

# Report on research, co-design and community engagement to inform the National Roadmap to Improve the Health and Mental Health of Autistic People:

Reimagining health and mental health services for Autistic people, their families and carers

## Report summary

March 2024



**How can health and mental healthcare services be improved for Autistic people?**

**Write your ideas**

Key ideas from the sticky notes include:

- Doctors providing neuro-affirming advice when diagnosing autism instead of deficit based info**
- Artistic Liaison Nurses/Workers (who are autistic)**
- Transparency from supports on their ethics + methods for practice**
- Better training for health/Education professionals - Understanding different presentations of autism & physical pain thresholdly/mental health presentations**
- More services to provide support & training in order to avoid burnout for parents/careers**
- PETS SUPPORT**
- Equality! Work therapies & work**
- Autism will TO PARL+PEP**
- More info given in the way we need it**
- NDIS need to recognise the funding required to support children who need help with hygiene, dental, occupational, hearing needs, etc...**
- Doctors providing neuro-affirming advice when diagnosing autism instead of deficit based info**
- Artistic Liaison Nurses/Workers (who are autistic)**
- Transparency from supports on their ethics + methods for practice**
- Better training for health/Education professionals - Understanding different presentations of autism & physical pain thresholdly/mental health presentations**
- More services to provide support & training in order to avoid burnout for parents/careers**
- PETS SUPPORT**
- Equality! Work therapies & work**
- Autism will TO PARL+PEP**
- More education/training of University/Healthcare workers - Inclusion of Autistic lecturers/teachers to deliver**
- Learning sees profiles to support mental health**
- More affordable + accessible assessments**
- Support with decision making processes (when complex + needed)**
- Autistic individuals need support when diagnosed in order to manage their mental wellbeing**
- Autism awareness for general community**
- More education/training of University/Healthcare workers - Inclusion of Autistic lecturers/teachers to deliver**
- Police Training**
- Run by autistic people**
- Physical health impact on mental health**
- Impact of sensory input - flow on effect to mental health if not understood & accommodated**
- Healthcare providers NEED to believe the autistic experience**
- By Making Diagnosing prices for Autism/ADHD Diagnostics cheaper**
- Access!!! Appointment**
- Psychology/therapy services**
- IB more work for fast path opportunity for a young adult is not acceptable**
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# Report on research, co-design and community engagement to inform the National Roadmap to Improve the Health and Mental Health of Autistic People: Reimagining health and mental health services for Autistic people, their families and carers

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## Autism CRC

Autism CRC is the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum.

We provide the national capacity to develop and deliver evidence-based outcomes through our unique collaboration with Autistic people, families, professionals, services providers, researchers, and government. Together, we are addressing agreed needs and co-producing outputs with these stakeholders for the benefit of the community.

Autism CRC was established in 2013 as the world’s first national, cooperative research effort focused on autism under the Australian Government’s Cooperative Research Centres (CRC) Program. We receive funding from a number of sources, including the Australian Government. Autism CRC is no longer part of, or associated with, the CRC Program.

[autismcrc.com.au](http://autismcrc.com.au)

## A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, we use the terms 'Autistic person', 'person on the autism spectrum' or 'person on the spectrum'. The term 'Autistic person' uses identity first language, which reflects the belief that being Autistic is a core part of a person's identity. In this document we are using 'Autistic' as a proper adjective or noun. This is the preferred language of the Australian Government Department of Health and Aged Care and the Autism Health and Mental Health Roadmap Working Group.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the health care sector and is used in the context of a person being 'diagnosed with Autism Spectrum Disorder'.

## A note on sensitive content

Please note this report includes discussion of sensitive topics related to health and mental health, including but not limited to medical trauma, suicide, self-harm, and domestic violence, and people who are deceased. In addition, to respect individual's personal expression, language priorities, preferences, or profanity we have not edited for terminology or language. Reader discretion is advised. This report aims to promote understanding of these issues, but it may evoke strong emotions. Please consider your own wellbeing in deciding to read further and contact the relevant support services shared below if this raises discomfort or distress for you.

## Free support services

### Autism Connect

Call 1300 308 699

Live chat: [www.amaze.org.au/autismconnect/#webchat](http://www.amaze.org.au/autismconnect/#webchat)

Website: [www.amaze.org.au/autismconnect/](http://www.amaze.org.au/autismconnect/)

### Lifeline Australia

Call: 13 11 14 or

Text: 0477 13 11 14

Live chat: [www.lifeline.org.au/crisis-chat](http://www.lifeline.org.au/crisis-chat)

Website: <http://www.lifeline.org.au>

### Beyond Blue

Call: 1300 22 46 36

Live chat: <https://www.beyondblue.org.au/support-service/chat>

Website: <https://www.beyondblue.org.au/>

### Kids Help Line

Call: 1800 55 1800

Live chat: <https://kidshelpline.com.au/get-help/webchat-counselling>

Website: <https://kidshelpline.com.au>

### Head to Health

Call: 1800 595 212

Website: <https://www.headtohealth.gov.au/>

### QLife

Call: 1800 184 527

Live chat: <https://www qlife.org.au/resources/chat>

Website: <https://www qlife.org.au/>

### 13YARN

Call: 13 92 76

Website: <https://www.13yarn.org.au/>

# 1. Report summary

## 1.1 Why we did this work

The Australian Government has committed to the development of a National Roadmap to Improve the Health and Mental Health of Autistic People (also referred to as the “Roadmap”). The aim of the Roadmap is to address issues faced by Autistic people in the health and mental health care systems, and outline actions to improve outcomes. The Department has established a Working Group of representatives of the Autistic and autism communities, professional bodies and government to guide the development of the Roadmap.

The development of the Roadmap is being informed by a collaborative research, co-design and community engagement process involving the perspectives of over **5,000** stakeholders. This report describes the combined findings, insights, practice considerations and recommendations arising from that process relating to the key elements and challenges to be addressed in the Roadmap.

This report was submitted to the Department of Health and Aged Care on 29 February 2024 for consideration by the Department and the Roadmap Working Group in development of the Roadmap.

## 1.2 What we did

The Roadmap project involved a series of co-design, research, and community engagement activities. These activities included input from stakeholders, including Autistic people from diverse backgrounds, life experiences and abilities, as well as families, carers, health and mental health practitioners and professionals.

The five specific activities undertaken as part of this work were:

- Establishment of a Stakeholder Reference Group including people with lived experience, health and mental health practitioners, and representatives of disability organisation and professional colleges and societies who provided strategic advice on the co-design and community engagement process, analysis and findings.
- Secondary analysis including review and re-coding several existing helpline queries and national data sets on health care experiences, needs and priorities, which combined contain information from almost **5,000** Autistic people, families, carers and professionals.
- In-depth focus groups and interviews with **107 people** including Autistic people, parents, carers and family members and professionals with experience working with the priority groups as determined by the Department of Health and Aged Care and the Autism Health Roadmap Working Group.
- ‘Reimagining health and mental health services’ co-design workshops with **51** stakeholders, including 30 Autistic people, 16 parents, carers or guardians and 30 health practitioners and disability professionals.
- The National Health and Mental Health Services Community Co-design Summit held on 2 February 2024, engaged **58** Autistic people, professionals in health, mental health, allied health and disability fields including Autistic and non-Autistic practitioners.

## 1.3 Who we engaged

In addition to 4,990 people represented in the help line queries and existing research data sets, we directly engaged a total of **197** stakeholders in the co-design and community engagement activities including workshops, focus groups, interviews and the Summit. This included **125 Autistic** people.

Of the 197 stakeholders, 83 individuals were parents, carers or guardians of Autistic people including 45 who identified as parents, carers or guardians of Autistic people with high or complex needs. 56 of the parents, carers or guardians of Autistic people also identified as Autistic.

Of the 197 stakeholders, 104 individuals were practitioners and/or disability professionals who work with Autistic people, 50 of these were Autistic.

Participants were aged between 18 to 70 years. Approximately 19% were male, 67% female, 12% identified as non-binary and 2% were not identified or disclosed.

All States and Territories across Australia were represented. New South Wales (n=32); Victoria (n=63); Queensland (n=24); South Australia (n=28); Western Australia (n=16); Tasmania (n=22); Northern Territory (n=2); and the Australian Capital Territory (n=7), and unknown or not provided (n=3).

**Table 1: Characteristics of co-design workshops and community engagement participants by priority group**

Characteristic	Interviews	Focus Groups **	Co-design workshop	Total
<b>People with high or complex needs and/or co-occurring health conditions that impact daily life</b>	38	16	16	70
High communication needs	9	1	-	10
High behaviour support needs	19	0*	-	19
People in residential settings	15	3	-	18
People with intellectual disability	16	1	1	18
Non-speaking/Unreliably speaking	12	7	-	19
<b>First Nations people</b>	2	1	2	5
<b>Culturally and Linguistically Diverse (CaLD) people</b>	7	22	8	37
<b>LGBTIQA+ people</b>	16	31	10	57
<b>Women and girls</b>	29	41	37	107
<b>People living in rural and remote areas</b>	16	18	13	47
<b>People from low socio-economic backgrounds</b>	16	19	-	35

\*\* Some focus groups also discussed experiences with individuals with high behaviour support needs in residential settings however were not recorded in these figures.

NB: Co-design participants were not asked about their socio-economic background and most participants identified with more than one priority group.

On 2 February 2024, a **National Health and Mental Health Services Community Co-design Summit** brought together **58** stakeholders (19 of whom had participated in Co-design workshops), including **29** Autistic people, **33** health practitioners in health and **15** professionals in disability fields, to collaboratively develop a series of recommendations for consideration in the development of the Roadmap. 8 representatives from the Department of Health and Aged Care, and the Department of Social Services and 7 non-facilitating Autism CRC staff were also present.

There was limited representation of Autistic First Nations people within the data sets and community engagement. It is important to acknowledge that the community engagement activities of the Roadmap coincided with other Government consultations and processes, such as the Voice to Parliament referendum. Consequently, we were advised it was culturally unsafe and inappropriate to conduct on-country activities during this period. This highlights an urgent and critical need for targeted, culturally appropriate and sensitive, community engagement with Autistic First Nations people to ensure their health and mental health care experiences are considered in the co-design of the Roadmap moving forward.

## 1.4 What we found

As we work towards developing Australia's first ever National Roadmap for Improving the Health and Mental Health of Autistic People, there is enormous commitment from the Autistic community and other stakeholders to help realise the potential of this landmark initiative. There is strong consensus that the stark health and mental health inequalities experienced by Autistic people, as evidenced by the substantial life expectancy gap, high suicide rates, and prevalence of co-occurring conditions, must be urgently and comprehensively addressed.

Through the co-design, community engagement and research summarised in this report, we heard the human stories behind the statistics. We heard from Autistic people from diverse backgrounds, abilities and life circumstances, as well as their families, carers, and the health practitioners and disability professionals who work with them. Autistic people, their families and carers shared significant challenges and barriers related to accessing, navigating, and receiving safe, respectful, appropriate, and connected health and mental health services. We also heard from practitioners and providers of health and mental health services about constraints in system capacity, funding barriers and limited understanding of autism that impacts the availability and quality of care. Many of the key themes from our engagement are consistent with evidence recorded and findings made by the Disability Royal Commission and the Senate's Autism Inquiry.

The overall concepts as related to elements the Roadmap, are summarised below. For information regarding priority group differences, please refer to section 5 of this report.

**Roadmap Element A:** Improving support for Autistic people, their families and carers in health and mental health services (**Navigation and access**):

- **Information and health system literacy** involves ensuring access to accessible and appropriate information about the health care services, including health care system, available services and support. This also includes information about diagnosis and implications, and ensuring information shared across practitioners was consistent. Information about service options and what to expect provided in advance of services by both providers and clients can be helpful in promoting health care accessibility.
- **Affordability** is impacted by the availability of bulk-billing General Practitioners (GPs), gap fees and high costs associated with services including assessments necessary to access supports pose a significant barrier to accessing health and mental health care, including in case of emergency.
- **Accessing services and making appointments** can be challenging, with access being affected by factors such as complex forms, waitlists, limited availability of services, lack of appropriate services, different service modalities, booking systems, referrals, and eligibility criteria.
- **Individual experiences** are influenced by various personal characteristics and life circumstances such as income, past experiences and interoception. Negative experiences and trauma such as not being listened to or respected can also have a significant impact on an individual's willingness to seek health and mental health care, even in case of emergency.
- **Listening, validating and obtaining informed consent** is critical. Difficulties in accessing and obtaining informed consent were highlighted by all stakeholders, including complexities for adults with high and complex disability support needs including intellectual disability, where participants shared experiences where their competence, or incompetence had been assumed, and/or parents and caregivers' perspectives and inputs being disregarded.



- The **sensory and the built environment** can include aversive sensory environments, noise, sound and proximity to others. Environmental factors can have a significant impact on the health care experience and lead some individuals to delay seeking health care even in a time of crisis.

**Element B:** Improving the quality, safety and availability of neurodiversity-affirming health and mental health care for Autistic people across their lifespan (**Quality and safety**):

- **Neurodiversity-affirming practices and effective models of care** involve approaches and strategies that recognise and address the impact of social and environmental barriers. It also includes affirming diverse neurotypes, gender identities and sexuality.
- **Appointment duration and continuity of care** can be affected by factors such as short appointment times, limited resources and lack of consistency of health care professionals and providers.
- **Individual experiences** can vary due to differences in communication and expression of pain can have a significant impact on both an individuals' and practitioners' understanding of health care needs and determine appropriate treatment or health care. Self and parent advocacy play critical roles in navigating health care, but we heard they are often met with inconsistent or unreliable service coordination and delivery. Practitioners advised of a need for **proactive health care**, and incentives to support GPs to provide additional support to patients.
- Effective **information sharing** involves ensuring consistent and accurate communication among practitioners, clients sharing information before appointments and written summaries of care in follow-up.
- **Mental health support services** include individualised, flexible and affordable mental health care options, alternatives to traditional hospitalisation and service gaps. Participants' shared experiences of **restrictive and harmful practices**, including treatment without consent resulting in medical trauma.

**Element C:** Building better connections between health, mental health and other service sectors including the NDIS (**Connections and collaboration**):

- Participants highlighted the value of **advocacy services**, including self-advocacy, parent and peer advocacy.
- **Fostering positive connections** between systems and services includes service co-ordination, connection to appropriate services and sharing of information. Participants highlighted the value of enabling clients to share information in advance of their service appointments and offered potential solutions such as implementing technology-based solutions such as individual needs profiles.
- **Coordination across systems** is important to ensure individuals receive comprehensive and appropriate support/treatment, including during transition between services such as child/adult services. This is critical when providing health care and disability services to individuals with high and complex disability and behaviour support needs in the community.

**Element D:** Improving autism education and training for health and disability professionals (**Education and training**):

- **Education and training opportunities** include dedicated training aligned to national standards, resources and tools to better equip practitioners to support autistic patients and

clients. Participants nominated a number of topics/areas that ought to be a focus including: neurodiversity-affirming approaches, diversity of autism and different presentations, adapting the sensory environment, understanding intersectionality including, but not limited to all priority groups included in this work, understanding differences in responses to medication, expressions of pain and supporting people with high and complex disability and behavioural support needs, and trauma informed care.

**Element E:** Research and data on health and mental health outcomes of Autistic people and their families and carers (**Research and data**):

- **Focus areas** identified include neurodiversity-affirming practice, intersectionality, co-occurring conditions, autistic burnout and lived-experience with emphasis on Autistic-led and participatory research.

**Element F:** Arrangements for oversight, monitoring, and implementation (**Implementation and evaluation**):

- The co-design and community engagement activities did not directly address this element, however, in all forums participants consistently raised the need for **evidence-based, co-designed** solutions developed in partnership with the Autistic community and health sector.

## 1.5 Conclusion

Throughout the co-design and community engagement, we witnessed the deep and abiding willingness of the Autistic and autism communities and key health and mental health sector stakeholders to collaborate now, and in future, to deliver marked improvements. Many practical ideas for improvements were shared and developed – some small, some large, some that could be implemented now, others with a longer-term view. For example:

- Improving access to primary care including through optional annual health care checks and an extended mental health treatment 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 factors and 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, priority projects in critical areas such as mental health and pregnancy, birth and post-natal care
- Strengthening workforce capability through training, tools, and recognition for practitioners and peer workers proficient in autism and neurodiversity affirming care.

The upcoming Roadmap presents the first nation-wide opportunity to coherently articulate the change the Autistic and autism communities want to see; the directions and **actions** that will help move us there; the **data, measures** and evaluative efforts needed to **monitor** how we are going; and the **governance** and oversight to keep this multi-level reform project on track and hold each of us to account for their part in its delivery.

## 1.6 Recommendations

### Recommendation 1:

Develop autism accessible information resources about the health system, co-produced with Autistic people, to build health literacy and support informed decision making about health care and treatment options. Key initial topics might include:

- when you might need to see a professional
- different professionals what they can help with.

### Recommendation 2:

Revise or expand provisions under the Medicare Benefits Schedule to:

- create an item for an annual health assessment for Autistic people (similar to the current approach for people with intellectual disability)
- extend the number of subsidised sessions under Mental Health Treatment Plans
- reduce gap payments and out-of-pocket costs for Autistic people, their families and carers.

### Recommendation 3:

Develop models of Autistic and autism-proficient navigators or liaison officers in health and mental health services to assist Autistic individuals to understand and navigate services and supports. Consider whether future local navigators (recommended in the NDIS Review) could be equipped to play this role.

### Recommendation 4:

Co-design and develop professional and community resources to promote understanding of symptomology, interoception and pain expression in autism. Co-design should include Autistic people and practitioners.

### Recommendation 5:

Develop and promote best practice models of care for supporting autonomy, facilitating support for decision-making, obtaining informed consent for treatment, and ensuring adequate and ethical safeguards for those that lack capacity to provide informed consent. These models should also consider the role of parents, carers and guardians.

### Recommendation 6:

Develop and incorporate autism sensory measures in the Australasian Health Facility Guidelines and related building and accessibility standards, co-designed with Autistic people, practitioners and health administrators.

### Recommendation 7:

Establish a clear definition and standards for neurodiversity-affirming care for Autistic people, through a co-design process involving a diverse representation of Autistic people and practitioners. Use this as the foundation for an accreditation process, accompanied by publicly accessible information or a directory identifying qualified neurodiversity-affirming health providers.

### Recommendation 8:

Identify and assess the effectiveness of existing autism-specific health and mental health initiatives and approaches to inform investments and initiatives under the Roadmap.

### Recommendation 9:

Align efforts to support GPs with the National Primary Health Care Plan 10-year plan, particularly actions around integrated person-centred care. Promote understanding of autism within existing sector reform efforts, advocating for provisions that enable GPs to spend more time with Autistic patients and consideration of the communication needs and diverse abilities of Autistic people, including those with co-occurring conditions and complex disability support needs.

### Recommendation 10:

Establish a National Clinical Care Standard for autism that describes the considerations and adjustments people should be offered by health professionals and providers. The Standard should be co-designed with Autistic people and practitioners and be neurodiversity-affirming. It should be accompanied by publicly accessible plain language resources so that Autistic people and their families are aware that they can request these adjustments.

### Recommendation 11:

Co-design and development of a technology-based comprehensive health profile that contains information on an individual's sensory, cognitive, communication, co-occurring conditions and treatment preferences. This profile would belong to the individual and shared with one or multiple practitioners as consent is provided. Individuals should have the option of linking this profile to their My Health Record.

### Recommendation 12:

Investigate, develop and promote best practice models of mental health care for Autistic people, including in community-based settings.

### Recommendation 13:

Develop mental health resources and tools, co-produced with Autistic people and practitioners that address:

- the high suicide risk in the Autistic community
- the prevalence of diagnostic overshadowing
- the intersection of autism and mental health conditions.

**Recommendation 14:**

Assess the Safety and Quality in Health Care Comprehensive Care Standards concerning the reduction of patient harm, encompassing self-harm, suicide risk mitigation, and the minimisation, and where possible the elimination, of restrictive practices, to ensure their applicability to autism. This review should be conducted collaboratively with Autistic individuals, their families, carers and practitioners.

**Recommendation 15:**

Establish a visible network of autism health specialists for professionals to get advice, support or second opinions from, particularly when supporting Autistic people with high and complex support needs and their families.

**Recommendation 16:**

Explicit consideration of the complex and challenging nature of supporting individuals with high and complex disability and behaviour support needs in the community, taking a whole-of-family approach to ensure people receive the necessary support and services tailored to their unique circumstances and challenges.

**Recommendation 17:**

Consider the establishment of multi-disciplinary health care centres in every State and Territory to provide comprehensive physical and mental health care planning and services, including telehealth, tailored to Autistic people.

**Recommendation 18:**

Establish a competency-based national program of professional development to improve pre-service and in-service health care workers' skills and knowledge in the areas of:

- autism, including diverse presentations, communication, interoception and pain expression
- intersectionality and complexity
- National Standards of care and how they apply to autism
- relevant legislative frameworks, adjustments and accommodations
- informed consent and assent for people who do not have the capacity to give informed consent
- supporting people with very high and complex disability needs
- trauma-informed care.

This program of professional development should also be extended to professionals in law enforcement, child protection services and disability services supporting Autistic people with very high and complex disability and health needs.

**Recommendation 19:**

Research investment aimed at: developing reliable and valid measurement tools; determining the effectiveness of practices and supports; and understanding their applicability to Autistic people with common co-occurring health and mental health conditions.

**Recommendation 20:**

Develop and establish national evidence-based standards in pain measurement for Autistic people, considering intersectional experiences and identities across diverse settings such as bedside care, ambulance transport and childbirth, ensuring applicability across all ages and abilities.

**Recommendation 21:**

Develop a national action plan to improve research and data collection efforts aimed at enhancing understanding of health and mental health outcomes including mental health data, unmet health and mental health needs, referrals, mandatory reporting of adverse outcomes, and other relevant metrics.

**Recommendation 22:**

Establish a Governance Group to oversee and monitor implementation of the Roadmap. This should include Autistic and autism representatives, practitioners and their representative bodies, federal, state and territory government representatives.

**Recommendation 23:**

Through the Governance Group, develop an Outcomes, Monitoring and Evaluation Framework in the first year of the Roadmap. This would also identify critical data gaps to be addressed.

**Recommendation 24:**

Report annually on implementation and progress of the Roadmap.

**Recommendation 25:**

Engage Autistic and autism community representatives, practitioners and their representatives and governments in the co-design and development of key initiatives under the Roadmap.

## Our values



### **Inclusion**

Valuing lived experience



### **Innovation**

Solutions for long term challenges



### **Evidence**

Truth in practice



### **Independence**

Integrity through autonomy



### **Cooperation**

Capturing opportunities together



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