

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.

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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'.

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Free support services

Autism Connect

Call 1300 308 699

Live chat: www.amaze.org.au/autismconnect/#webchat

Website: www.amaze.org.au/autismconnect/

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Call: 13 11 14 or

Text: 0477 13 11 14

Live chat: www.lifeline.org.au/crisis-chat

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

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Call: 1300 22 46 36

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

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

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

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Foreword

Over the past 73 years the Diagnostic and Statistical Manual (DSM) has stated the criteria that define and aid in assessment of autism (Horwitz, 2021). However, describing the criteria for a condition such as autism does not describe the experience of living with the condition. Consequentially, this has contributed to a lack of understanding of the lived experience of autism across health and allied health services, as well as in 'lay' and professional people.

Recently our understanding of autism and the various intersectional identities Autistic people live with have been highlighted, mostly because we are listening to the 'Autistic voices' (Benevides, et al 2020). It's in understanding what autism means for the everyday life of Autistic people, that health care, in all areas, will have a chance to be appropriate to Autistic needs.

The specific need to understand experiences of Autistic people, and therefore each person's associated physical and mental health needs, has led to the Government committing to the creation of the Roadmap to Improve the Health and Mental Health of Autistic People. The following report specifically highlights those individual health needs that concern autism and intersectional experiences and identities to better understand and signal ways forward for better physical and mental health for Autistic people, and those living with intersectional identities.

Intersection can be thought of as differing sections/roads meeting together at a point where the individual/driver needs to consider which way they will go. But, when it comes to intersection of identity, it's not about one way or another it's about many differing influences on an individual life, often all at the same time. So, autism plus an intersection with: power and domestic violence; autism and being female; autism and being culturally and linguistically diverse; autism and being black; autism and being a person of colour; autism and being older or a child; autism and poverty; autism and being physically disabled; autism and living with mental health issues; autism and living with social or gender challenges and so on, all impact Autistic people differently.

Being neurodivergent will mean a spectrum of difference. Although intersectionality and autism highlight issues that have previously been overlooked and this has caused despair, this report brings us back to listening to the Autistic perspective. Therefore, this report signposts us towards hope that health and mental health care for all Autistic Australians across all domains, will become more accessible, more appropriate and needed accommodations will be 'a given'. Read on to see the various sections and what the research found for the differing characteristics of what being Autistic means for individuals and ideas for how this understanding will enable appropriate concerns to be addressed and hopefully lead to a comprehensive Roadmap to improve health and mental health services for Autistic people across Australia.

Foreword by Dr Wenn Lawson, Autistic author and Psychologist



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
People with high or complex needs and/or co-occurring health conditions that impact daily life	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
First Nations people	2	1	2	5
Culturally and Linguistically Diverse (CaLD) people	7	22	8	37
LGBTIQA+ people	16	31	10	57
Women and girls	29	41	37	107
People living in rural and remote areas	16	18	13	47
People from low socio-economic backgrounds	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.

2. About the Autism Roadmap

2.1 The Roadmap priority groups

Many Autistic people have multiple intersecting factors in their lives which impact how they are treated in health and mental health services. Based on evidence and experience, the Department of Health and Aged Care, and the Roadmap Working Group identified seven priority groups who experience additional intersecting factors in their lives that impact their experience of health and mental health services.

These groups are Autistic people who also: culturally and linguistically diverse, are women and girls; are LGBTIQ+; are living in rural and remote areas; are from low socio-economic backgrounds; are First Nations; have high or complex disability needs including those who have high communication or behaviour support needs; are living in residential settings; have an intellectual disability; or are non-speaking. This also includes families and carers of people who identify with these priority groups.

2.2 Roadmap guiding principles

The Guiding Principles provided by the Department of Health and Aged Care, and the Roadmap Working Group, encompass the overarching objectives of the Roadmap. The table below shows how these Guiding Principles helped shape the co-design and community engagement discussed here.

Table 2: Guiding principles and how they were applied to the co-design, research and community engagement

Guiding principle	How these principles apply to the research, co-design and community engagement
1. Address the intersecting needs affecting Autistic people's experience of health and mental health services	The aim of this research, co-design and community engagement was to develop a deep understanding of Autistic peoples' needs, experiences and potential solutions in relation to health and mental health care services. Participants in co-design and community engagement activities were encouraged to consider their responses, reflecting on their (often) multiple and intersecting identities, backgrounds and life circumstances.
2. Acknowledge and address the specific needs of priority population's experience of health and mental health services	Autistic individuals from priority groups were specifically recruited. Community engagement in the form of interviews and focus group discussions were conducted to delve deeper into the experiences of these particular groups. Separate focus groups were tailored to different priority groups, allowing for a more comprehensive understanding of their specific needs.
3. Address mental health needs across the Roadmap	This project addressed both physical and mental health needs. Throughout the co-design and community engagement phases, facilitators encouraged participants to take both into account.

2.3 The Roadmap elements

The Autism Roadmap elements provided by the Department of Health and Aged Care, and the Roadmap Working Group, outline the scope and focus areas to be addressed by the Roadmap. The organisation of the findings in this report follows the Roadmap elements and presents findings, practice considerations and recommendations for each element.

Table 3: Autism Roadmap elements

Roadmap element	Description
<p>A. Improving support for Autistic people, their families and carers in health and mental health</p>	<p>Navigation and access (Element A)</p> <ul style="list-style-type: none"> • How health and mental health services, including preventive care and crisis support, can be better tailored to the needs of Autistic people. This may include: <ul style="list-style-type: none"> – Ensuring information is accessible and aligned with preferred forms of communication to accommodate complex communication needs – Making services more sensory friendly and better at accommodating people with varied communication needs, and – Ensuring Autistic people are not refused access to health and mental health services on the basis of their diagnosis, by ensuring services are capable and prepared to provide reasonable adjustments for Autistic needs. • How Autistic people, and their families and carers, can be supported to know and understand their rights, enabling them to navigate the health care system. A key aspect of this is ensuring rights are upheld where an Autistic person may not have the capacity to communicate their needs or provide consent.
<p>B. Improving the quality, safety and availability of neurodiversity-affirming health and mental health care for Autistic people across their lifespan</p>	<p>Quality and safety (Element B)</p> <ul style="list-style-type: none"> • Neurodiversity-affirming health and mental health care practices that are appropriate for children, young people, adults, and older people • Continuity of care, care coordination, and integration within the health and mental health systems, and • Eliminating the use of harmful restrictive practices and ensuring neurodiversity-affirming approaches to behaviours of concern.
<p>C. Building better connections between health, mental health and other service sectors, including the NDIS</p>	<p>Connections and collaboration (Element C)</p> <ul style="list-style-type: none"> • Considering ways Autistic people, including those with complex health care needs and co-occurring conditions, can be better supported by health professionals to access and coordinate services • Improving coordination and communication between the health and other Commonwealth, state and territory services, including community services, the NDIS, and other government services, such as education, early childhood services, justice and social services, and • Providing Autistic people, Autistic advocates, and Autistic-led organisations with up to date, accurate and relevant information to assist Autistic people navigate the health, mental health and other service systems.

Roadmap element	Description
D. Improving autism education and training for health and disability professionals	Education and training (Element D) <ul style="list-style-type: none"> • Improvements to health, mental health and disability professionals’ education and training in partnership with Autistic people and the autism sector • Address capabilities in the most practical settings for each profession, such as pre-registration education, vocational training, formal qualifications as well as post-graduate and in-service professional development • Improving competency in supporting Autistic people, disability literacy, and disability system literacy for the health and mental health sectors.
E. Research and data on health and mental health outcomes of Autistic people and their families and carers	Research and data (Element E) <ul style="list-style-type: none"> • Ways of addressing the gaps in research and data about health and mental health outcomes, with a focus on reducing health inequities, mental health and other inequities faced by Autistic people • Identifying opportunities for co-produced research and improved research translation that reflects the priorities of the Autistic community.
F. Arrangements for oversight, monitoring, and implementation	Implementation and evaluation (Element F) <ul style="list-style-type: none"> • Provide a framework that assists the Department and stakeholders to take necessary actions arising from the Roadmap to meet the needs of the autism community. It will include meaningful engagement with Autistic people and the autism community in as areas such as: <ul style="list-style-type: none"> – Communication strategy, including co-produced knowledge translation so that the community, end-users, and stakeholders have access to meaningful and relevant information, and the Autistic community is given the necessary knowledge to be empowered and advocate, – Implementation timeframes, and – Monitoring, evaluation and reporting framework.

3. Information and data sources

The findings and recommendations in this report are derived and synthesised from four specific research, co-design and community engagement activities designed to yield a deep understanding of the needs, challenges, practice considerations and ideas for change or potential solutions in relation to the Guiding Principles and Elements of the Roadmap. Additionally, consideration was given to findings related to health and mental health reported in the (draft) *National Autism Strategy Consultation Report*.

Table 4: Information and data sources activity objectives, methods and presentation of findings

Objective	Method	Presentation of findings
To understand the health care journey and experience end-to-end exploring challenges, experiences, and ideas for change	<p>‘Reimagining health and mental health services’ co-design workshops</p> <p>A co-design process was used to collaboratively construct a journey map reflecting individuals’ interactions with health and mental health services. The process crafted a current journey map, capturing existing experiences, and a future journey map envisioning desired changes in health and mental health services.</p> <p>In total, 51 stakeholders were engaged in six co-design workshops, four Autistic-only and two with representatives from disability organisations, professional colleges and societies and practitioners. All groups included Autistic parents, carers or guardians, practitioners and disability professionals.</p>	<p>Co-design insights and direct quotes are integrated into the Autistic person’s health care journey, findings, practice considerations and potential solutions presented within this report. A summary of Autistic people’s current health care journey is provided on page 22.</p> <p>The full report ‘Reimagining health and mental health services co-design’ is provided as Appendix A.</p>
To identify the problems, barriers and/or challenges that Autistic people, including people from the priority groups, experience when accessing health or mental health services	<p>Intersectionality matters research review</p> <p>Secondary analysis of several existing national data sets on health care experiences, needs and priorities, which combined contain information from over 6,500 Autistic people, families, carers and professionals. These data sets are:</p> <ul style="list-style-type: none"> • National Autism Strategy community views survey (n=253) responses from autistic people) • Amaze National Autism Helpline queries (n=4,500) • ‘How to make therapy better’ (n=130) survey of Autistic adults’ experiences of psychological services • ‘Barriers to accessing acute health care’ (n=107) survey of parents and carers of Autistic children aged 3-16 who accessed acute health care in the last four years. 	<p>The findings are integrated into the priority group needs presented in within this report.</p> <p>The full ‘Intersectionality matters research review’ is provided as Appendix B.</p>
To develop a deeper understanding of the intersecting needs and experiences from Autistic people, their families and carers in the priority groups	<p>Roadmap community engagement</p> <p>The community engagement comprised interviews (n=52) and six focus groups (n=55) with a total of 107 participants. This included 66 Autistic people, and 54 parents, carers and guardians of and Autistic person including 40 who were parents, carers or guardians of autistic people with high and complex disability needs.</p>	<p>The key findings and direct quotes from participants are integrated into the findings, practice considerations and potential solutions presented within this report.</p> <p>The full report ‘Roadmap community engagement’ is provided as Appendix C.</p>
To co-design a series of recommendations to improve health and mental health services for Autistic people	<p>National Health and Mental Health Services Community Co-design Summit</p> <p>The Summit was a large-scale collaborative workshop bringing together 58 stakeholders (19 of whom had participated in Co-design workshops), including 29 Autistic people, 33 health practitioners 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.</p>	<p>The co-designed recommendations and feedback from Summit participants provided the basis of recommendations presented in this report.</p>

4. The research, co-design and community engagement process

In this project, we used different methods to gain insights into the various individual, social and environmental factors impacting Autistic individuals' interactions with health and mental health services. This multi-layered approach aimed to support the co-design and development of recommendations for the Roadmap that are responsive to community needs, and incorporate feasible and practical ideas for change across a range of health and mental health settings. Below is an outline of each activity in the process and the key findings.

4.1 Exploring the health service journey

In the '**Reimagining health and mental health services**' co-design workshops a collaborative journey mapping process was used to explore and document people's experiences accessing health and mental health care services. The journey mapping process sought to first develop a *current* journey map of health and mental health care services - exploring the experiences that people currently have when accessing health and mental health care services. Then the groups focused on developing a *future* journey map of health and mental health services, with ideas on how people would like health and mental health services to be different in the future. To structure and focus the conversation, participants worked through the stages of awareness, contemplation, access, delivery, and continuing care.

Awareness: Experiences people have when they first become aware of their need for a health or mental health service or supporting others to identify a need to see a health or mental professional

Contemplation: How people make decisions and choices about the health or mental health services or how professionals support others to make informed decisions and choices

Access: Experiences people have when trying to access a health or mental health service or enabling access for others

Delivery: Experiences people have as they are receiving or delivering health or mental health services

Continuing care: Experiences people have after they have received the initial service or helping others to manage their ongoing care.

Participants in the co-design process shared their thoughts, actions, challenges, and emotions which were identified at every stage of the journey. This revealed that for Autistic individuals, the health care experience is marked by significant stress, anxiety, confusion, and overwhelm which starts well before an appointment, even before interacting with a health or mental health professional. A summary of this journey for Autistic people is presented below in Figure 1.

Input from both Autistic individuals and practitioners/professionals informed the practice considerations and potential solutions presented in the summary tables and discussions within this report.

Figure 1: Autistic peoples' current health care journey informed by Reimagining health and mental services co-design

Autistic peoples' current health care journey

Awareness

Becoming aware of need to seek help or care

Thoughts and actions

- Seeking external validation of concerns from peers and health professionals
- Researching concerns
- Relying on others to raise concerns
- Processing experiences and symptoms

Challenges

- Self-doubt
- Interoception and being aware of symptoms or need for help
- Not knowing what is normal vs not
- Communicating and describing concerns

Feeling anxious, stressed

"I would rarely make a decision to see a doctor on my own opinion of how I'm feeling."
- Autistic participant

Contemplation

Understanding available options and what is required

Thoughts and actions

- Considering the costs, waitlists and delivery modes
- Researching services and professionals
- Seeking recommendations
- Seeking peer support
- Seeking neuro-affirming or autistic health professionals
- Seeking expertise in autism or particular conditions

Challenges

- Cost, travel and transport
- Sensory environments
- Past negative experiences
- Prioritising health care
- Finding information and suitable options

Feeling overwhelmed, self-doubt, dread, concern

"Do I feed myself, or do I access health care?"
- Autistic participant

Access

Knowing who to contact and making an appointment

Thoughts and actions

- Learning and scripting the "right" words
- Writing a list and preparing medical history
- Organising finances
- Organising transport and travel
- Checking the current wait time

Challenges

- Preparation
- Reception staff
- Making phone calls
- Intake processes
- Waiting rooms and wait times

Feeling anxious

"I'm 64 and still can't work the system out"
- Autistic participant

Delivery

Health care interaction with a professional

Thoughts and actions

- Deciding to disclose or not
- Having a support person
- Being experienced in the process
- Am I communicating effectively?

Challenges

- Diagnostic overshadowing
- Being dismissed or not believed
- Behaving the "right" way and working hard to "show" symptoms
- Lack of understanding, choice, and control
- The clinical sensory environment

Feeling worried, unsafe, low, disappointed, confused

"I cannot be confident on her behalf that she will not experience the same gaslighting, medical overshadowing, neglect and even abuse and trauma that I have experienced in the medical settings."
- Autistic parent

Continuing care

Next steps and follow up or self-manage health/mental health

Thoughts and actions

- Seeking peer support
- Coordinating services and managing admin
- Self-managing needs
- Processing information
- GP as the central person

Challenges

- No continuity of care or follow-ups
- Managing ongoing needs and care
- Balancing the needs of the family
- Unable to afford ongoing care
- Finding and following up services and supports

Feeling stressed, overwhelmed, confused

"...having to be the one who rings up and makes the appointment or checks that the referral has even been received, for example, can mean that I really delay in doing that, longer than I should..."
- Autistic participant

4.2 Understanding why intersectionality matters

In the ‘**Intersectionality matters research review**’, four existing datasets were analysed to (a) identify the proportion of responses in the dataset related to one more of the specified priority groups, and (b) report on the health or mental health care experience data for that specific priority group. For each priority group, there were substantial differences in what was identified as the key problems/barriers that Autistic people face when accessing physical health and mental health services in Australia. There were also differences in the possible solutions identified by each priority group.

Whilst informative, this research does not, and could not, report on all of the issues or experiences with physical and mental health care services experienced by each priority group of Autistic people. It does not describe the impact of these **different experiences** on health and mental health outcomes for Autistic Australians, as this was not collected within the datasets. However, this research does provide **clear evidence** for the **importance of listening** to the experiences of Autistic people with intersecting identities to inform improvements and pathways for the Roadmap.

A second key takeaway is that the four datasets provide **clear evidence of an urgent need for improvements** in Autistic people’s access to physical and mental health care services which take into consideration people’s intersecting identities. There is similarly a need for health care providers with knowledge of autism and intersectionality, and who are skilled in neurodiversity-affirming approaches.

This urgent need is highlighted through the following Autism Connect data; in under five years, 1,500 people contacted Autism Connect asking for their help in finding somebody to support an Autistic person’s physical health or mental health. This represents 85% of the contacts with Autism Connect relating to physical health or mental health. This urgent need is also supported by the “1,000 insights” community views survey data, where almost half of all the respondents highlighted that the biggest problem for Autistic people trying to access physical or mental health services is a lack of health care providers or a lack of health care providers who understand autism and/or neurodiversity. The Roadmap has the potential to address this. In doing so, it can begin to reduce the physical health and mental health inequities experienced by Autistic people across Australia and, using this report and future in-depth consultations, address the specific barriers or problems faced by Autistic people from the Roadmap priority groups.

There was limited representation of **Autistic First Nations** people within the datasets. This highlights an urgent and critical need for community consultations with Autistic First Nations people to ensure their health and mental health care experiences are considered in the Roadmap.

A summary of the key findings for each priority group, compared to the entire Autistic sample, is presented in this report aligned to each Roadmap element.

4.3 Delving deeper through community engagement

In the **Roadmap community engagement**, direct conversations with people through focus groups and interviews provided greater insights into their lived experience, intersecting needs and the impact on their health or mental health. It also gave deeper understanding of the barriers to health care and the experiences of people, the expectations, behaviour, information and past experiences that an individual, or family, might be bringing to a health or mental health care provider.

The focus of recruitment in this phase was on Autistic people and their caregivers directly, with some service providers included incidentally. These providers often had **intersecting identities**, such as being Autistic themselves, or a parent of an Autistic person in a priority group. Targeted consultation with practitioners would likely yield significant insights into how this impacts their interactions with individuals and their decision-making. However, targeted focus groups and interviews with practitioners fell outside the scope of this project.

The community engagement was primarily directed at the priority groups who experience additional intersecting factors, and less is known or understood and focused on the unique experiences of these communities. This engagement was facilitated through a range of community partner organisations with deep connections and trusted relationships in the sector. This was designed to yield a **deep understanding** of the needs, experiences, priorities and potential solutions in relation to the guiding principles and elements of the Roadmap.

The majority of comments related to the Roadmap elements of **Navigation and access** (Element A), **Quality and safety** (Element B), **Connections and collaboration** (Element C) and **Education and training** (Element D). Fewer comments related to **Research and Data** (Element E) and there were rare comments relating to **Implementation and Evaluation** (Element F). The summary of findings is presented in the discussion that follows.

4.4 A summit to co-design recommendations for the Roadmap

To support the development of the Roadmap, Autism CRC held a **National Health and Mental Health Services Community Co-design Summit** which brought together health and mental health professionals, disability and autism organisations, and Autistic individuals to collaboratively develop a set of priorities and recommendations for consideration in the development of the Roadmap.

During the Summit, online and in-person attendees participated in breakout sessions where groups co-designed, drafted and chose their top three recommendations in relation to each of the following co-design questions:

1. 'How might we improve **navigation and access** to health and mental health care services for Autistic people?'
2. 'How might we improve **safety and quality** of health and mental health care for Autistic people, their families and carers?'
3. 'How might we **improve connections** between health, mental health and other service sectors to improve the **continuity of care** for Autistic people?'

Following the Summit, participants were provided a survey to rate their strength of agreement with each of the 34 co-designed recommendations with opportunity to provide comments and clarification.

The co-designed recommendations and feedback from Summit participants provided the basis of recommendations presented in this report.

5. Findings and recommendations

5.1 Element A: Improving support for Autistic people, their families and carers in health and mental health services

Overall concepts from the research, co-design and community engagement in relation to Element A: Improving support for Autistic people, their families and carers in health and mental health services (**Navigation and access**) are categorised as: Information and health system literacy; Affordability; Service access and making appointments; Individual experiences; Listening, validating and informed consent; and Sensory and the built environment.

In the co-design workshops with Autistic people, we heard that there are many personal factors and experiences that determine when and where an individual might seek a health or mental health service, including consideration of one's own financial position, additional family or caring responsibilities, distress and trauma of past experiences, understanding symptoms and when a problem is significant enough to seek a professional.

In the co-design workshops with practitioners and at the Summit, we heard about some of the challenges they face in knowing how to best support Autistic individuals, including whom to refer an individual to when their need is beyond the scope of their practitioners' service or expertise. We also heard that affordability measures, such as bulk-billing, are not financially viable for many practices, particularly those in rural and remote areas.

In the **Intersectionality matters** research related to **Navigation and access**, when compared to the entire Autistic sample, we found that:

- Autistic people with high and complex disability needs tended to focus on communication, including the option for multiple modes of communication, ensuring that all people communicating (be that the Autistic person or a family/carer) feel heard, believed and valued, and health care providers asking questions
- Autistic people living in rural and remote areas tended to focus on the limited availability of physical and mental health care practitioners and affordability of services and impacts of funding limitations
- Autistic women and girls tended to focus on the need for health care professionals to have enhanced training and knowledge in autism and diverse presentations of autism
- Autistic people from low socio-economic backgrounds tended to focus on limited accommodations or assistance provided to support access to services along with practical, pragmatic and financial challenges accessing services including prohibitive costs
- Autistic people from culturally and linguistically diverse backgrounds identified challenges with professionals dismissing or not believing the experience of Autistic people. This group also highlighted challenges associated with the sensory elements of health care settings.
- Autistic LGBTIQ+ people were more likely to highlight challenges with professionals not believing or trivialising the experiences of Autistic people.

In community engagement interviews and focus groups, problems in **navigation and access** of health and mental health care services were the **most common challenge** raised across all groups.

Table 5: Navigation and access (Element A): Synthesis of key challenges, priority group needs, practice considerations and potential solutions

Topic	Challenges	Priority group needs	Practice considerations	Potential solutions
Information and health system literacy	<ul style="list-style-type: none"> Knowing what support, including financial support, is available Inaccessible, inaccurate, unclear information with medical jargon Information not provided particularly in follow-up Difficulties identifying and/or finding autism-specific, neurodiversity-affirming or “safe” (culturally, gender/sexuality) services and professionals Accessing and finding information about health-topics, services and health professionals Finding and knowing what the most suitable option is 	<ul style="list-style-type: none"> CaLD people cited additional barriers in relation to language and cultural translation of health information and highlighted the value of information in plain English, multimedia format and language translation People with an intellectual disability identified importance of Easy Read resources CaLD people raised the value of translation services 	<ul style="list-style-type: none"> Health system literacy for patients/clients Practitioners identified they don’t necessarily know the most suitable options for Autistic patients/clients when considering referrals Reliance on health professionals by people to provide information/educate about services and supports Role of Autistic peers, social media groups and autism organisations in identifying service options and professionals Risks of reliance on anecdotal sources of information 	<ul style="list-style-type: none"> A directory or database of health professionals Co-designed health service information about service options Health care information and resources provided in multiple languages Peer reviews of services and professionals Psychoeducation for Autistic people and their supporters on navigating health/mental health system Resources to support health system literacy Accessible resources written in Easy Read, plain English and AUSLAN video Knowledge and understanding of different health professions, their scope and what they can provide Provision for translation services

Topic	Challenges	Priority group needs	Practice considerations	Potential solutions
Affordability	<ul style="list-style-type: none"> • Cost of health care services including follow-up specialist care, psychology and allied health care, private care and treatment including non-PBS prescriptions • Gap fees and cost of private services • Low number of bulk-billing GPs • High cost of diagnostic assessments • Having to pay upfront before appointment • People from low SES backgrounds cited affordability as a reason to delay seeking care even during an emergency 	<ul style="list-style-type: none"> • People living in rural and remote areas pay significant higher costs and have scarce access to bulk-billing • Rural and remote consideration of travel or transport costs 	<ul style="list-style-type: none"> • Feasibility of bulk-billing /viability for businesses • Medicare and subsidised services rules/laws and guidelines • Existing precedent of additional Medicare subsidies for eating disorders and chronic disease 	<ul style="list-style-type: none"> • Provide clearer information about fee structures and billing including gap fees and payment options • Access to bulk-billed GPs • Access to additional subsidised Mental Health Treatment Plan sessions including more sessions before review required and a higher number of sessions • Specific conditions access to additional subsidies • Reduce Medicare threshold

Topic	Challenges	Priority group needs	Practice considerations	Potential solutions
Service access and making appointments	<ul style="list-style-type: none"> Requirements to access services unclear with ambiguous and long forms to complete (often without support) Long waitlists Single modality booking options (e.g. online or phone only) do not suit everyone Diagnosis required to access services Restricting access to services due to diagnosis Services restricted only to NDIS participants Lack of flexibility in appointments / services Difficulties finding adult services with autism services (often focused on children) Additional barrier of needing to find/access a GP for a referral to get a Mental Health Treatment Plan Challenges finding a regular GP, particularly one that bulk-bills Potential home-visits Reception staff, waiting rooms and waiting times Several gaps in service provision were raised including a lack of autism appropriate: <ul style="list-style-type: none"> mental health crisis supports options, particularly for 18-25 year olds services for people with eating disorders, particularly for young people suicide prevention services adolescent autism diagnosis services affordable dental care 	<ul style="list-style-type: none"> CaLD non-Australian citizens ineligibility for services and lack of informal support available People living in rural and remote areas cited challenges with longer waitlists LGBTIQ+ people cited religious affiliations of disability services as an additional barrier Telehealth accessibility for people who are rural and remote, or who are non-speaking People from low SES backgrounds raised challenges with the pragmatics or practicalities of attending appointments, clinics or hospitals, transport, cost, organising care for other family members LGBTIQ+ people identified a lack of “safe” reproductive health support service Women identified a lack of preventative mental health support services All groups reported it is difficult to find services and professionals with an understanding of their intersectional identities 	<ul style="list-style-type: none"> Online booking systems are not always practical Telehealth is not always suited to the patient/client Need for information to direct and triage clients may require telephone consultation Helping clients or patients navigate the health or mental health system Patients or clients not adequately prepared at intake Patients and clients being told by professionals that they require referral or services based on diagnosis, irrespective of need Improved transparency and communication of wait times and waiting lists Patients being denied or refused service due to diagnosis including mental health No discharge system Barriers to telehealth Multiple referrals required or referrals being sent back System not designed for complexity or ongoing care 	<ul style="list-style-type: none"> A range of booking approaches with flexibility Support to assist with booking and attending appointments Text reminders Clear information about what to expect at appointments Improved transparency and communication of wait times and waitlists Training of intake and reception staff Allied health professionals being able to make medical or psychological service referrals

Topic	Challenges	Priority group needs	Practice considerations	Potential solutions
Individual experiences	<ul style="list-style-type: none"> • Parents and carers not being aware of when to seek health services • Challenges with interoception and differences in pain perception • Not being aware of symptoms or need for support • Pre-existing symptoms and conditions make it harder to identify a health or mental health concern • Autistic people internalising symptoms as being their own fault • Competing life demands including parent/carer responsibilities • Past negative experience and trauma of not being believed, misdiagnosis and mistreatment • Executive functioning (e.g., planning, booking, remembering) • Not having enough time, energy “spoons” to identify service options or make appointment • Autistic people and parents, adapting to, normalising and ignoring symptoms 	<ul style="list-style-type: none"> • People from low SES backgrounds and people living in rural and remote areas more likely to delay service due to cost • Women frequently indicated they might delay seeking care due to past trauma • Autistic people with high and complex needs, their parents and carers, noted even greater challenges in identifying if/when a health or medical concern was present including symptoms and cause for concern warranting a professional 	<ul style="list-style-type: none"> • Pre-existing behaviour makes it difficult to understand presenting issues • How to build rapport quickly and promote safety • Focus on diagnosing autism overshadows the need to identify health and mental health concerns 	<ul style="list-style-type: none"> • Information and resources to build capacity to recognise a health or mental health concern for Autistic people, parents and carers and when to seek help • Creating opportunities for validation of health concerns • Creating opportunities for “check-ins” to identify concerns • Information about patient/client rights and possible accommodations • Assistance in identifying options and making appointments • Information about health and mental health topics • Build health literacy and capacity to find health information • Develop self-awareness of body and health and mental health needs

Topic	Challenges	Priority group needs	Practice considerations	Potential solutions
Listening, validating and informed consent	<ul style="list-style-type: none"> • People not being listened to, believed, or respected • Treatment wishes being ignored • Medical trauma due to a lack of obtaining informed consent • Parents/carers being excluded or not listened to • Needing to correct reports with misdiagnosis and misinformation • Talking to a support person instead of the Autistic patient/client • Assent vs. informed consent • Assent and consent being ignored • Not understanding the process or the information • Assumptions of understanding and need to not overestimate understanding/knowledge based on communication 	<ul style="list-style-type: none"> • Individuals, parents and carers of people with high and complex needs stressed the importance of diverse communication methods to ensure that all parties involved, feel listened to, respected, and valued • Non-speaking Autistic people expressed challenges with people assuming incompetence due to communication differences • 	<ul style="list-style-type: none"> • How to determine level of ability to assent vs. consent and legal responsibilities for decision-making for individuals with very high/complex needs • Providing information to patients and clients • Building rapport and trust so patients/clients feel safe to disclose they are Autistic • Broader implications of diagnosis for life insurance, health care, and employment that may impact disclosure of being Autistic • Lack of time to engage in supported decision making 	<ul style="list-style-type: none"> • Training for professionals in diverse presentation and communication • Ask follow-up questions to check and ensure understanding • Include input from all stakeholders the Autistic person would like included, including inclusion of Autistic children's perspectives • Consideration of most appropriate source of information and key stakeholders for individuals with complex communication needs • Processes for seeking assent and consent for individuals with high and complex needs including how to include the person and legal guardians (especially for adults without capacity to give own informed consent) • Time to plan and process information • Ability to seek clarity post appointment

Topic	Challenges	Priority group needs	Practice considerations	Potential solutions
Sensory and the built environment	<ul style="list-style-type: none"> Built environments (e.g., hospitals, clinical rooms) being sensory unfriendly 	<ul style="list-style-type: none"> All groups raised sensory/environmental factors as a challenge in attending and utilising services and health and mental health care facilities 	<ul style="list-style-type: none"> The hospital and clinical environments are not set up for Autistic patients Patients supported to disclose diagnosis and support needs Lack of time, capacity, limits and restrictions to being able to consider and provide sensory support and accommodations 	<ul style="list-style-type: none"> Sensory adaptations for Autistic clients Develop and disseminate environmental audits (checking tool) to audit environments and adapt where possible and inform clients where unavoidable and advise to bring/use accommodations (e.g., headphones, sunglasses) Low sensory waiting areas or alternative options (such as waiting outside) Accessibility standards Improving patients' wayfinding and navigation of the service Increased access and provision of supports and accommodations in the reception and waiting room

5.1.1 Information and health system literacy

Information was raised as an area where changes could make **navigation and access** of health and mental health services better. Ideas included increasing **accessibility of information**, including health care system literacy (e.g., how the health care system works), services available, diagnosis and implications and ensuring information shared across practitioners was consistent. Lack of awareness regarding available support, including financial assistance, coupled with inaccessible and unclear information laden with medical terminology poses significant challenges, particularly for people with an intellectual disability or people from culturally and linguistically diverse backgrounds. These problems are reflected in the Autism Connect helpline data, where more contacts for mental health therapist recommendations and mental health advice were related to an Autistic person from culturally and linguistically diverse backgrounds than contacts not identified as culturally and linguistically diverse.

Improving the accessibility of information was raised, including through the use of **plain English** and videos for individuals with higher support needs or co-occurring intellectual or learning disabilities.

"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...maybe having maybe a series of videos like that to sort of help guide autistics through ... accessing the health system."

Providing **clear information** in advance of health and mental health appointments including assessments was raised particularly for individuals identifying as being from culturally and linguistically diverse backgrounds, from rural and remote locations and from low socio-economic backgrounds. Autistic people from culturally and linguistically diverse backgrounds also raised the importance of **translated** information, **multi-media** resources, AUSLAN and plain English.

In addition, providing mechanisms for clients and patients to share information to service providers in preparation for care was also identified. Finally, providing written summaries of care was also raised as a potentially valuable support to improve the accessibility of information.

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.
-

5.1.2 Affordability

The affordability of health care services, including follow-up specialist care and treatments, poses a significant barrier to health and mental health care. Gap fees and the expenses associated with private services further compound the financial burden for individuals. Additionally, the limited availability of bulk-billing General Practitioners (GPs) adds to the challenge, alongside the high costs associated with assessments necessary to access supports including via the NDIS. As one Autistic individual stated:

“Do I eat this week, or do I access health care?”

Echoing the sentiment, but in relation to mental health care:

“...you can buy groceries this week or you can talk to your psychologist.”

Individuals with low incomes often cited **financial constraints** as a reason for **delaying seeking care**, even in emergencies. Autistic people living in rural and remote areas face even greater financial strain due to elevated costs and a scarcity of bulk-billing services, compounded by considerations of travel or transportation expenses to attend appointments in metropolitan areas.

“...doctor that will come to me, which is great, and I've seen her twice now, but it costs me \$795 each (doctor) visit... it costs me \$975 for every psych visit once a fortnight.” [home visits]...the difficulty of how hard it is to not just access services but access the funding you need to pay for it. When you're in regional Australia, you don't get bulk bill doctors.”

We also heard from practitioners that bulk-billing is not financially viable for many practices, particularly practices in rural and remote areas.

Participants across all stakeholder groups indicated that addressing these issues will require **comprehensive reforms**, including increased Medicare funding, greater availability of bulk-billed GPs, and additional subsidised sessions under Mental Health Treatment Plans.

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.
-

5.1.3 Service access and making appointments

Through the co-design journey mapping and community engagement, we heard that accessing services is often fraught with uncertainty and obstacles, characterised by **unclear requirements** and lengthy, complex forms that individuals must navigate without adequate support. **Long waitlists**, coupled with **limited modalities** (e.g., online only or phone only), compounds challenges. A lack of flexibility in service options and/or scheduling appointments was cited as a significant challenge, along with shortages in the availability of adult services. Professionals noted the level of flexibility they can afford is often dictated by service guidelines. Some professionals reported they had received referrals when patients have been told they require services, based on an autism diagnosis, irrespective of need.

The current necessity of a **formal diagnosis** to access some services, along with the limitation of some health services to only NDIS participants, further exacerbates the difficulties. The requirement for a GP referral to obtain a Mental Health Treatment Plan, coupled with difficulties in finding a GP or having a regular GP, especially one that offers bulk-billing services, presents additional hurdles in accessing essential care. Non-Australian citizens from culturally and linguistically diverse backgrounds face ineligibility for services, coupled with a lack of informal support networks (e.g., family are not living in Australia). In rural and remote areas, accessing services is further complicated by prolonged waitlists. Members of the LGBTIQ+ community reported they encounter additional barriers stemming from disability service providers' religious affiliations.

Specific negative experiences included facing unsupportive staff from reception onwards, being overwhelmed with attempting to access services or supports with NDIS being particularly emphasised as *“a nightmare to get onto”*.

In the co-design process, some Autistic people shared that online booking systems are impractical for some. The inability for allied health professionals to make medical or psychological service referrals, despite their intimate knowledge of the client's needs, presents a significant gap in the system. Addressing these issues necessitates enhancing transparency and communication regarding wait times and waiting lists, offering a variety of booking approaches, and providing support to assist individuals in booking and attending appointments. Implementing measures such as text reminders and furnishing clear information about appointment expectations including costs and billing can contribute to a more navigable and inclusive service landscape.

While telehealth offers a promising solution, its universal suitability for all patients remains questionable with participants from rural and remote areas in particular highlighting gaps in reliable **internet coverage** and **digital literacy** for some individuals, as well as the value they placed on having in-person options available. The idea of health service navigators was raised by co-design participants and at the Summit, with mixed views on the value of this. Some expressed reservations, suggesting it could add another layer bureaucracy that could impede, rather than facilitate service access.

Developing models of Autistic and autism-proficient navigators or health and mental health liaison officers, akin to those foreshadowed in the National Roadmap for Improving the Health of People with Intellectual Disability, ought to be considered. It is noteworthy that the final report of the NDIS Review recommended that people with disability should be able to access to a local navigator for information, advice, support to access mainstream services (which include health and mental health services), community, disability programs and supports.

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.

5.1.4 Individual experiences

Various personal characteristics and life circumstances can influence individuals' access to and utilisation of health and mental health services. Competing life demands, such as parenting or caregiving responsibilities, can detract from the time and energy needed to explore available service options or schedule appointments.

"...so there's a pretty significant executive cost, for like trying to find services which are neurodivergent friendly, queer friendly, and also kind of close enough to get to and not be too stressed out about that as well."

Differences in **communication** style, executive functioning, **expression of pain**, **interoception** (ability to be aware of internal sensations in the body) and **alexithymia** (characterised by difficulty in identifying, processing, and describing one's own emotions and feelings) can further hinder the understanding of presenting problems and symptoms, and were raised as barriers to access.

"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."

Some positive experiences of supports for **executive functioning** including text reminders were raised by some participants.

Negative experiences with not being listened to or respected were raised across all priority groups. Practitioners not obtaining informed consent or ignoring clients wishes were reported as particularly negative experiences in navigating or accessing services, particularly for women. These negative experiences and trauma can also lead to reluctance or avoidance in seeking health and mental health care.

"I do not go to hospital for mental health because [of] so much trauma from one particular ward for myself and for all of my family, when things are bad, we avoid hospital at all costs..."

Numerous women reported past instances of health service providers contacting child protection services upon disclosure a diagnosis:

"...there is this underlying fear that you will have your children taken from you if you reach out [for help with mental health] or if you are even thought to be struggling, by anybody. So, I think ... that's the biggest barrier."

Regardless of the reason, when a patient or client delays seeking care, it often exacerbates or compounds the presenting issues, requiring more intensive treatment.

We heard that **recognising** the **need** for professional care poses a significant challenge for many Autistic people, as they may not be able to recognise their symptoms or understand when the problem is serious enough to need a professional. Compounding this issue are difficulties related to interoception, making it challenging to perceive internal bodily sensations accurately, and trust those feelings. Pre-existing symptoms and conditions can further obscure the identification of health or mental health concerns.

We heard that enhancing **general health literacy** is crucial in helping patients, particularly Autistic individuals and their caregivers to recognise when a problem arises and understand its symptomology. However, pre-existing behaviour can cloud the presentation of issues, complicating the identification process.

Building health literacy and awareness about when to seek professional help is crucial in overcoming these barriers. Creating an inclusive, respectful and accepting health care environment is essential for promoting access to care for all individuals. Providing information about **patient rights** and possible **accommodations**, as well as assistance in identifying individualised options and making appointments, can empower individuals to navigate the health care system effectively.

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.

5.1.5 Listening, validating and informed consent

Many Autistic people reported situations where they felt unheard, doubted, or disregarded, with their treatment preferences. In the worst cases, a lack of informed consent being obtained led to mistreatment and medical trauma. Difficulties in accessing and **obtaining consent** were highlighted by all stakeholders, including the **complexities** for adults with high and complex disability support needs, particularly those with an intellectual disability or people who were unable to provide consent themselves.

There were several reports of informed consent not being obtained, including for administration of sedation and for a genital biopsy.

*"She does a f*cking biopsy of my vulva without my permission...Like now, like, you know, like it ruined my sex life. It ruined a whole bunch of things: my self-esteem, my trust, everything."*

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."

Additionally, parents and caregivers raised challenges of being excluded or disregarded in health care discussions. Conversely, Autistic people cited challenges of health care professionals directing communication towards support persons instead of directly with them. People with high and complex needs, their parents and the people who work with them highlighted the importance of diverse communication approaches to ensure everyone feels valued, respected, and listened to. Non-speaking Autistic individuals particularly highlighted the challenges arising from **assumptions** about their **competence** based on their **communication differences**.

To address these issues, health care providers need support to meet diverse communication needs and must prioritise providing information in accessible formats and establishing rapport and trust to create an environment where patients or clients feel comfortable disclosing information. Follow-up questions should be used to confirm understanding, and input from parents, guardians, or caregivers should be considered alongside direct communication with the Autistic individual, where the individual has expressed desire to have those people included or where it is determined that the individual is able to communicate their needs. All stakeholders noted the importance of training encompassing diverse presentations and expressions of autism, intersectionality, communication strategies and informed consent. This training is considered a vital component of all professional development and will be discussed in more detail in section 5.4 **Education and training** (Element D) of this report.

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.

5.1.6 Sensory and the built environment

The **sensory environment** can have a big impact on an Autistic individual's experience in a particular setting. Aversive sensory environments were commonly discussed across mental health and health services for all groups. This included overstimulating environments (noise, sound and proximity to others) as well as poor quality physical environments due to renovations. Participants shared that such environments led to increased trauma and distress, as well as future avoidance of supports. People from all the priority groups identified sensory and environmental factors as barriers to health care access, underscoring the universality of this issue. Current hospital and clinical settings often fail to meet the needs of Autistic patients, lacking necessary adaptations and considerations for their sensory sensitivities.

"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..."

Addressing these challenges requires implementing **sensory adaptations** throughout health care facilities. This includes providing low-sensory waiting areas or alternative options, such as outdoor waiting spaces with a text or buzzer system to signal when it was time to attend the appointment. Some participants in the community engagement highlighted positive examples where practitioners were flexible in appointment scheduling (e.g. swapping between in-person and online appointments to **fit their needs** of the day) and scheduling regular appointments to support planning ahead. By prioritising these adjustments, health care environments can become more inclusive and accommodating for individuals with diverse sensory needs.

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.

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

Overall concepts from the research, co-design and community engagement in relation to 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**) are categorised as: Neurodiversity-affirming practice and effective models of care; Appointment duration and continuity of care; Individual experiences; Information sharing; Mental health support; and Restrictive and harmful practices.

In the co-design with Autistic people, almost every person told us about the importance of **neurodiversity-affirming care** and the value of Autistic and neurodivergent practitioners who can understand what they are going through. We heard about the need to understand intersectionality and view the **whole person**, knowing they come with individual differences, needs and complexities.

In the co-design with practitioners and at the Summit, we heard about some of the challenges of resourcing, time constraints and pressure on the health and mental health care system. We heard from dedicated practitioners that there simply is not enough time to provide the depth of care that they know would be beneficial, particularly for those with high and complex disability needs. We also heard that there are several national standards which are frequently not upheld and could be further developed and applied to autism.

In the **Intersectionality matters** research related to **Quality and safety**, compared to the entire Autistic sample, we found that:

- Autistic people with high and complex disability tended to focus on the importance of finding health care services and then developing a good relationship with a practitioner with the skillset to work with them
- Autistic people living in rural and remote areas often attributed a lack of autism knowledge held by professionals as the cause of many of the challenges they face
- Autistic women most frequently raised the problem of providers being dismissive or not believing the reports of Autistic people or their family members, including not believing a person is Autistic. They also raised challenges with professionals not tailoring strategies to be suitable for Autistic individuals and expressed concerns about the therapeutic skills of professionals (e.g., exhibiting discriminatory behaviour or a lack of empathy)
- Autistic people from low-socio-economic backgrounds were twice as likely to say that “nothing/not a lot” is working well for them in mental health care settings
- Autistic people from culturally and linguistically diverse backgrounds tended to focus on challenges with professionals dismissing and not believing the experiences of Autistic people, as well as a reluctance of professionals to adapt practices/strategies
- Autistic LGBTIQ+ people highlighted the reluctance of professionals to adapt practices, strategies or accommodations to support Autistic people.

In community engagement interviews and focus groups, problems in **quality and safety** in health and mental health care services were the **most common challenge** raised across all groups.

Table 6: Quality and safety (Element B): Key challenges, priority group needs, practice considerations and potential solutions

Topic	Challenges	Priority group needs	Practice considerations	Potential solutions
Neurodiversity-affirming practice and effective models of care	<ul style="list-style-type: none"> Practitioner gaps in knowledge or understanding of autism and its diverse presentations Expecting Autistic clients or patients to fit neurotypical expectations or expressions of distress and/or pain Autistic practitioner barriers to disclosure Power imbalances between professionals with qualifications and professionals with lived experience 	<ul style="list-style-type: none"> All groups affirmed the importance of neurodiversity-affirming practice, understanding and supporting the individual's intersecting needs, and the value of neurodivergent practitioners, particularly those who identify with the same identity 	<ul style="list-style-type: none"> Lack of consistent definition of neurodiversity-affirming care Autistic practitioners not disclosing for fear of persecution/discrimination Codes of ethics around professional disclosure 	<ul style="list-style-type: none"> Applying the social model of disability Autistic peer supports Research into operationally defining neurodiversity-affirming care as it applies to Autistic clients/patients Support networks for Autistic and neurodivergent practitioners
Appointment duration and continuity of care	<ul style="list-style-type: none"> Lack of resources resulting in short, inadequate appointment times Financially motivated services Self- and parent advocacy Inconsistent or unreliable service coordination Inconsistent service delivery 	<ul style="list-style-type: none"> CaLD and rural and remote people raised importance of consistency of health and mental health professionals Autistic women highlighted need for flexibility in services including appointment booking, longer therapy sessions 	<ul style="list-style-type: none"> Time and resource constraints including pressure on GPs Business context and privatisation of services (e.g., NDIS providers) Resourcing for support coordination 	<ul style="list-style-type: none"> Building community-based supports to reduce burden on public-services Stepped care models Longer (publicly funded) appointments Consistent supports and professionals Information sharing

Topic	Challenges	Priority group needs	Practice considerations	Potential solutions
Individual experiences	<ul style="list-style-type: none"> • Stereotyping and stigmatising the individual • Not 'seeing' the whole individual • Being under-treated, misdiagnosed, denied treatment, testing or diagnoses • Assuming ability or inability • Complaints/grievance processes unclear • Support people attending appointments not enabled • Patients not disclosing due to fear of discrimination or diagnostic overshadowing • Lack of consideration and provision of accommodations and accessibility requirements 	<ul style="list-style-type: none"> • Non-speaking people and people with intellectual disability raised challenges with people assuming incompetence due to a difference in communication and expression • LGBTIQ+ people raised importance of gender and sexuality affirming practice • CaLD people raised importance of cultural awareness and anti-racism • Intersectional biases (racism, homophobia, and transphobia) • Non-gender affirming practice • Autistic women spoke of the need for services to accommodate Augmentative and Alternative Communication (AAC) 	<ul style="list-style-type: none"> • Multi-disciplinary approach to service delivery • Informal support from peers/other family members • Professional learning that already exists for LGBTIQ+ and cultural awareness as a model for training in systems (e.g., in mandatory orientation trainings) • Cross-over with the National Roadmap for Intellectual Disability • Encouraging practice staff to find out what accommodations and accessibility requirements might be needed • Existing anti-discrimination legislation and codes of ethics 	<ul style="list-style-type: none"> • Understanding and tailoring care to the patient or client • Autistic, or autism-proficient liaison officers/advocates • Providing alternative ways to share information and communicate • Multi-disciplinary approaches • Complaints processes being clearly shared with clients and being followed • Advocacy services and support • Gender and sexuality affirming practice • Potential to leverage existing training programs • Developing better models of care akin to the ID Roadmap • Knowledge of and simplified complaint processes • Being informed of rights • Invite people to disclose and share their support needs • Individualised, person and family centred

Topic	Challenges	Priority group needs	Practice considerations	Potential solutions
Information sharing	<ul style="list-style-type: none"> • People having to repeat their story • Practitioners not connecting • Misdiagnosis and needing to correct reports • Important information not being shared between practitioners 	<ul style="list-style-type: none"> • Concern about poor information sharing was consistently raised across all priority groups 	<ul style="list-style-type: none"> • Data security and privacy • Data sovereignty • Limitations of access/writing in My Health records • Differences in data storage/sharing platforms across public/private and health/mental health posing barriers to information sharing • Data reporting requirements • Costly to provide wrap around care 	<ul style="list-style-type: none"> • Enable client sharing of information in advance of service • Written summaries of care • Technology-based individual needs profile editable by client and accessible and editable by professionals with their legal guardian's /delegated decision-maker's consent • New supports to build connections (Autism Hubs, Autistic/peer support, and better collaboration between government and health/mental health services)
Mental health support services	<ul style="list-style-type: none"> • Inconsistent mental health practitioners • Being directed to psychiatry when it is not the need • Diagnostic overshadowing of mental health diagnosis, autism and other neurodivergent conditions • Barriers to accessing psychiatrists (few available, costs, waitlists) • Medication shortages and scripts • Misdiagnosis • Lack of mental health support services for 18–25-year-olds • Mental health support for crisis and suicide risk • Disagreement of responsibility between treating team 	<ul style="list-style-type: none"> • More contacts to Autism Connect for mental health therapist recommendations and mental health advice were by, or for, Autistic CaLD people than for other priority groups 	<ul style="list-style-type: none"> • Trauma informed practice • Adapting existing therapies to address Autistic needs • Multiple services and treatments being provided to an individual at the same time 	<ul style="list-style-type: none"> • More Mental Health Treatment Plan sessions • Providing adaptations to therapy for Autistic clients • Improved behaviour support approaches • Whole-of-family approaches • Preventative mental health supports • Respite rather than hospital

Topic	Challenges	Priority group needs	Practice considerations	Potential solutions
Restrictive and harmful practices	<ul style="list-style-type: none"> • Use of restrictive practices • Unnecessary escalation to police or security • Behaviour linked to trauma • Escalation to police involvement for suicide risk • Forced sedation • Referral to psychiatric services not needed or not seeking 	<ul style="list-style-type: none"> • Restrictive practices most frequently raised by people living in rural and remote areas, and low SES 	<ul style="list-style-type: none"> • Risk assessments • Understanding communication differences 	<ul style="list-style-type: none"> • Trauma informed practice and training • Providing alternative practices - asking individual's preference

5.2.1 Neurodiversity-affirming practices and effective models of care

Throughout the co-design and community engagement, the importance of **neurodiversity-affirming practice** in assisting Autistic individuals was consistently emphasised. We heard about the importance of approaches and strategies that employ a **social model of disability** which considers the impact of social and environmental barriers. Autistic people and their families and carers, shared experiences that demonstrated a lack of understanding of autism by many health and mental health professionals.

"So, I went back to the psychiatrist, and I said...I might have, I probably have autism. And he goes, nah. He said that's the flavour of the month...I don't believe in it."

Experiences of stereotyping or **stigma** were commonly raised across all groups indicating a lack of understanding of autism as well as feeling non-autistic-practitioners *"don't get it"*. Incorrect assumptions of ability or inability were also raised, particularly by participants in regional and remote areas, LGBTIQ+ people, and individuals from low socio-economic backgrounds. Assumptions included over-estimating functioning leading to missing serious mental health challenges, or under-estimating and *"assum[ing] incompetence"*. Further, an expectation that Autistic people should fit with **neurotypical expectations** was highlighted as a barrier to support.

"I went into shutdown at a community mental health centre, so they put me in the psych ward, then the psychiatrist yelled at me for 'playing games' because I couldn't speak. He told me that I would have to stay there until I decided to cooperate...we shouldn't be required to emotionally regulate ourselves in what is an innately distressing context of seeking medical care."

Affirming practices that respected and understood an individual's neurotype, gender identity and sexuality were also raised. This included specific behaviours such as asking and using an individual's preferred pronouns and how they described autism (e.g., person-first, such as person with autism, or identity-first language such as Autistic person).

The value of a practitioner with lived experience who *"understands what I'm going through"* and that *"make me feel more competent"* was raised by individuals identifying as LGBTIQ+ as well as women. However, for Autistic practitioners, concerns regarding **disclosure** persist, driven by valid concerns of whether this violates codes of ethics, may lead to discrimination, or impact their vocational options. The need to support and protect Autistic people working in these roles was flagged as important, as we also heard about barriers to Autistic professionals disclosing and difficulties with **power imbalances** between lived and professional experience practitioners.

"The public hospital health care is all about equal opportunity. However, there is still very much... undercurrent when it comes to disclosing things like neurodivergency et cetera, because while the health service itself is...very amenable or you know, had, is accommodating or explicitly accommodating, the recruitment is not really led by the hospital itself...the vast majority of, you know, my career so far, the, the general advice was don't disclose it [own autism diagnosis]... There's still barriers to open disclosure of diagnosis..."

Participants also spoke of specific practices they had found helpful or unhelpful, which once more highlighted the need for individualisation as some practices such as mindfulness were raised as helpful by some participants but unhelpful for others.

Utilising the **social model of disability**, capacity-building for neurodiversity-affirming practice and establishing support networks for Autistic practitioners are important in enhancing inclusion in the

health care system. We heard that Autistic peer supports can, and already often do, play a valuable role in helping Autistic people access health and mental health care, and to advocate for their needs. Improving understanding and fostering a culture of acceptance are essential in ensuring that all individuals, including Autistic professionals, feel safe to share their identities openly.

Some participants were aware of discrete autism-specific health and mental health programs and initiatives that exist or have been piloted in different parts of the country over recent years. Examples of these include: dental programs; sensory sensitive health setting design; workforce capacity building measures; development of resources for Autistic people; communication tools; mental health service pilots; sensory profiles and practitioner tools. There is an urgent need to identify and assess these various initiatives to understand what has been tried, outcomes generated, related learnings and the potential for replication or upscaling of effective evidence-based approaches.

Participants at the Summit and in the co-design identified the need to address any current fragmentation of knowledge with a hub of expertise, resources and research which supports the development of co-produced evidence-based approaches, shared learning, capacity-building, and systemic reforms.

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.

5.2.2 Appointment duration and continuity of care

Individualised care is a key element of quality care, addressing the diverse health and mental health care needs of individuals. However, short appointment times and restricted resources, including a lack of consistency in health care professionals and providers, limits the depth of care that can be provided and exacerbates challenges for both practitioners and individuals. Participants across all stakeholder groups highlighted the issue of a lack of resources resulting in short, inadequate appointment times. Autistic people expressed feeling rushed “*out the door as quickly as possible*”.

“...seven-minute appointment that's supposed to be 15. You don't have time to process what the doctor's saying to you in those seven minutes.”

Some participants said that this led them to making complaints and found a lack of process or no follow-up. Conversely, practitioners expressed that there is simply **not capacity** to provide the depth of care they know would be beneficial.

“GP's, as the front door to accessing many health services, are limited in rural areas. We currently have 7 FTE GP's for over 17,000 people There isn't capacity to provide the comprehensive, slow care we wish we could”.

People shared both positive and negative experiences of GP interactions, with the former often dependant on continuity of care and an **understanding of autism**. Participants said that practitioners did not need to be Autistic per se, but they needed to “*GET Autistic people*”.

Consistency of health and mental health professionals, and the combination of supports provided, was raised in terms of both consistent support over time and regular access. The value of a consistent health practitioner was raised frequently by culturally and linguistically diverse participants and individuals in rural and remote areas. As one individual stated:

“...the (GP) is the only reason that I am still here, still alive, still breathing, still functioning, is because of <doctor name>, who is my doctor. And he's been my doctor for almost four years now. ”

In the Intersectionality matters research, flexibility, or a lack thereof, was also frequently reported as either a cause of the problems experienced or a possible solution/facilitator. Autistic women highlighted a need for flexibility in access to, and use within, physical and mental health care services including how appointments are made (e.g., online or via telephone), having longer therapy sessions (rather than shorter, which the ‘Making therapy better’ questionnaire indicated can be less helpful), or being able to use alternative and augmented communication methods.

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.

5.2.3 Individual experiences

Individual differences were again raised as impacting access and use of health and mental health care services. This included communication differences leading to discharge without help, differences in **pain expression** leading to treatment that did not meet needs, executive functioning “cost” to organise and remember appointments and reacting differently to medication as impacting quality of care. For example, one individual shared:

"I had the worst experience in a private hospital...giving birth...I didn't know I was Autistic, and Autistic people often react differently to medication. I reacted very, very, very badly to the Syntocinon [medication to induce labour] that was used to speed up labour and it became very traumatic, very, very quickly. And the midwife told me I was pushing wrong... I have poor interoception. I can't feel what muscles are what. And she's telling me that I'm pushing wrong, and I need to use this muscle and I don't even know what that muscle is. I wouldn't know how to isolate it. I wouldn't know how to push with it. I wouldn't have a clue what that muscle means. You need to give me an example of, 'Imagine you are doing this'. That was very traumatic. I wrote in my birth plan, "Do not tell me that I'm pushing wrong" for my second child...That was explicitly in my birthing plan. Do not tell me I'm doing it wrong."

Self and parent advocacy play critical roles in navigating these barriers, but we heard they are often met with inconsistent or unreliable service coordination and delivery. Participants provided many examples where complaints and grievance processes were unclear or not followed, leaving individuals without proper recourse for addressing substandard care. Non-speaking individuals and those with intellectual disabilities told us they face additional challenges, with their competence assumed or questioned due to differences in **communication** and expression. Additionally, participants identified that the expectation of Autistic individuals to conform to neurotypical standards was a barrier to support. Alternative communication methods can help ensure information sharing and effective communication. Practitioners advised of a need for proactive health care, and **incentives** to support GPs in particular, to provide additional support to patients.

"There needs to be incentives for GPs to do more of the health care for Autistic people, to make it more proactive and less reactive e.g. better Medicare rebates for consultations where communication supports are provided by the GP to the patient."

Resource and time constraints compound these issues, highlighting the need for longer appointments and support for practitioners. Consistent supports and professionals, along with adequate resourcing for support coordination, are crucial for fostering continuity of care and promoting positive outcomes for all individuals.

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.

5.2.4 Information sharing

Efficient **information sharing** is crucial for providing quality care, yet challenges persist in ensuring consistent and accurate communication among practitioners. Patients often find themselves in the frustrating and frequently traumatising position of having to repeat their medical and mental health history, and practitioners expressed frustration with various patient or client management systems. This highlights the need for streamlined processes that allow clients to share relevant information before their service appointments and enable practitioners to record important treatment details. However, we heard from health practitioners that there is a major challenge with **differing client management systems**, reporting and documentation requirements across public and private sectors, as well as between medical and mental health services. These differences create substantial barriers to the easy sharing of information.

Concerns about inconsistent practice and poor information sharing were consistently raised across all priority groups. We heard that **written summaries** of care can serve as invaluable tools for both patients and practitioners, ensuring that key information about treatment and care is documented and accessible.

Data security and **privacy** also remain significant concerns for people and important considerations, necessitating robust safeguards to protect patients' sensitive information. Issues of data sovereignty were also raised, with concern about what information might be stored, with whom it might be shared and under what circumstances.

Efforts to enhance information sharing include enabling clients to share information in advance of their service appointments and implementing technology-based solutions such as **individual needs profiles**. Additionally, new support structures such as multi-disciplinary health care centres and peer support networks aim to facilitate information sharing, **connections and collaboration** between government and health/mental health services, ultimately improving the continuity and quality of care for patients.

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.

5.2.5 Mental health support services

In consideration of **mental health support**, participants raised the need for individualised, **flexible** and affordable mental health care options. Several participants raised a need for alternatives to traditional hospitalisation, with respite and outpatient services a preferred option. Specific negative experiences were shared that led to substantial access barriers, leading some participants to avoid support services. For example, one individual shared:

“avoid hospital at all costs unless it's absolute necessary. ... that includes with mental health.”

There was concern raised about individuals being directed to psychiatry when it may not be the most appropriate course of action, highlighting the need for a more nuanced approach to treatment planning that considers individual needs comprehensively.

Participants shared service gaps they experienced including mental health services for their age group (children, young adults, and adults), reproductive health care for LGBTIQ+ people, help for children with eating disorders and crisis vs. non-crisis mental health supports. Further, gaps in services that incorporated and understood intersectional identities was raised, such as being both Autistic and LGBTIQ+.

This included “**silos**” where, for example clients were both Autistic and had mental health conditions, but a practitioner worked with one or the other rather than both. This also occurred for people with high behaviour support needs, traumatic brain injury and mental health, with different services for each, and each not being willing to work with the intersection. See section 5.3.3 **Connection and collaboration** (Element C) for further discussion of these challenges and an example.

Participants also shared difficulties across the continuum of mental health needs from having difficulty finding non-crisis services, to being rejected from services due to **complexity of needs** or level of support needed.

Experiences of **diagnostic overshadowing** were common across all participant groups, where patients with a mental health diagnosis felt they had been dismissed, not believed or trusted, upon disclosure.

“This contributes to medical gaslighting for Autistic people, and it means that when we do have significant health issues they're not treated quickly or at all. This gaslighting reduces the likelihood of Autistic people seeking medical assistance, and again may contribute to the worsening of our morbidity and mortality.”

Service coordination problems included unprofessional experiences with support workers, being directed to psychiatry when this was not their need and having police called in response to suicide risk. Difficulties in needing to advocate were raised both in terms of advocating for oneself and parents advocating for their Autistic child, including serious medical emergencies such as suicide risk following a number of attempts. This was underscored by one interview participant raising the difficulties with securing in-patient admission for their niece when she was suicidal, knowing hospital would be a place where she would be safe.

“If she had been with her mum, she'd be dead... she would not have been able to [advocate] as strong. ... I have a university education ... and it still was really hard for me [to advocate for inpatient admission].”

Several participants shared they had been turned away, due to **improper assessment** during a time of crisis, as one interview participant shared:

"And then, they kept on saying, you have to answer [when unable to communicate verbally], you have to cooperate. And then I got discharged, like somebody else said on a would not engage basis, they knew I was Autistic. ... and they said, it is not high risk. I just attempted suicide like a week and a half earlier."

A small number of participants in the community engagement shared experiences of abuse in hospital mental health settings. Improving mechanisms for feedback and regulation of care were highlighted as ways to improve services. Suggestions included providing clear processes for complaints such as on websites, following through on complaints processes in place, increasing provider regulation and having key communication points for complaints or concerns. The need to protect vulnerable Autistic people from harm including sexual **abuse** in mental health services was also raised.

Participants shared ways to improve mental health care aiming to reduce or eliminate stereotyping and stigma such as greater focus on **understanding the individual** and individualising (including in selecting/reducing use of restrictive practices. Further, utilising social and strengths-based models of disability to understand individuals and formulate care, and in this process: drawing from a range of alternative communication modalities (e.g., drawing, typing, and writing) to better receive the perspectives of clients; being patient; and allowing greater processing time for patients.

There were notable gaps in service provision raised, particularly in mental health and crisis support services tailored for young adults aged 18-25. Furthermore, there is an absence of suicide prevention resources and interventions that are tailored to Autistic people. Autistic people, families and practitioners highlighted a lack of specialised assistance for Autistic children struggling with eating disorders and challenges in obtaining adolescent diagnoses. Moreover, the distinction between autism support services and traditional health or mental health resources creates further hurdles for individuals seeking **comprehensive care**.

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.
-

5.2.6 Restrictive and harmful practices

Restrictive practices in health care settings remains a concerning issue, with various forms of intervention being utilised to manage behaviours of concern. These practices often escalate situations rather than addressing underlying issues, particularly when behaviours are linked to trauma. In some cases, situations escalate to the point of involving law enforcement, such as when addressing suicide risk, which can exacerbate rather than alleviate distress. **Forced sedation** is a form of chemical restraint that raises ethical and **human rights** concerns.

"I had a bad experience in hospital of me having a meltdown and being physically and chemically restrained by male security guards and police (even when they knew I had autism and specific severe trauma around men) they had no consideration for trauma, autism, sensory overload, or meltdowns, they had no idea how to handle a meltdown, and left me more traumatised as a result."

It was notable that individuals from rural and remote areas, as well as those from low socio-economic backgrounds, were most likely to raise issues related to restrictive practices. For rural and remote communities, this may be a result of the availability of more generalist than specialist services. Gaps in training/supports may be exacerbated in these locations demonstrating the need for training that may be scaled regionally to empower practitioners to meet the needs of more diverse clients, see section 5.4 **Education and training** (Element D).

Furthermore, serious breaches of ethics were shared around consent. This included a health professional slapping a child across the face to diagnose autism based on their response.

" So, my GP, he comes over the other side of the table and he slaps him across the face. Right slapped him across the face, right...You know, I didn't know this was gonna happen. So, my little boy sitting there and he just doesn't do anything. He doesn't seek comfort. He doesn't do... He doesn't cry. He doesn't do anything. Then the GP says to me, I think he's got autism. That was the way he was diagnosed."

Addressing restrictive and harmful practices requires a multifaceted approach that includes comprehensive risk assessments and a deep understanding of communication differences, particularly for individuals with neurodevelopmental conditions or other disabilities. Implementing relevant training for health care professionals may help mitigate the use of restrictive interventions. Additionally, offering alternatives and actively involving individuals in decision-making processes by asking for their preferences can empower them to participate in their own care, inform least restrictive options, and reduce reliance on more restrictive measures. Participants were broadly aware that reducing the use of restrictive practices in health and mental health care settings and related regulation and oversight was a focus of the Disability Royal Commission.

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.

5.3 Element C: Building better connections between health, mental health and other service sectors including the NDIS

Overall concepts from the research, co-design and community engagement in relation to Element C: Building better connections between health, mental health and other service sectors, including NDIS (**Connections and collaboration**) are categorised as: Advocacy services; Fostering positive connections; and Coordination across systems. In the co-design with Autistic people, we heard about the challenges people face in managing often multiple co-occurring health and mental health conditions and/or disabilities in the community. We heard about significant challenges accessing and coordinating disability services, including NDIS, and frustration at the lack of communication and connection between these services.

In the co-design with disability professionals and practitioners and at the Summit these challenges were echoed. People are complex and complexity is not limited only to a health or mental health context, it extends to early childhood, education, justice, disability and social services settings. We heard about the importance of information sharing and coordination to support health and mental health needs in the community. The need for case management was clear, and that, in the absence of dedicated case managers, this responsibility often falls to health professionals including allied health professionals.

We also heard about the critical role of families, carers and guardians of Autistic people with high and complex disability needs and the significant gaps in services and support for these individuals and families in the community. Also highlighted was the role of advocacy services and disability organisations in helping people find information and referrals to access and navigate disability services, including NDIS.

In the **Intersectionality matters** research related to Roadmap Element C - **Connections and collaboration**, compared to the entire Autistic sample, we found that:

- Contacts to Autism Connect for assistance finding a health professional beyond a GP were more often by/for Autistic people with high or complex disability support needs
- Autistic people living in rural and remote areas were more likely to report when NDIS plans and funding are approved for health support as ‘working’ or ‘having worked well’. This group also reported that improved paths to diagnosis could reduce problems (“1,000 insights” community view survey)
- Autistic people from low-socio-economic backgrounds rated challenges getting care after hours or on the weekend as a barrier to acute physical health care
- Autistic people from culturally and linguistically diverse backgrounds reported challenges accessing culturally appropriate services
- Contacts to Autism Connect for assistance finding a health professional beyond a GP were more often by/for Autistic LGBTIQ+ people
- Autistic women highlighted challenges with long or closed waiting lists to access services.

In community engagement interviews and focus groups, we heard about the importance of collaboration between health and disability services and the consequences of a lack of coordination, services support particularly for those with high and complex disability needs.

Table 7: Connections and collaboration (Element C): Key challenges, priority group needs, practice considerations and potential solutions

Topic	Challenges	Priority group needs	Practice considerations	Potential solutions
Advocacy services	<ul style="list-style-type: none"> Challenges engaging in self-, parent and other supporter advocacy Assumed abilities if bringing a support person 	<ul style="list-style-type: none"> Importance of advocacy support was particularly raised by CaLD, LGBTIQ+ and women 	<ul style="list-style-type: none"> Value of lived experience and peer support Building people's capacity to self-advocate 	<ul style="list-style-type: none"> Individual and parent advocacy services Building connections to link to Autistic and peer supports
Fostering positive connections	<ul style="list-style-type: none"> Local area coordinators not connecting Administration tasks to manage multiple services and referrals Poor communication leading to adverse outcomes Referred services not connecting with each other Repeating the same story and/or information 	<ul style="list-style-type: none"> The high and complex needs group raised all issues as the consequences of poor communication leading to adverse outcomes 	<ul style="list-style-type: none"> Disconnect between different state and territory system and criteria for access to services 	<ul style="list-style-type: none"> Building connections to Autistic and peer supports Connections to suitable services
Coordination across systems	<ul style="list-style-type: none"> Practitioners not connecting with each other (e.g., referring hospital staff and GPs) Lack of information sharing within and between services Support plans based only on information gathered by phone interview Inconsistent, unreliable support coordination Service funding disconnects; for example, NDIS funding and mental health support Transition from child/young adult to adult services High cost and challenges in accessing diagnosis resulted in missing out on mental health support Unprofessional conduct Undue escalation to police or child protection services 	<ul style="list-style-type: none"> Managing high and complex health needs in communities including schools and disability services including supported independent living 	<ul style="list-style-type: none"> Medicare billing systems Overreliance on GPs who do not have capacity to case manage or coordinate care Resourcing to support coordination Non-integrated client management systems between public and private providers Medicare funding for assessment and diagnosis, current limitations to 25 years of age and high gap payments Guardianship and public guardian 	<ul style="list-style-type: none"> Lists of available support coordinators New supports to build connections (Autism Hubs, Autistic/peer support, and better collaboration between government and health/mental health services) Remove age limit on Medicare diagnosis items Provide public services for diagnosis across the lifespan School nurses to coordinate services Integration of state and territory services Whole-of-family approaches Flexible funding and respite options Shared care plans Regular health or wellbeing checks Autism specialists

5.3.1 Advocacy services

Autistic participants raised the importance of promoting **self-advocacy, parent advocacy** and advocacy **service providers** in facilitating effective dialogue about their health and mental health experiences and needs. This also enables individuals to actively participate in discussions regarding care and service options. Self-, parent/carer, lived experience and professional advocacy were identified as helpful in linking to required supports. Of these, the more common positive experiences were health practitioners **fostering connections** and self-/parent advocacy. These were important for all groups and were raised most by individuals from rural and remote areas and from low socio-economic backgrounds.

5.3.2 Fostering positive connections

The need to **foster positive connections** between systems and services was raised consistently by all stakeholder groups. In the co-design and community engagement, participants discussed the challenge of telling their stories repeatedly across different supports and provided ideas to improve **information sharing** to reduce this. Participants shared positive experiences of being supported to connect to services by health practitioners, practice receptionists and administrative staff, support co-ordinators and disability workers. Conversely, they also shared negative experiences where there was a poor communication and disconnect between services.

In the community engagement, participants raised problems in terms of service coordination as being connected to services not sought or offering inappropriate support, challenges with advocating, problems with support coordination, disconnects between services and funding, and needing to repeat stories. Negative experiences with support coordination (**poor connection** within and between services) were the most commonly raised concern across all groups.

The burden of managing **multiple services** and referrals is compounded by administrative tasks and hinders seamless coordination. Poor communication among stakeholders was identified as a significant factor contributing to adverse outcomes, as practitioners and referred services struggled to connect effectively. This resulted in individuals having to repeatedly share their stories and information, leading to frustration and inefficiencies in the system.

"They don't really communicate...sometimes I get like medication from my GP and then medication from, my cardiologist and they're like, haven't communicated that... I'm like, guys, you know, I'm on this medication, right? And they're like, no."

Connections between services, the individual, and families were raised for people who are/were unable to provide their own consent and/or with high or complex disability needs (e.g., intellectual disability and presence of high behaviour support needs as particularly difficult. For example, in interviews, two parents shared significant **long-term harms** that occurred for their Autistic daughter as a result of poor service connections where incorrect dosage of medication was provided to supported independent living providers, resulting in an overdose of medication and collapsing in a public place. Due to this incident for 15 years after she would not take any oral medications resulting in a need for depot injections (requiring more intensive and intrusive health care) to meet medication needs.

Ideas for how to share key information were identified, such as setting up systems or health passports to enable better sharing of information across health and mental health providers. All stakeholder groups made comments about support coordination and how it could be improved,

such as having access to a support coordinator and lists of available services. Throughout these suggestions the importance of **lived experience** was emphasised with Autistic/peer supports the most common suggestion, and often over professional qualifications. Of note, the need for professional qualifications were viewed as a potential barrier for many who would be interested and suitable to provide peer support. Further, participants emphasised the need to ensure adequate compensation and funding to people with lived experience, as opposed to reliance on unpaid volunteers.

The development and use of a technology-based comprehensive health profile (Recommendation 11) that contains information on an individual's sensory, cognitive, communication, co-occurring conditions and treatment preferences may help foster positive connections.

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.

5.3.3 Coordination across systems

Effective service **coordination across systems** is essential for ensuring individuals receive comprehensive support, yet several challenges were identified in this area. We heard that for practitioners, there is a lack of consistency and integration with various client management systems which makes services coordination very difficult, even when providers are trying their best to collaborate. We heard that:

“Consideration of care coordinators could be an action, which is often needed. Most practitioners end up case managing and supporting which adds to clinician’s times.”

From a client’s perspective, this often results in the individual having to retell their story, incomplete assessments and **inadequate support** plans.

In the co-design, community engagement and at the Summit, Autistic women shared concerns about automatic escalation to child protection services upon disclosure of an autism diagnosis:

“...there is this underlying fear that you will have your children taken from you if you reach out [for help with mental health] or if you are even thought to be struggling, by anybody. So, I think... I think ... that's the biggest barrier.”

These challenges with escalation highlight the need for **education and training** to extend beyond health professionals, to other professionals who support individuals at times of crisis including, but not limited to, police, child protection and security staff.

Issues with service coordination were also raised with regard to bullying and coercion, long delays, difficulties changing providers, poor communication between health professionals leading to significant adverse outcomes, and the use of phone assessments instead of face-to-face support. The latter was raised in all groups. Disconnects between service systems were highlighted as a lack of **support to transition** between services including 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 was highlighted as particularly challenging.

“When I was a teenager, they really didn't have a lot of [mental health] services between sort of like 15 and 25... they had a big gap especially between 18 and 25. Once you turned 18, basically services were like oh we don't do 18-year-olds and they just kind of like good luck with adult services.”

In the co-design, community engagement and at the Summit, we learned that supporting individuals with high and complex disability and behaviour support needs in the community can be especially challenging. This is particularly true when **multiple services** are involved, as the coordination efforts become more crucial and difficult.

In interviews, participants who were caregivers (parents and siblings) of individuals with high and complex disability and behaviour support needs raised specific challenges around accessing and coordinating support in the community. The participants who raised these challenges described specific cases and needs for people with profound intellectual disability, very complex co-occurring medical conditions such as a traumatic brain injury, sensory impairments (e.g., Deafness), and high levels of externalising behaviour that put the physical safety of themselves and/or others at risk. We also heard examples where, due to a lack of support in the community and in the interests of safety

for the Autistic person, themselves and other family members, they felt they had no other choice than to place their children or family members in residential care.

“Care for people with severe and profound intellectual disability is even more difficult to access because they are hidden away and have no voice. I have been firmly told many times ‘This child is just a behaviour/placement problem and should not be in this hospital.’”

For example, two parents in interviews shared their experiences that led to placing their daughter in **residential care** as a teenager. Their daughter is Autistic and has a traumatic brain injury which results in ongoing impacts, anxiety and high behaviour support needs - presenting risk to herself and family members and reducing both her and her family’s participation in everyday activities and the community. They highlighted the significant challenges of accessing services that met all her daughter’s needs:

“they say <daughter’s name> has autism, but she also has brain injury. It is likely that we would get turned away, regardless of the service. Because as soon as they hear that other thing, that dual diagnosis, because you know, their resources are tight, and they go ‘oh no, we don’t do that’... this is what happened time and time again, it’s a terrible story. ‘We feel sorry for your situation, but we can’t help you’...”

Following repeated seeking of support across a variety of avenues and continued challenges, their other non-Autistic daughter attempted suicide resulting in hospitalisation. They reported that hospital staff would not release their non-Autistic daughter home for her own safety if the Autistic child was in the house. At this point her parents reported they were faced with the choice of which child they could support in their home, which led to **placement** of their Autistic child in residential care as a teenager, noting:

“there’s just so many records of people trying to help her. Good people. But nobody really could. And it came to that point where she had to leave home, unfortunately...”

A practitioner who attended the Summit raised additional challenges and practice considerations:

In Victoria (at least) if a child is aged between 16 and 18, child protection will not consider a referral as they do not have responsibility for this age bracket. It is a no man’s land until they are 18 when we can ask the Office of the Public Advocate to become involved to help the family get residential care... Since the inception of the NDIS, if parents can access a few hours of out of home respite care, they can no longer just refuse to pick their child up or leave their child at the facility in the hope the authorities will take action. The carers and facility managers are instructed to arrange to take the child home if parents do not arrive. So, parents are forced to relinquish care before anything can be done.

To address these challenges, there is an urgent need for increased funding and resources to **support families** and individuals with very high and complex disability and behaviour support needs. This includes supporting the family unit, including siblings as well as parents and caregivers, prior to reaching a crisis.

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.

5.4 Element D: Improving autism education and training for health and disability professionals

Overall concepts from the research, co-design and community engagement in relation to Element D: **(Education and training)** are categorised as **education and training** opportunities.

In the co-design and at the Summit, almost every person spoke of the need to provide training programs and resources for health and mental health practitioners to improve understanding and acceptance of autism and intersectionality. The consensus among nearly all stakeholders including practitioners was that the training ought to be co-designed and developed with Autistic individuals, as well as health and mental health practitioners. Furthermore, it was recommended that the training should be co-facilitated by Autistic individuals, with many emphasising the preference for Autistic practitioners leading the sessions.

In the co-design with practitioners and at the Summit, once again we heard about the challenges of resourcing and pressure on the health and mental health care system. We heard of the need to prioritise Continuing Professional Development (CPD) in clinical education and that regulatory compliance often took time away from other important topics. Ideas explored included aligning autism training with existing training in culturally safe practices and LGBTIQ+, and incentives for practitioners to undertake in-depth, accredited training to become 'Autism specialist providers'.

In the **Intersectionality matters** research related to **education and training**, compared to the entire Autistic sample, we found that:

- Many Autistic people with high and complex disability identified that professionals made assumptions about or dismissed the lived experience and/or diagnosis of Autistic people. This could be linked with the commonly reported lack of autism knowledge held by professionals or the quality and/or quantity of autism training they receive
- Autistic people living in rural and remote areas attributed many of the challenges they face to professionals' lack of autism knowledge. They also reported professionals' preconceived ideas of autism as a cause of the problems in mental health services
- Autistic women indicated that improved training could increase professionals' autism knowledge and their ability to select or modify strategies to better support autistic women and girls, including the use of neurodiversity affirming strategies. Autistic people from low-socio-economic backgrounds discussed health care practitioners' limited autism knowledge and mental health care practitioners limited autism training or education
- Autistic people from culturally and linguistically diverse backgrounds identified problems with professionals holding a limited knowledge of autism and its presentation
- Autistic LGBTIQ+ people reported that the right physical health provider was one who was knowledgeable about autism, understanding, caring, patient and non-judgemental slightly more frequently than other groups.

In community engagement interviews and focus groups, **education and training** of professionals was consistently raised as an idea to improve health and mental health services and care for Autistic people.

Table 8: Education and training (Element D): Key challenges, priority group needs, practice considerations and potential solutions

Topic	Challenges	Priority group needs	Practice considerations	Potential solutions
Education and training opportunities	<ul style="list-style-type: none"> Lack of understanding and acceptance of autism, including diverse presentations, communication and pain expression Legislative frameworks, adjustments and accommodations Obtaining informed consent and assent for people who do not have the capacity to give informed consent Trauma-informed care Acknowledge and build an understanding of intersectionality and complexity 	<ul style="list-style-type: none"> Women raised the need for focus on women’s reproductive health care, breast cancer and birth People with high and complex needs identified diverse presentation and alternative communication (informed consent vs assent) CaLD people raised the need for cultural competency and anti-racist frameworks to be embedded in any autism training 	<ul style="list-style-type: none"> Training needed at all levels – executive, management and community-facing Co-designed and co-delivered with Autistic people and health practitioners from specific professions Crowded pre-service curriculums Acknowledge real constraints on practitioners/sector Very little CPD is mandatory for health professionals Opportunity to align with other training related to culturally safe practices and LGBTIQ+ Time-poor providers don’t have time to engage in in-depth autism training 	<ul style="list-style-type: none"> Pre-service training for university students Micro-credentialled continued professional development for in-service professionals Training to promote understanding and acceptance of autism, including diverse presentations, communication and pain expression Funding staff release time to facilitate training uptake Incentivised training programs National accreditation of specialists, potentially with a list of specialists made publicly available

5.4.1 Education and training opportunities

Autistic individuals and families emphasised that a professional's **understanding of autism** makes a significant difference in health and mental health care interactions and experiences. Autistic people with different life circumstances and backgrounds shared their personal experiences of practitioners with little autism understanding or acceptance. For example, minimising expressions of pain resulted in one participant avoiding future breast examinations.

Participants appreciated practitioners who are willing to acknowledge their own gaps in understanding and who research or learn from their patients or clients. The importance of covering the **diversity** of autism was highlighted across all priority groups.

“That everyone is different with autism... that even within the same person there can be different presentations on different days.”

Finally, participants highlighted important considerations with regard to future training as feasibility of implementation, financial incentives or reimbursements, the need to look at knowledge translation and implementation in practice, and legislative frameworks regarding reasonable adjustments.

“Educating Autistic people as well as practitioners about the legislative frameworks around reasonable adjustments for access can be helpful in getting buy-in: both for services to know that the onus is on the service to say why a requested adjustment is an unjustifiable hardship or suggest an alternative adjustment that is less intrusive to their service but no less beneficial to the Autistic person (when it comes to providing different booking methods, transport assistance, etc).”

We heard about the pressure on health and mental health practitioners and the genuine constraints they, and the health sector, is facing. Also, it was clear that the pre-service **curriculum is crowded**, and time-poor practitioners are unable to undertake extensive Continuing Professional Development (CPD) beyond staying up to date with treatment options and regulatory compliance.

A strong consensus across our engagements and research was the need for dedicated training, resources and tools to better equip health and mental health practitioners to care for Autistic people. Similar recommendations were made by the Senate's Autism Inquiry and the Disability Royal Commission, although the emphasis on the latter is people with cognitive disability with wide ranging recommendations relating to a health capability framework).

Autistic individuals and practitioners emphasised the benefits of co-developing these approaches and the value of Autistic co-delivery of training, including the use of Autistic practitioners where possible.

Participants nominated a number of topics/areas that ought to be a focus in training or professional resources including:

- using a neurodiversity-affirming approach
- adapting the (sensory) environment
- understanding intersectionality
- navigating diverse presentations and debunking stereotypes and myths about autism
understanding differences in responses to medication, expressions of pain and interoception (and the harms that can result from ignoring or minimising this)
- supporting people with high and complex disability and behaviour support needs

- trauma-informed care.

The opportunity to understand and apply health standards and regulatory requirements in practice with Autistic individuals was emphasised, including: the National Standards of Care; the Disability Discrimination Act; Australian Psychological Society Guidelines; Reasonable adjustments and clinical care standards under the Australian Commission on Safety and Quality in Health Care.

The challenge – and opportunity – is to embed requirements for autism competency in the standards and codes of health and mental health professional bodies and registering authorities, and in professional education.

Another suggested way of building and recognising workforce capability was through incentives for practitioners to undertake in-depth, accredited training to become ‘Autism specialist providers’ – this is also addressed above in the section on neuro-affirming care.

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 high and complex disability and health needs.

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

Overall concepts from the research, co-design and community engagement in relation to Element E: Research and data on health and mental health outcomes of Autistic people and their families and carers (**Research and data**), focused on topics and future research priorities.

Participants raised:

- the need for research that enhances understanding of the diverse presentations of autism and intersectionality
- the value of co-production and for research to be undertaken in partnership with Autistic individuals, their families, carers and the professionals that work with them
- the importance of evidence-supported practice for individuals with high or complex disability needs.

These focus areas broadly align with other community-driven consultation to identify research priorities. In particular, research priorities relating to Autistic health and wellbeing identified by the Australasian Autism Research Council (who in 2019 engaged over 1,000 stakeholders to develop a series of national research priorities, later updated by further consultations in 2021) include:

- the impact of accessible, appropriate and informed health services on Autistic wellbeing
- health professionals' understandings and attitudes regarding autism and co-occurring health conditions and how can gaps in Autistic-informed, evidence-based practice can be improved
- whether and how Autistic people want to communicate and collaborate with health professionals, including through contributions to health professional training.

The **Intersectionality matters** data sets did not specifically consider the topic of **research and data**, however, there were relevant key themes that emerged including the importance of evidence-supported practice which was highlighted by individuals with high or complex disability needs, and their families and carers.

In the community engagement interviews and focus groups, relatively few participants made comments relating to research and data. Where participants discussed research, there was alignment across 'what is working well', 'what doesn't work well' and 'what would make it better' for two areas related to centring lived experience and understanding heterogeneity (i.e., diversity of Autistic people).

Table 9: Research and data (Element E): Key challenges, priority group needs, practice considerations and potential solutions

Topic	Challenges identified	Priority group needs	Practice considerations	Potential solutions
Focus areas	<ul style="list-style-type: none"> • Understanding the lived experience and diversity of autism including in children and young people • Pain expression for Autistic people • Autistic burnout • Intersectionality • Autism and physical disability • Autism and First Nations • Autism and co-occurring health conditions • Autism and CaLD • Autism and LGBTIQ+ • Focus on autism genetics and prevention considered problematic 		<ul style="list-style-type: none"> • Value of Autistic-led and co-produced research • Prioritise research that seeks better understanding of autism • Better understand the challenges from a practitioner perspective • Focus on translation – to improve real life outcomes • Other perspectives are often prioritised over lived experience. 	<ul style="list-style-type: none"> • Invest and prioritise research • Targeted specific calls to address key topics and promote collaborative solutions (e.g. CRC model) • Autistic measures of therapeutic change • Develop evidence base for quality and safe care

5.5.1 Focus areas

The need for central inclusion of lived experience was highlighted, including the value of **Autistic-led** and **participatory research**, not prioritising other (e.g., neurotypical experience) over autistic experience, and the need for more research that explores lived experiences of health and mental health care for Autistic people. The inclusion of **intersectional experiences** in research was highlighted as needed, such as exploring the experiences of Autistic people who are also LGBTIQ+, culturally and linguistically diverse and First Nations. This was raised by people in these priority groups. Participants also identified a need for research and investment in First Nations communities more broadly.

In the co-design with practitioners and at the Summit, participants identified a clear need for research investment into understanding of **co-occurring** health and mental health conditions and treatment outcomes. Some of the conditions mentioned included epilepsy, ADHD, brain injury, anxiety, depression and eating disorders.

In interviews some participants raised concerns with the focus of research to date (genetics/causes), misinterpretation of findings, research not investigating areas of their own lived experience nor intersecting identities, non-Autistic perspectives being prioritised over Autistic perspectives and narrow conceptualisations of autism (i.e., not understanding/including diversity or intersectionality).

“A lot of the stuff that I've seen come out has been... genetic research and I'm very against that because I feel like as soon as people like figure that out, they'll be like, okay, well how do we get rid of it? Yeah. Just not ideal.”

Community engagement participants highlighted areas for improvement as the need for **knowledge translation** (translation of research into health and mental health practice) and priority areas to address in future research including autistic burnout, community bias, late diagnosis, real-life outcomes, and understanding heterogeneity. Of note, the focus on genetics/cause and risk of focussing on “cures” was raised most commonly as of concern to LGBTIQ+ priority group members.

Across the co-design, community engagement and at the Summit, the concept of **neurodiversity-affirming care** was consistently raised. However, there was little agreement about what this actually means in a health or mental health context. As one practitioner explained:

“I think that it would be good to define neuro-affirming care. I think that it would be good to embed a research focus to this to ensure that this intervention was the most optimal for the community. I think that some care principles and education would be very helpful in guiding care. I am concerned that the reach of what is described may be limited to those who already have a good understanding of neurodiversity-affirming care.”

Participants raised areas that they felt would be important to cover in **future research**, including the need for consensus about what needs researching and key problems, and specific ideas including autistic burnout, community bias, research that could improve real-world quality of life outcomes, and research that explores intersectional experiences and identities (raised most often within the culturally and linguistically diverse priority group), individual differences and heterogeneity.

Autistic people, professionals and practitioners highlighted the need for better understanding of interoception, diverse communication and pain expression in Autistic people, although it was noted that significant research already exists that needs to be translated in to **practice-based tools** and

training for both practitioners and Autistic people. This highlighted the need for knowledge translation in research to ensure findings are shared and implemented in health and mental health care, and outlets to support dissemination including through systems-levels, universities, and social media to support reach and uptake.

Finally, in the co-design, practitioners raised the challenges of national data collection.

“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.”

“...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.”

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.

5.6 Element F: Arrangements for oversight, monitoring, and implementation

The co-design, research and community engagement activities did not specifically address this element. However, in all forums and across all stakeholder groups, participants consistently raised the need for **evidence-based, co-designed solutions** developed in partnership with the Autistic community and health care sector.

Developing **transparent, robust and inclusive** oversight and monitoring arrangements for the Roadmap will be critical. While not explicitly discussed at the Summit, co-design or community engagement, there was a strong sentiment that governments, service providers and other stakeholders need to be accountable for implementing the Roadmap, reporting on progress and ensuring it achieves its aims. The Roadmap needs to be designed to achieve **clear outcomes**, with **tangible actions** (short – medium and longer term) that will contribute to attainment of outcomes.

Effective governance is needed to steer implementation and refine actions under the Roadmap. It would bring together Autistic community members, autism organisations, health providers and their representative bodies, and national, state and territory government representatives.

An **Outcomes and Monitoring Framework** ought to be developed as part of the Roadmap to measure and track progress against key program/service, population level and community attitudes indicators and measures. This needs to be complemented by evaluation at key points and stages. Evaluation will assess what, why, how and for whom the Roadmap is making a difference. What has been implemented? How is it working? Why? Under what conditions? For whom? What difference has been produced?

There is broad awareness of existing data limitations, some of which should be addressed through this Roadmap, and also through the National Disability Data Reform project underway as part of the Australian Disability Strategy.

The Roadmap is being designed to complement the National Autism Strategy. It will serve simultaneously as both a standalone Roadmap and a detailed component of the National Autism Strategy. Given that the Roadmap is led by the Minister for Health and Aged Care, it will require **fit-for-purpose governance, outcomes measurement, implementation and reporting arrangements** that are **distinct** from **but also connected** to the **National Autism Strategy**.

There is opportunity for close alignment with the National Roadmap for Improving the Health of People with Intellectual Disability. This is because of the high prevalence of Autistic people with co-occurring intellectual disability, the cross-over of Disability Royal Commission recommendations related to people with cognitive impairment, and the significant opportunities for **shared learning**. For example, use of roundtables and purpose designed advisory groups to inform and design key initiatives under the National Roadmap for Improving the Health of People with Intellectual Disability appears to be an effective at involving key stakeholders.

Recommendations 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 representatives, practitioners and their representatives and governments in the co-design and development of key initiatives under the Roadmap.

6. Limitations

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, 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.

7. What happens next?

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 stakeholders to help realise the potential of this landmark initiative.

The research findings and community insights established through this body of work have been handed over to the Department of Health and Aged Care and the Autism Roadmap Working Group for their consideration in development in the National Roadmap to Improve the Health and Mental Health of Autistic people, which is expected to be released for public consultation in mid-2024.

The Roadmap presents the first nation-wide opportunity to coherently articulate the change the Autistic and autism community 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.

8. References

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Our values



Inclusion

Valuing lived experience



Innovation

Solutions for long term challenges



Evidence

Truth in practice



Independence

Integrity through autonomy



Cooperation

Capturing opportunities together



AutismCRC

Independent national source of evidence for best practice



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