- how to navigate services, including making appointments
- regulation strategies that may be effective during health and mental health appointments.

Action A5. Develop resources for all relevant health and mental health professionals to improve their understanding and capability regarding autism. Develop this 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. Resources could include information about:

- Autistic traits
- how Autistic people experience sensations and common experiences differently to non-Autistic people
- alternative methods of communication and practical communication strategies
- sensory considerations for Autistic people that reflect the range of health environments they may encounter e.g. general practice waiting rooms and emergency room settings
- self-regulation strategies that may be effective for supporting Autistic people in health and mental health settings
- identifying risks to safety (including sexual safety) and upholding health care rights
- common co-occurring health and mental health conditions.

Action A6. 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 Health and Mental Health Framework such as fact sheets, evidence briefs and webinars (see Focus Area B for a description of the Framework).
- 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 all Autistic people's needs in ongoing work related to health literacy (see Focus Area B).

Stage three (years 8 to 10)

Action A7. Review and refine existing, or if needed co-develop and promote, tools for best practice models of care for empowering autonomy, shared decision-making, providing informed consent for treatment, and ensuring adequate and ethical safeguards for those that lack the capacity to provide informed consent. These tools should include:

- when this support is most likely to be needed e.g. recommending medications, pre- and post-surgery, considering reproductive needs and processes, and end of life care
- risks to safety (including sexual safety) and human rights
- consideration of the role of parents, carers, and guardians.

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 the general, and typically non-Autistic, population. Health professionals and services may be under equipped to meet the complex and often unique needs of Autistic people.[64] 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".[65] 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.[66]

> 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.[67]

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 administered 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. Symptoms of a person's mental illness or neurological disorder may not be addressed, or reports of these symptoms may not be understood. Instead, the person's experience is incorrectly attributed to their autism diagnosis or alternatively their mental or neurological health condition. As a result, an Autistic person may miss out on evidence-informed 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).

In response to the public consultation, Autistic people and their families also shared experiences of misdiagnosis, sometimes occurring for many years, where they or their loved one was diagnosed with a mental health condition that was later found to be incorrect or in addition to their diagnosis of autism, leading to mental health care not appropriate to their needs.

Difficulty finding suitable mental health services is a common experience for Autistic people and their families and carers. There is limited availability of autism-specific mental health services, and most mental health services don't provide the level of complex support required. Crisis mental health services appropriate to Autistic needs were also highlighted as a significant gap by Autistic people and their families through feedback to the Autism Health Roadmap public consultation, including examples of the distress endured by individuals where police intervention resulted.

In such situations, 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)

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

Outcome 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.

Outcome B3. Autistic people are welcomed, accommodated and supported in all health and mental health service settings. Autistic people are not dismissed or refused service because of their autism diagnosis but are still able to receive ongoing assessment, treatment and health and mental health support for their autism and the conditions they presented for.

Outcome B4. All relevant health and mental health services reduce all restrictive practices and eliminate all harmful restrictive practices used on Autistic people, including mechanical restraint, physical restraint, and chemical restraint. Alternative interventions are available and used as routine practice.

Outcome B5. All relevant health and mental health professionals are skilled and proactive in upholding all 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.

Outcome B6. All relevant health and mental health professionals understand what constitutes chemical restraint, the evidence and harm associated with using medicines to control the behaviour of Autistic people, as well as how to support Autistic people in safely fading out the use of restrictive practice.

Outcome B7. All relevant health and mental health services take proactive steps to avoid diagnostic overshadowing.

Steps to get to an improved future (actions)

Stage one (years 1 to 3)

Action B1. Promote autism affirming care within existing and future primary health care reforms, including exploring further provisions that enable general practitioners, and other primary health care providers to spend more time with Autistic patients, families and carers. Provide accommodations for the communication needs and diverse abilities of Autistic people, including those with co-occurring conditions and high and complex support needs.

This will be continued across the life of the Autism Health Roadmap.

Action B2. Co-design and develop an Autism Health and Mental Health Framework. The Autism Health and Mental Health Framework will be a nationally co-designed theory, practice, workforce and service capability framework. The development of it will include broad sector consultations and development to build consensus about what is best practice care for Autistic people across health and mental health service settings. It will create the foundational descriptors for acute-to-community health and mental health services, workforces, facility design, curriculum and quality/safety standards. The Autism Health and Mental Health Framework will be mapped to existing health, mental health and suicide prevention practice guidelines and service models.

Action B3. As part of an upcoming review of the National Safety and Quality Health Services (NSQHS) Standards, consider how these may be able to be more applicable to autism and alignment to an Autism Health and Mental Health Framework. This should include taking an approach that investigates and addresses the high levels of self-harm and suicide among Autistic people, as well as works to eliminate harmful restrictive practices.

Action B4. Promote pathways and advocacy services for Autistic people, their families and carers to be able to raise complaints with all relevant health and mental health services and practitioners. This should be done to enhance respectful approaches to providing care and give further assistance in how to escalate complaints if required.

Stage two (years 4 to 7)

Action B5. Promote best practice care of Autistic people within existing sector reform efforts based on an Autism Health and Mental Health Framework (the Framework). This could include:

- consideration of the communication needs and abilities of all Autistic people, especially for people with high support needs and specific communication needs, such as non-speaking Autistic people and people who use alternative communication methods
- guidance, resources and existing relevant training for health and mental health professionals about how to assist Autistic people in distress or who are presenting with challenging behaviours. In line with competencies developed in the Framework, include approaches that prevent escalation and support Autistic people to regulate emotions and behaviour safely, with minimal or no use of chemical restraint. (For further detail on training and education, see Action D4)
- consideration of further health service provisions that enable health practitioners to spend more time with all Autistic people, their families and carers.

Action B6. Pilot and promote best practice models of Autism Affirming care, as defined by an Autism Health and Mental Health Framework. This should include the ways that health and mental health services are delivered for Autistic people in acute settings, in hospitals, in private practice and in the community. Ensure that the specialised needs of the priority populations are considered in selection of the pilots.

Action B7. Consider ways to integrate practice approaches and competencies from the Autism Health and Mental Health Framework into future reviews of standards, strategies and initiatives, including future reviews of health and mental health service standards, such as future National Safety and Quality Health Services Standards.

Action B8. Consider developing crisis line/web services which are tailored to all Autistic people, their families and carers. As part of this, consider options for the establishment of a specific autism crisis line/

web service, or ways to for the upskilling of existing services. Irrespective of the approach taken, work to establish no wrong door approach that can be adopted across crisis lines/web services.

Stage three (years 8 to 10)

Action B9. 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 Health and Mental Health Framework.

Action B10. Consider options for a national practice recognition initiative to make it easier for Autistic people to identify relevant health and mental health professionals who, within their scope of practice specialise in services for Autistic people. This should be done in partnership with relevant autism organisations, professional colleges and specialist societies.

Action B11. 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:

- the Autism Health and Mental Health Framework
- the Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard
- existing evidence and practice guidance on the use of medicines to address challenging behaviours with Autistic people. This should include systematic reviews of pharmacological interventions, alternatives to prescribing medicines (including mental health assessment and intervention), and deprescribing practices.
- the need to acknowledge the rights of Autistic people to access and be educated about both pharmacological and non-pharmacological treatment for mental health conditions

Action B12. Review the safety and quality aspects of health and mental health service practice guidance and education material on the use of psychotropic medicines to consider the needs and experiences of all Autistic people.

Focus Area C

Building better connections between health, mental health, and other service sectors, including the National Disability Insurance Scheme (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, and for some 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 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 and mental practitioners have shared their challenges working with inconsistent information systems. Data security and privacy also remain significant concerns, particularly considering 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 option for Autistic people to opt-out of data collection.

Self and parent advocacy play a critical role for Autistic people engaging with relevant health and mental health services. Advocacy facilitates dialogue about improving health service experiences and responding appropriately to patient needs. Advocacy is also a mechanism that encourages active participation of Autistic people as health care consumers, which will in turn improve health services and their ability to provide tailored care for Autistic people. Unfortunately, inconsistent or unreliable service coordination and delivery can reduce avenues for advocacy.

What the future could look like (outcomes)

Outcome 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 diverse and intersecting needs.

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

Outcome C3. All 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 (actions)

Stage one (years 1 to 3)

Action C1. Establish or build upon existing primary health communities of practice to connect and support relevant health and mental health professionals to improve coordination and responsiveness to health, mental health, suicide prevention and preventative health needs of Autistic people. Consider this particularly for rural and remote areas.

Action C2. Consider potential models, such as Autistic peer support workers, for Autistic and autism-proficient service navigators/liaison officers in health and mental health services. Consider whether disability health navigators (recommendation 6.34 in the Disability Royal Commission final report) could be equipped to play this role.

Stage two (years 4 to 7)

Action C3. Co-develop and publicise an 'autism passport'. The passport could be an optional practical tool provided in an accessible format, such as a downloadable document, that Autistic people may choose to use to assist them in sharing information with relevant health and mental health services. It could contain information on an individual's sensory, cognitive, communication, other health or mental health conditions and treatment preferences.

Action C4. Consider ways to support Autism organisations to ensure that they have the capability and appropriate resourcing to assist Autistic people, their families and carers with engaging in health, mental health, suicide prevention and connected service systems. This will include prioritising support for Autistic led organisations and those that are autism affirming.

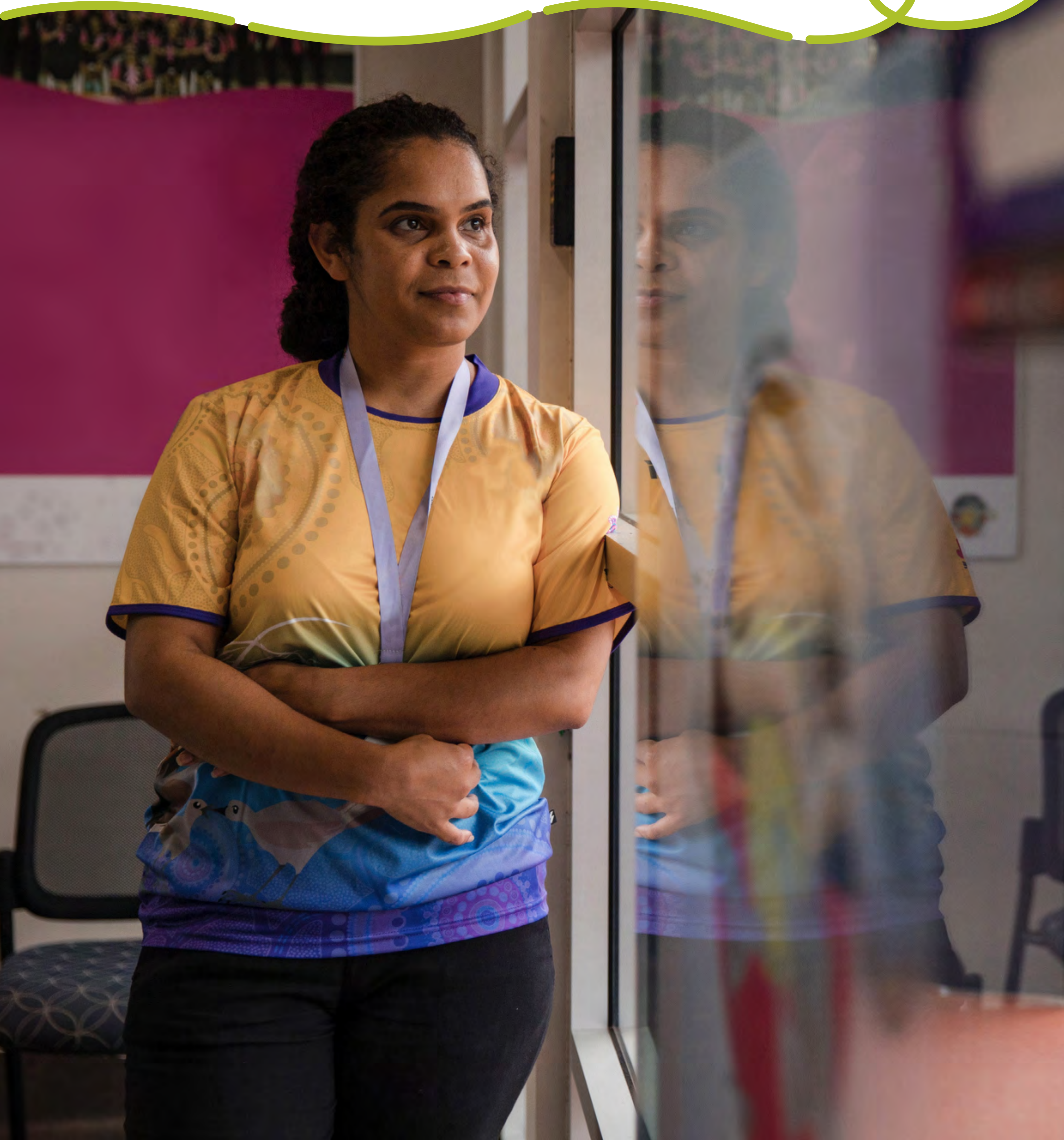
Stage three (years 8 to 10)

Action C5. Work in partnership with states and territories on specialised complex needs multi-disciplinary health and mental health care service options, either improving existing statewide services or establishing new services. Existing highly specialised services in Australia are generally based at a large tertiary hospital within a jurisdiction. They take referrals from across a state or territory, and primarily provide services to people with neurodevelopmental disorders (not just autism) with high and complex support needs.

These specialised services could utilise a stepped care approach to expand or assist existing services providing comprehensive, physical, mental, suicide prevention and crisis care services, including telehealth and phone service, tailored to Autistic people and capable of working with people with complex support needs and co-occurring mental health, physical health and neurological conditions.

Focus Area D

Improving autism education and training for health and mental health professionals



Why this is important

Relevant health and mental health professionals play a critical role in the recognition, diagnosis, and ongoing health and mental health 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.[68] This capability 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 and mental health practitioners often lack autism-specific training in their professional education.[69] This can have significant impacts on Autistic people's health-related quality of life, including:[70]

- Autistic people having poorer communication experiences with providers,[71] and relevant health and mental health professionals not understanding differences in communication methods and sensory experiences in autism
- relevant health and mental health providers misinterpreting or making assumptions about Autistic people's behaviours and/or communication
- health care providers not understanding or being able to support Autistic people who respond to a setting that is overwhelming or distressing
- Autistic people, their families and carers perceiving that health professionals hold stigmatising attitudes towards autism
- lack of continuity of care/collaboration between relevant health and mental health care professionals for an Autistic person's health care journey.[72]

Autistic people consistently highlighted the importance of improving autism education and training for health and mental health 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 capability in professional standards and registration.

Introducing education and training about autism in a way that is productive for all relevant health and mental health professionals and appropriately involves Autistic people, their families and carers 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. For example, the training curriculum is crowded, and many practitioners do not have time to undertake professional development beyond their specific specialty and regulatory compliance requirements

Another way that the health and mental health workforce can be supported to improve health outcomes for Autistic people is by supporting Autistic health professionals to provide high quality care to fellow Autistic people. This is because some Autistic individuals may prefer to be cared for or treated by Autistic health professionals, because of a perception that they may be more likely to adopt a strength-based approach in their practice. Additionally, many Autistic people have reported feeling dismissed or humiliated when seeking health services, which may contribute to a stronger desire to access services from professionals with lived experience.

Given this, Autistic health professionals need to feel safe disclosing that they are Autistic to their colleagues and clients or patients. A key part of this will be ensuring that they are protected against any long-term negative repercussions based on misconceptions about their ability to practice.

Autistic health professionals may also be more vulnerable to burnout because of their own lived experience. Because of this, consideration should be given to providing additional support to manage their workload and mental health.

What the future could look like (outcomes)

Outcome 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.

Outcome D2. Health, mental health, and disability professionals capably communicate and engage with Autistic people using communication methods appropriate to the person they are engaging with.

Outcome D3. Health and mental health professionals capably address and understand the health and mental health needs of Autistic people at different life stages and the intersecting needs of priority populations.

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

- understanding the experiences of Autistic health and mental health professionals and peer support workers
- working with professional bodies to address potential barriers to Autistic people accessing and training and openly identifying in their workplaces
- improved provision of reasonable adjustments in health and mental health service workplaces for Autistic practitioners.

Steps to get to an improved future (actions)

The preliminary actions which inform this Focus Area come from other Focus Areas, specifically the work to develop the Autism Health and Mental Health Framework in Focus Area B. As such, there is only one action in stage one and three actions in stage two.

Stage one (years 1 to 3)

Action D1. The Department of Health and Aged Care to engage with other Government areas agencies to support work that they are doing in improving the health or mental health of Autistic people (e.g. Social Services, Education, NDIA, NDIS Commission). This may include work to ensure that Autistic people are involved in development of government funded health and mental health programs. This will be continued across the life of the Autism Health Roadmap as required.

Stage two (years 4 to 7)

Action D2. Enhance existing resources and/or establish additional resources or services for health and mental health practitioners working in primary care to support Autistic patients who need care beyond their direct expertise. Examples might include:

- an extension of Health Pathways
- hotline to a specialised health practitioner
- Primary Health Network resources provided to local practitioners.

Action D3. Consider options for a capability-based national program of professional development about autism for relevant health and mental health professionals. Ensure that this program is co-designed and delivered by and with Autistic people. Content in the program should include:

- diverse presentations of autism, 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 decision making for all Autistic people, with a specific focus on people who do not have the capacity to give informed consent
- supporting people with high and complex support needs
- unpacking complex or challenging behaviours and determining respectful and appropriate health and mental health treatment options
- supporting Autistic people when they are in crisis situations or expressing suicidal ideation
- trauma-informed care, including acknowledging how stigma may affect Autistic people.

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 all Autistic people. There are currently significant gaps in what we know about the health and mental health of Autistic Australians.

One reason for these gaps is that there is no routine data collection or reporting on the health and mental of 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, including a 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 about this data on a regular basis would provide insights into the prevalence of autism in Australia and co-occurring health and mental health conditions. This could lead to better understanding of how best to address Autistic people's health and mental health care needs. Additionally, national data would more clearly demonstrate the need for further meaningful research about Australia's Autistic population and autism community.

> … 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).

While there are many specific areas of research and data that are lacking, some specific topics which have been identified while developing the Autism Health Roadmap include:

- understanding the mental health of Autistic people;
- information on the health and mental health inequities that Autistic people experience and;
- the experiences of Autistic people from priority population groups.
- Future research and data need to be routinely co-designed and co-produced with Autistic people and the autism community, to generate more appropriate, productive, and Autistic-led health strategies.[73] Research and data collection should also consider that many Autistic people may self-identify, and there are approaches and interventions that may be of benefit to Autistic people who have not yet obtained a formal diagnosis.

Co-produced research would align future health care opportunities with the priorities of Autistic people and the 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 Aboriginal and Torres Strait Islander led research.

What the future could look like (outcomes)

Outcome E1. Health and mental health services, and relevant national data sets, routinely collect data in a way that accurately identifies Autistic people, and is in accordance with best practice privacy, security and ethical research standards. This should include:

- autism diagnosis (including a consideration of self-identified diagnosis where appropriate to the data collection or research)
- service usage
- co-existing health and mental health conditions and disabilities
- satisfaction with services
- use of restrictive practices or alternatives used in place of restrictive practices
- clinical and individual recovery mental health outcomes.

Outcome 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.

Outcome 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 (actions)

Stage one (years 1 to 3)

Action E1. 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 all 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
- the needs and experiences of the priority populations, such as those outlined at the start of the Autism Health Roadmap.

Action E2. 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.

Stage two (years 4 to 7)

Action E3. Consider funding and prioritising research that identifies strategies to improve all Autistic people's overall health and health care. Projects funded as part of this should reflect the diversity and intersectionality of the Autism community and include opportunities for Autistic led research.

Action E4. Develop and establish national evidence-based standards in pain measurement for all Autistic people. This should have applicability across diverse settings such as primary care, bedside care, ambulance transport and childbirth, as well as across all ages, abilities and intersectional experiences. It should also recognise the broad variety of Autistic expressions of pain.

Action E5. 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 all Autistic people including people with co-occurring conditions and 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 all 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 all Autistic people.

What the future could look like (outcomes)

Outcome F1. A program of work to improve the health and mental health of all 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 with diverse needs and from 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.

Outcome 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 the ongoing implementation of the Autism Health Roadmap.

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

Steps to get to an improved future (actions)

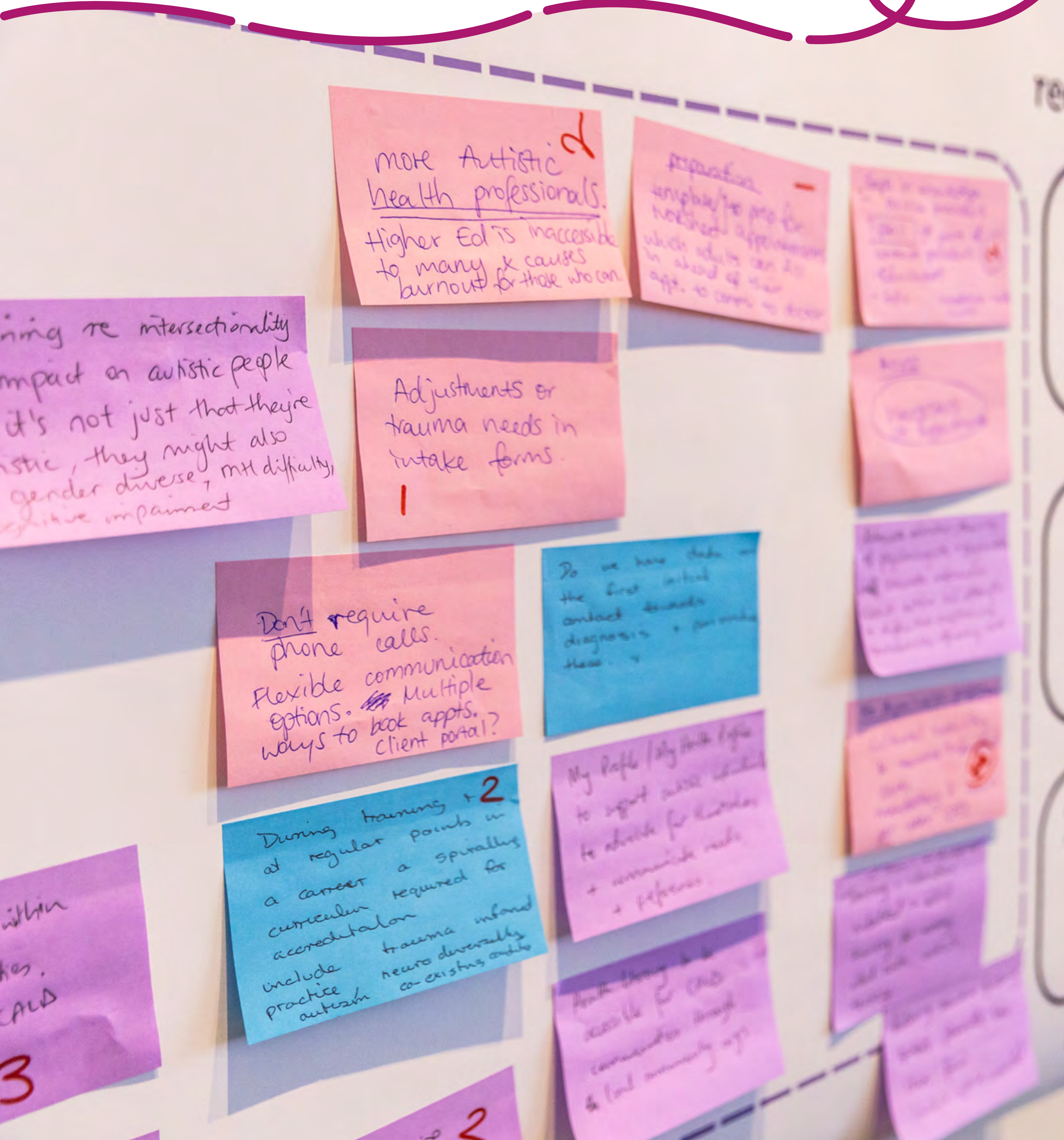
Action F1. Establish a Governance Group to oversee and monitor work to improve the health and mental health of all Autistic people. This should include Autistic and autism representatives, family/carer representatives, health and mental health practitioners, peak bodies and government stakeholders.

Action F2. Report annually on implementation of the Autism Health Roadmap and progress of work to improve the health and mental health of Autistic people.

Action F3. 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.

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), described further below.

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 Working Group was the primary stakeholder group which supported and guided the development of the Autism Health Roadmap. The Working Group supported 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 action
- providing linkages to other key stakeholders for the development and 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 is listed below. Please note that due to the duration of the Working Group, some organisations had various specific representatives attend Working Group meetings. Where this occurred, no specific person is named in the list below.

Name	Organisation being represented
Dr Melanie Heyworth	Autistic individual member
Geraldine Robertson	Autistic individual member
Hayley Clapham	Autistic individual member
Dr Jac den Houting	Autistic individual member
Julianne Higgins	Autistic individual member
Dr Lionel G. Evans	Autistic individual member
Monique Blakemore	Autistic individual member
Dr Wenn B. Lawson	Autistic individual member
Genevieve Brookman	Autistic Self Advocacy Network of Australia and New Zealand
Jenny Karavolos	Australian Autism Alliance
Bob Buckley	Autism Aspergers Advocacy Australia (A4)
Nominated staff member	First Peoples Disability Network (FPDN)
Nominated staff member	National Aboriginal Community Controlled Health Organisation (NACCHO)
Nominated staff member	National Ethnic Disability Alliance (NEDA)
Nominated board member	Australian Advisory Board on Autism
Nominated board member	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)
Andrew Davis	Autism Cooperative Research Centre (Autism CRC)
Dr Catherine Marraffa	Royal Australasian College of Physicians (RACP)
Dr James Best	Royal Australian College of General Practitioners (RACGP)
Nominated fellow	Royal Australian and New Zealand College of Psychiatrists (RANZCP)
Nicole Pates	Allied Health Professionals Australia (AHPA)
Nominated representative	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
Territory Government Representative	ACT Health Directorate, ACT Government
State Government Representative	Ministry of Health, NSW Government
Territory Government Representative	NT Health, Northern Territory Government

Name	Organisation being represented
State Government Representative	Children's Health Queensland Hospital and Health Service, Queensland Government
State Government Representative	Queensland Health, Queensland Government
State Government Representative	Department for Health and Wellbeing, Government of South Australia
State Government Representative	Department of Health, Victoria State Government
State Government Representative	Department of Health, Tasmanian Government
State 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.

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:

- Autistic people with co-occurring intellectual, psychological, cognitive, physical or developmental health conditions
- Autistic people in residential settings
- Autistic people in correctional settings
- Autistic Aboriginal and Torres Strait Islander people
- Culturally and linguistically diverse (CaLD) Autistic people
- Autistic women and girls
- Autistic people who identify as LGBTQIA+
- Autistic people and families who live in rural and remote areas
- Autistic people and families who are from low socio-economic backgrounds
- Autistic people who were diagnosed later in life
- Autistic children and young people
- 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 informed, 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.

Public consultations

A public consultation phase was held from 14 August 2024 to 27 September 2024.

To ensure that the consultation was accessible to as many people as possible two main ways to respond were offered. The first was to provide feedback directly to the Department of Health and Aged Care and the survey, which was offered in three forms. Based on feedback Autistic members of the Working Group, three versions of the survey were created the long form, the short form and an Easy Read version.

- The long survey asked for views on the exact draft wording of the Autism Health Roadmap, using technical language familiar to health professionals and policy makers.
- The short survey used less technical language and was more suitable for people who need support. Autistic members of this group gave feedback this version of the survey to improve accessibility.
- The Easy Read survey used simple words and visuals.

The key purposes of the consultation were to find out:

- Did we include the right issues?
- Did the actions seem appropriate, achievable and cover the right areas?
- Was the language used appropriate?
- How can the Autism Health Roadmap be improved?

Submissions could also be emailed to the Department of Health and Aged Care from individuals and organisations, including in other formats such as audio recordings. Free form submissions gave individuals and organisations the opportunity to respond in greater detail to the strengths of the Autism Health Roadmap, as well as identifying opportunities and gaps.

Responses to the public consultation

A total of 313 submissions in all formats were received including the long, short and Easy Read survey formats. The table below shows the number of responses in each of the available formats. Please note that the number of Autistic responses among the free form emails and written submissions were not able to be ascertained, given most of them were made by organisations or did not provide this detail.

Response option	Number of responses (total)	Number of Autistic responses
Long form survey	216	119
Short form survey	48	27
Easy Read survey	2	2
Free form emails, responses in other formats and written submissions	47	N/A
Total	313	148

Overall themes from the public consultation

Key themes across all feedback types included:

- Improve health service access and remove barriers to accessing equitable support
- the Autistic community, and Autistic-led organisations, to have their voices heard, needs understood and to be able to make contributions to the design and implementation of research, services and the Autism Health Roadmap itself
- greater focus on co-occurring physical conditions such as epilepsy, gastrointestinal and autoimmune conditions
- improve access and availability of health and mental health services for Autistic people.

Specific areas that were identified as key areas to be addressed or highlighted further in the Guiding Principles and Focus Areas were:

- Preventing sexual violence, self-harm and suicide
- Addressing specific needs for Autistic adults over 65
- The needs of culturally and linguistically diverse populations
- Prevention of chronic illness
- Mental health crisis support.

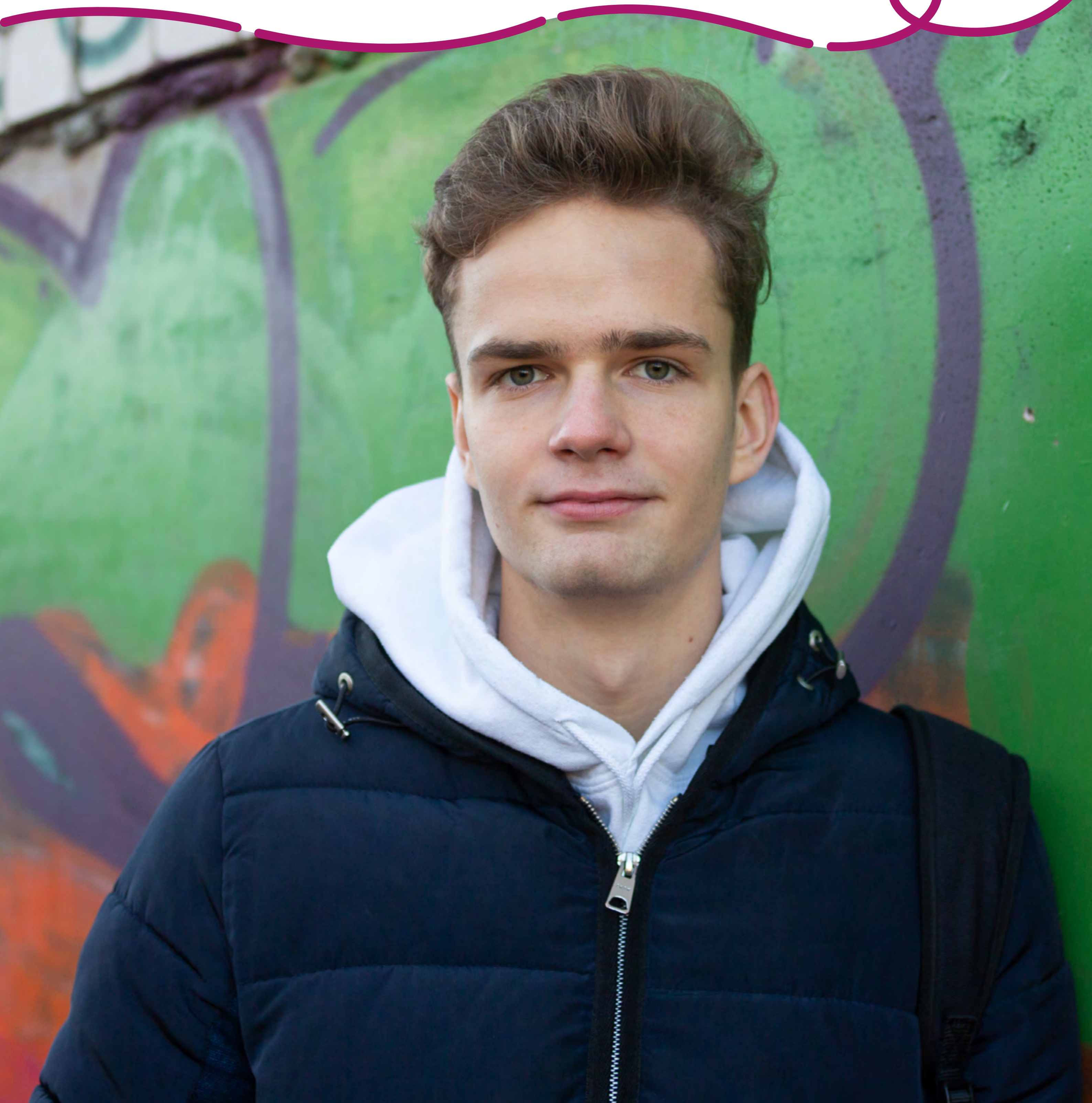
The feedback was reviewed in detail by the Department of Health and Aged Care. Changes were made to the Autism Health Roadmap following the feedback.

Issues raised in the which were out of scope of the Autism Health Roadmap

Respondents to the public consultation identified and raised some issues which were out of scope of the Autism Health Roadmap. These issues were referred to the team leading the National Autism Strategy for further consideration. These issues included:

- improving support for accessing and sustaining employment
- increasing funding available to people through the Disability Support Pension and the NDIS
- improving education and training for schools and NDIS providers and staff about autism
- better access to diagnosis services in the community.

Appendix B – Glossary of terms and used in the Autism Health Roadmap



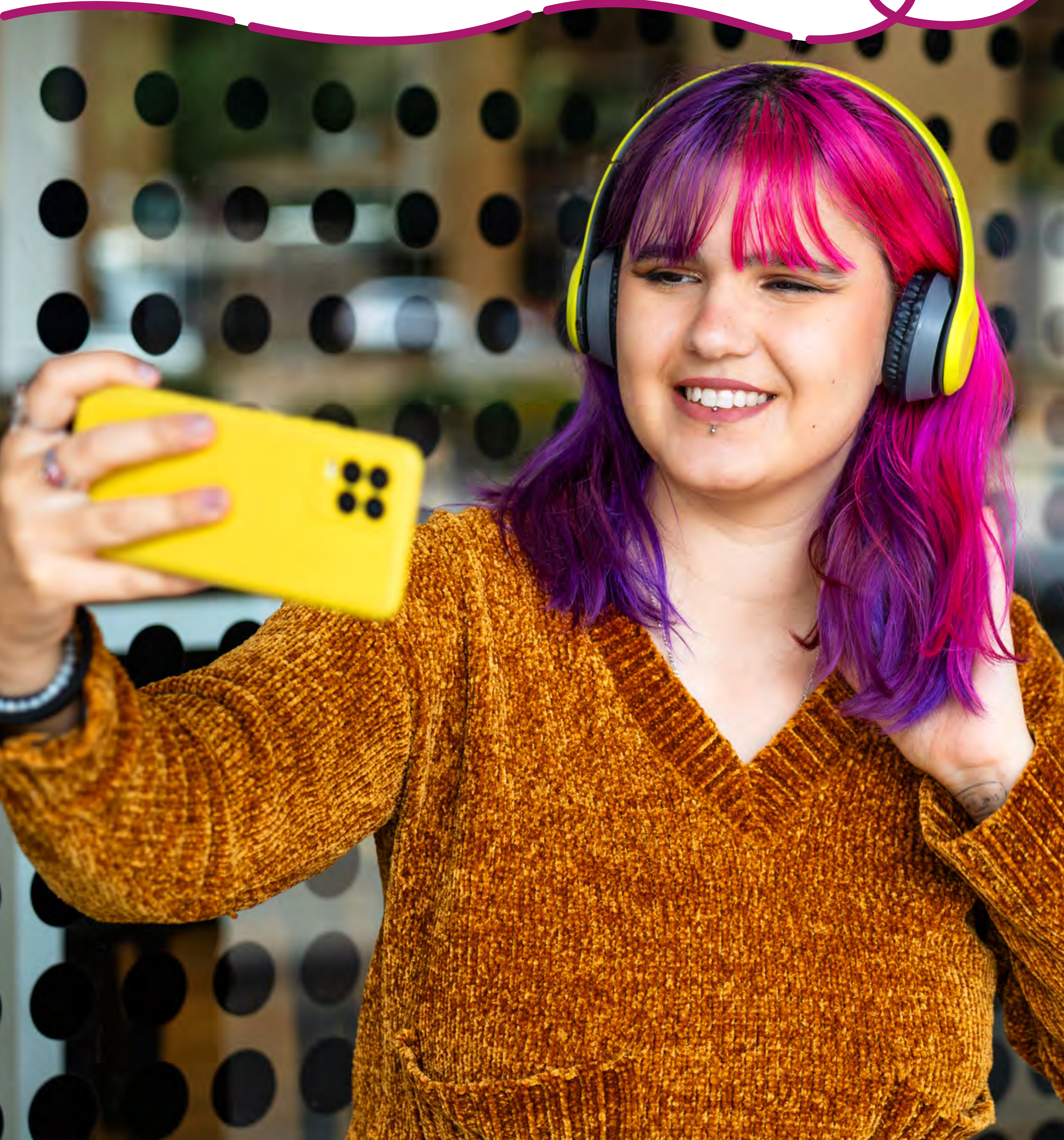
Term	Definition
Accessible	Environments, facilities, services, products and information that people can use and interact with in a way that suits their needs.
Autistic people and autism community members	Refers to the collective communities of Autistic people, their families and carers, friends and support 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. Some legislation refers to 'carers' and some people with disability prefer the term over 'support person'. We acknowledge that other people prefer the term 'family or chosen supporters' instead of carers.
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.

Term	Definition
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. Whilst cultural safety is used to discuss the components of safety through respect for cultures more broadly, it is a term that has particular application for First Nations peoples. In this context, cultural safety is determined by Aboriginal and Torres Strait Islander individuals, families and communities. Culturally safe practice is the ongoing critical reflection of health practitioner knowledge, skills, attitudes, practicing behaviours and power differentials in delivering safe, accessible and responsive health care free of racism.
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. Some Culturally and Linguistically diverse people are also culturally and racially marginalised.
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 informed	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 informed.
Health literacy	The ability, or level of ability, to read and understand health care information, and to translate this information into practice.
Health system	Refers to the complex mix of service providers and other health professionals that make up a whole system. This includes a range of organisations—from Australian and state and territory governments, to the non-government sector and the private sector. Collectively this system works to meet the physical and mental health care needs of Australians.
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.

Term	**Definition**
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.
Psychotropic medications	Psychotropic medications are any drug capable of affecting the mind, emotions and behaviour. The three main classes of psychotropics prescribed are antidepressants, anxiolytic/hypnotics (mostly benzodiazepines to manage anxiety and insomnia) and antipsychotics. Other psychotropic classes include anticonvulsants and stimulants. While psychotropic medicines play an important role in treating diagnosed mental health conditions, they are also commonly used to manage behaviours of concern experienced by people with cognitive disability or impairment. When implemented without a diagnosed mental health condition in order to manage or control behaviour, this constitutes chemical restraint – restrictive practice (see below).
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.

Term	Definition
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.

Appendix C – Focus Area actions



Focus Area A - Improving support for Autistic people, their families and carers, in health and mental health services

Stage one (years 1 to 3)

Action A1. Regularly review existing Australian Government health and mental health information and resources (including digital resources) for consumers and health practitioners, to ensure all Autistic people's needs are explicitly addressed. This will be continued across the life of the Autism Health Roadmap.

Action A2. As a priority action, consider how to improve access to and affordability of primary care services, including general practice, that address the health and mental health needs of all Autistic people across their lifespan. This could include:

- 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 and allied health services
- longer consultations to accommodate different cognitive processing and communication needs, and complex mental health needs
- preventative health support including for co-occurring and emerging chronic conditions through annual health checks for Autistic people
- otherwise increasing affordability and ways that health professionals can provide additional health and mental health supports to all Autistic people, including referring Autistic people to free publicly available services if appropriate and/or peer support services.

This will be continued across the life of the Autism Health Roadmap.

Action A3. 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. This work would provide examples for the further development of literacy resources. Ensure that these resources are in formats accessible to Autistic people, including people with complex and high support communication needs.

Stage two (years 4 to 7)

Action A4. Develop information, resources and education for Autistic people, their families and carers, in areas identified as key gaps in health literacy resources. Ensure that these resources are accessible for all Autistic people and include resources that are accessible and relevant to Autistic people with high support and/or complex needs. Key topics could include:

- the traits/characteristics and varied presentations of autism, including gender and cultural differences
- how Autistic people experience sensations and common experiences differently to non-Autistic people
- common co-occurring health and mental health conditions
- when you might need to see a professional
- how different kinds of professionals can help
- what you should expect from a health care professional
- how to navigate services, including making appointments
- regulation strategies that may be effective during health and mental health appointments.

Action A5. Develop resources for all relevant health and mental health professionals to improve their understanding and capability regarding autism. Develop this 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. Resources could include information about:

- Autistic traits
- how Autistic people experience sensations and common experiences differently to non-Autistic people
- alternative methods of communication and practical communication strategies
- sensory considerations for Autistic people that reflect the range of health environments they may encounter e.g. general practice waiting rooms and emergency room settings
- self-regulation strategies that may be effective for supporting Autistic people in health and mental health settings
- identifying risks to safety (including sexual safety) and upholding health care rights
- common co-occurring health and mental health conditions.

Action A6. 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 Health and Mental Health Framework such as fact sheets, evidence briefs and webinars (see Focus Area B for a description of the Framework).
- 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 all Autistic people's needs in ongoing work related to health literacy (see Focus Area B).

Stage three (years 8 to 10)

Action A7. Review and refine existing, or if needed co-develop and promote, tools for best practice models of care for empowering autonomy, shared decision-making, providing informed consent for treatment, and ensuring adequate and ethical safeguards for those that lack the capacity to provide informed consent. These tools should include:

- when this support is most likely to be needed e.g. recommending medications, pre- and post-surgery, considering reproductive needs and processes, and end of life care
- risks to safety (including sexual safety) and human rights
- consideration of the role of parents, carers, and guardians.

Focus Area B – Improving the quality, safety and availability of Autism Affirming health and mental health care across their lifespan

Stage one (years 1 to 3)

Action B1. Promote autism affirming care within existing and future primary health care reforms, including exploring further provisions that enable general practitioners, and other primary health care providers to spend more time with Autistic patients, families and carers. Provide accommodations for the communication needs and diverse abilities of Autistic people, including those with co-occurring conditions and high and complex support needs.

This will be continued across the life of the Autism Health Roadmap.

Action B2. Co-design and develop an Autism Health and Mental Health Framework. The Autism Health and Mental Health Framework will be a nationally co-designed theory, practice, workforce and service capability framework. The development of it will include broad sector consultations and development to build consensus about what is best practice care for Autistic people across health and mental health service settings. It will create the foundational descriptors for acute-to-community health and mental health services, workforces, facility design, curriculum and quality/safety standards. The Autism Health and Mental Health Framework will be mapped to existing health, mental health and suicide prevention practice guidelines and service models.

Action B3. As part of an upcoming review of the National Safety and Quality Health Services (NSQHS) Standards, consider how these may be able to be more applicable to autism and alignment to an Autism Health and Mental Health Framework. This should include taking an approach that investigates and addresses the high levels of self-harm and suicide among Autistic people, as well as works to eliminate harmful restrictive practices.

Action B4. Promote pathways and advocacy services for Autistic people, their families and carers to be able to raise complaints with all relevant health and mental health services and practitioners. This should be done to enhance respectful approaches to providing care and give further assistance in how to escalate complaints if required.

Stage two (years 4 to 7)

Action B5. Promote best practice care of Autistic people within existing sector reform efforts based on an Autism Health and Mental Health Framework (the Framework). This could include:

- consideration of the communication needs and abilities of all Autistic people, especially for people with high support needs and specific communication needs, such as non-speaking Autistic people and people who use alternative communication methods
- guidance, resources and existing relevant training for health and mental health professionals about how to assist Autistic people in distress or who are presenting with challenging behaviours. In line with competencies developed in the Framework, include approaches that prevent escalation and support Autistic people to regulate emotions and behaviour safely, with minimal or no use of chemical restraint. (For further detail on training and education, see Action D4)
- consideration of further health service provisions that enable health practitioners to spend more time with all Autistic people, their families and carers.

Action B6. Pilot and promote best practice models of Autism Affirming care, as defined by an Autism Health and Mental Health Framework. This should include the ways that health and mental health services are delivered for Autistic people in acute settings, in hospitals, in private practice and in the community. Ensure that the specialised needs of the priority populations are considered in selection of the pilots.

Action B7. Consider ways to integrate practice approaches and competencies from the Autism Health and Mental Health Framework into future reviews of standards, strategies and initiatives, including future reviews of health and mental health service standards, such as future National Safety and Quality Health Services Standards.

Action B8. Consider developing crisis line/web services which are tailored to all Autistic people, their families and carers. As part of this, consider options for the establishment of a specific autism crisis line/web service, or ways to for the upskilling of existing services. Irrespective of the approach taken, work to establish no wrong door approach that can be adopted across crisis lines/web services.

Stage three (years 8 to 10)

Action B9. 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 Health and Mental Health Framework.

Action B10. Consider options for a national practice recognition initiative to make it easier for Autistic people to identify relevant health and mental health professionals who, within their scope of practice specialise in services for Autistic people. This should be done in partnership with relevant autism organisations, professional colleges and specialist societies.

Action B11. 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:

- the Autism Health and Mental Health Framework
- the Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard
- existing evidence and practice guidance on the use of medicines to address challenging behaviours with Autistic people. This should include systematic reviews of pharmacological interventions, alternatives to prescribing medicines (including mental health assessment and intervention), and deprescribing practices.
- the need to acknowledge the rights of Autistic people to access and be educated about both pharmacological and non-pharmacological treatment for mental health conditions

Action B12. Review the safety and quality aspects of health and mental health service practice guidance and education material on the use of psychotropic medicines to consider the needs and experiences of all Autistic people.

Focus Area C – Building better connections between health, mental health, and other service sectors, including the NDIS

Stage one (years 1 to 3)

Action C1. Establish or build upon existing primary health communities of practice to connect and support relevant health and mental health professionals to improve coordination and responsiveness to health, mental health, suicide prevention and preventative health needs of Autistic people. Consider this particularly for rural and remote areas.

Action C2. Consider potential models, such as Autistic peer support workers, for Autistic and autism-proficient service navigators/liaison officers in health and mental health services. Consider whether disability health navigators (recommendation 6.34 in the Disability Royal Commission final report) could be equipped to play this role.

Stage two (years 4 to 7)

Action C3. Co-develop and publicise an ‘autism passport’. The passport could be an optional practical tool provided in an accessible format, such as a downloadable document, that Autistic people may choose to use to assist them in sharing information with relevant health and mental health services. It could contain information on an individual’s sensory, cognitive, communication, other health or mental health conditions and treatment preferences.

Action C4. Consider ways to support Autism organisations to ensure that they have the capability and appropriate resourcing to assist Autistic people, their families and carers with engaging in health, mental health, suicide prevention and connected service systems. This will include prioritising support for Autistic led organisations and those that are autism affirming.

Stage three (years 8 to 10)

Action C5. Work in partnership with states and territories on specialised complex needs multi-disciplinary health and mental health care service options, either improving existing statewide services or establishing new services. Existing highly specialised services in Australia are generally based at a large tertiary hospital within a jurisdiction. They take referrals from across a state or territory, and primarily provide services to people with neurodevelopmental disorders (not just autism) with high and complex support needs.

These specialised services could utilise a stepped care approach to expand or assist existing services providing comprehensive, physical, mental, suicide prevention and crisis care services, including telehealth and phone service, tailored to Autistic people and capable of working with people with complex support needs and co-occurring mental health, physical health and neurological conditions.

Focus Area D – Improving autism education and training for health and disability professionals

Stage one (years 1 to 3)

Action D1. The Department of Health and Aged Care to engage with other Government areas agencies to support work that they are doing in improving the health or mental health of Autistic people (e.g. Social Services, Education, NDIA, NDIS Commission). This may include work to ensure that Autistic people are involved in development of government funded health and mental health programs. This will be continued across the life of the Autism Health Roadmap as required.

Stage two (years 4 to 7)

Action D2. Enhance existing resources and/or establish additional resources or services for health and mental health practitioners working in primary care to support Autistic patients who need care beyond their direct expertise. Examples might include:

- an extension of Health Pathways
- hotline to a specialised health practitioner
- Primary Health Network resources provided to local practitioners.

Action D3. Consider options for a capability-based national program of professional development about autism for relevant health and mental health professionals. Ensure that this program is co-designed and delivered by and with Autistic people. Content in the program should include:

- diverse presentations of autism, 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 decision making for all Autistic people, with a specific focus on people who do not have the capacity to give informed consent
- supporting people with high and complex support needs
- unpacking complex or challenging behaviours and determining respectful and appropriate health and mental health treatment options
- supporting Autistic people when they are in crisis situations or expressing suicidal ideation
- trauma-informed care, including acknowledging how stigma may affect Autistic people.

Focus Area E – Strengthening research and data on health and mental health of Autistic people and their families and carers

Stage one (years 1 to 3)

Action E1. 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 all 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
- the needs and experiences of the priority populations, such as those outlined at the start of the Autism Health Roadmap.

Action E2. 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.

Stage two (years 4 to 7)

Action E3. Consider funding and prioritising research that identifies strategies to improve all Autistic people's overall health and health care. Projects funded as part of this should reflect the diversity and intersectionality of the Autism community and include opportunities for Autistic led research.

Action E4. Develop and establish national evidence-based standards in pain measurement for all Autistic people. This should have applicability across diverse settings such as primary care, bedside care, ambulance transport and childbirth, as well as across all ages, abilities and intersectional experiences. It should also recognise the broad variety of Autistic expressions of pain.

Action E5. 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 all Autistic people including people with co-occurring conditions and priority populations.

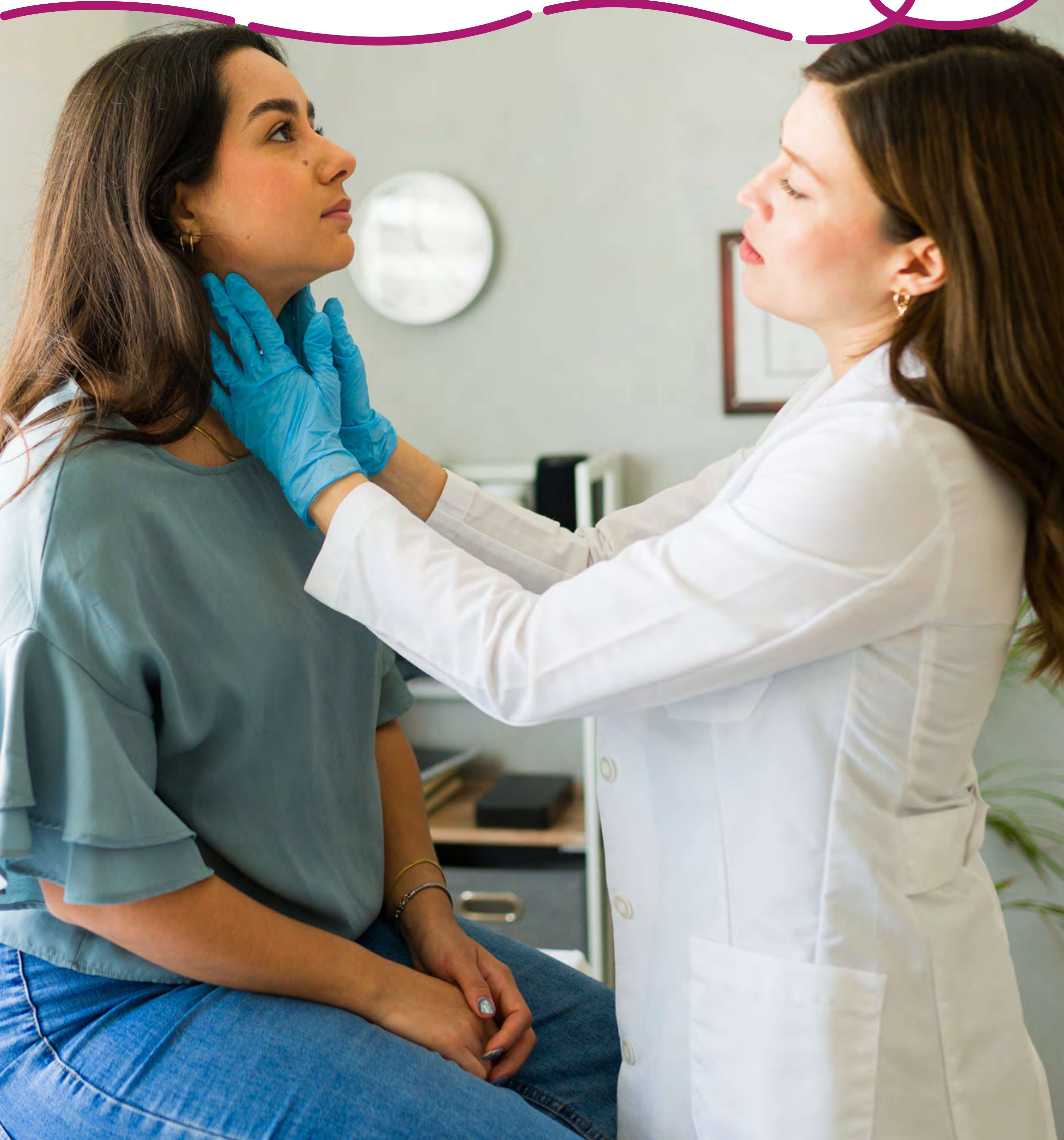
Focus Area F – Arrangements for oversight, monitoring, and implementation of the Autism Health Roadmap

Action F1. Establish a Governance Group to oversee and monitor work to improve the health and mental health of all Autistic people. This should include Autistic and autism representatives, family/carer representatives, health and mental health practitioners, peak bodies and government stakeholders. This will include connecting with and complementing the governance structures in place to support the National Autism Strategy where there are areas of overlapping interest, while also delivering on the Autism Health Roadmap's specific mandate.

Action F2. Report annually on implementation of the Autism Health Roadmap and progress of work to improve the health and mental health of Autistic people.

Action F3. Consider development of an Outcomes, Monitoring and Evaluation Framework. Critical data gaps should be identified and addressed.

Appendix D – Concurrent Australian Government reforms and reviews



The below section outlines key Australian Government reforms which are in development at the time that the Autism Health Roadmap was being drafted. They are included to demonstrate related work that the Government is doing which may impact on the lives of Autistic people.

The National Autism Strategy

The Australian Government 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 funding amounts 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, including through tripling the bulk billing incentive for children under 16, pensioners and concession card holders
- 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 to improve management of chronic conditions and reduce avoidable hospitalisations.

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 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 of the NDIS Review 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.

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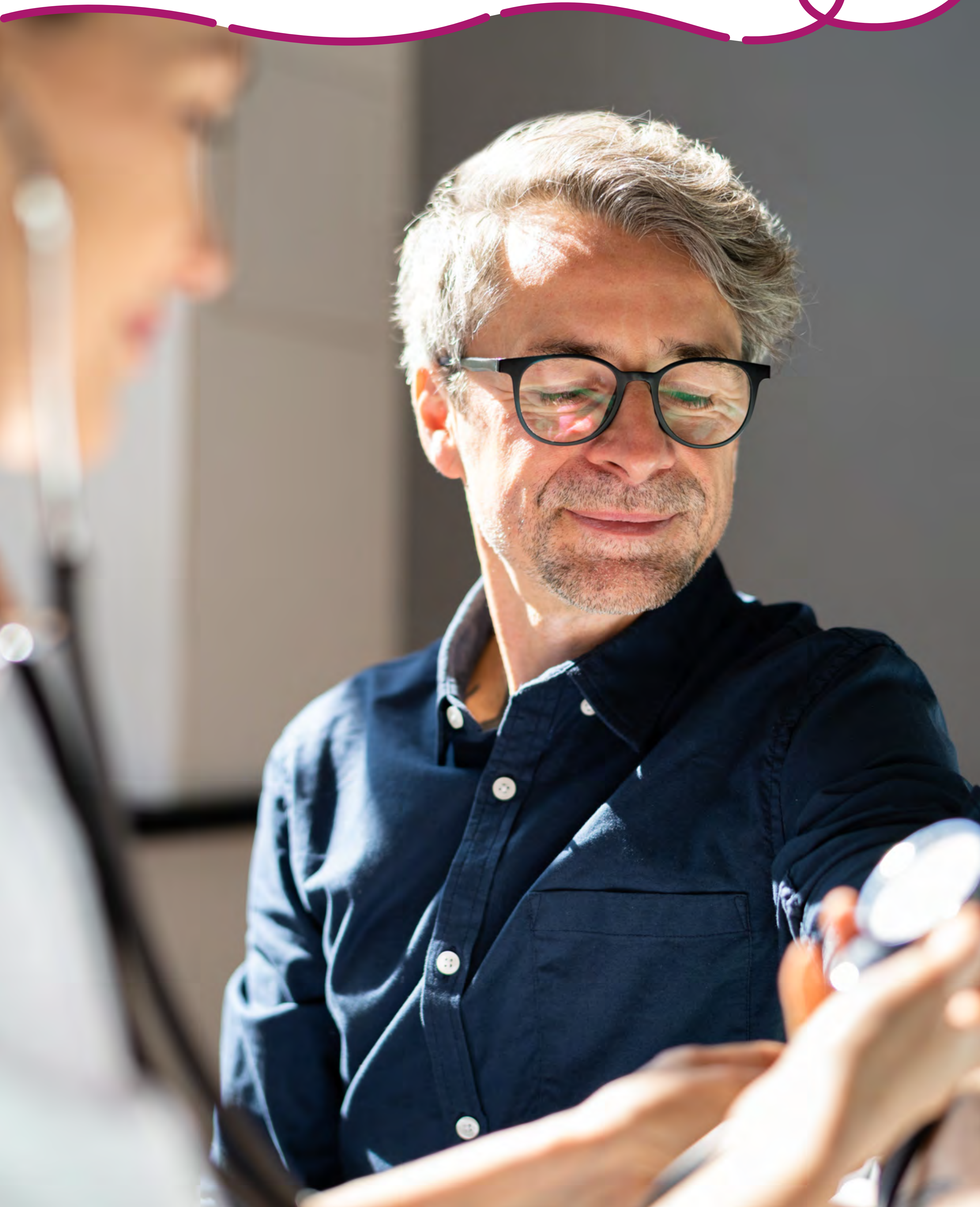

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