AutismCRC

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

Appendix C:

Roadmap community engagement

March 2024

Griffith UNIVERSITY

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

Appendix C:

Roadmap community engagement

Jessica Paynter
Griffith University

Cheryl Mangan
Autism CRC

Hayley Clapham
Autism CRC

Kathy Isaacs
Autism CRC

Connie Allen
Griffith University

Madison Jones
Griffith University

Tianna Jones
Griffith University

Stephanie Malone
Griffith University

Jessica O'Loghlen
Griffith University

Bonnie Ray
Griffith University

Dawn Adams
Griffith University

This document is an appendix to the following report: Autism CRC (2024). *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*. Brisbane: Autism CRC.

Acknowledgements

The authors acknowledge the financial support of the Australian Government Department of Health and Aged Care.

This work would not have been possible without the significant contributions of the Autistic individuals, their families, carers and the people that work with them who shared their experiences. Special thanks to the community partners and teams at A4, Amaze, Autism Spectrum Australia (Aspect), Autism Tasmania, First Peoples Disability Network, National Ethnic Disability Alliance, NT Lived Experience Network, Queensland Centre for Intellectual and Developmental Disability (The University of Queensland), Spectrum Space (WA), The South Australian Rainbow Advocacy Alliance, The Autistic Realm Australia, The Autistic Self-Advocacy Network of Australia and New Zealand, and Yellow Ladybugs for their direct facilitation of focus groups and support for recruitment. Thank you also to our volunteer James McDermott who assisted with data analysis.

The authors acknowledge the financial support of Autism CRC. Staff and non-staff in kind were provided by Autism CRC member Griffith University.

Autism CRC

Autism CRC is the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum. Autism CRC provides 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 addressing agreed needs and co-producing outputs with these stakeholders for the benefit of the community.

autismcrc.com.au

A note on terminology

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

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

Copyright and disclaimer

A note on sensitive content and profanity

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

Free support services

Autism Connect

Call: 1300 308 699

Website: lifeline.org.au

Lifeline Australia

Call: 13 11 14 or

Text: 0477 13 11 14

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

Website: lifeline.org.au

Beyond Blue

Call: 1300 22 46 36

Live chat: beyondblue.org.au/support-service/chat

Website: beyondblue.org.au/

Kids Help Line

Call: 1800 55 1800

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

Website: kidshelpline.com.au

QLife

Call: 1800 184 527

Live chat: qlife.org.au/resources/chat

Website: qlife.org.au/

13YARN

Call: 13 92 76

1. Contents

List of tables

2. Executive summary

2.1 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 (subsequently 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. This is being informed through a collaborative research, co-design and community engagement process. This report forms part of the community engagement component of this process.

2.2 What we did

The community engagement was primarily directed at those groups where less is known or understood and focused on their unique experiences. These groups are shown on Table 1. Engagement included focus groups (*n* = 55) and interviews (*n* = 52) with Autistic people (*n* = 66), their family and carers (*n* = 54), and professionals (*n* = 26) including service providers and health and mental health practitioners. 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 ideas for change in relation to the guiding principles and elements of the Roadmap.

The work within this report was undertaken by a team of Autistic, neurodivergent, and non-Autistic researchers from Griffith University. The format and design were agreed with the Department of Health and Aged Care and included face-to-face and online interviews, and online focus groups conducted by Griffith University, Autism CRC, and community partner organisations. Data were analysed using content analysis. These findings represent a range of ideas from the sampled individuals. It is not intended, nor appropriate to generalise these findings to encompass all Autistic people.

Table 1-1: Group participation and demographics by priority group

Participant demographic information	Interviews *n* = 52	Focus groups *n*= 55	Total *n* = 107
People with high or complex disability needs	38	16	54
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	17
Non-speaking/Unreliably speaking	12	7	19
First Nations people	2	1	3
Culturally and linguistically diverse people	7	22	29
LGBTIQA+ people	16	31	47
Women and girls	29	41	70
People who are living in rural and remote areas	16	18	34
People from low socio-economic status backgrounds	16	19	35

Table 1-2: Group participation and demographics by personal status

Participant demographic information	Interviews *n* = 52	Focus groups *n*= 55	Total *n* = 107
Autistic person	27	39	66
Parent, carer or guardian of an Autistic person	32	22	54
Autistic person who is also a parent, carer or guardian of an Autistic person	13	17	30
Parent, carer or guardian of an Autistic person with high or complex support needs	21	19	40
Parent, carer or guardian of an Autistic person from another priority group	15	12	27
Professional who works with Autistic people	13	13	26
Autistic person who is also a professional	5	13	18

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

Note: Many participants identified with two or more priority groups and/or personal status, so total numbers equal more than 107. Where demographic information was not provided, total numbers equal less than 107.

Table 1-3: Group participation and demographics by age group

Participant demographic information	Interviews *n* = 52	Focus groups *n*= 55	Total *n* = 107
< 18**	1	0	1
18 to 24	1	0	1
25 to 29	3	2	5
30 to 39	5	6	11
40 to 49	7	12	19
50 to 59	12	16	28
60 to 69	12	5	17
70 or over	5	0	5
Prefer not to answer, or age not disclosed	6	7	13
Age group data collected in different brackets by community partner	0	7	7

*** <18 years of age individual was interviewed with guardian.*

Table 1-4: Group participation and demographics by gender

Participant demographic information	Interviews *n* = 52	Focus groups *n*= 55	Total *n* = 107
Male	15	8	23
Female	33	32	65
Non-binary	4	13	17
Prefer not to answer, or not identified	0	2	2

Table 1-5: Group participation and demographics by State or Territory

Participant demographic information	Interviews *n* = 52	Focus groups *n*= 55	Total *n* = 107
NSW	6	8	14
VIC	14	22	36
QLD	1	4	5
SA	6	14	20
WA	7	2	9
TAS	16	2	18
NT	1	0	1
ACT	1	0	1
Unknown/no details provided	0	3	3

2.3 What we found

The majority of comments related to Navigation and access (Element A) of the Roadmap with fewer comments relating to Research and data (Element E), and rare comments relating to Implementation and evaluation (Element F). Due to the paucity of data on Roadmap implementation and evaluation, this element is not included in this overview of results. Findings are overviewed below by Roadmap element in terms of what works well when available or offered, what does not work well, and what would make it better, to show alignment and non-alignment across these.

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

Due to the large number of concepts included in Element A: Improving support for Autistic people, their families and carers in health and mental health (Navigation and access), subgroupings of codes in this element are included in Table 2 as well as codes under what works well when available or offered, what doesn't work well, and what would make it better. The overall concepts covered by participants, and included under navigation and access, were categorised as access, affordability, bookings, consent, information, listening and validating, practice flexibility, service gaps, sensory and built environment, and telehealth. Some areas (e.g., service gaps) were predominantly identified as areas that were not working well, whereas others were predominantly identified as areas working well when available or offered (e.g., service choice and flexibility) as outlined below.

Table 2: Navigation and access (Element A): What is working well, what doesn't work well and what would make it better

Category	What is working well when available or offered	What doesn't work well	What would make it better
Access: (general)	Positive help-seeking experiences	Negative help-seeking experiences leading to avoiding services due to access barriers or prior/potential harm.	Improved access to services
	Recommendations from word of mouth, online, social media groups, and autism associations	Finding autism-specific services/reputable service providers	Autism-friendly clinician lists
	Short waitlists	Long waitlists	More practitioners
	Private care	Waiting on specific day and inflexibility for lateness	Home visits/services
		Difficulties finding/navigating services including being overwhelmed by process	Improve access to services
		Unsupportive staff	Autism-specific services/health practitioners who have a specialised understanding of autism
			More subsidised Mental Health Care Plan sessions
			Services (more affordable and easier to navigate)
			Systemic change

Category	What is working well when available or offered	What doesn't work well	What would make it better
Access: Booking systems	Online bookings including provider biographies	Online bookings only	Online or email booking being available
	Phone booking made by family member	Phone bookings only	In-person bookings being available
	Provider makes contact for booking	Email or online bookings unavailable	
	Support worker assists with booking and attending appointments	Unable to contact	
Access: Diagnosis	Adult diagnosis accessible	Adult diagnosis hard to access and misdiagnosis	Earlier diagnosis to facilitate supports
		Adolescent diagnosis hard to access	Medicare funding for diagnosis
		Barriers to access from late diagnosis not taken as seriously	Understand the implications of diagnosis
	Child diagnosis accessible	Earlier detection/ identification needed to get help or improve health/mental health	
		Needing formal diagnosis to access services	
		Stigma around diagnosis	Reduce stigma and negative implications around diagnosis
Access: Finding services that meet needs or funding	Home visits/services		
	Carer support	Difficulty finding services for adults	
	Getting services recommendations from websites and social media groups	Difficulty finding services that meet individual needs	
	Word of mouth	Regional and remote lack services	
	Recommendations from autism associations	Religious affiliations of organisations a barrier	
		Restricted to NDIS clients only	

Category	What is working well when available or offered	What doesn't work well	What would make it better
Access: Personal characteristics	Building strengths to support access (e.g., interoception)	Personal challenges to access: executive functioning, interoception, and differing communication or responses	Executive functioning supports
	Text reminders		
Access: Physical navigation and transport		Physical navigation, transport, distance and cost	Innovative modalities (e.g., virtual reality)
Access: Barriers to GPs and psychiatrists		GP "bottleneck" for access	
		Medication shortages and scripts	
		Needing to correct reports	
		No regular GP to make referrals	
Affordability		Needing to self-fund assessments	
	Mental health care plans	Cost of diagnostic assessments	
	Bulk-billing and low-cost services	Out-of-pocket costs	Improve or broaden access to Mental Health Care Plans
	NDIS-funded supports	NDIS driving price increases	
		Private health care limitations	

Category	What is working well when available or offered	What doesn’t work well	What would make it better
Appointment/ Service choice and flexibility	Appointment choice (when)	Appointment choice lacking	Appointment flexibility
	Bookings made in advance	Appointments times are not long enough	Modality flexibility/availability
	Flexibility in appointments/rescheduling		Session length flexibility
	Flexibility in modality		
	Flexibility in session length		
Consent		Consent (treatment wishes) ignored	
		Lack of informed consent	
		Complexities around consent for parents/ guardians of Autistic adults who do not have capacity to provide informed consent themselves	

Category	What is working well when available or offered	What doesn’t work well	What would make it better
Information	Accessible	Inaccessible	Increase accessibility
	Accessibility of information easy as health professional	Contradictory information given	Psychoeducation (e.g., about health care system)
	Autistic social media groups a useful source of information		Provide complaint forms
	Clear information provided in advance to client/patient	Unclear information (e.g., medical jargon)	Ask (clinician) follow up questions to check understanding
	Client/patient prepared information shared in advance to practitioner	Inaccurate information	Consistent, accurate information shared across practitioners
		Requirements to access services unclear	Provide clear information in advance
		Measures to collect information not suited to Autistic interpretation/style/experience	Facilitate client sharing of information in advance of service
	Written summary of care	Information on aftercare not provided	Written summary of care
		Information on what is available unknown	Provide information on services available and quality
		Lack of information following diagnosis	Provide information about diagnosis and implications
		Unclear expectations	Information on service quality

Category	What is working well when available or offered	What doesn’t work well	What would make it better
Listening and validating	Engages with child as well as parent/carers		
	Listening and validating	Not being listened to, believed, or validated	Listening/validating and accommodating needs
	Trust and rapport	Distrust/fear of child safety involvement	
	Working collaboratively with autistic client/patient	Talked to support person instead of Autistic client/patient	Talking to Autistic client/patient (not support person)
	Working collaboratively with parents/families	Parents/carers excluded or not listened to	Consider input from parent/guardian/caregiver

Category	What is working well when available or offered	What doesn’t work well	What would make it better
Service gaps	Service gap being addressed (18-25-year-old mental health)	Mental health for 18-25-year-olds	Education and training options for parents/carers/ families
		Autistic women and girls	
		Complexity and intersectionality	Provide diverse solutions for diverse needs and groups
		Eating disorders	
		Family support	Whole family approach
		Health and mental health for children	
		Mental health services for adults in general	
		Mental health supports for crisis and suicide risk	
		Mental health supports non-crisis	Preventative mental health supports
		Mental health vs. autism services for adults	
		Reproductive health support for LGBTIQA+	
			Support services and groups for adults

Category	What is working well when available or offered	What doesn't work well	What would make it better
Sensory	Sensory adaptations	Aversive sensory environment	Adapt sensory environment
			Accessibility standards
Telehealth	Telehealth helpful	Telehealth challenges	Telehealth/e-health
	Help lines helpful	Phone helplines redirecting/poor support	Helpline for Autistic adults

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

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), participants discussed ideas relating to the benefits of Autistic practitioners, consistency of providers and services, stereotyping and stigma vs. understanding the individual, neurodiversity-affirming practice, gender and sexuality-affirming practices, feedback processes, restrictive practices, other specific mental health practices, trauma, as well as commenting on quality both high and low more generally within the area of services, see Table 3.

Table 3: Quality and safety (Element B): What is working well, what doesn't work well and what would make it better

Category	What is working well when available or offered	What doesn't work well	What would make it better
Autistic practitioners and insights	Autistic and neurodivergent health and mental health practitioners	Autistic practitioner barriers to disclosure	Support Autistic peer supports/professionals
	Autistic peer supports	Power imbalances between formal training and lived experience professionals	Autistic health and mental health practitioners
		Neurotypical professionals not understanding autism	Autistic people for mental health supports
			Autistic/neurodivergent liaison officers
Consistency	Consistent health and mental health practitioners	Inconsistent health and mental health practitioners	
	Consistent combination of supports	Inconsistent service delivery	
	Consistent service delivery		
Feedback processes	Giving feedback	Lack of complaints/grievance procedure	Provide complaint forms
			Complaints process followed
			Connection points (e.g., key contacts when problems arise)
			Regulation over providers
Individualising and understanding the person vs. stereotyping and stigma	Intersectional competence (e.g., culturally safe practitioners)	Stereotyping and stigmatising the individual	Understanding and tailoring care to the patient or client
	Providing non-speaking communication options	Intersectional biases (racism, homophobia, and transphobia)	Using social instead of a medical model of disability
	Understanding and tailoring care to the individual	Lack of intersectional competence	
		Assuming ability or inability (including based on communication modality)	Providing other ways to communicate

Category	What is working well when available or offered	What doesn't work well	What would make it better
Neurodiversity-affirming practice	Neurodiversity-affirming practices	Expecting Autistic clients or patients to fit neurotypical expectations or expressions	Neurodiversity-affirming practices
Gender and sexuality-affirming practice	Gender and sexuality-affirming practice	Non-gender affirming practice	
Quality	High quality experiences	Low quality experiences	
		Focus on quantity of life, not quality of life	Protection from harm (e.g., sexual abuse)
		Financially motivated services	Focus on quality rather than financial aspects
		Lack of resources	
Restrictive practices	Reduction or elimination of restrictive practices	Use of restrictive practices	Asking individual's preference regarding potentially restrictive practices
Specific practices for mental health	Specific practices experienced as helpful for mental health (e.g., Acceptance and Commitment Therapy [ACT]/ Mindfulness, adapted Dialectical Behaviour Therapy [DBT])	Specific practices experienced as unhelpful for mental health (e.g., Cognitive Behaviour Therapy, medication, mindfulness, weighing in-patients)	Providing alternative practices and adapting existing measures and practices to be more autism-specific
			Multidisciplinary approach
Trauma	Trauma-informed practice	Quality of care linked to trauma	Trauma-informed practice
			Respite rather than hospital to prevent trauma

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

In relation to Element C: Building better connections between health, mental health and other sectors including NDIS (**Connections and collaboration**), participants highlighted sharing information, fostering useful connections, information on connections, self and parent advocacy, and support coordination as areas working or not working well and as aspects that would make service coordination better, see Table 4. 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, health reception, support coordinators and workers. Conversely, they also shared negative experiences where there was a lack of connection between services, disconnect between funding and connections made, and unsuitable or undesired services being linked such as police or psychiatry. The role of support coordinators and examples where this had worked well, not worked well, and potential ways to strengthen this were also raised. Self-advocacy and parent advocacy were highlighted as being helpful, but also challenging to do by some participants. Finally, participants shared ideas for strategies that could foster more helpful, useful or meaningful connections across health and mental health services.

Table 4: Connections and collaboration (Element C): What is working well, what doesn't work well and what would make it better

Category	What is working well when available or offered	What doesn't work well	What would make it better
Advocacy	Self, parent/caregiver, lived experience, and professional	Challenges engaging in advocacy for stakeholders	Supporting stakeholders to advocate
Fostering useful connections	Fostering useful connections	Practitioners not connecting	New supports to build connections
		Inconsistent or unreliable support coordination	Provide lists of available services and support coordinators
		Local area coordinators not connecting	Connection to suitable services
	Providing information on supports that may be helpful	Referred to services not seeking	Risk assessment
		Police involvement for suicide risk	
		Poor communication leading to adverse outcomes	
Service/ Funding disconnect		Disconnect between hospital and community supports	
		Disconnect between different states/territories services	
		Medicare billing barriers	
		Service/funding disconnect	
Sharing information within and across services	Collaboration between government health/mental health services	Repeating story and/or information	Sharing key information between services

Category	What is working well when available or offered	What doesn’t work well	What would make it better
Support Coordination	Allowing community supports into hospitals	Service coordination (Phone assessment)	Accessing support coordination
	Positive experiences of support coordination	Support coordinators unprofessional conduct	Resourcing support coordination
	Support worker connecting	Lack of transition from child/young adult to adult services	Shorter waitlists for support coordination
		Poor quality/inconsistent or unreliable support co-ordination	Support coordinators with lived experience

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

In relation to Element D: Improving autism education and training for health and disability professionals (**Education and training**), participants identified health professionals' knowledge and understanding of autism including pain expression, intersectional understanding, and low self-efficacy working with Autistic clients as areas of professional competence that were both working and not working well, and that could be targeted via training to improve competence, see Table 5. While gaps in knowledge or understanding were identified, this extended to how practitioners responded to their own gaps with participants raising that acknowledging gaps and conducting research or learning from patients or clients was a helpful response to this. In contrast, not acknowledging or admitting knowledge gaps was raised as a concern and harmful for clients. Participants identified important components for future training to improve professional competence including who should be trained (all staff including reception teams), who should deliver training (with an emphasis on Autistic people delivering training for health and mental health professionals), consideration for training (incentives/ reimbursements and feasibility to fit practitioner needs) and the content of training.

Table 5: Education and training (Element D): What is working well, what doesn't work well and what would make it better

What is working well when available or offered	What doesn't work well	What would make it better
Acknowledging gaps in knowledge and open to learning or researching	Professionals not admitting or acknowledging gaps in knowledge	Training: What should be covered
Understanding and knowledge of autism	Not understanding or lacking knowledge of autism	Training topics: autism and heterogeneity, debunking stereotypes, disability broadly, eating disorders.
	Lack of awareness of specific accommodations	Training topics: adapting the environment
	Low self-efficacy to work with Autistic people	Training topics: neurodiversity-affirming/social model/strengths-based training, trauma-informed practice.
	Lacked autism content in university training	
Individualising supports to meet client/patient needs	Not understanding pain may be expressed or experienced differently	
Understanding intersectionality		Training considerations: compensation for services to upskill, feasible training modules for practitioners, and incentives to upskill
	Parents/carers/clients feeling forced to train or educate practitioners	Training: Who should deliver training: Training delivered by Autistic people
		Training: Who should be trained
		Training for all workers in health and mental health including management.

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

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**), results for research should be interpreted with some caution as fewer participants made comments relating to research. 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), see Table 6. 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 healthcare for Autistic people. Participants highlighted the diversity of Autistic people across what is working well, not working well, and how to improve research in the future. Areas only included in what would make it better were 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.

Table 6: Research and data (Element E): What is working well, what doesn't work well and what would make it better

What is working well when available or offered	What doesn't work well	What would make it better
	Lack of research on lived experience	Focus on lived experience across research phases
Autistic-led and participatory research	Non-Autistic academic researcher perspectives prioritised over Autistic perspectives	
Including diversity and intersectionality	Not understanding or including diversity or intersectionality	Include diversity of Autistic experience including children and young people
	Inaccurate interpretation of results	Knowledge translation (systems level, and via universities, social media)
	Focus on genetics and prevention viewed as problematic	Priority areas for future research (e.g., Autistic burnout, community bias, late diagnosis, quality of life, intersectionality and understanding heterogeneity)
	Lack of research into intersectional identities	
	Stigma a barrier to research participation	

2.4 What happens next?

These data will inform development of a final report that synthesises information across all phases to inform the Roadmap. Limitations however including limited representation of First Nations people and few comments on implementation should be considered and we recommend further community engagement and consultation activities implemented to address these gaps.

3. Context and method

3.1 Context and aims

The Department of Health and Aged Care is developing a National Roadmap to Improve the Health and Mental Health of Autistic People (henceforth the "Roadmap"). This is being informed through a co-design and community engagement process. This report forms part of the community engagement component of this process.

The aim of this work was to understand the needs, health and mental health care experiences and ideas for change from the perspective of Autistic people, their families and carers. The focused community engagement in this stage was primarily directed at those groups where less is known or understood about the unique experiences of these communities, referred henceforth as priority groups. The priority groups were identified by the Department of Health and Aged Care and the Roadmap Working Group and are:

- Women and girls
- LGBTIQA+ people
- People who are living in rural and remote areas
- People who are from low socio-economic backgrounds
- Culturally and linguistically diverse (CALD) people
- First Nations people
- People with high or complex disability needs, including:
  - high communication needs
  - high behaviour support needs
  - people in residential settings
  - people with intellectual disability
  - non-speaking.

Community engagement included focus groups and interviews facilitated through a National network of community partners including Autistic-led organisations, autism organisations and disability peak bodies. These partners have deep connections and trusted relationships in the Autistic community and with the priority groups. This was designed to yield rich insights and ideas for change in relation to the guiding principles and elements of the Roadmap, see Table 7.

Table 7: Overview of Roadmap elements

Element (Short title)	Main theme	Element name	Description
Navigation and access (Element A)	How Autistic people are supported by health and mental health services	A. Improving support for Autistic people, their families and carers in health and mental health	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: A. Ensuring information is accessible and aligned with preferred forms of communication to accommodate complex communication needs B. Making services more sensory friendly and better at accommodating people with varied communication needs, and C. 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.
Quality and safety (Element B)	The quality of care received in health and mental health services	B. Improving the quality, safety and availability of neurodiversity-affirming health and mental health care for Autistic people across their lifespan	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. Eliminating the use of harmful restrictive practices and ensuring neurodiversity-affirming approaches to behaviours of concern.
Connections and collaboration (Element C)	The way government and support services work together with medical and mental health services to support Autistic people and the way Autistic people navigate the systems	C. Building better connections between health, mental health and other sectors, including the NDIS	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. Providing Autistic people, Autistic advocates, and Autistic-led organisation, with up to date, accurate and relevant information to assist Autistic people navigate the health, mental health and other service systems.

Element (Short title)	Main theme	Element name	Description
Education and training (Element D)	Health professionals' knowledge of autism and capacity to support Autistic people	D. Improving autism education and training for health and disability professionals	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.
Research and data (Element E)	Research and data on health and mental health outcomes for Autistic people	E. Research and data on health and mental health outcomes of Autistic people and their families and carers	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 iniquities faced by Autistic people. Identifying opportunities for co-produced research and improved research translation that reflects the priorities of the Autistic community.
Implementation and evaluation (Element F)	The way the roadmap is implemented	F. Arrangements for oversight, monitoring, and implementation	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 Autistic community in areas such as: A. 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 B. Implementation timeframes, and C. Monitoring and evaluation and reporting framework

3.2 Recruitment and participants

3.2.1 Recruitment

The project delivery team consisted of Autistic and non-Autistic Autism CRC and Griffith University personnel. This team worked with specialist community partner organisations to reach and engage Autistic Australians from the priority groups (see section 2.1). A comprehensive Community Engagement Partner Toolkit was provided to community partners to support recruitment for focus groups and interviews. The Community Engagement Partner Toolkit included:

- Background information about the Roadmap
- Frequently Asked Questions
- Suggested recruitment emails and communications designed to be adapted by community partner organisation
- Suggested script for focus group facilitators
- A Participant Guide for Focus Groups and a Participant Guide for Interviews, including the questions that would be asked, accessibility information, an introduction to facilitators (with photos), and information about what to do if people feel stressed or upset before, during or after the engagement
- A one-page "Quick Guide" with important information for community partners and participants.

Participants were invited to read an online Participant Information Statement (available in Plain English and Easy Read formats) and complete an online Expression of Interest [EOI] form collecting demographic information about their age, location and information related to the priority groups. Participants were also invited to identify their preferred method of engagement (focus group or interview). Focus group participants provided consent to participant via this form. Participants interested in being interviewed were directed to provide consent at the same time as they scheduled their interview via an online scheduling calendar, which enabled them to choose a time that suited them. All participants were invited to provide information about accessibility needs that would help them to feel comfortable and participate meaningfully. A closed recruitment process was used, which involved organisations sharing the advertising materials directly to targeted individuals within their networks rather than through open, publicly available channels such as social media. This targeted recruitment process focused on priority groups and safeguarded against participation of non-genuine respondents due to the potential enticement of gift cards ($50 per person).

The community engagement period officially closed on 22 December 2024 with no further recruitment beyond this date. However due to participant illness and organisation scheduling challenges, some community engagement activities continued into January.

3.2.2 Participants

The focus groups and interviews focused on Autistic people who identify as belonging to one or more of the seven priority groups. Families and carers and professionals working with Autistic people were also engaged to understand their perspective and experience in supporting Autistic people, particularly those with high or complex disability needs.

The findings within this report are based on data collected or received by Griffith University from Autism CRC and community partners by 15 February 2024. A total of 107 individuals participated across six focus groups (*n* = 55) and individual interviews (*n* = 52).

Table 8 provides an overview of priority group participation and demographics of participants. Priority group membership was determined based on EOI responses combined with information shared in interviews. Participants included a mixture of ages and genders, including individuals who identified as Autistic (*n* = 66), parents/carers of Autistic people (*n* = 54), and professionals working with Autistic people (*n* = 26). Please note that many participants identified with two or more priority groups and/or personal status categories.

Table 8-1: Group participation and demographics by priority group

Participant demographic information	Interviews *n* = 52	Focus groups *n*= 55	Total *n* = 107
People with high or complex disability needs	38	16	54
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	17
Non-speaking/Unreliably speaking	12	7	19
First Nations people	2	1	3
Culturally and linguistically diverse people	7	22	29
LGBTIQA+ people	16	31	47
Women and girls	29	41	70
People who are living in rural and remote areas	16	18	34
People from low socio-economic status backgrounds	16	19	35

Table 8-2: Group participation and demographics by personal status

Participant demographic information	Interviews *n* = 52	Focus groups *n*= 55	Total *n* = 107
Autistic person	27	39	66
Parent, carer or guardian of an Autistic person	32	22	54
Autistic person who is also a parent, carer or guardian of an Autistic person	13	17	30
Parent, carer or guardian of an Autistic person with high or complex support needs	21	19	40
Parent, carer or guardian of an Autistic person from another priority group	15	12	27
Professional who works with Autistic people	13	13	26
Autistic person who is also a professional	5	13	18

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

Note: Many participants identified with two or more priority groups and/or personal status, so total numbers equal more than 107. Where demographic information was not provided, total numbers equal less than 107.

Table 8-3: Group participation and demographics by age group

Participant demographic information	Interviews *n* = 52	Focus groups *n*= 55	Total *n* = 107
< 18**	1	0	1
18 to 24	1	0	1
25 to 29	3	2	5
30 to 39	5	6	11
40 to 49	7	12	19
50 to 59	12	16	28
60 to 69	12	5	17
70 or over	5	0	5
Prefer not to answer, or age not disclosed	6	7	13
Age group data collected in different brackets by community partner	0	7	7

*** <18 years of age individual was interviewed with guardian.*

Table 8-4: Group participation and demographics by gender

Participant demographic information	Interviews *n* = 52	Focus groups *n*= 55	Total *n* = 107
Male	15	8	23
Female	33	32	65
Non-binary	4	13	17
Prefer not to answer, or not identified	0	2	2

Table 8-5: Group participation and demographics by State or Territory

Participant demographic information	Interviews *n* = 52	Focus groups *n*= 55	Total *n* = 107
NSW	6	8	14
VIC	14	22	36
QLD	1	4	5
SA	6	14	20
WA	7	2	9
TAS	16	2	18
NT	1	0	1
ACT	1	0	1
Unknown/no details provided	0	3	3

3.3 Data collection measures and process

The interview and focus group questions were developed through an iterative co-design process with Autistic and non-Autistic members of the project delivery team. The initial step involved a review of the Roadmap elements and objectives, identifying main themes and potential research questions. This formed the basis for developing the draft interview and focus group questions, ensuring their alignment with the Roadmap elements, see Table 7.

The draft interview and focus group questions then underwent multiple rounds of iteration, incorporating feedback from the project delivery team, Autistic advisors and the Department of Health and Aged Care. The purpose of which was to ensure accessibility to participants, and effectiveness and relevance in capturing meaningful insights to inform the Roadmap.

The interviews and focus group inquiries invited participants to reflect on their experiences of accessing and using health or mental health care services, through a series of open-ended questions, see Table 9. These were provided to participants in advance as part of confirmation of their focus group session, and within the booking process and confirmation of the interview sessions.

Table 9: Focus group and interview questions

Question 1: Think of a time or times when you needed to find out about or make an appointment for a health or mental health service:
What worked well?
What didn't work well?
What would make it better?
Question 2: Think of a time when you had to use a health or mental health care service. This could include seeing a doctor, or psychologist for example:
What worked well?
What didn't work well?
What would make it better?
Question 3: Is there anything else you would like us to know about your experience, or how the Australian Government might improve health or mental health services?

Additional prompt questions aligning with the Roadmap elements were asked to elucidate further information if required (e.g., if participants shared mental health experiences only, they were prompted to share health experiences) or to address specific Roadmap elements.

The **focus groups** used the Zoom platform, which tends to be well understood and accessible to participants. All Zoom meetings were configured to have a waiting room, and to allow for continuous chat, session recording, closed captioning and participant video to be on or off.

Individual **interviews** were conducted in person (for individuals willing to travel to one of our community partners for on-location interviews), or online using Microsoft Teams or Zoom where this was unavailable or the preference of the interviewee. Interviews were recorded (audio for in-person, video for online) with participants' consent for transcription.

Interviewers/facilitators included Autistic and non-Autistic people, taking into account the stated preferences of participants (e.g., if requested a specific team member or Autistic person was requested for the interview). All interviewers had expertise in autism and mental health.

In addition to focus groups and interviews facilitated in-person or online, participants were also given the option to provide written or video/audio pre-recorded responses to the interview questions. This enabled time for people to prepare, process information and respond meaningfully, considering the diverse communication needs of respondents.

3.4 Coding and data analysis

Interviews and focus groups were transcribed using computer automated transcription and were then manually checked by researchers for accuracy. The accuracy of interview transcripts were additionally checked by e-mailing transcripts to each interview participant. This provided the participant an opportunity to make revisions, edits or add additional comments which were then included in transcripts for analysis. To safeguard the confidentiality of individual participants in the focus groups, transcripts were sent to the focus group facilitator for checking in a similar manner.

All participants were offered the opportunity to provide additional information in their desired format (e.g., email, text, or submission of image/video/audio) within seven days of their participation. Any feedback received in this manner was added to the transcripts and subsequently included in coding. Transcripts were de-identified to protect the identity of participants, including removing names of people, organisations, and specific locations (e.g., Coomera may be replaced with “Queensland city”, postcodes re-coded into regions).

De-identified transcripts were analysed using directed content analysis. Using this method, transcripts were first coded by pre-defined categories, in this case, the Roadmap elements. Then within elements they were coded into subcategories of experiences of what works, what doesn’t work, and ideas for improvement for each participant. Then within these existing categories and subcategories, codes were developed to describe specific ideas arising (e.g. long waitlists as an example of what doesn’t work). Codes were discussed across the team of Autistic and non-Autistic researchers until consensus was reached. Discussion related to appropriate name/concept for the code and which category (i.e. Roadmap element) it best fitted under.

For each participant, the presence of each code was documented in an excel spreadsheet along with one representative quote. The number of transcripts that mentioned each code by priority group were then compared and grouped into percentages to show trends of ‘code raised’ vs. ‘not raised’ and an indication of frequency. Due to the small participant numbers in the First Nations group (n = 3) these data are not compared as meaningful comparison was not possible. Further due to smaller subgroups (e.g., n = 9 interviews included high communication needs) within the complex and high support needs, the larger category was compared only. Results were tabulated by element and what works/what doesn’t work/ideas for improvement, and colour coded for being never raised (white), raised sometimes (up to 24.9% of participants in a group), often (25-74.9%) and frequently (75% or more) within each priority group. Given the relatively small group sizes for quantitative comparisons, colour coding rather than numerical data were determined to be the more meaningful level of comparison to understand trends across groups and should be interpreted tentatively. Key differences and similarities were extracted for group comparisons that were common (e.g., >50% in one group and rare in others) or salient (e.g., consent while rarely mentioned was associated with significant distress and was thus extracted).

Data has been extracted to illustrate within each Roadmap element what is working well, what does not work, ideas for improvement and group comparisons. Please note the results should be interpreted as representing a range of ideas from a sample of individuals and should not, and are not intended to, be used to generalise to all Autistic people.

4. What we found

The majority of comments related to Navigation and access (Element A), with only a few comments relating to Research and data element (Element E), and rare comments on Implementation and evaluation (Element F). Due to the paucity of data on Implementation and data this element is not included in this overview of results.

Findings are presented by Roadmap element. For each element, the following are included:

- an overview of what works well, what does not work well, and what would make it better
- sub-sections providing detailed information on what works well followed by what does not work well, then what would make it better. Each of these sub-sections includes illustrative quotes and provides comparison tables by priority group.

Please note, with regard to quotes:

- square brackets (i.e. [ ]) indicate clarifying or contextual information added
- round brackets (i.e. ( )) is how the participating person provided this information in written form (e.g., chat in video interview, email content)
- P# = participant number (for interviews)
- FG# = the focus group number the person participated in.

Linguistic elements, such as “ums” and “ahs,” were edited or omitted from direct quotes for the purpose of clarity and readability.

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

In relation to Element A: Improving support for Autistic people, their families and carers in health and mental health (**Navigation and access**), the overall areas covered by participants were: access; affordability; appointment/service choice and flexibility; consent; information; listening and validating; service gaps; and, sensory (see Table 10). These areas are used as subheadings due to the large number of concepts covered in this element. Some (e.g., service gaps) were predominantly identified as areas that were not working well, whereas others were predominantly identified as areas working well (e.g., service choice and flexibility) as outlined below.

Access included general feedback of experiences both positive and negative, booking systems, diagnosis, finding services that meet needs or funding, personal characteristics that made access challenging, physical navigation and specific barriers related to psychiatrist and GP referrals/scripting. A mixture of easy, hard and overwhelming access experiences were described. Participants who identified as having professional networks or Autistic networks where they could learn about available supports through word of mouth were more likely to find finding it easy to access services. However, many participants raised challenges with initial access, including not knowing what was available.

Difficulties finding autism-specific services were raised, while providing listings of autism-friendly services were suggested as a possible solution that may address this. Waitlists were raised as problematic across a range of services including GPs, allied health professionals, hospitals, and broadly both health and mental health. Some participants shared using private care to mitigate, although raising the barrier of affordability for others. Broadly the need for more practitioners was raised as needed across both health and mental health.

Participants reported mixed experiences when making **bookings**. A range of preferences from preferring to disliking online or phone bookings were raised. This highlights the need to offer a range of booking approaches, and flexibility/choice rather than a single approach for all.

Formal **diagnosis** was raised as a barrier to accessing health and mental health care services. Mixed feedback on accessing a diagnosis was reported for both adults and children. Stigma was raised as a barrier to seeking a diagnosis. Barriers to accessing a diagnosis in terms of affordability and misdiagnosis were also expressed for adults.

Finding services to meet an individual's specific needs, and **gaps in service provision**, were raised mainly as negative experiences (with the exception of home visits being helpful) across a range of areas and groups. These included both crisis and non-crisis mental health supports for children, early adulthood (18-25) and adults more broadly, which are discussed in more detail in 3.1.2.

Personal characteristics such as differences in communication style, executive functioning, expression of pain, and interoception were raised as mainly barriers to access. Some positive experiences of supports for executive functioning including text reminders and potential future solutions of providing supports were raised by some participants.

Physical navigation and transport, and GP/Psychiatrist areas were only raised in regard to what did not work, for more detail see 3.1.2.

In terms of **affordability**, positive experiences included accessing bulk-billing and low-cost services (including using Mental Health Care Plans) and NDIS-funded supports. Negative experiences included needing to self-fund high-cost diagnostic and functional assessments for access to supports such as NDIS, changes and cuts to NDIS supports reducing access availability and leading to significant stress, and out-of-pocket costs. Potential solutions were shared in this area including greater Medicare funding for assessments, increasing the number of sessions of Mental Health Care plans (MHCP, e.g., back to 20) and referrals for more sessions at a time before needing to revisit GPs (e.g., increasing from 4 or 6).

Appointment choice/flexibility included several helpful experiences including phone lines being helpful and having choice in timing, making bookings in advance, flexibility in (re)scheduling, modality, and session length. Similarly, participants shared having flexibility in session length would be helpful in future. Mixed feedback on telehealth was shared with some participants finding it helpful or suggesting greater access to telehealth/e-health would be beneficial, however other participants raised telehealth being challenging for them. Of concern, **consent** being ignored or a lack of informed consent were raised.

Information provided yielded differing feedback on whether it had or had not worked well and solutions. The only area where there was alignment was around aftercare, where a lack was experienced as a negative experience and provision of written summaries of care as helpful, as well as being recommended for future implementation.

Health and mental health practitioners **listening to, believing and validating people** was raised as a negative, positive, and future solution. Further challenges raised were not listening to supporters or conversely, talking only to supporters. Talking and involving the patient/client to the fullest extent possible was raised as a crucial factor in making support better in future.

Service gaps were predominantly discussions of negative experiences, see 3.1.2 for further discussion. One exception was an experience where a service gap (for young adults transitioning to adult services) was raised and addressed.

The **sensory environment** of health and mental health services was identified as a negative, positive, and an area for future change. Adaptive and low-sensory experiences were raised as positive experiences. Conversely, bright lights, noise, and a lack of flexibility in the environment and poor built environments (e.g., low quality physical environment mid renovations) were raised as negative experiences. Ways to improve navigation and access in future raised included adapting sensory environments and implementing accessibility standards that included sensory access and sensitivity, see section 3.1.3 for further discussion.

Table 10: Navigation and access (Element A): What is working well, what doesn't work well and what would make it better

Category	What is working well when available or offered	What doesn't work well	What would make it better
Access (general)	Positive help-seeking experiences	Negative help-seeking experiences leading to avoiding services due to access barriers or prior/ potential harm.	Improved access to services
	Recommendations from word of mouth, online, social media groups, and autism associations	Finding autism-specific services/reputable service providers	Autism-friendly clinician lists
	Short waitlists	Long waitlists	More practitioners
	Private care	Waiting on specific day and inflexibility for lateness	Home visits/services
		Difficulties finding/navigating services including being overwhelmed by process	Improve access to services
		Unsupportive staff	Autism-specific services/health practitioners who have a specialised understanding of autism
			More subsidised Mental Health Care Plan sessions
			Services (more affordable and easier to navigate)
			Systemic change

Category	What is working well when available or offered	What doesn't work well	What would make it better
Access: Booking systems	Online bookings including provider biographies	Online bookings only	Online or email booking being available
	Phone booking made by family member	Phone bookings only	In-person bookings being available
	Provider makes contact for booking	Email or online bookings unavailable	
	Support worker assists with booking and attending appointments	Unable to contact	
Access: Diagnosis	Adult diagnosis accessible	Adult diagnosis hard to access and misdiagnosis	Earlier diagnosis to facilitate supports
		Adolescent diagnosis hard to access	Medicare funding for diagnosis
		Barriers to access from late diagnosis not taken as seriously	Understand the implications of diagnosis
	Child diagnosis accessible	Earlier detection/ identification needed to get help or improve health/mental health	
		Needing formal diagnosis to access services	
		Stigma around diagnosis	Reduce stigma and negative implications around diagnosis
Access: Finding services that meet needs or funding	Home visits/services		
	Carer support	Difficulty finding services for adults	
	Getting services recommendations from websites and social media groups	Difficulty finding services that meet individual needs	
	Word of mouth	Regional and remote lack services	
	Recommendations from autism associations	Religious affiliations of organisations a barrier	
		Restricted to NDIS clients only	

Category	What is working well when available or offered	What doesn't work well	What would make it better
Access: Personal characteristics	Building strengths to support access (e.g., interoception)	Personal challenges to access: executive functioning, interoception, and differing communication or responses	Executive functioning supports
	Text reminders		
Access: Physical navigation and transport		Physical navigation, transport, distance and cost	Innovative modalities (e.g., virtual reality)
Access: Barriers to GPs and psychiatrists		GP "bottleneck" for access	
		Medication shortages and scripts	
		Needing to correct reports	
		No regular GP to make referrals	
Affordability		Needing to self-fund assessments	
	Mental health care plans	Cost of diagnostic assessments	
	Bulk-billing and low-cost services	Out-of-pocket costs	Improve or broaden access to Mental Health Care Plans
	NDIS-funded supports	NDIS driving price increases	
		Private health care limitations	

Category	What is working well when available or offered	What doesn't work well	What would make it better
Appointment/ Service choice and flexibility	Appointment choice (when)	Appointment choice lacking	Appointment flexibility
	Bookings made in advance	Appointments times are not long enough	Modality flexibility/availability
	Flexibility in appointments/rescheduling		Session length flexibility
	Flexibility in modality		
	Flexibility in session length		
Consent		Consent (treatment wishes) ignored	
		Lack of informed consent	
		Complexities around consent for parents/ guardians of Autistic adults who do not have capacity to provide informed consent themselves	

Category	What is working well when available or offered	What doesn't work well	What would make it better
Information	Accessible	Inaccessible	Increase accessibility
	Accessibility of information easy as health professional	Contradictory information given	Psychoeducation (e.g., about health care system)
	Autistic social media groups a useful source of information		Provide complaint forms
	Clear information provided in advance to client/patient	Unclear information (e.g., medical jargon)	Ask (clinician) follow up questions to check understanding
	Client/patient prepared information shared in advance to practitioner	Inaccurate information	Consistent, accurate information shared across practitioners
		Requirements to access services unclear	Provide clear information in advance
		Measures to collect information not suited to Autistic interpretation/style/experience	Facilitate client sharing of information in advance of service
	Written summary of care	Information on aftercare not provided	Written summary of care
		Information on what is available unknown	Provide information on services available and quality
		Lack of information following diagnosis	Provide information about diagnosis and implications
		Unclear expectations	Information on service quality

Category	What is working well when available or offered	What doesn't work well	What would make it better
Listening and validating	Engages with child as well as parent/carers		
	Listening and validating	Not being listened to, believed, or validated	Listening/validating and accommodating needs
	Trust and rapport	Distrust/fear of child safety involvement	
	Working collaboratively with autistic client/patient	Talked to support person instead of Autistic client/patient	Talking to Autistic client/patient (not support person)
	Working collaboratively with parents/families	Parents/carers excluded or not listened to	Consider input from parent/guardian/caregiver

Category	What is working well when available or offered	What doesn't work well	What would make it better
Service gaps	Service gap being addressed (18-25-year-old mental health)	Mental health for 18-25-year-olds	Education and training options for parents/carers/ families
		Autistic women and girls	
		Complexity and intersectionality	Provide diverse solutions for diverse needs and groups
		Eating disorders	
		Family support	Whole family approach
		Health and mental health for children	
		Mental health services for adults in general	
		Mental health supports for crisis and suicide risk	
		Mental health supports non-crisis	Preventative mental health supports
		Mental health vs. autism services for adults	
		Reproductive health support for LGBTIQA+	
			Support services and groups for adults
Sensory	Sensory adaptations	Aversive sensory environment	Adapt sensory environment
			Accessibility standards

Category	What is working well when available or offered	What doesn’t work well	What would make it better
Telehealth	Telehealth helpful	Telehealth challenges	Telehealth/e-health
	Help lines helpful	Phone helplines redirecting/poor support	Helpline for Autistic adults

4.1.1 Navigation and access (Element A): What is working well

Participants reported areas relating to access, affordability, appointment flexibility, information, listening and validating, service gaps being addressed, and sensory adaptations as working well in the element of **navigation and access**, see Table 11. For group comparisons see Table 12. The most common areas identified as working well when present/available were when clients/patients felt listened to and believed, when there was available access to services (e.g., increases in services available over time), when sensory-friendly environments were available, and telehealth.

In terms of **access**, participants shared positive experiences how they were able to find help, where they were able to access help easily including benefits of private health care, while acknowledging this is not available to all. Positive experiences were more often shared (often however in contrast to challenging ones as covered in 3.1.2) by individuals reporting on or experiencing high/complex disability needs or living in rural and remote areas. **Booking systems** were raised as a specific area that facilitated access including being able to book online with accompanying biographies or information about providers online, having supporters (support workers, partners, family members) make phone bookings or providers making contact to arrange bookings. Participants shared positive experiences of affordable and timely child and adult **diagnoses** including through GPs, hospital in-patient supports, psychologists via payment plans, and through telehealth. Finding services who were willing to provide services in home visits was raised as a positive, although it should be noted this was also (see 3.1.2) at substantial expense. Text reminders and building skills to identify health care needs (e.g., building interoceptive awareness) were raised as helpful in supporting access.

Participants shared aspects that supported **affordability** of health and mental health. This included accessing supports via NDIS and Mental Health Care Plans, as well as via bulk-billing medical and mental health services, and low/no-cost options such as university clinics for mental health supports.

Appointment flexibility accommodations were raised as helpful. These included making a series of bookings in advance, being flexible and allowing rescheduling when appointments are missed or forgotten, offering of **telehealth** and help lines and allowing flexibility in shifting between modalities depending on needs on the day (e.g., telehealth, in-person, and phone). The latter was most commonly raised by culturally and linguistically diverse participants.

Participants shared positive experiences accessing health **information**. This included where information was accessible via online information and autism service providers, as well as finding social media groups run by Autistic people. Finally, sharing of information in advance for medical procedures and written information to summarise care instructions afterwards were viewed as beneficial.

Providers **listening** to mental and physical health experiences was raised as valuable for adults and children across all groups. This extended beyond listening to meaningful engagement with the Autistic person and their supporters (e.g., family), having a strong relationship and good rapport, as well as **validating** experiences and respecting autonomy, as described in this participant quote:

> *"...the best therapists I've had and also like health professionals are really affirming and like, they respect my autonomy and they meet me where I'm at" (P1).*

Addressing a service gap was raised as something that had worked well. Specifically, a participant discussed her mother advocating for the need for services for young adults transitioning from youth mental health care to adult services, and the difficulties experienced when placed with adults of varying ages and mental health needs (P102). She shared that a new service was developed for young people in response to her mother's advocacy.

Finally, **sensory** adaptations were raised as working well. This included providing sensory supports such as fidgets and bean bags, low sensory environments such as dimmed lighting or music turned off or down and reducing the number of people in waiting areas.

Table 11: Navigation and access (Element A): What is working well when available or offered

Category	What is working well when available or offered	Illustrative quotes
Access (general)	Positive help- seeking experiences	“I've had a few that haven't been able to help, but for the most part, everybody, the people that I've contacted have actually been available.” (P4)
	Private care	“I've always put them into private paediatricians. I find I've got better support the private system... It is better than the public... I can get the children in there when I need. And I know from the hospital you just you cannot. As I said, most foster children do go through the public system, and I have found that my experiences have been much better than what I hear other people talking about.” (P34) “...my GP said, do you wanna try private? And I said yes. And it was just such a markedly different experience...” (P63)
Access: Booking system	Online bookings	“What worked well was being able to book online, so I am one of those autistic slash millennials who will not pick up the phone if I can avoid it. So being able to book online makes such a difference, and it means that I'm actually going to make that appointment. Whereas if I have to call, I'm probably not going to.” (P16) “...our GP, so their service has an app that they use. So, I don't have to ring, I don't have to go in there. I can just go on my app any time of day or night. Look [at] when my GPs available, when my kids [are], 'cause they always have lots of appointments and just sort of say, right. That you, I can look at my calendar and tee it all up and be like, right. That, you know, at that time suits me really well. And that to me is really, really helpful.” (P63)
	Online booking systems including provider biographies	“I guess the most helpful is just having online booking system. And then also having descriptions and bios of each doctor to choose...That is what I do. I just look at each doctor and then, or whatever it is, and then just decide who I like.” (P124)
	Phone booking made by family member	“I can get my partner to make the phone calls.” (FG3)
	Provider makes contact to book	“...they [health care provider] referred me to them and then I called them up and like they called me up, which is great cause they called me up rather than me call them up. And we connected and then I got the appointments that I wanted.” (P43)
	Support worker assists with booking and attending appointments	“So, the first appointment, I had a support worker help me make it.” (P106)

Category	What is working well when available or offered	Illustrative quotes
Access: Diagnosis	Adult diagnosis accessible	"I did it [autism diagnosis] via telehealth [...] so that brought it [the wait-time] forward by about three or four months." (P8) "...she was able to work with me and my limited financial means to actually get me diagnosed.... She was like, 'I know we can organise, you know, we'll organise a payment plan. That's not a problem. You know, as long as you can make regular payments towards it and pay it off." (P4) "... two weeks or whatever... the hospital got someone in...I didn't have to wait like months and months and months...I didn't have to pay anything." (P104 describing receiving a diagnosis during an inpatient mental health admission as an adult)
	Child diagnosis accessible	"With (daughter), it was very easy. She was diagnosed when she was 2." (P34)
Access: Finding services that meet needs or funding	Carer support	"Their ability to access the services will directly relate to the help that they get and the quality of their caregivers, you know, they'll have to have really good caregivers that really care about them and work with the, with the professionals to actually get them [individuals with more complex disability and/or cooccurring intellectual disability] the help that they need."
	Home visits/services	"...until the NDIS came into our house, thank Christ. And we were able to then finally access those services. And my support coordinator found me a doctor that will come to me, which is great, and I've seen her twice now." (FG3)
	Getting recommendations from websites and social media groups	"...having access to information, digital information has been really helpful in enabling me to find a therapist and match them to my needs." (FG4) "...when I had to find a gynaecologist... I asked...[name] autistic adult support group online who'd they use. And they came with this name. So that's why, that's generally the way I find, find people now asking who other like, but just asking other autistic people." (P124)
	Recommendations from autism associations	"...speaking to other people in our community [from the autism associations] has been so helpful. I got so much help and information from other people that helped me skip some of the hurdles and trauma of diagnosis and has now been so useful in just finding what I need." (FG4)
	Word of mouth	"...person to person has been the best way to find out about people." (P28)
Access: Personal characteristics	Building strengths to support access (e.g., interoception)	"I've been able to develop my interoception, and now getting early warning signs of stress in my body and able to do things to help myself." (FG1)
	Text reminders	"...text to remind you of the appointment." (FG3)

Category	What is working well when available or offered	Illustrative quotes
Affordability	Bulk-billing and low-cost services	“I'm on a pension and he [GP] bulk-bills me.” (FG3) “I am seeing a psychologist once a month through my university, which is fantastic because it's free.” (P3) “She [Paediatrician] was willing to bulk, this is private, but she was willing to bulk bill 'cause they were telehealth…” (P63)
	Mental Health Care plan	“When I talked to my GP, she had the Mental Health Care Plan and that was really helpful because of the cost is covered and I didn’t have NDIS yet.” (P1)
	NDIS-funded supports	“…now that I'm an NDIS participant I can access the support I choose to access.” (P8) “…since I've had the NDIS, I've been using a private psychologist.” (P4)
Appointment/ Service choice and flexibility	Appointment choice (when)	“…being able to get the appointments that suited me when I wanted them.” (P63)
	Bookings made in advance	“…we always make an appointment for about six weeks, three to six weeks in advance, long appointment that I can actually cut down or cancel.” (FG3)
	Flexibility in appointments/rescheduling	“…a lot of the services I have accessed have had like a level of flexibility to them, that's been pretty good. There's also been, at least my therapist has been like a level of understanding so I can, you know, if I've incidentally missed an appointment, I can just message her and be like, ‘Hey, sorry I missed this.’ And she'll be like, ‘That's okay, we can reschedule.’ Like there's no pressure to it.” (P5).
	Flexibility in modality	“He engages with people in whatever way or platform is best for them. So, if they can't make a phone call, they can send a text message number of times I text message to assistant and say, can I, can I do telehealth by text today?” (FG3)
	Re-scheduling	“A lot of the services I have accessed have had like a level of flexibility to them… my therapist has been like a level of understanding so I can, you know, if I've incidentally missed an appointment, I can just message her and be like, ‘Hey, sorry I missed this.’ And she'll be like, ‘That's okay, we can reschedule.’ “ (P55)
	Flexibility in session length	“…he (GP) also does things like he makes 30-minute appointments as his standard appointment time.” (FG3)

Category	What is working well when available or offered	Illustrative quotes
Information	Accessible	"...if there's online material and it's clearly designed and it's spaced out and there's all the information that's there." [positive] (FG2) "I was looking recently at the, I think it was the [autism organisation] website. Yeah. It had some resources. I didn't, didn't look at it much, but it seemed like that might be useful." (P58)
	Accessibility of information easy as health professional	"I think I'm a bit of a, like, extraneous case example. Like I, I'm, you know, a highly qualified professional. So, for me, accessing that information is really easy. Often 'cause I know the people, so it's like not hard for me." (P63)
	Autistic social media groups a useful source of information	"Peer support online. There's a couple of groups that I'm a part of on Facebook that we will say like, who knows a great psychologist who would help me deal with this condition and that is in my area, and I can afford kind of thing. Those peer reviews I will take a hundred times over than Google." (FG2) "Someone put me onto a Facebook group and that's where I got all my information from another group of parents who had been through it all before you know all those things ..." (P15)
	Information prepared by client in advance to share with practitioners	"I have a script/letter now for getting blood tests so that I don't need to explain sensory issues and my vasovagal response every time (especially since it is often dismissed or I feel judged)." (FG4)
	Clear information provided in advance	"...they quietly explain to me everything that was gonna happen." [in a breast examination following a negative experience] (P103) "If accommodations can be made, especially in the if information can be given early and I like to read so I like her, she like, you know, it was really useful to see what I've done was really useful for me to download those questions and write a whole bunch of stuff." (P103) [Discussing a recent surgery] "...they send you out lots of information about what things will look like on the day, what to expect. I'm just gonna follow up. And that was so helpful 'cause I could read it all... I was all well prepared for." (P63)
	Written summary of care	"And then in the end, he will write down notes or points that I can take away with me is just a very brief synopsis, right?" (FG3)

Category	What is working well when available or offered	Illustrative quotes
Listening and validating	Engages with child as well as parent/carers	"Yeah, she's [family GP] very good at actually speaking to the kids themselves and giving them agency as well. Especially as they're getting older, yeah, really, really engages with them and that's been like a really good thing." (P35)
	Listening and validating	"...he'll [psychologist] sit when I say to him, I look, I'm really sensitive to noise and that he'll really listen and take that on." (P52) "My daughter's psychologist. They were lovely, understanding. Very helpful. They believed us and respected us and worked with us to find strategies to improve mental health outcomes." (P3) "The GP that listened to me and sent me to specialists to check things out. She was lovely. She was very helpful, and I felt supported and believed." (P3)
	Trust and rapport	"...it's relationship, I suppose it's about understanding the importance of the relationship has been the key." (P61) "I think like the one, the one thing that comes to mind in terms of access is that so much of developing like an early rapport with a, a mental health professional. And determining whether they're going to be the right fit for you..." (P59)
	Working collaboratively with autistic client/patient	"...have the approach of joining with them and working together as a bit of a team." (P61)
	Working collaboratively with parents/families	"Any problems, they talked to me as well. They don't keep me out of the loop. They keep me in the loop." (P27)
Service gaps	Service gap being addressed (18-25-year-old mental health)	"...like it was for people that were like, I think 16 to 21 and it was like a like a step up from, you know, it was probably a step, I don't know how it works step up step down but a different thing from hospital inpatient mental health care." (P102 discussing new service being developed in response to gap)
Sensory	Sensory adaptations	"The entire area was set up in ways that were quite sensory as well. So, you know, they had fidgets and they had bean bags, and they had rooms that you could go and relax in, with recliners." (FG5) "They changed the lighting down...It wasn't like all these bright lights shining down..." (P103) "Much quieter [at new GP office].There's no music blaring. Nobody yells. They're friendly and there's only, you know, maybe three or four people at a time in the waiting room. It's a much calmer environment." (P19)

Category	What is working well when available or offered	Illustrative quotes
Telehealth	Telehealth helpful	“But my current sessions, we do them over Zoom generally and I really like it.” (P55) “…there's so many reasons that telehealth makes it easier… I've noticed that I'm mask less on telehealth or Zoom, and things like that. I have no idea why. Maybe it's because I'm in my environment and so I'm in control of all of that. Or maybe it's that even though I know the person on the other side is absolutely real person, like I don't maybe see all of the body language that I would normally like stress about or interpret. As you know, potentially like judgment or negative feelings and stuff like that. So, I'm not as worried about all of that.” (P19) “…some of the telehealth services have continued [since COVID], which is good. Also, sometimes because of chronic illness, I can't get places.” (P1)
	Help lines helpful	“I have found the Suicide Call-Back Service to be helpful sometimes. I have also found 1800 Respect web chat to be very helpful (that's not specific mental health).” (FG5) “I only mainly had access to things like Kids Helpline, which is up to 25…But like other than that, I mean, and I would really say they're a great service.” (P102)

Table 12: **Navigation and access (Element A): What works well when available or offered – Group comparison**

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Access (general)	Access	C	A	B	B	C	B
	Private health care	B	A	B	B	A	A
Access: Booking system	Access (online booking services)	A	A	B	B	B	A
	Access: booking system: Support workers assistance with access and attending appointments	B	A	A	A	B	B
	Access: getting recommendations from autism associations	A	B	B	A	A	A
	Online booking	B	A	B	A	A	A
	Online booking including provider biographies	B	A	B	B	A	B
	Phone booking by others	A	A	A	A	B	A
	Provider makes contact to book	B	A	A	B	A	A
Access: Diagnosis	Child diagnosis is accessible	B	A	A	B	B	B
	Adult diagnosis is accessible	B	A	B	B	B	B

Legend

Percentage of participants per group raising idea	0%	Up to 24.9%	25-74.9%	More than 75%
Band	A	B	C	D

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Access: Finding services that meet needs or funding	Carer support	B	A	A	A	B	B
	Home visits/services	B	A	A	A	B	A
	Getting services recommendations from websites and social media groups	B	A	B	B	A	B
	Word of mouth	B	A	A	B	B	B
Access: Personal characteristics	Personal strengths building to support access	B	A	A	B	A	B
	Text reminders	A	B	A	B	B	A
Affordability	Bulk-billing and low-cost services	B	B	B	B	B	A
	Mental Health Care Plan	B	A	A	B	B	B
	NDIS funded supports	B	A	A	B	B	B
Appointment/ service choice and flexibility	Appointment choice (when)	B	B	B	B	A	A
	Bookings made in advance	B	A	A	B	B	A
	Flexibility in appointments/rescheduling	A	A	B	A	B	A
	Flexibility in modality	B	C	B	B	B	B
	Flexibility in session length	B	B	A	A	B	A

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Information	Clear information provided in advance to client/patient	B	A	B	B	B	B
	Accessibility of information easy as health professional	B	A	B	A	A	A
	Information accessibility (present)	B	A	B	B	B	B
	Pre-prepared notes or info before appointment	A	A	A	B	A	A
	Written summary of care	A	A	B	B	B	A
Listening and validating	Engages with the child (not just parent/carer)/ gives agency	B	B	B	B	B	B
	Listening/believing and accommodating needs and validating/ rapport	C	C	C	C	C	C
	Trust/familiarity/rapport with individual practitioner	B	B	B	B	B	B
	Working collaboratively with clients/patients	B	A	B	B	A	A
	Working collaboratively with parents/families (child client)	B	A	B	B	B	B
Service gaps	Service gap being addressed (Mental Health 18-25)	B	A	B	B	B	B
Sensory	Sensory/environment	B	B	C	B	C	B
Telehealth	Access (Phone helplines)	B	A	B	B	B	B
	Telehealth/e-health	B	B	C	B	C	B

4.1.2 Navigation and access (Element A): What doesn't work well

Participants commented on issues relating to access, affordability, appointment choice, consent, information, (not) listening and validating, service gaps, and the sensory environment as not working well in the area of **navigation and access**, see Table 13. For group comparisons see Table 14. The most commonly raised concerns were waitlists (raised by a majority of participants), difficulties accessing services, unsuitable sensory environments, affordability of health/mental health services, and not being listened to or believed. Of note, **problems in this element were the most common ideas across all elements**.

Negative experiences with **accessing** health and mental health services were reported commonly across all priority groups. 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.” (FG5) These negative experiences led to substantial access barriers leading some participants to, “avoid hospital at all costs unless it’s absolute necessary that includes with mental health.” (FG2)

Autistic people who identified as culturally and linguistically diverse raised specific access issues related to this intersectional identity as shared in the related focus group (see quote below). This included mixed views on having practitioners with shared cultural backgrounds (with some participants raising this as important, while others commenting that this could bring differing challenges). They raised specific challenges with being ineligible for services or supports when they were not an Australian citizen, Western medicine not incorporating family/broader systems in their approaches and processes, challenges where family were living in another country (i.e. fewer informal supports available), and the interplay of differences in Autistic and cultural communication styles approaches bringing additional challenges to accessing and receiving care.

> *“You can no more separate my neurodivergence from my blackness, than you can separate my blackness from my neurodivergence.” (FG4)*

Challenges in finding autism-specific services were raised and long waitlists across health and mental health including for GPs, paediatricians, allied health professionals (e.g., Occupational Therapists, Speech Pathologists), psychiatrists and psychologists were raised across all groups. Waitlists were raised particularly by participants living in regional and remote areas. Further difficulties were identified in finding adult services (with services often focused on children), services that met individual or intersectional needs, services taking NDIS clients only, a lack of services in regional areas, and religious affiliations of services being a particular barrier for LGBTIQA+ communities. Difficulties in services not returning contacts or calls, was raised as an access barrier. Finally, difficulties on the day of service including long waits and intolerance for patient/clients being late were emphasised as challenging.

> *“...most of the kind of disability support providers are affiliated with churches and religious organisations, which can have...complex relationships with both people who have...queer people, people with neurodivergence... I think that there needs to be some kind of exploration into safer, support organisations, particularly because there are a lot of people in our community specifically who have trauma around organised religion.” (FG5)*

Further barriers to making **bookings** were raised including where bookings were restricted to a specific modality of phone or online that was not a good fit for the individual. For example, a participant in FG3 raised, “I can’t do emails,” while in contrast, a participant in FG2 raised, “I’d literally need to be on my deathbed to actually make the appointment via a phone call.” Of note, the issue of online only bookings was raised only by a participant in a regional and remote area, highlighting in combination with waitlists raised that online services may not be the solution for all. Participants described failed attempts to book via their selected modality and being redirected to their non-preferred or in some cases, impossible booking modality (e.g., not owning a computer, severe anxiety using telephones). This resulted in not making needed health or mental health care appointments for some participants, missing vital care.

Practical barriers to accessing health care in terms of **physical navigation** were raised. These included feeling stressed finding health or mental health services, a lack of transport options to access appointments resulting in using telehealth when in-person was preferred, and the distance, time, and cost to access services. Physical navigation and transport were particularly raised by individuals from regional and remote communities which may intersect with the long waitlists reported and distance to services highlighted, for example,

> *“…when you’re in Sydney, you can go to the next suburb over and find another doctor to an extent… in regional Australia, you, you don’t have that option and you’re traveling. I used to travel eight times a year, 500 kilometres each way to Sydney just to get health care.” (FG3)*

The need for referrals or scripts from GPs and psychiatrists was raised as a barrier to accessing timely mental health and health services. Requiring a GP for referral to services such as Mental Health Care Plans was described as a “bottleneck,” and particularly challenging to source and access where a regular GP for health care had not been needed and GPs refused to write Mental Health Care plans without regular contact. Further, participants reported sometimes needing to correct or rewrite reports to support their access requests to other supports such as NDIS applications. Finally, the need for ongoing appointments for scripts from psychiatrists was highlighted as a challenge, particularly when there were national shortages of Vyvanse (a medication typically prescribed for attention deficit hyperactivity disorder [ADHD] which commonly co-occurs with autism).

Affordability was raised as a challenge to accessing both health and mental health services commonly across all groups. This included needing diagnoses to access supports, but lacking funding (e.g., not covered in Mental Health Care Plans, or for adults >25 years, substantial gap fees) resulting in self-funding diagnostic and functional assessments. Further needing re-assessments or responding to rejected attempts to access (e.g., NDIS), price rises in an NDIS environment, and changes or reductions in NDIS plans at review, were raised as exacerbating affordability issues and inducing significant stress and distress. Finally gap fees and private costs were raised as substantial barriers across GPs, allied health professionals, non-pharmaceutical benefits scheme (PBS) medications, psychologists and psychiatrists with bulk billing emphasised as particularly rare in rural and remote areas. One participant from FG2 shared, “…you can buy groceries this week or you can talk to your psychologist.” Further specific challenges for those earning below a living wage were emphasised as being a gap for support by another participant int this group,

> *"...there is a fair bit of support for people who are on full pensions and full Centrelink ... But there's a really big portion of the community, that are in that sort of no man's land between not actually earning a living wage but not being eligible for that kind of government support that are still trying to find 90 bucks up front to see a GP for 15 minutes." (FG2)*

Personal characteristics were raised as impeding accessing 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, P3 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. Guide me how I'm supposed to do it. Don't just say that's wrong, because that's not helpful." (P3)*

Difficulties around autism **diagnosis** were raised across the lifespan. This included affordability (discussed later in this section), experiencing stigma around diagnosis that was a barrier to seeking diagnosis, adults experiencing misdiagnosis (e.g., Borderline Personality Disorder, Bipolar Disorder) before having access or consideration of an autism diagnosis, and missing out on supports in response to not getting a diagnosis as a child or requiring a formal diagnosis to connect with or access supports. For those accessing an adult diagnosis some participants reported feeling they were consequently not taken as seriously based on assumptions of why they were diagnosed later in life, this was particularly emphasised by individuals from the LGBTIQA+ community and low socio-economic status backgrounds.

A lack of **flexibility** in appointment elements was raised as not working well. This included appointments not being long enough, inflexibility of appointments available and examples where telehealth or phonelines did not work well for the client. For example, where they would prefer in-person, not owning a computer, no/reduced Medicare rebates, and scripting challenges.

Negative experiences with not being **listened** to or respected were raised across all priority groups. These included a lack of informed consent or ignoring clients wishes as particularly negative experiences. Further, measures used to collect data not fitting with Autistic communication styles, poor rapport and not listening to the client themselves, talking only to support workers in their place or excluding parents/caregivers from the process were raised. Differences in reporting of pain and hypo- or hyper-sensitivity to sensory input (as is often experienced by Autistic people) led to missed diagnosis or significant trauma in medical examinations (e.g., breast examination) for some participants. In terms of listening, a participant in FG5 highlighted the contrast between reporting health and mental health conditions or concerns being listened to, sharing:

> *"...wouldn't believe the autism diagnosis just based on our, our verbal, a verbal cue. I, I just wanted to point out that I have never ever had that same experience when it was a physical thing. If I say to them, I have EDS [Ehlers Danlos Syndrome], I believed immediately if I say that I have diverticular disease, which I do... I'm believed immediately in every physical thing that is going on inside my body, if I tell them they just believe it instantly. But anything, if I tell them I have panic disorder, I need proof. If I tell them I'm Autistic, I need proof." (FG5)*

Difficulties in accessing and obtaining **consent** were highlighted, including the complexities for adult with complex support needs who were unable to provide consent themselves. Challenges around processes to seek informed consent, sharing of information to legal guardians, and specific barriers to communication between services, the individual, and families arising for individuals who are/were unable to provide their own consent were raised as particularly challenging. Further serious breaches of ethics were shared around consent. This included a client's wishes to have ovaries removed disregarded during a hysterectomy, slapping a child across the face to "diagnose" autism based on their response, and a lack of informed consent for administration of sedation, for a genital biopsy, and for diagnostic evaluation for autism. Particular challenges for women and girls and LGBTIQA+ participants were shared including:

> *"...biopsy of my vulva without my permission.... it ruined my sex life. It ruined a whole bunch of things my self-esteem, my trust, everything..." (P103)*

> *"there's this whole intersection of reproductive healthcare that, you know, like I spent 10 to 15 years trying to get someone to take me seriously and not say, oh, just get a hot water bottle or, you know, take some ibuprofen. And I'm just like, I can't even walk upright...this is not normal... There's like hundreds of thousands of people in Australia who are trying to get taken seriously for Endo [endometriosis] and PCOS [polycystic ovarian syndrome] and everything else." (FG2)*

Information accessibility was raised including being inaccessible, inaccurate, unclear (e.g., COVID procedures, medical jargon), or absent. This included gaps in information available across health and mental health services and information being hard to access or find, including not knowing what was available (e.g., what could be accessed under NDIS vs. Medicare), particularly commonly for LGBTIQA+ participants. Examples of being given incorrect information such as referral options were also shared. Requirements to access services (e.g., NDIS access requirements) were raised as unclear. The absence of information on aftercare following medical procedures or about autism or available services following diagnosis were raised as examples of what was not working well.

Participants shared **service gaps** they experienced, including complexity and intersectionality, mental health services for their age group (children, young adults, and adults/lifespan), reproductive health care for LGBTIQA+ people, help for children with eating disorders, and crisis vs. non-crisis mental health supports. 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 severe challenging behaviours, traumatic brain injury and mental health, with different services for each, and each not being willing to work with the intersection. Further, gaps in services that incorporated and understood intersectional identities was raised such as being both Autistic and queer. Participants further 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 needs.

Aversive **sensory environments** were shared across mental health and health services for all groups, although not as frequently by culturally and linguistically diverse individuals. 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.

Table 13: Navigation and access (Element A): What doesn’t work well

Category	What doesn’t work well	Illustrative quotes
Access	Access (Negative experiences)	“...you do have more problems getting appointments with GP's because it's just so hard these days. Hard to get occupational therapists or speech pathologists. Ah, just I think because there's a shortage with all therapists and same as with GPS, et cetera.” (P34) “Most community and mainstream services have either been defunded, are too underfunded, have been privatised or being outsourced to religious organisations...I'm a member of too many minorities to be able to have access to most mainstream and community services that, that are still left with enough funding to even run...In the last 40 years to too many, services have just disappeared.” (P56) “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 unless it's absolute necessary.... that includes with mental health, because ... many, many of us, we've had some pretty gnarly, systemic barriers put in our way when we've presented with acute crisis for mental health.” (FG2)
	Difficulties finding/navigating services including being overwhelmed by process	“...there is an enormous amount of emotional load that goes along with navigating the health care system and the appointments can only, the appointment making process, but also the process of maintaining relationships with doctors.” (FG3) “I recently went to check out my local (service provider), had a really big scary gate that was closed. I didn't go in and ask about their services 'cause I just felt intimidated.” (FG2)
	Finding autism-specific services/reputable service providers	“I have a lot of challenges getting into autism services or finding people who can work with their [client's Autistic] kids for not autism specific ways.” (P63)
	Long waitlists	“I think when I’d started there, it took me like a year to get an appointment and in that time, like my mental health was really bad, so it was not helpful at all at that time.” (P55) “I think when people are asked go to seek help, the wait list is far too long. By the time we seek help, we are on the breaking point.” (P6) “Go see a psychiatrist. I’ve been waiting for a year and a half.” (FG3) “There’s good psychologists who have really good reputations. So, using Facebook groups of who do you recommend, but as soon as the name gets mentioned as good, they then get fully booked out because everyone else also is looking.” (P3) “You have to wait three months sometimes for another [GP] appointment.” (P103)
	Unsupportive staff	“Staff could be nicer instead of just assuming everyone's an idiot, or everyone's horrible or aggressive, or mean. So, they seem to be on the front foot and being aggressive and mean themselves. And that's a terrible thing to say, but that's how it felt.” (P19) “...reception staff who are unfriendly...like where reception, it is a huge thing that by the time you get to the specialist or doctor's room that you're already frazzled. Yeah. That's a challenge. So, to me, reception staff are a huge part of the story.” (P63)

Category	What doesn't work well	Illustrative quotes
Access	Waiting on specific day and inflexibility for lateness	"...The biggest issue there is just purely with, with our hospital, you know, if you go to the, the public ER, that can be like a six to eight hour wait to get seen in a, you know, busy, crowded environment." (P33) "I've now met, three or four GP practices which have a zero tolerance for being late. Where I've been a very very good patient. And then because I haven't wanted to sit twiddling my thumbs for an hour to make certain I get there on time. I've gone done something else and then looked at coming late or they've called me and go said are you coming in And I've gone...I'll be there in five and they wouldn't believe me. I could be there in five and they said don't come in. And when you're aching and in need of a medical appointment and when you are normally sitting there for 40 minutes waiting for the doctor." (FG1)
Access: Booking system	Email or online bookings unavailable	"I like online bookings. Now if I have to ring up, I don't go." (P124)
	Online bookings only	"I can't do emails... the three doctors that are surrounding me, I can't access them unless I do it online. I've gotta go online and choose an appointment time. So, there's no phone calls, there's no emails, there's none of that. It's an online booking service. So, I go to their booking service, and I choose a slot and a doctor, et cetera. I find that overwhelming." (FG3)
	Phone bookings only	"If I can't do it via email, it's not gonna get made. So, I've even, I've even had the experience of emailing doctors, psychologists to make an appointment and they have emailed me back saying, please call to make an appointment 'cause they just won't do it." (FG3)
	Unable to contact	"I've been trying to get in to see a psychiatrist because I need to get my ADHD meds changed 'cause they're not working for me. Yep. And I think it's been like six months since I've been trying to do that, and I still haven't heard back from anyone." (P55)

Category	What doesn’t work well	Illustrative quotes
Access: Diagnosis	Adolescent diagnosis hard to access	“...so they get to 15 or 16 or something and they haven't had an assessment...it's really hard to access an assessment when you get to their age” (P61)
	Adult diagnosis difficult to access and misdiagnosis	“Well, he [GP] ended up writing six referrals because I would ring them up and say, did you do autism assessments for adults? Yes, yes. The receptionist say, oh we do assessments. And so, I'd get a referral I to find that no, they only do children.” (P52) “...getting the actual diagnosis was hard.” [it took 9 years] “My mother tried to get me a diagnosis earlier [... but] high functioning autism wasn't diagnosed in Australia in until, you know, probably, I don't know, fairly late in the game.” (P4) “I was misdiagnosed in my twenties, as having BPD, which is borderline personality disorder.” (FG5) “A lot of misdiagnosis happens before you get to diagnosis, right? Ohh, perhaps you've got some bipolar... all of these misdiagnosis, before you get to the point where you just go, oh, here it [autism diagnosis] is.” (P103)
	Barriers to access from late diagnosis not taken as seriously	“I feel that support services still sort of inherently have a bias against people that get diagnosed later... obviously I've managed like 22 years of my life, so it I can't be that “disabled” in quotation marks.” (P102)
	Earlier detection/ identification needed to get help or improve health/mental health	“My mum tried to get me diagnosed growing up like so many times and it just never went anywhere... So it, it would've made my life a lot easier if I'd been diagnosed younger. 'cause you know, I spent a lot of years thinking there was something wrong with me...if that had been available earlier, then that wouldn’t have happened.” (P55)
	Needing formal diagnosis to access services	“Unfortunately, the way the 'system' is modelled one must get a diagnosis to be able to receive support.” (P103)
	Stigma around diagnosis	“One of the barriers to diagnosis & access to services is the 'perceived shame' around 'difference' especially Autism. With all of the poor media coverage around Autism & the NDIS, every taxpayer has an opinion and how this has filtered down in my family is that my 12year old doesn't want to be identified as having ASD as he feels shame...That was also at a time when there was a lot of mother shaming for autism symptoms where you know you there, there's the whole attachment theory based start from that so.” (written submission by P103)

Category	What doesn't work well	Illustrative quotes
Access: Finding services that meet needs or funding	Difficulty finding services for adults	"… because we don't have the services. We're only like an hour out of (City in Victoria). We're not even like, we're quite a big city. And yet it just seems we don't have the access to a lot… so this I find particularly for adults. We are great, you know, with OTs and stuff for kids, but it's just finding stuff that's for adults is really tricky." (P52)
	Difficulty finding services that meet individual needs	"A bit of ageism going on, presuming that because I am married on paper, I guess particularly, you know, that I meet what they think is heterosexual criteria that I won't have any needs to talk about my sexual health or to have advice or for them to talk about any of the changes that have happened to me as I'm aging and particularly post hysterectomy." (FG2)
	GP "bottleneck" for access	"…because of the referral process [for mental health care], it ends up kind of trickling down to other, other disciplines because GPs are a hard bottleneck." (FG5)
	Regional and remote lack services	"…we live regionally … there's no child mental services or supports…groups like (Autism organisation) or whatever. They run so many f*cking programs in [capital city]. Do they run anything in other districts at all? Not a single thing. Like I wrote to them once and they're like, oh, we don't have enough funding to do that." (P15)
	Restricted to NDIS clients only	"…without that [NDIS] it doesn't really seem like there's many places at all. A lot of them are like NDIS only." (P55) "I found that some services are advertised that seem really great, but you have to be on the NDIS to get them." (P18)
	Religious affiliations of organisations a barrier	"We were trying to get services to help us, but because we were trans…they could legally discriminate against us based on their religious status." (P56)
Access: Barriers to GPs and psychiatrists	Medication shortages and scripts	"I have thirty-eight tablets a day for my medical conditions, thirty-eight. That means for every single one of those appointments, I have to go to a doctor, which I already have a significant anxiety about, and I have to get a script and I have to pay for that appointment." (FG3) "I don't know how many of us have ADHD, but one of the ADHD meds, the long-acting, dexamphetamine Vyvanse [ADHD medication], actually went out of stock in like four of its six prescription strengths. So, if you were on one of those strengths, not only were you not able to get your medication, but if you couldn't get back into your psychiatrist to rescript it because it's not a GP script… it was really difficult to get those scripts re-written." (FG5)

Category	What doesn’t work well	Illustrative quotes
Access: Barriers to GPs and psychiatrists	Needing to correct reports	“So, in terms of like what I'm sending in from my psychiatrist, it's essentially the assessment things that we did with like, no discussion from her and a letter that I've had to rewrite multiple times so that it has, you know, long term and permanent disability. And then essentially get her to sign it because the first couple of times that I like sent her feedback, she just didn't do it like she or she did it, but it wasn't what I'd requested.” (P16)
	No regular GP to make referrals	“So, I had very little medical history kind of unknown in the Medicare program, I guess. So, when I went to look for a Mental Health Care Plan, which obviously the psychologist, you know, recommended going to get … I just needed to be able to sit down with someone to do it…I would've called probably six places…each time the problem told to me, the challenge was well, we don't know you, so we can't offer you that service… even if I made an appointment with the doctor for Mental Health Care Plan, or at least to meet, I'd be called back to say, no, the doctor's rejected that because you haven't been to this clinic before.” (FG5)
Access: Personal characteristics	Personal challenges based on communication differences, executive functioning, presentation differences, and expression of pain.	“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. They knew I, and they said, it is not high risk. I just attempted suicide like a week and a half earlier.” (FG3) “Look, our different presentations and our individual different presentations, I, I would be screaming with a blister, but, very silent when I'm in, in big trouble.” (FG3) “…she’s grown up with that, you know, she’s grown up to be a people pleaser. And so, you know, we we’re going to the doctor, I still go into the doctor with her sometimes, and, the doctor says, how are you? And she says, I’m fine. And she’s not. She’s at the doctor because she’s sick and she’s gotta be pretty sick to go to the doctor. But it’s, it’s just this mentality that if I, if I am good, then they will like me.” (FG3) “…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.” (FG5) “…once you book the appointment, you have to be like, these are all the things I have to remember, which is really hard. And then actually get there in the car. And then once you’re there you have to remember.” (P1) “..like one of the things I’ve bounced up against quite a lot is because my experience of pain is fairly different to other like,to people with a more kind of typical neuro type, it can be very difficult to be taken seriously by kind of run of the mill, kind of walk-in clinician doctors.” (FG5) “ I couldn’t effectively communicate in a way that nurses were expecting that I was in pain.” (FG5)

Category	What doesn’t work well	Illustrative quotes
Access: Physical navigation and transport	Physical navigation and transport	“I often feel rushed or, and navigating...the stress that's involved in actually getting to an appointment.” (P52) “And it definitely would've been like if there was more transport options or whatever, I would've loved to have had more in person appointments...no one could get me anywhere.” (P55) “Firstly, she sent me for a referral to an excellent clinical psychologist in (location). Now (location) is an hour's drive for me right, an hour's drive...It cost me $80.00 in fuel just to drive [to location], right?” (P103)
Affordability	Cost of diagnostic assessments	“Financial barrier to actually accessing either a ADHD or autism or, you know, both whatever diagnoses.” (FG2) “But like as an adult, it's quite hard to get a diagnosis because very expensive in Australia... I had to save up for, like, months and months.” (P102)
	Needing to self-fund assessments	“Cost is the single biggest issue I see with my own clients - accessing assessments to be able to access supports.” (FG5) “... I have to get a whole new functional capacity assessment and more psychology reports out of pocket to try again [to access the NDIS], only to have them more possibly rejected all over again. So, what's the point? And my mental health, to put myself through that.” (P3)
	NDIS driving price increases	“I found it quite confronting dealing with occupational therapists now versus when I was a nurse, you know they bill you like a lawyer now. I was getting bills for like a phone call or responding to an email and I understand, but they're made to account for every second.” (P35)

Category	What doesn’t work well	Illustrative quotes
Affordability	Out-of-pocket costs	“We tried to go with a private psychiatrist, but it was very expensive, and we really couldn't afford it.” (P102) “...you can buy groceries this week or you can talk to your psychologist.” (FG2) “I've had to stop seeing [my psychologists] because I couldn't afford to see them even with the Mental Health Care Plan.” (FG2) “...private GP, and they were all charging like, a huge amount of money and they wanted my credit card details. I'd never had that before. I'd never, I'd never rung a GP service and had them ask for my credit card details to book an appointment two weeks in advance that was really offensive and couldn't find any GPs that bulk-billed.” (P56) “...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.” (FG3) “...doctor that will come to me, which is great, and I've seen her twice now, but it costs me $795 each (doctor) visit. Wow. Yes. Yes, it does. It costs me, it costs me $930 to see the OT each time because he comes to me, it costs me $975 for every psych visit once a fortnight.” (FG3) “I have to pay for the 50% of medications that are not on the PBS, including my mental health medications and my ADHD medications.” (FG3)
	Private health care limitations	“So, I had to do my own research about what that might mean and ended up getting a private referral to a psychologist for a diagnosis... which was great because we started that process I think within a week, but it was incredibly expensive.” (P31). “...physical therapies are really helpful. Things like reflexology. ... There's no support [via private health care fund]. You just gotta find the money.” (FG4)
Appointment/ Service delivery choice and flexibility	Appointment choice	“...the only downfall I have with him [psychologist] is he doesn't tend to, have like book regular appointments. Whereas I had thought regular appointments might've been easier for me.” (P52) “...my experience of trying to go through the children's hospital as a public patient was just a living nightmare...you don't get a choice of appointments.” (P63)
	Appointment times are not long enough	“And there's obviously great time pressure on GPs and a 10 minute consultation just doesn't give the opportunity, to build a relationship.” (P31)

Category	What doesn’t work well	Illustrative quotes
Consent	Complexities for parents/guardians of those who do not have capacity to provide consent	“And it becomes tricky because (name) is nonverbal and doesn't have the cognitive capacity to sign... So with things like, you know, I can't get a power of attorney for him or anything...they said, oh, he has to consent to it. And I'm like, well, how does he do that? And she said, oh, well, you could bring him in here and I could ask him. And if he sort of nods his head, you know, and I just remember thinking are you dead set serious. Yeah, I mean that to me, that's one, demeaning. And two, I said, well, that's not to me, that's not true consent because he doesn't understand. So yeah, the legalities around that.” (P38)
	Consent (treatment wishes) ignored	“I signed documents to say that I would like my ovaries removed. I signed the consent and then I double signed...I woke up with my ovaries, so they've given me a hysterectomy, but I've still got sticky bits that could keep causing me more issues” (FG2)
	Lack of informed consent	“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.” (P19) “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.” (P103) “...the hospital actually didn't tell me that they were planning to, or they were organising a psychiatrist to diagnose me as being on the Autism Spectrum. 'cause like one day they said, okay, well, the psychiatrist, yeah, he, he'll have talks you, I see Asperger's syndrome or, or Autism and that, so, yes. So, it was only a few minutes, or even a few seconds.” (P104)
Information	Contradictory information given	[Context: Participant told they could not access an art therapist by NDIS.] “And I looked it up and that was the art therapist that I had referred to. So, I could see that. But then it was all I was being told yes, and then I was being told no by the same person.”

Category	What doesn't work well	Illustrative quotes
Information	Inaccessible	"GPs. They don't really have enough information about that [e.g., eating disorders, suicidality] and like where to go with all these things" (P15) (information about the health care system) "not easy to access. Like there's information, but like actually finding the website that has the right information and the right format that's easiest to understand." (P102)
	Information given is not accurate	"...sometimes they (GPs) may not give advice that is accurate. I would say. At one point they suggested seeing if they could get me into (hospital), to get assessed by a psychiatrist, not knowing that that was actually not a feasible option at the time." (FG5)
	Information is unclear/jargon	"...but then when she [GP] went to explain what he had read in the letter [from the psychiatrist] she used all the big medical terms and big terminology and I just went, I went out of the session not understanding anything and really stressed." (P52)
	Information on aftercare not provided	"And then just kind of walks out of the room and doesn't tell me how to self-care afterwards" [following vulva biopsy] (P103)
	Information on requirements to access services unclear	"...a lot of these services need to actually be a lot more transparent with their information and actually be like, forthcoming with what they expect." (P102) "I find it hard too, knowing what's covered by NDIS, what covered by Medicare. And also advocating for myself, like, am I entitled to this?" (P52)
	Information on what is available unknown	"We didn't know anything, we didn't know that we had rights and eligibility to ask for things because we didn't know what they were called. And we didn't know they existed. It was complete. We were completely ignorant and there was no transparency. So, we couldn't ask for things that we didn't know existed." (P56)
	Lack of referrals/information following diagnosis	"...the communication was really, really difficult where I don't think enough was explained to me about things.... I didn't get much like follow-up [following adult autism diagnosis] in terms of like these are some resources, these are some articles to read kind of thing." (P16)
	Measures not suited to Autistic interpretation/ style/experience	"re: the questions is very exclusionary for Autistic people or any person who pays close attention to wording/only responding the truth. "Have you ever considered doing X? or Are you considering doing X? " can sometimes be on the same line or same section. And it is so broad that I would have to write 'YES' even if that means 25 years ago and not relevant to the present day situation." (FG5)

Category	What doesn't work well	Illustrative quotes
Listening and validating	Distrust/fear of child safety involvement	"...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." (FG4)
	Not being listened to, believed, or validated	"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." (P52) "We've all felt that we've all gone to doctors multiple times and felt like, why we even here, they're not listening, they're not paying attention. They're just saying, oh, it's just anxiety. It's not a stomach ache, and then five minutes later you're being diagnosed with diverticular disease." (FG5)
	Parents/carers excluded or not listened to	"...my daughter was too afraid to talk to him [GP]. She was 12 or 13, I suppose, and I would answer for her, he'd say, and he'd go, no, I need to hear it from your daughter." (FG3) "...treated with respect in a parenting role if we are advocating for our children or speaking to support our children. But even when our children get to a certain age, it's then viewed as a negative if we're trying to support." (FG3)
	Talked to support person instead of Autistic client/patient	"In general, I'm often not taken seriously, and also have had many experiences where people will talk to my support person instead of me as if I'm not there." (FG5)
	Unclear expectations	"COVID it was challenging when some of them were still doing face-to-face. So, you had to come in and it's a bit like going to the airport, which is my worst Autistic nightmare. But they change the rules all the time. So sometimes you'd walk in [to health service] and it'd be mask and wash your hands and the next time you walk in it'd be like, I try and walk in and be like, why don't I walk to with my mask on? They're like, no, you can't have your mask on. You have to put one of these on. I was like, so I had could take my mask off in the space and put another one on." (P63)

Category	What doesn’t work well	Illustrative quotes
Sensory	Aversive sensory environment	“…even finding a GP was really hard. I just went 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 easy 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…” (P19) “I don't know if you've ever been to the [Hospital Emergency Department]…mental health section, it's very bright, it's very it's very hospitaly. There's lots of security guards, there's lots of noise when they make announcements over the speakers, it pipes into every single cubicle…at that time, the waiting room in emergency was, going undergoing a… renovation. So, it was a temporary building… they basically stuck me literally outside of a temporary building, underground undercover. Eventually my name was called, and I was stuck in a wheelchair and [taken] to a very mysterious part of the hospital, which I discovered was the mental health area. It was basically a standard emergency room with all of the furniture ripped out. So, like you could see all the holes and screw holes where all of the medical devices had been completely removed. There was no bedding, there was a bed, but everything was absolutely soaking on water. So, like the mattress and there was a chair and they, they basically just dumped me in that room and just left me there…” (FG5)
Service gaps	Autistic women and girls	“…not enough services for Autistic girls and women” (FG4)
	Complexity and intersectionality	“…if I want to talk to talk about issues related to being queer, I have to talk to a queer professional. If I want to talk about my sexual assault, I have to talk to a professional in that. If it's something that's autism related, then I have to see an autism specialist. But they're all related to me, and my experience and I find it really frustrating…. People don't understand the intersection and they don't understand the individual strands of the intersections.” (FG5) “I was trying to go to appointments, and I had people saying to me, you are too difficult, it completely de-legitimised who I was as a person because it was like, it wasn't, your condition is too difficult, it's, you are too difficult.” (FG3)
	Eating disorders	“We actually removed our daughter from hospital care because it [eating disorder intervention] was just delivered in a way that was absolutely brutal. Like no child should have to be treated that way…. we couldn't access services because, we needed them, but they were just being delivered in a way that was so traumatic that, there was no way as parents we could allow that to continue.” (FG4)
	Family support	“Yeah, and the explosion was of such a level, that I'm probably the most battered person you'll ever come across…. I think she [Autistic daughter] clocked [hit] me like 21/2 thousand times at a minimum. I think over that time and through that time, we approached every different service that we could think of for support. And our other teenage [non-Autistic] daughter at the time was she was under the pressure of it as well. Got to the point where we had nothing throwable in the house…. And in the end, it got so much for our other [non-Autistic] daughter that she took an overdose of Panadol.“ (P36)

Category	What doesn’t work well	Illustrative quotes
Service gaps	Health and mental health for children	“...we live regionally .... there's no child mental services or supports” (P15) “If we went to hospital where she knew she was safe and she couldn't kill herself that would bring it [her anxiety] down. And I did have people say like we can't just use this as a break. Like I think they were thinking I was using it as a break me but actually it was more exhausting being at the hospital for me because I had to be there with [her] all the time because she was in the paediatric ward.” (P15)
	Mental health for 18-25-year-olds	“When I was a teenager, they really didn't have a lot of [mental health] services between sort of like 15 and 25...The last thing I will say my mom actually when I was a teenage like once I turned 18 cause when I was saying earlier they had a big gap especially between 18 and 25. Once you turned 18, basically services were like ohh we don't do 18 year olds and they just kind of like good luck with adult services, especially in Brisbane.” (P102)
	Mental health services for adults in general	“In Perth, there's, I mean, there's very few neurodiverse psychologists, and especially ones that treat adults. And I think there’s, one really well known good one and her books are closed.” (P8) “...there aren't enough program services for Autistic adults, especially older Autistic adults.” (FG2)
	Mental health supports for crisis and suicide risk	“Crisis services simply do not exist to the level we need for anyone, let alone people who are Autistic and have sensory issues.” (FG5) “... my mental health was really quite severe at the time. They probably said it in quite a lot more professional terms, but the way that my brain’s remembered it now it's kind of them kind of saying like that my case is a bit too like serious for them to deal with.” (P102)
	Mental health supports non-crisis	“...after about four of those type of calls [where GP would not see for a MHCP [Mental Health Care plan], I called through, you know, started asking, well, where can I go? And they said, or, you know, is it a crisis? I said, well, no, not yet. And therefore, they obviously, I couldn't be channelled into crisis services.” (FG5) “...the public mental health system is severely underfunded, and they have to prioritise people who are violent and ... you fall through those cracks there, you, you're not prioritised.” (FG2)
	Mental health vs. autism services for adults	“I've seen like a clinical psychologist...I'd have to see another clinical, psychology. They only deal with like autism, but like not mental health, mental health issues, like life are two sort of kind of go like hand in hand.” (P104)

Category	What doesn’t work well	Illustrative quotes
Service gaps	Reproductive health support for LGBTIQA+	“...there's this whole intersection of reproductive health care...I spent 10 to 15 years trying to get someone to take me seriously and not say, oh, just get a hot water bottle or, you know, take some ibuprofen. And I'm just like, I can't even walk upright...this is not normal... it's not just me...There's like hundreds of thousands of people in Australia who are trying to get taken seriously for Endo [endometriosis] and PCOS [polycystic ovarian syndrome] and everything else. And it's just, it's just become this, you know, unless you've got the money and are lucky and have access to good queer medical professionals, you're pretty much just stuck with the Oh, well, you know, you know, 10 years time you might want children. So, we don't want to do anything too harsh.” (FG2)
Telehealth	Phone helplines redirecting/poor support	“I had a good experience with Kids Helpline but once I turned 25, I found LIfeline only directed me to call 00 if my life was in danger and go to hospital and Beyond Blue only wanted to connect me to service and not actually talk to me.” (FG4)
	Telehealth challenges	“And I've sort of tried to do telehealth psychiatry, but for me, I didn't find it super accessible because just having someone in the state where you can see them in person and like walk through stuff and like get prescriptions, I just found it easier to have that in person and so it can be really hard when you don't know what support options are available.“ (P18) “I can only make phone calls and, I can't do email, I can't do text...I don't own a computer.” (FG3) “...the telehealth appointments, which I have been able to access, you get zero Medicare rebate if you haven't seen the doctor face-to-face.” (FG3) “I know is difficult if you need to do a physical assessment. And it can be challenging with scripting, which I think we have a long way to go on this country. Like some specialists from like paediatric specialists will do in scripts and some won't.” (P63)

Table 14: Navigation and access (Element A): What doesn't work well – Group comparisons

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Access	Access (Negative experiences)	C	C	C	C	C	C
	Difficulties finding/navigating services including being overwhelmed by process	B	C	C	C	C	B
	Finding autism-specific services/reputable service providers	B	A	B	B	B	B
	Long waitlists	C	C	C	C	D	C
	Unsupportive staff	B	A	B	B	B	B
	Waiting on specific day and inflexibility for lateness	B	A	B	B	B	B
Access: Booking system	Email or online bookings unavailable	B	A	B	B	B	B
	Online bookings only a barrier	A	A	A	A	B	A
	Telephone only	B	B	B	B	B	A
	Unable to contact service	B	B	B	B	B	A

Legend

Percentage of participants per group raising idea	0%	Up to 24.9%	25-74.9%	More than 75%
Band	A	B	C	D

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Access: Diagnosis	Adolescent diagnosis hard to access	B	A	B	B	A	A
	Adult diagnosis hard to access and misdiagnosis	B	A	B	B	C	C
	Barriers to access from late diagnosis not taken as seriously	B	A	C	B	B	C
	Earlier detection/ identification needed to get help or improve health/mental health	B	A	B	B	B	B
	Needing formal diagnosis to access services	B	A	B	B	B	B
	Stigma around diagnosis	B	B	B	B	B	B
Access: Finding services that meet needs or funding	Difficulty finding services for adults	B	A	B	B	B	B
	Difficulty finding services that meet individual needs	B	B	B	B	B	B
	Regional and remote lack of services	B	B	B	B	B	B
	Religious affiliations of organisations a barrier	B	A	B	A	B	B
	Restricted to NDIS clients only	B	A	B	B	B	A
Access: Barriers to GPs and Psychiatrists	GP bottleneck	A	A	B	A	A	A
	Medication shortages and scripts	A	A	B	B	B	A
	Needing to correct own reports	A	A	B	B	A	A
	No regular GP to make referrals	A	A	B	B	A	

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Access: Personal characteristics	Personal challenges based on communication differences, executive functioning, presentation differences, and expression of pain.	B	C	C	B	B	B
Access: Physical navigation and transport	Physical navigation and transport	B	B	B	B	C	B
Affordability	Cost of diagnostic assessments	B	B	B	B	B	B
	Needing to self-fund assessments	A	A	B	B	B	A
	NDIS driving price rises	B	B	B	B	B	B
	Out of pocket costs	C	C	C	C	C	C
	Private health care limitations	B	A	A	A	A	A
Appointment/ Service delivery choice and flexibility	Appointment choice	B	A	B	B	B	A
	Appointment times are not long enough	B	B	B	B	B	B
Consent	Complexities for parents/ guardians of those who do not have capacity to provide consent	B	A	A	B	A	A
	Consent (treatment wishes) ignored	B	A	B	A	A	
	Lack of informed consent	B	A	B	B	B	B

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Information	Contradictory information given	A	A	A	B	B	B
	Inaccessible	B	A	B	B	B	B
	Information on requirements to access services unclear	B	A	B	B	B	B
	Information given is not accurate	A	A	B	B	A	A
	Information is unclear/jargon	B	A	A	B	B	B
	Information on aftercare not provided	B	A	B	B	B	B
	Information on what is available unknown	B	B	C	B	B	B
	Lack of referrals/information provided following diagnosis	B	B	B	B	A	A
	Measures not suited to autistic interpretation/style/experience	A	A	B	B	A	A
	Unclear expectations	B	A	B	A	A	A
Listening and validating	Distrust/fear of child safety involvement	A	A	A	B	A	A
	Not being listened to, believed, or validated	C	C	C	C	C	C
	Parents/carers excluded or not listened to	B	A	A	B	B	A
	Talked to support person instead of autistic client/patient	B	A	B	B	A	B
Sensory	Aversive sensory environment	C	B	C	C	C	C

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Service gaps	Autistic women and girls	A	A	A	B	A	A
	Complexity and intersectionality	B	C	C	B	C	B
	Eating disorders	A	A	A	B	A	A
	Family support	B	B	B	B	B	B
	Health and mental health for children	B	A	A	B	A	A
	Mental health services for adults in general	B	B	B	B	B	B
	Mental health for 18-25-year-olds	B	A	B	B	A	B
	Mental health supports for crisis and suicide risk	B	A	B	B	B	B
	Mental health supports non-crisis	A	A	B	B	A	A
	Mental health vs. autism services for adults	B	A	B	B	A	A
	Reproductive health support for AFAB, non-binary and trans people	A	A	B	B	A	A
Telehealth	Phone helplines redirecting/poor support	A	A	A	B	A	A
	Telehealth challenges	B	B	B	B	B	B

4.1.3 Navigation and access (Element A): What would make it better

Participants shared ideas of what would make **navigation and access** better in terms of service access, affordability, appointment choice, information, listening and validating, service gaps, and the sensory environment, see Table 15. For group comparisons see Table 16. The most common suggestion was adapting/improving the suitability of the sensory environment which was raised by all priority groups, followed by increasing access to information generally, which was raised in most groups, and specifically providing information in advance and following treatment/support which was raised in all groups.

In terms of **access**, the development and availability of lists of autism-friendly services and practitioners was raised including information about service quality, with an emphasis on this list being led by the Autistic community. Participants said that practitioners did not need to be Autistic per se, but they needed to “GET Autistic people” (P63). Further, greater access to services and more practitioners being available was raised as a general idea across all groups.

The need for a range of **booking** options including in-person and online were raised as being desirable to fit with individual needs and preferences. Providing supports to manage executive functioning challenges to facilitate access, such as templates of what to do or expect in appointments and descriptions of who to call when (e.g., health passport), were shared. Further, access or greater access to phone lines for adults, and telehealth (particularly for participants identifying as LGBTIQA+) and e-health, including e-scripting, were raised as elements that would make navigation and access better. Finally, being able to individualise bookings to suit people’s own needs, preferences and abilities were raised. For example, a participant in FG3 shared,

> *“…being able to choose an appointment length or type - if an OT or psych ‘only’ accept 60 min appts it limits choice, sometimes I can’t tolerate a long appointment. I would like other times to be able to have a longer appointment with a GP so we can spend time actually working through issues.” (FG3)*

To address **affordability**, participants raised the need for additional Medicare funding for assessments and Mental Health Care Plans. Participants raised the gap in funding for diagnostic and functional assessments (noting no Medicare items for diagnosis over 25 years) and a need for Medicare funding for assessments. Further, while participants praised the benefits of access to Mental Health Care Plans, they identified logistical challenges with returning to GPs for re-referrals, noting waitlists and access challenges, as noted above. A return to 20 sessions available during COVID or in early implementation of Mental Health Care Plans, was considered helpful.

Information was raised as an area where changes could make navigation and access better. Ideas included increasing accessibility of information around psychoeducation (e.g., how health care system works), services available, diagnosis and implications, and ensuring information shared across practitioners was consistent. Further, easier access to information was raised such as improving how it is shared and what is shared e.g. simple English and videos for individuals with higher support needs or co-occurring intellectual or learning disabilities. Providing clear information in advance of health and mental health services, including assessments, was raised particularly for individuals identifying as culturally and linguistically diverse, from regional and remote locations and from lower socio-economic backgrounds. In addition, providing mechanisms for clients and patients to share information to service providers in preparation for care was also raised. Finally, providing written summaries of care was also raised as a potentially valuable support to improve care in the future.

Listening and, in particular, **validating** individuals' health, mental health, and Autistic identity was raised as important to making care better in future, particularly by individuals in regional and remote areas. This included ensuring the Autistic person was included, as opposed to talking predominantly or only to support people.

Participants raised that providing proactive mental health supports would improve care in future by mitigating escalation to greater mental health care needs.

Sensory and accessibility standards were raised as elements that could make care better into the future. This included adapting the sensory environment to allow individualisation and reduce potential sensory overload (e.g., lighting, sound, and proximity). Further, establishing accessibility standards that incorporated sensory-friendly environments as well as meeting the needs of individuals with co-occurring sensory impairments were also emphasised for health and mental health services.

Table 15: Navigation and access (Element A): What would make it better

Category	What would make it better?	Illustrative quotes
Access (general)	Autism-friendly clinician lists	"A practitioner's list, a safe, ethical practitioner's list that was free and available online from any Autistic person to access...I mean, it would have to be run by the Autistic community. It couldn't be run by an organisation or the government or any funding body." (P56) "...a centralised register/directory of medical and allied health practitioners that have some way to have reviews or customer feedback, and things like their specialties so we can work out who we should see that will actually support us." (FG3) "...they don't have to be Autistic. Like, you know, we have a list here in South Australia, trans friendly clinician, but three of them are trans. Yeah. The rest of us are just knowledgeable and skilled and have been vetted. So, it could be people who have kids or brothers and sisters or siblings or whoever who are not just related to Autistic people but GET Autistic people." (P63)
	Autism-specific services/ health practitioners who have a specialised understanding of autism	"...access to autism-specific mental health help... like in community mental health, you know, you have like your case manager, then you've got like OTs and psychologists and then you've got like the psychiatrist having a team that all has really deep knowledge of autism would be helpful." (P124)
	Home visits/services	"...having more accessible at home services." (P42)
	Improved access to services	"...more everything... especially in the health setting for people with autism just being tailored." (P41) "...the government could....do something just to reassure people that they are going to be able to access it even if you don't have, because I wouldn't have the money too." (P52)
	More practitioners	"...there's so many people that are needing the services and there's only so many professionals." (P4) "Definitely more options...there's very few options." (P55)
	More subsidised Mental Health Care Plan sessions	"12 or even 9 consult access [between GP referrals for MHCP [Mental Health Care Plans] would be much more reasonable, and allow for a longer time allowance." (FG5) "....my ideal world things is how, back in COVID, they extended it [Maximum annual sessions under a Mental Health Care Plan] to 20 sessions. Yeah, absolutely. Amazing. If you were diagnosed with something like autism or a complex long-term condition, you could, you know, be put on a program where you do get the 20 sessions because I feel like if you were Autistic, 10 sessions for a lot of people wouldn't be enough... I feel like a lot of people would benefit from having, yeah, more sessions and access." (P18)

Category	What would make it better?	Illustrative quotes
Access (general)	Services (more affordable and easier to navigate)	"But yeah, if it was done differently. If they just let you pay the gap, it would be much easier instead of having to pay that huge fee upfront, out of pocket. And when you're doing it for multiple children, sometimes I can have like 10 to 12 appointments a week." (P35) "...the government could make it [mental health care] cheaper or easier to navigate." (P52)
	Systemic change	"We need deep systemic change to a culture of care and curiosity, rather than a paternalistic medical system which is limited and judgmental. a culture of empathy and care." (FG4)
Access: Booking systems	Online or email booking being available	"...if we could just email to make the appointment or text." (FG3)
	In-person booking options	"Having a conversation with somebody in person rather than either through an email contact or and having that reassurance that the information is being collected and that the service is in progress and that you're being assisted into that space rather than you're just another number..." (P48)
Access: Diagnosis	Earlier diagnosis to facilitate supports	"...if you get it early and you intervene in the right way and have the system and society kind of set up to, to work for everybody, then a diagnosis doesn't necessarily have to...trigger the most extreme resource intensive solutions...It can...be managed...more financially equitably, but also improve people's quality of life and interaction with society." (interviewer summary of P54 who agreed with this summary)
	Medicare funding for diagnosis	"I think to this is just like putting like mental and neurological stuff in general onto Medicare, I guess. Yeah. Because, yeah, like I, I sort of have the impression that like Autistic people in general are less likely to have, you know, resources to be able to access expensive diagnoses like this." (P58)
	Reduce stigma and negative implications around diagnosis	"... it would be much easier to make this diagnosis if we were to, you know, broaden our concept and, and not make it...potentially life changing thing...in certain...careers or other social options...they would pretty much exclude you on the basis of that." (P54)
	Understand implications of diagnosis	"I suppose, you know, the broader implications of what a diagnosis means." (P54)
Access: Personal characteristics	Executive functioning supports	"I think it would be a template of sorts to help organise what...I need to say in an appointment and get done like a, like a to-do list, but more structured." (P1) "I couldn't verbalise, I could just like have something in the health passport that's like, ring this person." (P1)
Access: Physical navigation and transport	Provide innovative delivery modalities	"...stuff in like VR [virtual reality] or whatever, like that could be cool...it's quite easy when it's virtual to just be like, okay, I'm just here on a screen for a bit." (P55)
Affordability	Improve or broaden access to Mental Health Care Plans	"it would be really helpful if it {Mental Health Care Plan] was more accessible in terms of diagnosis, because that didn't cover, unfortunately the assessment, it was only for the sessions." (FG4)

Category	What would make it better?	Illustrative quotes
Appointment/ Service choice and flexibility	Appointment flexibility	"…being flexible around appointments and things like that… if things aren't going well on the day, you might not necessarily get to the appointment or you might not be able to get from the car into the building." (P42)
	Modality flexibility/availability	"There's a lot of people that have that dual diagnosis with autism and you know, their complex health needs are needing to see that doctor weekly or, you know, and it makes it extremely hard when you can't get in or of course, you can't actually be in the physical environment of a GP practice." (P54)
	Session length flexibility	"…being able to choose an appointment length or type - if an OT or psych 'only' accept 60 min appts it limits choice, sometimes I can't tolerate a long appointment. I would like other times to be able to have a longer appointment with a GP so we can spend time actually working through issues." (FG3)

Category	What would make it better?	Illustrative quotes
Information	Ask (clinician) follow up questions to check understanding	"…just saying, do you have any questions? Just let me know if you need anything. What is the scope of the conversation that I'm allowed to tell you what my needs are?" (P54)
	Clear expectations/advance information	"…if accommodations can be made, especially in the information can be given early and I like to read so I like her, she like, you know, it was really useful to see what I've done was really useful for me to download those questions and write a whole bunch of stuff. And that's what it could be for things like assessments as well. You know for children, because quite often you'll go to a for an OT assessment for a child. Even for myself, functional capacity assessment…So there's so much." (P103) "More info on everything. More information, kind of what are you doing so that you, like what are you putting in, into my body? What is it?" (for hospital admission) (P101)
	Increase accessibility	"I guess support materials and places to go for Autistic people to get support." (P8) "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." (P4)
	Information on service quality	"…user groups or, or family groups or information sites that provided some insight into that [service quality]" (P42)
	Information shared across practitioners being consistent	"Having that consistent message across the board, you know, so it's not 20 people giving you 20 different bits of information, it's the same information in the same way. And it's the, the way they're conveying information" (P105)
	Facilitate client sharing of information in advance of service	"I would love to be able to send info or questions ahead of time and have them have already digested all of it so the appt can be useful and time effective (for me) rather than them spending time reading info and then not getting to the helping part." (FG3)
	Provide psychoeducation (e.g., about health care system)	"I think including an element of psychoeducation around how the health care system even works and mental health care specifically is so, so important." (P59)
	Provide information on services available	"…more clarity from GPs and professionals on what we can actually access and what supports there are" (FG4)
	Written summary of care	"I'd love information to be followed up in writing" (FG5)

Category	What would make it better?	Illustrative quotes
Listening and validating	Consider input from parent/guardian/caregiver	“I think the other thing that probably should be is so much, so many people in these spaces really don't appreciate the value of the parents and the families. And these parents and families know the, the children. They know that the person with autism, and yet clinicians and bureaucrats and politicians completely disrespect it and, and think they know better.” (P50)
	Listening/validating and accommodating needs	“I just can't think of a better word than the validation… it doesn't matter whether it, it, it's not just about validating a person is Autistic, but also validating the experience of whatever they're going through in that moment as valid. Because often we think we're not valid as people. I certainly felt that way, that like, we're not, I'm not a valid person, or my, my condition or my experiences are not valid because people don't validate them.” (FG3)
	Talking to Autistic client/patient (not support person)	“Communicating with the Autistic individual and not to the support if they're able to, you know asking them what they need or even like watching them” (P44)
Service gaps	Education and training options for parents/carers/ families	“I think if we can educate [parents] knowledge is power. Like if we can educate people, sometimes I find going to a session with the speechie or the OT without the child is far more beneficial than taking the child… if you can do the PD's [professional development] and most of online these days and do them in your own time, then why not fund it?” (P32)
	Preventative mental health supports	“…getting in earlier before we have these [mental health] problems…. we've got to improve interpersonal connection earlier and it's gonna save the government money in the long run. So, like it's you know do funding of community engagement let's you know and in the health sphere and all that too. So, let's really work on getting in early and hopefully preventing these mental health issues before they come, you know, that's what we're aiming to do, isn't it?” (P15)
	Provide diverse solutions for diverse needs and groups	“…help all our neurokin - have services for First Nations and Torres strait Islanders, and refugees, and people who English is a second language, and all different cultures” (FG1) “The other thing is that we need to recognise that different people ask for different things, and the solution is not to choose one thing.” (P50)
	Support services and groups for adults	“People don't stop having autism once they turn 18 and adults get diagnosed and they need to meet each other and get support. There needs to be services and supports medics, like psychologists so forth that are available for adults, particularly women, because there's nothing” (P30)
	Whole family approach	“Family retreats: Where the family can stay together… where the meals are taken care of the cleaning is done, family activities but also separate therapies for each member of the family. respite available for the parents.” (FG4)

Category	What would make it better?	Illustrative quotes
Sensory	Accessibility standards	“Establish and enforce accessibility standards in health care facilities to ensure that they are equipped with the necessary infrastructure and technology to cater to individuals with sensory impairments. This includes providing sign language interpreters, accessible communication devices, and creating sensory-friendly environments.” (P57)
	Adapt sensory environment	“…if there was an option [instead of sitting in waiting rooms]… like at a pub where you get that beeper so a system where I could put my headphones on or I could go somewhere else or I could manage and regulate myself in the way that I need to potentially not in front of a room full of people and then be like collected or have a beeper go off.” (P16) “…for waiting rooms…if there was separate like sort of quiet, you know, waiting area sections, it would be really beneficial…treatment areas could be more sensory-friendly, like we do often associate hospitals and doctors with, you know, those bright fluorescent lights very white and overwhelming and intense. But maybe there are some situations where it doesn’t always have to be as clinical, and that might help, you know, reduce people’s anxiety… I think, in many ways, when we implement Autistic design principles, it actually benefits many people.” (P18) “…the ability to go to a quieter place in emergency or other large areas (e.g., day-visit procedure intake “waiting room” at (service)… not only the patient – but also the support person (parent/sibling/friend) may also have communication or overstimulation type alternate needs is important.” (FG5) “…not dimly lit, but tastefully lit and quiet music and lots of noise and, you know, not either over air conditioned or under air conditioned.” (P63)
Telehealth	Helpline for Autistic adults	“Something similar to Kids Help Line but for adults.” (FG4)
	Telehealth/e-health	“Zoom can offer some really great accessibility, particularly for those who use AAC or utilise written word” (FG5) “…e-scripting would definitely improve things, but across the board, greater access to telehealth would definitely improve things for me.” (P63)

Table 16: Navigation and access (Element A): What would make it better – Group comparison

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Access	Autism-specific services/ health practitioners who have a specialised understanding of autism*	A	A	A	A	A	A
	Autistic-friendly clinician list	B	A	B	B	B	B
	Home visits/home services	B	A	A	B	B	A
	Improve access to services	B	A	B	B	B	B
	More practitioners	B	B	B	B	B	B
	More subsidised mental health sessions	A	A	B	B	A	A
	Services (more affordable and easier to navigate)	B	B	B	B	B	B
	Systemic change	A	A	A	B	A	A
Access: Booking system	Online or email booking	B	B	B	B	B	B
	In-person contact to access	A	A	A	A	A	A

Legend

Percentage of participants per group raising idea	0%	Up to 24.9%	25-74.9%	More than 75%	*
Band	A	B	C	D	Raised in dyad or group where the specific priority group membership could not be categorised (e.g., unclear speaker attribution)

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Access: Diagnosis	Earlier diagnosis to facilitate supports	A	B	B	A	A	A
	Medicare funding for diagnosis	B	A	B	B	A	B
	Reduce stigma and negative implications around diagnosis	A	B	B	B	B	A
	Understand the implications of diagnosis	A	B	B	A	A	A
Access: Physical navigation and transport	Provide innovative delivery modalities	A	A	B	B	B	A
Access: Personal characteristics	Executive functioning assistance (e.g., memory)	B	A	A	B	A	B
Affordability	Improve or broaden access to Mental Health Care Plans	A	A	B	A	A	A
Appointment/ Service choice and flexibility	Appointment flexibility	B	A	A	B	B	A
	Modality flexibility/availability	B	B	B	B	A	A
	Session length flexibility	B	B	A	B	B	A

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Information	Ask (clinician) follow up questions to check and ensure and check understanding	A	B	B	A	A	A
	Clear expectations/advance information	B	C	B	B	C	C
	Facilitate client sharing of information in advance of service	B	A	A	B	B	B
	Increase accessibility	B	A	C	B	C	C
	Provide information on services available	A	A	B	A	A	A
	Information on service quality	B	A	A	B	B	A
	Information shared across practitioners being consistent	B	B	A	B	A	A
	Psychoeducation (e.g., about the health care system)	B	B	B	B	B	B
	Written summary of care	B	A	B	B	B	B
Listening and validating	Consider input from parent/guardian/caregiver	B	A	A	B	B	A
	Listening/validating and accommodating needs	B	A	B	B	C	B
	Talking to Autistic client/patient (not support person)	B	A	A	B	A	A
Sensory	Accessibility standards	B	B	A	A	A	A
	Sensory/environment	B	C	C	C	B	C

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Service gaps	Education and training options for parents/carers/ families	B	A	A	A	A	A
	Preventive mental health approach	B	A	A	A	A	A
	Provide diverse solutions for diverse issues/groups	B	A	A	B	A	A
	Support services and groups for adults	B	A	B	B	A	B
	Whole family approach	A	A	A	B	A	A
Telehealth	Help line for Autistic adults	A	A	A	B	A	A
	Telehealth/e-health	B	A	C	B	B	B

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

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**), participants discussed ideas relating to the benefits of Autistic practitioners and their insights, consistency of providers and services, stereotyping and stigma vs. understanding the individual, neurodiversity-affirming practice, gender and sexuality-affirming practices, feedback processes, restrictive practices, other specific mental health practices, and trauma, as well as commenting on quality both high and low more generally within the area of services, see Table 17.

At a general level, participants shared both high- and low-**quality** experiences. Specific factors negatively impacting quality were shared and included financially motivated services, a focus on quantity (i.e., extension of life) over quality of life, services systems being stretched and under-resourced, and a lack of follow-through in **feedback processes** including complaints and grievance procedures. This contrasted with some participants reporting positive experiences.

The value of receiving health or mental health care from **Autistic practitioners** was raised both as something working well and to make health/mental health care better in future. The challenges of neurotypical people (i.e. referring to people who were non-Autistic and non-neurodivergent) in understanding Autistic experiences, conversely, were raised as something not working well. **Consistency** of both health and mental health practitioners was raised as valued when present and a problem when absent. Experiences of **stigmatisation and stereotyping**, including incorrectly assuming people's ability level (both over and under estimating) were problems raised. This contrasted with valuing practitioners that understand the person as an individual with emphasis on individualising supports, including using a range of communication options to build this understanding, and drawing from strengths-based, as opposed to medical models, in formulating this understanding. The value of **affirming practices** was highlighted for **autism**, **gender**, and **sexuality** and the trauma arising from non-affirming experiences, such as misgendering. The importance of considering **trauma** and **restrictive practices** were raised both as negative experiences and positive where trauma was considered, or restrictive practices were avoided.

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. Ideas for training to respond to many of these challenges (e.g., stereotyping/stigma may be addressed through understanding autism and heterogeneity) were highlighted and discussed, however, have been classified and summarised under service coordination, outlined in section 3.3.3.

Table 17: Quality and safety (Element B): What is working well, what doesn't work well and what would make it better

Category	What is working well when available or offered	What doesn't work well	What would make it better
Autistic practitioners and insights	Autistic and neurodivergent health and mental health practitioners	Autistic practitioner barriers to disclosure	Support Autistic peer supports/professionals
	Autistic peer supports	Power imbalances between formal training and lived experience professionals	Autistic health and mental health practitioners
		Neurotypical professionals not understanding autism	Autistic people for mental health supports
			Autistic/neurodivergent liaison officers
Consistency	Consistent health and mental health practitioners	Inconsistent health and mental health practitioners	
	Consistent combination of supports	Inconsistent service delivery	
	Consistent service delivery		
Feedback processes	Giving feedback	Lack of complaints/grievance procedure	Provide complaint forms
			Complaints process followed
			Connection points (e.g., key contacts when problems arise)
			Regulation over providers
Individualising and understanding the person vs. stereotyping and stigma	Intersectional competence (e.g., culturally safe practitioners)	Stereotyping and stigmatising the individual	Understanding and tailoring care to the patient or client
	Providing non-speaking communication options	Intersectional biases (racism, homophobia, and transphobia)	Using social instead of a medical model of disability
	Understanding and tailoring care to the individual	Lack of intersectional competence	
		Assuming ability or inability (including based on communication modality)	Providing other ways to communicate

Category	What is working well when available or offered	What doesn't work well	What would make it better
Neurodiversity-affirming practice	Neurodiversity-affirming practices	Expecting Autistic clients or patients to fit neurotypical expectations or expressions	Neurodiversity-affirming practices
Gender and sexuality-affirming practice	Gender and sexuality-affirming practice	Non-gender affirming practice	
Quality	High quality experiences	Low quality experiences	
		Focus on quantity of life, not quality of life	Protection from harm (e.g., sexual abuse)
		Financially motivated services	Focus on quality rather than financial aspects
		Lack of resources	
Restrictive practices	Reduction or elimination of restrictive practices	Use of restrictive practices	Asking individual's preference regarding potentially restrictive practices
Specific practices for mental health	Specific practices experienced as helpful for mental health (e.g., Acceptance and Commitment Therapy [ACT]/ Mindfulness, adapted Dialectical Behaviour Therapy [DBT])	Specific practices experienced as unhelpful for mental health (e.g., Cognitive Behaviour Therapy, medication, mindfulness, weighing in-patients)	Providing alternative practices and adapting existing measures and practices to be more autism-specific
			Multidisciplinary approach
Trauma	Trauma-informed practice	Quality of care linked to trauma	Trauma-informed practice
			Respite rather than hospital to prevent trauma

4.2.1 Quality and safety (Element B): What is working well

Participants commented on high quality experiences broadly most commonly out of all codes in this element, and across all priority groups. They highlighted the specific value of Autistic practitioners, consistent practitioners, affirming (neurodiversity, gender, and sexuality) practices, feedback processes, reduction/elimination of restrictive practices, and specific mental health practices, individualising practice, and using trauma-informed approaches, see Table 18. For group comparisons see Table 19.

In terms of Autistic practitioners and their unique insights the value of a practitioner with lived experience who “understands what I’m going through” (P1) and that they “make me feel more competent” (FG3) was emphasised. This was raised by individuals identifying as LGBTIQA+ as well as women and girls. 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. A consistent health practitioner as being valued was raised most frequently by culturally and linguistically diverse participants and individuals in regional and remote areas. Affirming practices that respected and understood and respected 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).

Participants also raised approaches (trauma-informed) and specific practices (e.g., ACT/mindfulness, DBT, adapted therapies) they had found helpful in their mental health care. However, it should be emphasised the need and value of individualising and understanding the person was emphasised, rather than a one-size-fits-all approach. This included working “at the speed of trust” (FG3) which including working at a speed the patient/client feels safe and meeting them there. The value of considering variability in functioning within the same person was also emphasised.

Table 18: Quality and safety (Element B): What is working well when available or offered

Category	What is working well when available or offered	Illustrative quotes
General	Autistic and neurodivergent health and mental health practitioners	"...my psychologist has autism too, so I can see like a psychologist who understands what I'm going through." (P1) "...having neurodivergent people support me is absolutely incredible. It also means that that's wonderful. I feel less broken. Yeah. And that is a really big deal because these people are experts in their field. They're really good at what they do. They're amazing. And they also have similar neurotype to me, and that makes me feel more competent automatically. Just, I don't even know how to explain that, but it just does." (FG3)
	Autistic peer supports	"...it's so important to have those peer events and the peer connections, like, you know, even just from today, I've learned so many from hearing from you guys, about different ways to do things. So, the protective factors for mental health is really important to have those peer groups peer get together as a peer community where we can learn and share from each other. Because, you know, like everyone said, we don't know what we don't know, and the only way we know is by coming together." (FG4)
	Consistent combination of supports	"...having a combination of supports in place and regular supports is the number one thing for me." (FG4)
	Consistent health practitioners	"It's a lot easier having the same doctor." (P101) "...he (GP) 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." (FG3)
	Consistent mental health practitioner	"So, it was good because I had somebody that I could fortnightly going to talk to." (P103)
	Gender and sexuality-affirming practice	"They asked and respect pronouns." (FG5) "They're very LGBTQ affirming." (P19)
	Giving feedback	"I would suggest anybody who has had a bad experience with the (hospital), reach out to them if you're able to, because I actually were, I actually found them more help than the actual emergency department themselves because I got to talk about all of the experiences that I had and give suggestions to them. And I actually got a phone call from back from them a few weeks ago, basically saying they're still following up and getting reports from everybody and trying to put some of the suggestions that you've made on board." (FG5)

Category	What is working well when available or offered	Illustrative quotes
General	Intersectional competence (e.g., culturally safe practitioners)	"...what has worked for me is looking for a culturally safe support that are culturally competent because that matters. You can no more separate my neurodivergence from my blackness, than you can separate my blackness from my neurodivergence...when you come from a minority community, you learn that the world isn't built for you and you have to navigate it and you have to find safe ways to navigate it." (FG4)
	Neurodiversity-affirming practices	"They're very neuro-affirming." (P19) "Autism-friendly." (FG5)
	Quality (high)	"My psychologist. My daughter's psychologist. They were lovely, understanding. Very helpful. They believed us and respected us and worked with us to find strategies to improve mental health outcomes. The GP that listened to me and sent me to specialists to check things out. She was lovely. She was very helpful." (P19)
	Reduction or elimination of restrictive practices	"I think like even with NDIS like this, they've generally now they try to avoid using restrictive practices." (P102)
Specific practices for mental health	Acceptance and Commitment Therapy (ACT)/ Mindfulness	"ACT [Acceptance and Commitment Therapy] is helpful. I found learning mindfulness and grounding techniques was really helpful." (FG5)
	Animal-assisted therapies	"She actually is lucky enough to have had horse therapy funded. And that has been, horses have always been her thing. That's her obsession but she is her calmest around them alright. Animal therapy gets me emotional cause it's such. It's just been the most amazing thing." (P32)
	Behaviour Support	"...some support in terms of developing behaviour protocols and all that kind of stuff for school...got him back into school." (P42)
	Complementary approaches including using a wider range of practitioners (e.g., mental health occupational therapists)	"I do think generally that like mental health OTs, they have such a great, the best framework of looking at life, I think is, and, and their practice is really helpful for Autistic people. But just such a variety of things that they can work with or sensory things or emotional things, so also very practical things." (P51)
	Dialectical Behaviour Therapy (adapted for autism)	"I've found DBT [Dialectical Behaviour Therapy]-specific workbooks for autism and like, oh, great, yeah, which is, which is great as well." (P18)

Category	What is working well when available or offered	Illustrative quotes
Specific practices for mental health	Narrative therapy	"..narrative therapy and I still use a lot of those principles... not being the professional, not being the expert, but the person who's the expert in their own lives and those kind of the things....it's like a strengths perspective really. So, I think that's a really good approach to working with people who are kind of a bit diverse." (P61)
	Residential transitional care after hospital	"...it wasn't outpatient but It was like an old and old age care place where you got your room and then it got staff that monitor meals and monitor medication that kind of thing..." (P43)
	Structured approaches	"[describing adapted DBT] it's quite sort of a cognitive approach to understanding emotion, which I find great because that's how I, that's the way I approached the world. Yeah. This very cognitive, logical, rational way of trying to get through the world...this real structure and understanding it...this is what, this is what this emotion can be like, and this is what it can be... I find that that that structure really helpful and it, to me, it fits with that running that sort of order." (P51)
	Tailoring psychological services for the needs of neurodivergent individuals	"In terms of using, in terms of using mental health services? I think that the approaches the, like focus psychological strategies most often used in services do tend to be appropriate or can be tailored for the needs of many neurodivergent people, not all....one thing that is done well is yes, just with those, particularly I'm thinking about CBT and ACT, I think that obviously those are just like commonly used...in general and then they can be applied in ways that are helpful for people." (P54)
	Therapies that focus on interoception/body awareness	"My OT and I have done a lot of stuff with... interoception. She brings a bit more of the body signal... And that's been absolutely completely invaluable to me, to get a better understanding and better connection with my body and being able to notice what the body signals are... the difference it's made to my life in terms of coping with things." (P51)
	Trauma-informed practice	"...trauma-informed amazing." (FG5)
	Understanding and tailoring care to the individual	"...just specifically sit down and work with the person and see what their individual and medical situation is." (P103) "My doctor use as phrase called moving at the speed of trust. I love that it sounds, it, it sounds like a strange thing if you don't know what they're talking about, but essentially, he says, you know, he can only move at the speed that everyone feels safe at, but also, he needs to meet us where we are at, not the other way around." (FG3) "They just treat everyone like an individual person because like for me, right? Like I'm diagnosed level two, but depending on the day, you know, my support needs vary massively. Like that's part of autism. So, the fact that we even had functioning labels in the first place doesn't make sense for my brain at all." (P101)

Table 19: Quality and safety (Element B): What works well when available or offered – Group comparison

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Autistic practitioners and insights	Autistic and neurodivergent health and mental health practitioners	B	A	B	B	C	C
	Autistic peer supports	A	A	B	B	A	A
Consistency	Consistent combination of supports	B	A	A	B	A	A
	Consistent Health Practitioner	B	C	B	B	C	B
	Consistent Mental Health Practitioner	B	A	B	B	B	B
	Consistent service delivery	B	A	A	B	B	B
Feedback processes	Giving feedback	A	A	B	A	A	A
Individualising and understanding the person vs. stereotyping and stigma	Intersectional competence (e.g., culturally safe practitioners)	A	A	A	B	A	A
	Providing non-speaking communication options	B	A	B	B	A	A
	Understanding and tailoring care to the individual	C	C	C	C	C	C
Neurodiversity-affirming practices	Neurodiversity-affirming practices	B	A	B	B	C	B

Legend

Percentage of participants per group raising idea	0%	Up to 24.9%	25-74.9%	More than 75%
Band	A	B	C	D

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Gender and sexuality-affirming practice	Gender and sexuality-affirming practices	A	A	B	B	B	A
Quality	Quality (high)	C	B	B	C	C	C
Restrictive practices	Reduction or elimination of restrictive practices	B	A	B	B	B	B
Specific practices for mental health	Acceptance and Commitment Therapy and Mindfulness	A	A	B	A	A	A
	Adapted Dialectical Behaviour Therapy	B	A	B	B	B	B
	Animal-assisted therapies	B	A	A	A	A	A
	Behaviour support approaches	B	A	A	B	B	A
	Helpful complementary approaches (e.g., art therapy, somatic approaches, MH OT)	B	A	A	B	B	B
	Narrative Therapy	B	A	B	B	A	A
	Providing residential transitional care after hospital	B	A	A	B	A	A
	Structured approaches	B	A	A	B	B	B
	Tailoring psychological services for the needs of neurodivergent individuals	A	A	B	A	A	A
	Therapies that focus on interoception/body awareness	B	A	A	B	B	B
Trauma	Trauma-informed practice	B	A	B	B	B	B

4.2.2 Quality and safety (Element B): What doesn't work well

Participants across priority groups most commonly raised negative experiences related to service quality, followed by a lack of resources, and being stereotyped or stigmatised. The latter two were both raised across all groups to varying degrees. Participants shared experiences of low or poor service **quality** generally, as well as specific examples including financially motivated services, a focus on quantity of life (e.g., prolonging life) over increasing quality of life, **neurotypical practitioners not understanding autism** or expecting "fitting" to neurotypical norms, experiencing **stereotyping** and **stigmatisation**, **inconsistent** practitioners and service delivery, and **specific practices** experienced as unhelpful and **trauma** resulting from such practices, see Table 20. For group comparisons see Table 21.

Participants highlighted **quality** and the issue of a lack of resources resulting in short, inadequate appointment times, limited resources for health or mental health, and feeling rushed "out the door as quickly as possible" (P63). Some participants said that this led to making complaints and finding a lack of a process or no follow-up.

Experiences of **stereotyping** or **stigma** were commonly raised across all groups. These included not understanding "females can be Autistic" (FG5), stereotypes of "rain-man" (P63) and assuming "one-size-fits-all" (P16), as well as feeling neurotypical practitioners "don't get it" (P63). Stigma and bias also extended to intersectional identities including, "mainly being intersex or a person of colour" (FG2) being raised most commonly by individuals who identified as culturally and linguistically diverse and/or as women and girls. Incorrect assumptions of ability or inability were also raised, particularly by participants in regional and remote areas, LGBTIQA+, and individuals from low socio-economic status backgrounds. Assumptions included over-estimating functioning leading to missing serious mental health challenges, or under-estimating and "assum[ing] incompetence" (FG3). Further, an expectation that Autistic people should fit with neurotypical expectations was highlighted as a barrier to support with participants in FG3 raising that:

> *"it shouldn't be our responsibility to have to regulate ourselves to such chance, degree that people find us tolerable before we can actually get mental health or physical health support." (FG3)*

Practitioner issues were raised as challenges. Participants raised barriers to **Autistic professionals** disclosing (although clients/patients sought and valued disclosure) and difficulties with power imbalances between lived and professional experience practitioners. Further, practitioner availability was raised as a concern including only male gynaecologists or psychologists being available following practitioner changes. The need for better consistency to cover maternity leave, illness, and locum changes were highlighted. Further, inconsistent service delivery and service rules were also raised:

> *"most Autistic people like is consistency. And you know, we'd like to know what's gonna happen next. And if you don't know what's gonna happen next, you don't want to go there, right?" (P103)*

Taken together these flag serious issues where inconsistent practitioners or services led to Autistic people not accessing essential health or mental health supports.

Experiences of a lack of knowledge through to intersectional bias (e.g., sexism, racism) and stigma were highlighted. Specific non-affirming negative experiences were raised as not only directly impacting service quality but ongoing mental health. For example, repeatedly misgendering a transgender Autistic patient, who shared in writing:

> *"Repeatedly correcting people is emotionally and mentally exhausting, so much of the time I don't bother (which doesn't help my mental and emotional wellbeing. It can be a bit of a vicious cycle, sometimes)." (FG5).*

> *"...if I want to talk to talk about issues related to being queer, I have to talk to a queer professional. If I want to talk about my sexual assault, I have to talk to a professional in that. If it's something that's autism related, then I have to see an autism specialist. But they're all related to me and my experience and I find it really frustrating.... People don't understand the intersection and they don't understand the individual strands of the intersections." (FG2)*

Participants raised **specific practices** or approaches that did not work well for them or were restrictive practices. These included unstructured approaches, not adapting therapies for the needs of Autistic clients, CBT, medication for mental health, mindfulness, and weighing in hospital. For example, one participant (P15) shared an unnecessary weighing in response to hospital admission for a suicide attempt that led to an eating disorder. Participants also emphasised the need for formulating both medical (medications) and therapeutic (e.g., CBT, mindfulness) interventions to consider Autistic experiences and needs, as well as acknowledging for many individuals, "It's the environment that needs changing, not the person" (P103). This highlights the need to consider the foci of intervention (i.e., person vs. environment). Finally, participants importantly raised that poor quality care led to trauma impacting likelihood to seek ongoing or future care.

Table 20: Quality and safety (Element B): What doesn't work well

What doesn't work well	Illustrative quotes
Assuming ability or inability	"…presumptions of competence or incompetence…it's not to say that a presumption of competence is somehow a worse kind of ableism, but if you, if you are articulate and, and, you can communicate, then quite often you are not necessarily taken seriously, especially if you present to an emergency mental health kind of scenario. Like they go, oh, well, you know, you can talk really well and you can advocate really well for yourself and, and you can't, you know, you can't possibly be that distressed, not understanding that…They also tend to be on two sides of a spectrum of they'll see "Level 3" and believe the diagnosis but assume incompetence…" (FG5) "…if you're an adult with someone else supporting you as an Autistic person, you are judged as less capable, able, or valid." (FG3)
Autistic practitioner barriers to disclosure	"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 my career so far, the general advice was don't disclose it… There's still barriers to open disclosure of diagnosis…" (P54)
Expecting Autistic clients or patients to fit neurotypical expectations or expressions	"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." (FG3)
Financially motivated services	"I get a lot of targeted ads on Facebook for autism assessments … it's blatant, you know, money making and it's, it, it, it is really cashing in on, you know, on desperation and misery and it's, it's bloody awful." (FG2)
Focus on quantity of life, not quality of life	"…when you are actually in, you know, a critical condition when you do present at the ED [emergency department] and, and you might die, they, they're there, they jump in and they make sure you don't die because that's when they have a stake in it. You know, they don't wanna lose their registration, they don't wanna wind up in court. They're gonna make sure that they do everything they can to, you know, keep you breathing….they're quite interested in preserving your life because they have a stake in it, but they're not interested in your quality of life, which, you know, is often much harder." (FG2)

What doesn’t work well	Illustrative quotes
Inconsistent health practitioners	“…all my GPs keep moving or leaving because it's really hard to be GP.” (P16) “Not even gynaecologist. There was one gynaecologist who used to come up from (city in South Australia), but she doesn't come in anymore. It's just a male. So, I don't [access that service] anymore….That's [a] problem.” (P19) “We've been waiting for a speech pathologist. We had one she, left on maternity leave and so we had another one, then maternity leave…we've been waiting a good 18 months I reckon with no, no speech pathologist” (P34) “All of a sudden your doctor's away and you are offered a locum and you're just like ohh my God, this person doesn't know me.” (P103)
Intersectional biases (racism, homophobia, and transphobia)	“Racism” (FG4) “…accessing different services I've always found difficult. And I've guess there's a lot of trauma within that as well due to, I guess mainly being intersex or a person of colour. There's definitely had a lot of sort of biases there.” (F2) “…the queer Autistic person actually has two things to fear, not one…” (P54)
Inconsistent mental health practitioners	“…once I had a referral made to a specific psychiatrist, but for some reason when I came to the appointment, it was completely different psychiatrist, and it was just a gross experience.” (FG2) “Well yes, but also like just when I started with (mental health service) like I started with one caseworker and then it was like every month or two something would happen like they would leave or like, get sick or something. And then I'd have to go to another caseworker and start all over again. And so, they just, it was like they didn't really have, a thought-out plan of what to do with clients that had caseworkers that like left.” (P102)
Inconsistent service delivery	“…there never seemed to be any notes like passed down and I'm like surely you should have all this information, we've been here before but why is there no continuation of (hospital) care?” (P15) “I think there's a lot of mistrust in access to services because it's not consistent. There's no consistency, right? There's no consistency and what us Autistic people like most, most Autistic people like is consistency. And you know, we'd like to know what's gonna happen next. And if you don't know what's gonna happen next, you don't want to go there, right?” (P103)
Lack of resources	“…you finally get seen by someone who's overworked and underpaid, and they…get you out the door as quickly as possible.” (P63) “…my local (mental health service) has a very large service area. I think it covers like the majority of the (location) voting district. So, there's just not enough resources to go around.” (P55) “A 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.”(FG3)

What doesn’t work well	Illustrative quotes
Lack of intersectional competence	“they [health practitioners] have no understanding of intersectionality and they bring with them all their sexism, racism, elitism.” (FG4) “…my daughter is assigned male at birth. So, I need to keep her safe from that. It's just been horrific. And of course, none of the services understand that. And every support worker doesn't understand and are not appropriately trained, it's been impossible to get them.” (P30) “I think gender is also quite poorly understood among most health professionals, to be frank. Yeah. Because we, we operate very much on the basis of sexual dimorphism you've got male organs and you've got female organs, and you've got everything else.” (P54)
Neurotypical professionals not understanding autism	“Because you can say, oh, train all clinicians, but NTs [neurotypicals] are clueless. Like they don't get it. So, they, they'll think they get it, or training is always tick boxy.” (P63)
Non-gender affirming practice	“…they misgendered me the whole time…Repeatedly correcting people is emotionally and mentally exhausting, so much of the time I don't bother (which doesn't help my mental and emotional wellbeing. It can be a bit of a vicious cycle, sometimes).” (FG5)
Power imbalances between formal training and lived experience professionals	“Power imbalance between “formally trained” and “lived experience” (FG4)
Quality (low)	“I haven't honestly had that many positive experiences that I can remember.” (P102) “The mental health system in the hospital isn't very user friendly at all.” (P4) “I had a reaction to that ketamine infusion… it caused me to collapse coming back from the bathroom to my bed in the hospital. And the response of the nurse was to come in and spend 25 minutes…telling me that I was quote unquote an issue to her that I was in the hospital because I was Autistic.” (FG3)
Quality of care linked to trauma	“And I had deteriorated to such a degree from the traumatising assessments of the NDIS and complete neglect that not even a mental health service that was the best private mental health clinic in town in my state could care for me.” (P56)
Specific practices experienced as unhelpful for mental health (Cognitive Behaviour Therapy, medication, mindfulness, weighing in patients)	“I can tell you right now Cognitive Behaviour Therapy for Autistic people does not work often, and unfortunately it's the go to, you know, therapy of the through Medicare et cetera.” (P103) “Lots of the strategies and therapies like CBT. They're good up to a point, but then the therapist must be adaptable and change according to the individual needs of the Autistic person.” (P03) “I’ve had a lot of psychology treatments that are very sort of standard in terms of you know, anxiety depression, CBT [Cognitive Behaviour Therapy] kind of things. Still, they're not always very effective for an Autistic brain, and they definitely weren't for me.” (P18)

What doesn’t work well	Illustrative quotes
Stereotyping and stigmatising the individual	“But just I think there's still so much stereotyping and there's just so much that is taught that is surface level and like one size fits all kind of thing which you know that's not the same for typically developing people.” (P16) “I think also the medical world/community catching up with the fact that adult/females can be Autistic.” (FG5) “...again doing autism equals rain man.” (P63) “...there's a lot of trauma within that as well due to, uh, I guess mainly being intersex or a person of colour. There's definitely had a lot of sort of biases there.” (FG2)
Trauma leading to avoiding seeking/accessing supports	“If I had a bad experience, and this is something that I've also seen with clients that I support. If we've had a bad experience, we're likely to just not go back... it would even be like at a, in a medical thing... I would just not go back... I'd feel like that place is dead to me. I don't want to go there...that's a common thing that I've seen across like multiple people that I've supported.” (P33)
Unstructured or inconsistent approach/routine	“We've got a psychologist....a different psychologist might be better if they were more structured, but the one that I see I isn't so structured.” (P28) “And then the change of routine and stuff, they don't realise how much that affects you... like rules that are there one minute and not the next. I found that difficult in hospital. Like one nurse would be like, this is your role. And then another would be like, you don't have to do that kind of thing...in the mental health ward, especially, there's certain things... you are not allowed cords and shoelaces..., but not just that, it's stuff like you are not allowed to sleep on the sofa in the common rooms or you have to go to bed at 11 o'clock. But then some let you stay up till like midnight. So, then it's always things changing... Just little things that people don't notice... I hate the change... and when it's not consistent.” (P124)
Use of restrictive practices	“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.” (FG5) [When someone mentioned feeling like they want to punch someone without a risk of immediate or intended harm] “... and this mental health nurse will suddenly throw up a red flag and before you know it, they're having like a code black or whatever called against them and being led out basically grabbed underneath their shoulders and dragged out of the hospital.” (P4) “But putting her under [anaesthesia] was extremely difficult. We often had to restrain her and yeah, then she'd wake up, but also extremely anxious, and screaming the recovery ward down.” (P45)

Table 21: Quality and safety (Element B): What doesn’t work well – Group comparison

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Autistic practitioners and insights	Autistic practitioner barriers to disclosure	A	B	B	A	A	A
	Neurotypical professionals not understanding autism	B	A	B	A	B	A
	Power imbalances between formal training and lived experience professionals	A	A	A	B	A	A
Consistency	Inconsistent health practitioners	B	C	C	C	C	B
	Inconsistent mental health practitioners	B	B	B	B	B	B
	Inconsistent service delivery	B	B	B	B	B	B
Feedback process	Lack of complaints/grievance procedure	B	A	B	B	B	B
Individualising and understanding the person vs. stereotyping and stigma	Assumptions of ability or inability	B	A	C	A	C	C
	Intersectional biases including racism, homophobia, transphobia	A	B	B	B	A	A
	Lack of intersectional competence	B	C	B	C	B	B
	Stereotypes/Stigma/not seeing whole person/not individualising	C	C	C	C	C	C

Legend

Percentage of participants per group raising idea	0%	Up to 24.9%	25-74.9%	More than 75%
Band	A	B	C	D

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Neurodiversity-affirming practices	Expecting Autistic clients or patients to fit neurotypical expectations or expressions	B	B	B	B	B	B
Gender and sexuality-affirming affirming practice	Non-gender affirming practice	A	A	B	B	A	A
Quality	Financially motivated services	B	A	B	A	A	A
	Focus on quantity of life, not quality of life	A	A	B	A	A	A
	Low quality experiences	C	C	C	C	C	B
	Low quality experiences	C	C	C	C	C	C
Restrictive practices	Use of restrictive practices	B	A	B	B	C	C
Specific practices experienced as unhelpful for mental health	Cognitive behaviour therapy (CBT)	B	A	B	B	B	B
Specific practices for mental health	Lack of an autism-specific or tailored approach	B	A	A	B	A	B
	Medication	B	A	B	B	A	B
	Mindfulness	B	A	A	B	B	B
	Unstructured or inconsistent approach/routine	B	A	B	B	B	B
	Weighing people when admitted for suicide attempts and putting them on ADHD meds (appetite suppressing)	B	A	A	A	A	A

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Trauma	Trauma caused by service	B	A	B	B	C	C
	Trauma leading to avoiding seeking/accessing supports	B	B	B	B	B	B

4.2.3 Quality and safety (Element B): What would make it better

Participants shared a number of ideas that could improve the **quality** of the care including **Autistic practitioners** and supports, **individualising** care, drawing from strengths-based models, improving **feedback**/regulation processes, using multidisciplinary and neurodiversity-affirming practice and adapting/using **specific practices**, see Table 22. For group comparisons see Table 23. While only a few comments were made for each suggestion, with mixed results across priority groups, individualising care was raised most commonly in total and was raised across all priority groups. Please note that in addition to suggestions outlined below, improved training and topics for this were also outlined; training is covered in **Education and training** (Element D), see section 3.4.3.

In terms of **Autistic practitioners** and supports, the value of Autistic practitioners across both health and mental health were raised. In addition, providing access to non-professional Autistic peers or supporters was also raised as helpful to offer more broadly in future. Further, the use of Autistic liaison officers similar to First Nations liaison officers was raised as a potentially helpful future support. The need to support and protect Autistic people working in these roles was flagged as important.

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 that are in place, increasing provider regulation, and having key communication points for complaints or concerns. The need to particularly protect vulnerable Autistic people from harm, including sexual abuse in mental health services, was raised.

Participants shared ways to reduce or eliminate **stereotyping** and **stigma** such as greater focus on understanding the individual, individualising (including in selecting/reducing use of restrictive practices such as in response to self-harm or risk), drawing from social and strengths-based models of disability to understand individuals and formulate care. To facilitate this, it was suggested that a range of alternative communication modalities (e.g., drawing, typing, and writing) would be helpful, and to allow greater processing time.

The need for greater use of **neurodiversity-affirming practices** was emphasised including, as discussed in FG3, that:

> *"our [Autistic] responses/experiences as actually being expected/normal for us as ND [neurodivergent] people, so should be reframed so they are not an abnormal or unexpected response." (FG3)*

Participants also commented on the need to adapt **specific practices** including therapies and assessment tools to be more Autistic-specific and provide alternatives to Cognitive Behaviour Therapy and incorporate the impact of **trauma** in formulation and treatment.

Table 22: Quality and safety (Element B): What would make it better

What would make it better	Illustrative quotes
Adapting existing therapies and assessments to be more autism-specific	"...once you find sort of resources and techniques that are designed for Autistic people, it changes things significantly. So, yeah, a lot of health and health and mental health. If you go through the standard...it might not work for specific people." (P18)
Asking individual's preference regarding potentially restrictive practices	"You know it's different for every person, so it's best to ask that person what helps [to respond to self-harm instead of immediately using restrictive practices]" (P102)
Autistic health and mental health practitioners	"Get Autistic health care professionals. That's what you need. Like seriously you need it...Like I certainly know through my practice Autistic clinicians, but I don't know like Autistic, you know, surgeons..." (P63)
Autistic people for mental health supports	"...what it actually helped me embrace my autism like being Autistic was being amongst other Autistic people, learning about autism... they were learning about other Autistic people, being accepted." (P104)
Autistic/neurodivergent liaison officers	"I think all psychiatric hospitals, in particular, should have a dedicated... specialist in that area can upskill the staff and train...almost like what we have for our First Nations support workers for a similar reason." (P36)
Complaints process followed	"Complaints procedures that are followed" (P56)
Connection points (e.g., key contacts when problems arise)	"....connection points...a key person in health, a key person in education... you could contact that person if there was some kind of issues with communication or you know, someone who could sort of get things moving when there was problems." (P61)
Focus on quality of services/supports (rather than financial aspects)	"..if providers were held to account over what they actually support people to achieve in their lives or, or, or the support quality of supports that they provide. That would be a much better measure than just measuring dollars all the time." (P42)
Improve behaviour support approaches	"Well, behaviour support. We actually need to start doing behaviour support properly in this country...and there's massive resistance to most of the evidence-based practice." (P50)
Multidisciplinary approach	"Encourage a multidisciplinary approach to health care that involves collaboration between professionals from various fields, including autism specialists, mental health professionals, and experts in deafness. This approach can help develop comprehensive and integrated care plans that consider both the Autistic and deaf/hard of hearing aspects." (P57)
Neurodiversity-affirming practices	"...our responses/experiences as actually being expected/normal for us as ND [Neurodivergent] people, so should be reframed so they are not abnormal or unexpected response." (FG3 quotes)
Protection from harms (e.g., sexual abuse)	"more protective factors for risk of sexual abuse in a hospital mental health setting" (FG4)
Provide complaint forms	"...perhaps on the website there is a complaint form integrated into that thing." (P59)

What would make it better	Illustrative quotes
Providing alternative practices (to cognitive behaviour therapy)	“Trauma is very much related to our disability because we are vulnerable and trusting and we believe people who try to groom us. There's a lot of mental health work needed to recover from those things. And it does have to be specifically targeted for a neuro-affirming strategy in order for it to be effective. For us, just using CBT [Cognitive Behaviour Therapy] isn't going to overcome childhood abuse trauma. And how we are able to heal and recover is very much tied in to how our brains function and how our brain can rewire certain pathways to be able to heal and to no longer ruminate on negative experiences. It is very Autistic, autism-specific in how that is done...” (P3)
Providing other ways to communicate	“Patience from GPs listening and to be able to overcome communication challenges.” (P3) “GPs and specialists understanding that people have different communication styles and just that awareness so that they are a bit more patient in trying to listen to what you're trying to say...a bit more...compassion [...and] extra processing time to form the words.” (P3) “I like wrote something down like notes on my phone and handed it to them like with a little explanation of what was happening [to explain shut-down and non-speaking]” (P102) “I get stuck in my brain. I can't make the words come out. So like art therapy does it for me... I can draw a bunch of squiggles and my art therapist will work with me to be like, oh, how do you feel about this colour? And if this had a sound, what would it be? And like, I think it also, for anyone who's like non-speaking or struggling, then that would also be helpful.” (P1)
Regulation over providers	“...more regulation over providers.” (P42)
Respite rather than hospital to prevent trauma	“This [respite] would be a nice alternative to staying in a hospital where you are more traumatised.” (FG4)
Support Autistic peer supports/professionals	“...supporting the neurodivergent people who are supporting others and how we protect them in the industry.” (FG4)
Trauma-informed practice	“...trauma informed training across the board in all health care, it's not happening. ... there needs to be some kind of from the top-down training across the board so that everyone's on the same page.” (FG4)
Understanding and tailoring care to the patient or client	“...health care needs to be a personalised approach. It doesn't need to be a one-size-fits-all.” (FG3) “I think that's psychiatrist and mental health, like professionals shouldn’t make blanket generalisations.” (P104)
Using a social instead of a medical model of disability	“[psychiatrists and mental health, professionals] should like come from a strength-based approach. Or even like a social model of disability or neurodiverse model of disability... The psychiatrist, like he was coming from a medical model. Which looks at deficit.” (P104)

Table 23: Quality and safety (Element B): What would make it better – Group comparisons

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Autistic practitioners and insights	Autistic health and mental health practitioners	B	A	B	B	A	A
	Autistic people for mental health supports	B	A	B	B	A	A
	Autistic/neurodivergent liaison officer	B	A	A	B	B	A
	Support Autistic peer supports/professionals	B	A	A	B	B	B
Feedback processes	Complaints process followed	B	A	B	B	B	B
	Connection points	B	A	B	B	A	A
	Provide complaint forms	A	A	B	A	A	A
	Regulation over providers	B	A	A	B	B	A
Individualising and understanding the person vs. stereotyping and stigma	Providing other ways to communicate	B	A	B	B	B	B
	Understanding and tailoring care to the patient or client	B	B	B	B	B	B
	Using social instead of a medical model of disability	B	A	B	B	B	B

Legend

Percentage of participants per group raising idea	0%	Up to 24.9%	25-74.9%	More than 75%
Band	A	B	C	D

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Neurodiversity-affirming practice	Neurodiversity-affirming practices	B	A	B	B	B	A
Quality	Focus on quality rather than financial aspects	B	A	A	B	B	A
	Protection from harms	A	A	A	B	A	A
Restrictive practices	Asking individual's preference regarding potentially restrictive practices	B	A	B	A	A	B
Specific practices for mental health	Adapting existing therapies and assessments to be more autism-specific	B	A	B	B	A	A
	Improve behaviour support approaches	B	A	A	A	A	A
	Multidisciplinary approach	B	B	A	B	A	A
	Providing alternative practices	B	A	A	B	B	B
Trauma	Respite rather than hospital to prevent trauma	A	A	A	B	A	A
	Trauma-informed practice	A	A	B	A	A	A

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

In relation to Element C: Building better connections between health, mental health and other sectors including NDIS (**Connections and collaboration**), participants highlighted **advocacy**, **sharing of information**, **fostering useful connections**, **support coordination** and **service/ funding disconnect** as areas working or not working well and as aspects that would make service coordination better, see Table 24.

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, health reception (e.g., administration staff), support coordinators and workers. Conversely, they also shared negative experiences where there was a lack of connection, disconnect between funding and **connections** made, and unsuitable or undesired services being linked, such as police or psychiatry. The role of **support coordinators** and examples where this had worked well, not worked well, and potential ways to strengthen this were also raised. **Advocacy** across various stakeholders (parents/caregivers, self, others with lived experience, professionals) was highlighted as being helpful, but also challenging to do by some participants. Finally, participants shared ideas for strategies that could foster more helpful, useful, or meaningful **connections** across health and mental health services in future, as outlined in more detail in section 3.3.3.

Table 24: Connections and collaboration (Element C): What is working well, what doesn't work well and what would make it better

Category	What is working well when available or offered	What doesn't work well	What would make it better
Advocacy	Self, parent/caregiver, lived experience, and professional	Challenges engaging in advocacy for stakeholders	Supporting stakeholders to advocate
Fostering useful connections	Fostering useful connections	Practitioners not connecting	New supports to build connections
		Inconsistent or unreliable support coordination	Provide lists of available services and support coordinators
		Local area coordinators not connecting	Connection to suitable services
	Providing information on supports that may be helpful	Referred to services not seeking	Risk assessment
		Police involvement for suicide risk	
		Poor communication leading to adverse outcomes	
Service/ Funding disconnect		Disconnect between hospital and community supports	
		Disconnect between different states/territories services	
		Medicare billing barriers	
		Service/funding disconnect	
Sharing information within and across services	Collaboration between government health/mental health services	Repeating story and/or information	Sharing key information between services

Category	What is working well when available or offered	What doesn’t work well	What would make it better
Support Coordination	Allowing community supports into hospitals	Service coordination (Phone assessment)	Accessing support coordination
	Positive experiences of support coordination	Support coordinators unprofessional conduct	Resourcing support coordination
	Support worker connecting	Lack of transition from child/young adult to adult services	Shorter waitlists for support coordination
		Poor quality/inconsistent or unreliable support co-ordination	Support coordinators with lived experience

4.3.1 Connections and collaboration (Element C): What is working well

Participants shared **fostering of useful connections**, **fostering of useful connections**, **sharing information within and between services**, **advocacy**, and **support coordination** as areas that had worked well for them, see Table 25. For group comparisons see Table 26. They also discussed positive experiences with health, mental health, and supporting staff (e.g., health reception) as well as support coordinators and workers supporting **useful connections** (particularly in rural and remote) and referrals to services. Specific provision of information on what services may be helpful was valued, including the scope and role of potential supports, such as speech pathology. 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. This was raised across all groups, however, self/parent advocacy was raised most commonly in individuals from rural and remote areas and from low socio-economic status backgrounds).

Table 25: Connections and collaboration (Element C): What works well when available or offered

Category	What is working well when available or offered	Illustrative quotes
General	Collaboration between government health/mental health services	"...what people have done well at times is work collaboratively with other services and other health providers." (P42)
	Lived experience advocacy	"...advocacy in lived experience roles and, and increasing number of lived experience roles and pathways for lived experience workers to gain qualifications, and work in the lived experience sector is also something that I see as a really positive step" (P59)
	Parent/caregiver advocacy	"As I said, I'm a big, big advocate for the children and yeah I will, I will push ahead with these things. I know the doctors etc they understand I'm a big advocate." (P34)
	Professional advocacy	"...having my social worker has been the next level. Just having that advocate as, as I'm a human rights activist, I need an advocate for those moments 'cause they emotional and I am needing to regulate. I just need somebody to take control, have my back and tell people, this is how you would treat them. This is where their rights are and we're watching you." (FG4)
	Providing information on supports that may be helpful	" I went to the planning meeting and the LAC [Local Area Co-ordinator, NDIS]...she did actually say to me at my planning meeting, I think you'd benefit from a speechie, a speech pathologist...I didn't even know that would be an option because I thought it was just for people that couldn't talk, like I never had someone explain to me that it could help me, like communicate more effectively." (P102)
	Self-advocacy	"I went to the new ultrasound/biopsy session saying look, I'm Autistic. I get very high anxiety, so they made accommodations." (P103)
Useful connections were fostered by:	Allowing community supports into hospitals	"...one of the quirk here about things like NDIS that, that has improved is that originally in previous sort of schemes and arrangements, workers were... disallowed from coming into the hospital because that would be considered funding double dipping... that seems to have improved quite significantly. I think there have been some provisions from NDIS made that they can get the carer to attend now, whereas even three years ago, that was a real problem." (P54)

Category	What is working well when available or offered	Illustrative quotes
Useful connections were fostered by:	Health and mental health practitioners	“The psychologist that diagnosed me also helped with the [NDIS] application. She made the process incredibly simple. So, she did a functional capacity assessment for me as well… when it came to completing the forms, she just gave me these incredibly clear, like colour coded instructions on what I needed to do, what the GP needed to do, she filled out the form… that made it really simple.” (P8) “I was experiencing a mental health crisis, and I called the mental health triage number, which, they were really good. Someone stayed on the phone to me. They sent out a team, to come and talk to me, which were, like mental health nurses.” (FG5) “She [GP] did really well was she was able to unpack my specific complexities and refer me to people, resources that were in the general area.” (P103) “That psychiatrist referred me to, to this clinical psychologist…the receptionist said, well, this particular clinical psychologist, like she isn't taking anymore appointments…later on their phone back and they said, well, actually the clinical psychologist, like she was approached by this diagnosis psychiatrist and, and I, so she will take me on.” (P104)
	Health reception personnel	“I broke down in the, in the waiting room… the staff at the desk came over to me and she asked me what was wrong. And I told her, and there she took me aside. We went, I discussed all the difficulties I had. She also organised a meeting with the manager of the surgery… I had the meeting with the manager and she and this woman sat in with me” (FG3)
	Positive experiences of support coordination	“I have an excellent support coordinator and my support coordinator has found me an excellent GP, an excellent OT, an excellent physio.” (FG3) “I just had help trying to find the people with regards to NDIS services and stuff and my plan, not my plan manager, my support coordinator helped find people who were available.” (P4)
	Support workers	“I think I also had had was like texting my support worker and they had like called the hospital and stuff.” (P102 discussing linking to supports)

Table 26: Connections and collaboration (Element C): What works well when available or offered – Group comparison

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Advocacy	Lived experience	A	A	B	A	A	A
	Professional advocacy	A	A	A	B	A	A
	Self, parent/caregiver, and other supporters	B	B	B	B	C	C
Fostering useful connections	Health or mental health practitioner connecting	B	B	B	B	B	B
	Health reception staff connecting	A	A	A	A	B	A
	Providing information on supports that may be helpful	B	A	B	B	B	B
Sharing information within and across services	Collaboration between government health/mental health services	B	A	A	B	B	A
Support coordination	Allowing community supports into hospitals	A	B	B	A	A	A
	Positive experiences of support coordination	B	A	B	B	C	B
	Support worker connecting	B	A	B	B	B	B

Legend

Percentage of participants per group raising idea	0%	Up to 24.9%	25-74.9%	More than 75%
Band	A	B	C	D

4.3.2 Connections and collaboration (Element C): What doesn’t work well

Participants raised problems including being connected to services not sought (e.g., directed to a psychiatrist when not seeking mental health support) or not fitting (e.g., inappropriate support), challenges with **advocating**, problems with **support collaboration**, disconnects between services and funding, and needing to repeat stories as not working well, see Table 27. For group comparisons see Table 28. Negative experiences with **support coordination** (poor connection within and between services) were the most commonly raised concern (all groups).

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. The need to advocate was 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.

Issues with **service coordination** were also raised, including bullying and coercion, long delays, difficulties changing providers, poor communication between services and health professionals regarding medication and 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 including a lack of support to transition between services including across states/territories, child/adult services, and hospital/community supports including the intersection of health and NDIS supports. Participants also discussed trauma arising from being required to re-tell their stories to each provider and a lack of information sharing across services.

Connections between services, the individual, and families were raised for individuals who are/were unable to provide their own consent or with high or complex support needs (e.g., intellectual disability and high behaviour support needs) as particularly challenging. For example, parents P36 and P37 shared significant long-term harms that occurred in response to 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 for their Autistic daughter. 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.

Table 27: Connections and collaboration (Element C): What doesn't work well

What doesn't work well	Illustrative quotes
Challenges engaging in advocacy for stakeholders	"I didn't have the skills to speak up or know that it wasn't right." (P8) "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." (P3) "If she had been with her mum, she'd be dead… she would not have been able to be [advocate] as strong. … I have a university education … and it still was really hard for me." (P15, describing advocating for an Autistic adolescent following multiple suicide attempts) "She (Autistic young person) was too afraid to ask for extra pain relief or anything like that. She was too afraid to say what her needs were." (FG3)
Disconnect between different states/territories services	"The fact that the family violence system is state by state means that if you have to leave a state for family violence, it means you cannot access any family violence services in the state you're safe in. Which means that survivors cannot access any counselling, which means that they have no opportunity to recover, which further impacts autism, any other preexisting things. The system needs to be national." (P30)
Disconnect between hospital and community supports	"When somebody goes into the hospital, the process of getting out of hospital, it's sort of like these NDIS patients who go into hospital and then they're not, they can't get NDIS services while they're in hospital, yet you need NDIS services to find somewhere to leave hospital services. That intersection stuff is really shocking." (P50)
Lack of transition from child/young adult to adult services	"When I turned 25 they discharged me from their service without transferring me to an adult service." (FG4)
Local area coordinators not connecting	"So local area coordinators. They give you the information like you reach out to them response times poor. You reach out to them to find you know what services are available for my son who needs let's say OT for example. They'll send you a list and that's about it. Like, no, give these guys a call. Let me know if you need any support. Nothing. They'll just send you a list and these are the providers and then you've got to question It saying well are these providers in Tasmania? Because I don't want a mainland provider because my child needs face to face." (P44)
Medicare billing barriers	"My children all have their own Medicare card. So, we went up afterwards to pay and she said, right, that'll be back on his card within 24 hours. I said, he's a child, he doesn't have a bank card connected to his thing. Here's mine…our system doesn't do that. So, I had to race home to log into his Medicare, his myGov… to put a bank account on his thing…thank God I did. Otherwise, they sent to a cheque. And what rigmarole would I have trying to get a cheque cash for my child who has no phone." (P63)

What doesn’t work well	Illustrative quotes
Police involvement for suicide risk	“...mental health crisis and I called the mental health triage number... They did also have police ...I hadn't made any threats of, of violence or anything.” (FG5) “...trigger warning for police once I had a wellness check called on me. And it was honestly the worst experience and made me feel so much worse afterwards. And that's actually a huge thing that people don't take into account.” (FG2)
Poor quality/inconsistent or unreliable support coordination	“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.” (P1)
Practitioners not connecting	“...so the hospital, because they required him to be discharged to one, found an appointment for him, a, a GP in town that when we got there, they were the rudest doctor I've ever seen. We actually put in a complaint. She was just like, why are you here? What, where's the information? And we were like, we don't even know what information you want. It was supposed to be sent from the hospital... I know hospitals are understaffed and things like that, but, but that sharing of information...is probably like the, the biggest thing. So having relevant parties be able to access, access the information. (P33)
Poor communication leading to adverse outcomes	“...the thing that happened affects <daughter’s name>to this very day... the staff rang up because <daughter’s name> had an explosive moment there, and he said, increase the dose of liquid Haloperidol [antipsychotic medication], and the staff weren’t clear on what the dosage was and they end up giving her a mix up 10 milligrams and millilitres or something like that... she got a very high dose. By a mistake. An innocent mistake., because it wasn’t written down. It was verbal over the phone. They gave her a double dose. <daughter’s name> was put onto the school bus that morning because she’s had the blow up. She’s had this really high dose. It’s quickly brought it down. She gets on the bus, and she collapses on the bus...she would later say, that she was humiliated; that was the word she used. And from that day until about 15 years ago, she would not take any oral medication of any sort whatsoever.” (P36)
Referred to services not seeking	“I've also been redirected to psychiatry when that was not my reason, nor need, for help.” (FG5)
Repeating story and/or information	“I have trauma associated with a particular medical procedure I have to have a few times a year and even after so many times noting with the clinic about having the same nurse and doctor every time to avoid them asking me the full history every visit (resulting in re-living the trauma) I have had too many times when I turn up and they've swapped me to a different doctor or nurse. and when I reiterate my needs, they keep asking for why and more info and why again.” (FG3) “I hate having to tell my story again, again and again to people who more often than not really don't give two sh*ts...” (P63)

What doesn’t work well	Illustrative quotes
Service coordination (phone assessment)	“...their assessment of me was just from over the phone and obviously you can't really make a full assessment of someone's disability like that. And so yeah, it was just not an accurate picture of my disability.” (LAC developing first plan without meeting client in person, P102)
Support coordinators unprofessional conduct	“So, at one point, <daughter’s name> had a worker who swore at all the clients. And the reason we know this is the clients, the residents, they used to come up and talk to me in the car park, and one said, this worker <name of worker>, she's on the phone to her boyfriend 'Hang on, just talking to a retard'.” (P37)
Service/funding disconnect	“... psychologist didn't really want to do funding through the NDIS, didn't wanna deal with my plan manager, just wanted me to pay and then get reimbursed. And that basically threw me for a loop for a few times and wanted, she wanted me to use the mental health plan.” (FG5)

Table 28: Connections and collaboration (Element C): What doesn't work well – Group comparisons

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Advocacy	Challenges engaging in advocacy for stakeholders	B	A	B	B	B	A
Fostering useful connections	Local area coordinators not connecting	B	A	A	B	A	A
	Police involvement for suicide risk	B	B	B	B	A	A
	Poor communication leading to adverse outcomes	B	A	A	B	B	A
	Practitioners not connecting	B	B	A	B	B	B
	Referred to services not seeking	B	A	B	B	B	B
Service/funding disconnect	Disconnect between hospital and community supports	B	A	A	B	B	A
	Disconnection between states/territories	B	A	B	B	A	B
	Medicare billing barriers	B	B	B	B	A	A
	Service/funding disconnect	B	A	B	B	B	B

Legend

Percentage of participants per group raising idea	0%	Up to 24.9%	25-74.9%	More than 75%
Band	A	B	C	D

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Sharing information within and across services	Repeating story and/or information	B	A	B	B	B	B
Support coordination	Lack of transition from child/young adult to adult services	B	A	A	B	B	A
	Service coordination (phone assessment)	B	B	B	B	B	B
	Poor quality/inconsistent or unreliable support coordination	C	B	C	C	C	C
	Support coordinators unprofessional conduct	B	A	A	B	B	A

4.3.3 Connections and collaboration (Element C): What would make it better

Participants raised that support to build **advocacy** skills, **connection** to suitable services, **better sharing of key information** between services and improvements to support coordination would make connections better, see Table 29. For group comparisons see Table 30. They also shared ideas for new supports to improve service **connections and collaboration**. This included ensuring participants were aware of the range of services available. Further, ideas for how to share key information, such as setting up systems or health passports to enable better sharing of information across health and mental health providers were shared.

Participants made a number of comments around support **coordination** and how it could be improved, such as having access to a support coordinator where this had not been available to the person. This was raised by all priority groups. Additional ideas included a list of support coordinators to combat challenges finding/sourcing support coordinators, ensuring sufficient resources and reducing waitlists to access support coordinators, and support coordinators with lived experience of autism (including parents/caregivers) or who are Autistic themselves. Participants also raised suggestions for new or improved service coordination including incorporation of risk assessments, the need to strengthen connections between government support services, developing autism-specific hubs (Autism Hubs) or Autistic/peer supports to foster connections around both health and mental health. 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, professional qualifications were viewed as a potential barrier for many who would be interested and suitable to provide support. Further, participants emphasised the need to ensure adequate compensation and funding to people with lived experience, as opposed to reliance on unpaid volunteers.

Table 29: Connections and collaboration (Element C): What would make it better

Category	What would make it better	Illustrative quotes
General	Advocacy program for Autistic people	"We need individual advocacy for Autistic individuals. And so far the government has absolutely refused to think about that. So, there's a national disability advocacy program… but there are none for autism…the generic ones doesn't understand autism… we need proper advocacy services that understand autism and actually advocate for the benefit of Autistics, not for the benefit of the NDIS or, or, you know, the service provider" (P50) "…advocacy groups that can help, particularly for people who aren't… supported through the NDIS…if there was somewhere like that, that you could go as an Autistic person that you could end up like, on a semi-regular basis, even if it was just for peer meetups and things, and there were people that you knew and felt, felt comfortable with, that then could help you make bookings if you needed something." (P33)
	Connection to suitable services	"There could be a bunch of other people I could be seeing on my Mental Health Care Plan that I just have no idea…that information would be so useful for so many people." (P16)
	Sharing key information between services	"For me, a system that is better linked up where, you know, with your consent, people can access that information. You don't have to tell the story 500 times would make my life so much easier" (P63) "I think having a health passport for like adults, that isn't as like child focused on the, the developmental milestones more focused… like a log that's…the date, and this is the doctor I saw and this is what I needed and what they gave me…this is my last hospital admission, and these are who my support workers are." (P1)
	Provide lists of available services and support coordinators	"…more knowledge and also more, I don't know whether it's advertising… more knowledge of the services that are out there." (P52) "So, like having this list of companies on a database." (P104)
	Supporting stakeholders to advocate	"…being able to advocate for a care plan, to know who to ask within the hospital to know what you can demand, that is really important." (FG4) "…we need to have the language, how to ask for accommodation and access needs, but also be aware that the person on the other end, might, you know, be a risk about being asked these things." (FG4)
Support coordination improvements	Accessing support coordination	"… if I had a support coordinator…that person can actually like help direct me to services and stuff I can get with my funding, which would be really helpful." (P102)

Category	What would make it better	Illustrative quotes
Support coordination improvements	Lists of support coordinators	"...if people had just said to us from the start, this is everything, we would have just got it all in one go and it would have been cheaper. It would have been faster." (P16)
	Reduce wait times	"...wait-times and in like...support coordination" (P104)
	Resourcing support coordination	"And I'm not sure kind of whether that's a state, state or a federal thing, but sort of looking at how to kind of really organise and make sure these groups do have the capacity to help everybody. Because yeah, they just seem incredibly busy, like the demand has just kind of skyrocketed, but the money is not there...having services like that can definitely help navigate and find out what's available and out there, but just making sure they have the time for it I guess as well." (P18)
	Support coordinators with lived experience	"Getting more lived experience people into those [service coordinating] organisations... I still think that getting lived experience people in those roles is the easiest way to make the change. Well, not the easy the best way to make the change." (P16)
Fostering useful connections	Autism hubs	"We need, like an Autism hub...that isn't specifically related to and NDIS ...run by people who have lived experience...Parents need a place to go and just have a chill space where they don't have to feel like they're comparing their child to somebody else's child and going 'Oh, you know he's not meeting his milestones'...Go and have a place where they can just have some couches, nice lighting, chill out, and if they need referral to somebody, there's information there...it's really important not to be staffed by people who have qualifications because there's so many barriers to receive...education and employment and stuff like that. It needs to be and not volunteers either, like people need to be paid for their contributions to these services." (P103)
	Autistic/Peer support	".... peer support group, maybe like an Autistic teens group or something like that." (P15) "...she would learn better from peers...some kind of social network groups that she could meet other Autistic girls." (P15) "...what they really need to invest in are peer-led community programs that are funded. So, they're paid properly, paid positions" (FG5)
	Better collaboration between government and health/mental health services	" I feel like there needs to be a lot more co-collaboration between government support services to make sure that that sort of stuff (disability accommodation knowledge) is spread at least statewide through health, if not nationwide through health." (FG5)
	Risk assessment	"...the NDIS could have done a risk assessment or a vulnerability assessment when I became a client and worked out that I was high in complex needs." (P56)

Table 30: Connections and collaboration (Element C): What would make it better – Group comparisons

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Advocacy	Supporting stakeholders to advocate	A	B	B	B	A	A
Fostering useful connections	Autistic/Peer supports	B	A	B	B	B	B
	Autism Hubs	B	A	B	B	B	B
	Better collaboration between government health/mental health services	B	A	B	B	B	A
	Connection to suitable services	B	A	B	B	A	A
	Provide lists of available services and support coordinators	B	A	B	B	B	B
Sharing information within and across services	Sharing key information between services	B	A	B	B	B	B
Support coordination	Accessing a support coordinator	B	A	B	B	B	B
	Resourcing for support coordination	B	B	B	B	B	B
	Shorter waitlists for support coordination	B	A	A	B	A	A
	Support coordinators with lived experience	B	A	B	B	A	A

Legend

Percentage of participants per group raising idea	0%	Up to 24.9%	25-74.9%	More than 75%
Band	A	B	C	D

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

In relation to Element D: Improving autism education and training for health and disability professionals (**Education and training**), participants identified elements that were both working and not working well, and that could be targeted via **training** to improve competence as including health and mental health professional knowledge and understanding of autism including pain expression, intersectional understanding, and low self-efficacy working with Autistic individuals, see Table 31. Gaps in knowledge or understanding were identified and this extended to how practitioners responded to their own gaps. In this regard, participants raised that acknowledging gaps and conducting research or learning from patients or clients was a helpful response to this. In contrast, not acknowledging or admitting knowledge gaps was raised as a concern and harmful for clients as outlined further in section 3.4.2. Finally, participants identified important components for future training to improve professional competence, including **who should be trained** (all staff including reception staff in health and mental health settings), **who should deliver training** (with an emphasis on Autistic people delivering training for health and mental health professionals), and the **content of training**, see section 3.4.3. Of note, in terms of professional competence identified training areas aligned with issues in quality, including experiencing stereotyping or stigmatisation by health professionals and inaccurate assumptions of ability/non-ability. These may be addressed via training in autism and heterogeneity, debunking stereotypes, and intersectionality, as examples.

Table 31: Education and training (Element D): What is working well, what doesn't work well and what would make it better

What is working well when available or offered	What doesn't work well	What would make it better
Acknowledging gaps in knowledge and open to learning or researching	Professionals not admitting or acknowledging gaps in knowledge	Training: What should be covered
Understanding and knowledge of autism	Not understanding or lacking knowledge of autism	Training topics: autism and heterogeneity, debunking stereotypes, disability broadly, eating disorders.
	Lack of awareness of specific accommodations	Training topics: adapting the environment
	Low self-efficacy to work with Autistic people	Training topics: neurodiversity-affirming/social model/strengths-based training, trauma-informed practice.
	Lacked autism content in university training	
Individualising supports to meet client/patient needs	Not understanding pain may be expressed or experienced differently	
Understanding intersectionality		Training considerations: compensation for services to upskill, feasible training modules for practitioners, and incentives to upskill
	Parents/carers/clients feeling forced to train or educate practitioners	Training: Who should deliver training: Training delivered by Autistic people
		Training: Who should be trained
		Training for all workers in health and mental health including management.

4.4.1 Education and training (Element D): What is working well

Participants highlighted knowledge/understanding of autism and acknowledgement and openness to learning where gaps existed as areas that are working well, see Table 32. For group comparisons see Table 33. Understanding autism and knowledge of autism was raised most commonly as working well when experienced by participants and was raised across all groups. Further, participants raised the value of an openness to learning through practitioners acknowledging and actively addressing their own knowledge gaps and/or deferring to clients' knowledge. For example, one participant shared the experience of their practitioner being open to learning about what they required to be included in a report to apply for supports.

Table 32: Education and training (Element D): What is working well when available or offered

What is working well when available or offered	Illustrative quotes
Acknowledging gaps in knowledge and open to learning or researching	"Willing to admit their lack of knowledge and do research or defer to me. So, one example of that was seeing a psychologist, a clinical psych for a letter confirming that I was...to be considered for HRT [Hormone Replacement Therapy]... luckily I had an example of what that letter should look like and I'm a counsellor myself, so I was able to approach the psychologist and say, here's what I'm looking for. Is this something you can help me with? And he luckily was humble enough to say, I haven't done this before, but I'm really happy to ask around, figure out how to do this, use the example you've given me and basically write something up that resembles that obviously spending the time to talk to me as well." (FG5) "I really like the current psychologist that I have, even though she doesn't have a sort of focus in autism, she's quite willing to try to learn and adapt. So that's kind of good in the kind of closest thing that I've found." (P18)
Understanding and knowledge of autism	"Having mental health professionals that understand autism and understand how it presents." (P4)

Table 33: Education and training (Element D): What works well when available or offered – Group comparison

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Knowledge and understanding	Acknowledging gaps in knowledge and open to learning or researching	B	A	C	C	B	B
	Understanding and knowledge of autism	C	B	C	C	C	C

Legend

Percentage of participants per group raising idea	0%	Up to 24.9%	25-74.9%	More than 75%
Band	A	B	C	D

4.4.2 Education and training (Element D): What doesn't work well

Participants raised lack of awareness of specific accommodations, low self-efficacy, and low understanding/knowledge exacerbated when professionals did not acknowledge gaps as areas that were not working well in terms of professional **education and training**, see Table 34. For group comparisons see Table 35. Low knowledge was raised as the most common issue and was raised commonly across all priority groups. Participants reported practitioner lack of knowledge led to their autism and/or common co-occurring diagnoses (health and mental health) diagnoses not being made or identified. The Sunflower Lanyard for Hidden Disabilities was raised as a specific example where practitioners (e.g., hospital staff) were not aware of specific accommodations that individuals may use. Gaps in knowledge of these types of specific accommodations was raised across priority groups. That pain may be experienced or expressed differently by Autistic people was raised as a specific gap in knowledge, specifically within the high/complex needs, LGBTIQA+ and women and girls priority groups. Participants raised the challenges in needing to upskill or educate practitioners about their knowledge gaps. This was identified by parents/caregivers as well as Autistic individuals.

Difficulties working with Autistic people (e.g., due to stereotypes and fear) and people with intersecting identities (e.g., transgender and Autistic) were raised as an area where professionals had expressed feeling low in confidence (low self-efficacy). This may relate to some participants raising that gaps may be due to the absence of autism content in their university training. A lack of knowledge or understanding of autism was raised, particularly in rural and remote areas and in professionals nearing retirement who were perceived to be reluctant to engage in additional training. Experiences of professionals not raising or acknowledging their own gaps in knowledge and this exacerbating health or mental health challenges of patients or clients was raised as an issue in this area.

Table 34: Education and training (Element D): What doesn't work well

What doesn't work well	Illustrative quotes
Client feeling forced to train/educate practitioners due to knowledge gaps	"I was talking about masking… And he hadn't really heard of that. And I actually showed him my research study that I'd done and it just got published…I was explaining that like camouflaging or masking leads to like Autistic burnout because you having to like subconsciously or consciously, to fit in or whatever, or, so he'd never heard of that [Autistic burnout]. I was telling him what it was and that there's like new research, coming up about it and how it can look similar to like depression. But the reason it's so important to understand the difference is because of the way they're treated… you know, depression you need to sort of get back into a routine and try and do things. Whereas burnout, Autistic burnout, you've obviously got to rest and just try and reset your, your system kind of thing. So that's what I was trying to explain to him." (P124)
Lacked autism content in university training	"I do not know what the medical curricula is like now going through med school now, but I can say definitely that autism was not one of the topics that we studied…it was maybe given one sentence… So in my current crop…the early specialist stage and above, I would say that understanding would be negligible." (P54)
Lack of awareness of specific accommodations	"a few things I had noticed is none of them [hospital staff] knew what a disability hidden disability lanyard was or what it represented." (FG5)
Low self-efficacy to work with Autistic-people	"Like they, I see a lot of, they seem like fear-based response to me of just like, I don't know what to do…. they're like Autistic people have meltdowns, Autistic, Autistic people freak out or people steam or, so they're, they're, they're primed for these things that they do as negative. 'cause for them they would be embarrassing, or you know, distressing or shameful." (P63)

What doesn't work well	Illustrative quotes
Not understanding or lacking knowledge of autism	“I’ve had things before where a doctor has not understood the concept of sensory issues and has attempted to sort of make it like an anxiety thing and suggesting that I do CBT [Cognitive Behaviour Therapy] with my therapist and I’m just, and that I went to my therapist to mention this and because I had heard that wasn’t really a common sort of good thing for sensory issues, and she looked it up and was like, no, that’s, that wouldn’t really fix that wouldn’’t really, it’s not really what’s done. Doctor was a bit out of date.” (P23) “I also am concerned when doctors dismiss the ‘known’ co-morbidities for autism like hypermobility (and hypermobile Ehlers-Danlos Syndrome) and eating issues and dental complexities.” (FG1) “I’m finding a lot of regional and rural professionals of all backgrounds are aging and they’re at the end of their careers. So, they don’t necessarily wanna go and proactively research what the latest information is on neurodiversity because it’s all too complicated for them at this point in their career.” (P103) “With autism, 100% they don’t understand.” (P102)
Not understanding pain may be expressed or experienced differently	“I've been dealing with like a chronic sort of intermittent pain. And I have sort of realised that when doctors do like the physical examination, I have to like consciously go, oh, ouch, ouch. Like, because it hurts… I won't necessarily express that in the way that a neurotypical doctor would expect. But if I just say I'm in pain and then don't go, ouch, they don't believe me.” (FG2) “…surgeon was asking me what pain score I was getting this time and that time. And so I tried to, I took a moment to say, actually I'm Autistic. So, I find doing pain score is really difficult, but I can tell you what things are hard and what things are easy.” (FG2)
Parents/carers feeling forced to train or educate practitioners about autism due to knowledge gaps	“…that's what we're finding the hardest is training or informing the staff.” (P37)
Professionals not admitting or acknowledging gaps in knowledge	“Professionals who do the opposite and pretend they know something when they don't. And then I end up, um, I guess bearing the brunt of that and, you know, injured either psychologically or physically because of it.” (FG5)

Table 35: Education and training (Element D): What doesn't work well – Group comparisons

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Knowledge and understanding	Client/patient needing to educate/ train practitioners about autism	B	A	B	B	A	B
	Lack of awareness of specific accommodations	B	B	B	B	B	B
	Low self-efficacy to work with Autistic people	B	A	B	B	B	B
	Not understanding or lacking knowledge of autism	C	C	C	C	C	C
	Not understanding pain may be expressed or experienced differently	B	A	B	B	A	A
	Parents/ carers feeling forced to train or educate practitioners	B	B	A	B	B	A
	Professionals not admitting or acknowledging gaps in knowledge	B	B	A	B	B	B
Training	Lacked autism content in university training	A	B	B	A	A	A

Legend

Percentage of participants per group raising idea	0%	Up to 24.9%	25-74.9%	More than 75%
Band	A	B	C	D

4.4.3 Education and training (Element D): What would make it better

Participants specified professionals working in health and mental health **should be trained**, **by whom**, and in **what**, see Table 36. For group comparisons see Table 37. A need for train all workers was emphasised most often and by participants across all priority groups. Participants also highlighted the need for top-down, systems-level supports.

In terms of **whom should be trained**, participants explicitly highlighted the need for front-line professionals working in emergency services required training as they are the, “first point of contact,” and because, “Autistic people … don’t behave how you expect someone in pain to behave.” Participants discussed significant impacts on their health and mental health resulting from a lack of understanding or training as a result, such as giving birth without pain relief, receiving medical procedures without adequate informed consent, and dismissal of serious concerns including suicidality resulting in later hospitalisations. Participants also emphasised the need for, “mandatory training for any allied health or medical professionals (right down to reception staff) on neurodivergence (good training by us)” highlighting the need for all points of contact to be included in training and that training delivered by Autistic people was valued. This aligns with feedback in quality regarding the value and need for lived experience.

In terms of the **content of training**, while basic autism knowledge was raised by some participants, many emphasised further the need to cover heterogeneity which was highlighted across all groups, for example, “That everyone is different with autism… that even within the same person there can be different presentations on different days.” (P102). Other areas raised as important topics for training included how to adapt the (sensory) environment for Autistic people including using Autistic perspectives to audit this, debunking stereotypes and myths about autism (e.g., narrow perceptions of autism, reduced awareness of female presentations, and generalisations of child to adult presentations), understand intersectionality (i.e. intersection between Autistic and other identities and needs), emphasising the need to move from medical to social and strengths-based focus that is neurodiversity-affirming, and trauma-informed training. Specific topics also included ensuring practitioners are aware of differences in responses to medication and expressions of pain. Participants raised that significant harms had arisen from practitioners not understanding these differences in the past, including pain being minimised or denied resulting in significant medical trauma and heightened risk such as future avoidance of breast examinations. Finally, participants highlighted important considerations for incorporation of training as including feasibility of implementation, financial incentives or reimbursements, and the need to look at knowledge translation and implementation in practice.

Table 36: Education and training (Element D): What would make it better

Category	What would make it better	Illustrative quotes
Considerations for training	Feasible training modules for practitioners (that work within schedules)	"… it's tricky because sometimes, especially if you work in private practice, training can be, it's hard to make space for it unless it's sort of some kind of like a short online. Seminar, you know, because it's, you wanna be able to engage in the training, but if you've gotta go to somewhere and, you know, take a day out or something like that. So I find the types of professional development works for me is sort of shorter kind of online things that you can, you can listen to in your lunch break or, you know, make a little bit of time for… That sort of thing would be really handy." (P61)
	Provide incentives for domain specific training (e.g., ND-affirming care)	"Specific incentives for clinicians to gain extra training in these areas [racism, ableism, trauma informed care, ND affirming care] and see these [Autistic] patients." (FG4)
	Services compensated to upskill	"…some of those things in the allied health would be a good thing. But for somebody in a small practice, they might need financial support as well…to give up their time or to have them in the office same as, young GPs… to go into the practice." (P39)
	Translation of knowledge of neurodiversity to practice	"…it's not necessarily that people aren't informed at this point, though for some people maybe, I think a lot of the folks that I work with are reasonably informed about neurodiversity, but then it's just that next step of how do I put this into practice? What does this actually mean for my day to day? And then really committing to that, I can see how it would be easy from the perspective of a neurotypical person, especially if you primarily work with neurotypical people to sort of treat it as a side issue, to see it as, I guess like a special area of practice or something that you just sort of put on your cultural competency hat on for the appointment and then take it off again. But I think that it goes so much deeper than that. And really, in order to make or practice is more accessible, it has to be done in like an integrated way. It has to go all the way through." (P59)

Category	What would make it better	Illustrative quotes
What should be covered	Adapting the environment	"So, we're [Autistic people] evaluating your space now. We're telling you what you could do differently. Both adapting your space and adapting aspects of your practice." (P63)
	Adult diagnosis and differential diagnosis	"I want psychiatry training. Especially like when people go to do the consultant training. 'cause I looked at the syllabus the other day… they only cover, developmental disorders in their language, which obviously would include autism in child and adolescence practice…. And basically they learn about autism in a child and adolescence setting, but then they learn nothing about the possible presentation as adults. So, I want basically the training of psychiatrists to change for a start and beyond just the DSM, like understanding different presentations like in women and girls and that. And also being open to like screening patients or especially like people with BPD [Borderline Personality Disorder] diagnosis or anorexia nervosa or schizophrenia." (P124)
	Autism and heterogeneity	"That everyone is different with autism and there's like, even though there's three levels categorised even within those three levels, people can make different presentations. And also, that even within the same person there can be different presentations on different days." (P102)
	Autistic burnout	"I think they all need to be trained in it [Autistic burnout]. What it means as supposed to regular burnout." (P30).
	Debunking stereotypes	"More awareness of what autism looks like in adults, how it looks in women. How the diagnostic criteria and stereotypes, are not an accurate way to represent the expression of autism in in adults… showing people… what it looks like from both sides, you know from a struggle side and from… what people can achieve as well…I guess the positive side, but then you know the cost that can come with that…a conference presentation might result in like a week of rest or you know…we can perform like neurotypical people, but it comes at a cost." (P8) "More than just the strengths… again, the stereotype of, the gifted male engineer type. So yeah, different strengths, other than those really classic and well-known ones." (P8)
	Disability broadly	"All around disability training, mental and physical." (P101)
	Eating disorders	"…training for health care providers… specific to whatever environment they're working in, because I have had situations, particularly where it's more of a specialised area…my personal experience, I have an eating disorder and I've had a lot of experiences where, like nurses who do encounter that a lot in their everyday life or like, but it may not necessarily be like that, like it may not be an even the sort of ward, but like, say, for example, an emergency department." (P102)
	Intersectional experiences and identities	"But when is the medical/therapeutic world going to catch up with us so they can support us in our diversity, rather than each individual thing/diagnosis/identity as a silo that doesn't impact on anything else." (FG5)
	Medication response differences	"Awareness of how medications can cross over and affect us and things like that." (FG5) "Autistic people may have atypical reactions to common medications." (P3)

Category	What would make it better	Illustrative quotes
What should be covered	Neurodiversity-affirming, strengths-based, social model of disability	"Psychologists [should] have autism training and it's a neuro affirming training. ...making sure that the professionals are able to help the Autistic person to discover their strengths and how to support and advocate for their challenges while uplifting their value as a person and then to enhance wellbeing rather than trying to fix and change the very nature of who they are. They've gotta tie in with all the masking and the suicide rates as a result of camouflaging. Yes. Or, as I prefer adaptive morphing." (P3) "[Discussing training needed for health practitioners] "...it's important to allow Autistic people to be themselves where they feel comfortable like stimming and stuff, is perfectly normal and something that should be allowed as long as it's not harmful to someone else or themselves" (P102)
	Pain expression and experience differences	"...that pain is experienced differently for different people... not even just people with autism, but people in general. That sort of having that underlying language to communicate...people who are doing kind of diagnostic or triage work to kind of know how to ask those questions. 'cause what was it, how much pain you in from one to 10 where 10 is the worst pain you can imagine? Everything ends up a three for me because I'm like, I can imagine some pretty horrible things. I don't know how to take that, not literally enough, give them the information they need." (FG5) "My interoception is really poor. I don't know if I'm in pain half the time because I've had this level of pain for so long that I'm just used to it." (P3)
	Trauma-informed practice	"...trauma informed training across the board in all health care, it's not happening. ... there needs to be some kind of top-down training across the board so that everyone's on the same page." (FG4)
Who should be trained	Acute care workers	"Public emergency room staff definitely need a professional learning module [because] Autistic people ... don't behave how you expect someone in pain to behave." (P3) "I personally feel that emergency nurses and doctors should have at least a general understanding of it [eating disorders and autism], because they do see it a lot like it, and that's the first point of contact for a lot of people that are medically unstable with that type of thing." (P102)
	All workers	"Mandatory training for any allied health or medical professionals (right down to reception staff) on neurodivergence" (FG3)
	Management level training	"And it is training ... which is the management level training... Workers maybe 90%, have been lovely people and they genuinely have, they seem to be doing the best they can, but a lot of them don't use their initiative. They're again, they're not trained. So, it's this level here that need to be employing people." (P36)
Who should deliver training	Autistic people	"Good training by us (Autistic people)" (FG3)

Table 37: Education and training (Element D): What would make it better – Group comparisons

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Considerations for training	Feasible training modules for practitioners	B	A	B	B	A	A
	Provide incentives for domain-specific training	A	A	A	B	A	A
	Service compensated to upskill	B	A	A	A	A	A
	Translation of knowledge of neurodiversity to practice	A	A	B	A	A	A
What should be covered	Adapting the environment	B	A	B	B	B	A
	Adult diagnosis and differential diagnosis	B	A	B	B	A	B
	Autism and heterogeneity	C	C	C	C	B	C
	Autistic burnout	B	A	B	B	A	B
	Debunking stereotypes	B	A	B	B	B	B
	Disability broadly	B	B	B	B	A	B
	Eating disorders	B	A	B	A	A	B

Legend

Percentage of participants per group raising idea	0%	Up to 24.9%	25-74.9%	More than 75%
Band	A	B	C	D

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
What should be covered	Intersectional experiences and identities	B	B	B	B	C	B
	Medication response differences	A	A	B	B	A	A
	Neurodiversity-affirming, strengths-based, social model of disability	B	B	B	B	A	B
	Pain expression and experience differences	A	A	B	B	B	A
	Trauma-informed practice	A	A	A	B	A	A
Who should be trained	Acute care workers	B	A	B	B	A	B
	All workers	C	B	C	C	C	C
	Management level training	B	A	A	B	B	A
Who should deliver training	Autistic-led and/or delivered by Autistic people	B	A	B	B	B	B

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

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**), results for this element should be interpreted with some caution as relatively few participants made comments relating to research. 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), see Table 38. The need for central inclusion of lived experience was highlighted, including the value of Autistic-led and participatory research, not prioritising other (e.g., non-Autistic experience) over Autistic experience, and the need for more research that explores lived experiences of health and mental health care for Autistic people.

Participants highlighted the diversity of Autistic people across what is working well, not working well, and how to improve research in the future. The areas considered for improvement were 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, which are outlined in more detail in section 3.5.3.

Table 38: Research and data (Element E): What is working well, what doesn’t work well and what would make it better

What is working well when available or offered	What doesn’t work well	What would make it better
	Lack of research on lived experience	Focus on lived experience across research phases
Autistic-led and participatory research	Non-Autistic academic researcher perspectives prioritised over Autistic perspectives	
Including diversity and intersectionality	Not understanding or including diversity or intersectionality	Include diversity of Autistic experience including children and young people
	Inaccurate interpretation of results	Knowledge translation (systems level, and via universities, social media)
	Focus on genetics and prevention viewed as problematic	Priority areas for future research (e.g., Autistic burnout, community bias, late diagnosis, quality of life, intersectionality and understanding heterogeneity)
	Lack of research into intersectional identities	
	Stigma a barrier to research participation	

4.5.1 Research and data (Element E): What is working well

Participants highlighted **Autistic-led and participatory research** (raised most frequently and across all priority groups) and the **inclusion of diversity and intersectionality** in research were areas that were working well currently, see Table 39. For group comparisons see Table 40. This included highlighting the value of research led by Autistic people and the inclusion of participatory measures where Autistic-led research was not possible. The inclusion of intersectional experiences in research was highlighted as a strength, such as exploring the experiences of Autistic people who are also LGBTIQA+ which was raised in this priority group.

Table 39: Research and data (Element E): What is working well when available offered

Research and data on health and mental health outcomes of Autistic people and their families and carers

What is working well when available or offered	Illustrative quotes
Autistic-led and participatory research	“...you [Autistic interviewer] are a good example, a shift with Autistic people doing the research. Yeah. But that's still, that's still slow. You know, like I'm seeing it five or more years ago I never saw that. So that change is very welcomed. I think it needs to keep happening. Even if it can't be Autistic led research, it definitely needs to be consumer led and, and participatory engagement.” (P63)
Including diversity and intersectional experiences and identities	“A huge crossover between LGBTIQA+ and autism.... and research is starting to support our experiences/knowledge” (FG5)

Table 40: Research and data (Element E): What works well – Group comparison

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Heterogeneity	Including diversity and intersectionality	A	A	B	A	A	A
Lived experience	Autistic-led and participatory research valued	B	B	B	B	B	B

Legend

Percentage of participants per group raising idea	0%	Up to 24.9%	25-74.9%	More than 75%
Band	A	B	C	D

4.5.2 Research and data (Element E): What doesn't work well

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), see Table 41. For group comparisons see Table 42. Of note, the focus on genetics/cause and risk of focusing on "cures" was raised most commonly as of concern to LGBTIQA+ priority group members. Other perspectives (e.g., academic researchers, non-Autistic health practitioners) being prioritised or listened to over lived experience was raised most often as a concern by participants. Further, the need for Autistic researchers to also consider diversity was raised, with P63 noting it was important to:

> *"…realise your experience of autism is not THE experience of autism." (P63)*

Table 41: Research and data (Element E): What doesn’t work well

Category	What would make it better	Illustrative quotes
Heterogeneity	Not understanding or including diversity or intersectionality	“Some of those people coming through doing Autistic research. I'm like, you're not necessarily any better than, than the NTs [neurotypicals] who are doing the research before. Like, you need to take a step back and realise your experience of autism is not THE experience of autism.” (P63)
Lived experience	Lack of research on lived experience	“...when I was doing psych class, I was trying to do a whole thing on... how testosterone affects ADHD and autism. All I could find was Reddit posts...There were no medical papers... it was really disheartening. Like I made jokes about like, oh, I'm like a human guinea pig.” (P55)
	Non-Autistic academic researcher perspectives prioritised over Autistic perspectives	“...health professionals who had done like, you know, inhumane experiments are still listened to over Autistic voices.” (P1)
	Stigma a barrier to research participation	“And I think mental health and that particularly hard to get people on board with research cause they don't wanna talk about their experiences with strangers. I suppose it's I suppose it's all that stigma.” (P52)
Knowledge translation	Inaccurate interpretation of results	“There's a failure to understand the evidence base from key people and, and if that sort of stuff is going on, you know, I mean the people outside the field have got no chance of understanding it.” (P50)
Priority areas	Focus on genetics and prevention viewed as problematic	“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.” (P55)
	Lack of research into intersectional identities	“...people that have got mental health issues who are Autistic, the mental health community and professionals don't really know what to do because there just isn't that body of research.” (P43)

Table 42: Research and data (Element E): What doesn't work well – Group comparison

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Heterogeneity	Not understanding or including diversity or intersectionality	B	A	B	A	A	A
Knowledge translation	Inaccurate interpretation of results	B	A	A	A	A	A
Lived experience	Lack of research on lived experience	B	A	B	A	B	A
	Non-Autistic academic researcher perspectives prioritised over Autistic perspectives	B	A	B	A	B	A
	Stigma a barrier to research participation	A	A	A	B	B	B
Priority areas	Focus on genetics and prevention viewed as problematic	A	A	C	A	B	A
	Lack of research into intersectional identities	B	A	A	B	A	A

Legend

Percentage of participants per group raising idea	0%	Up to 24.9%	25-74.9%	More than 75%
Band	A	B	C	D

4.5.3 Research and data (Element E): What would make it better

Participants raised the need for greater **focus on lived experience** across research phases, the need to **include diversity of Autistic experiences**, the importance of **knowledge translation**, and outlined areas they would like to see included in **future research**, see Table 43. For group comparisons see Table 44. The most commonly raised areas were the need to include the **diversity** of Autistic experience which was raised across all priority groups, to conduct future research about **lived experiences**, and for research to focus on **real-life outcomes**. Participants raised that **future research** could be improved through greater inclusion of lived experience across all phases of the research process including in the initial formulation of theories and the exploration of lived experience within research. Further, the need to include a **range of perspectives** was emphasised to ensure, "people who have different ways of communicating are heard..." (P63). The need for health practitioners to be up to date with research was highlighted and for better promotion of research to the community via social media, businesses, and universities.

Participants raised areas that they felt would be important to cover in **future research** as 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. Finally, participants emphasised the need for **knowledge translation** to be included in the research process to ensure findings were 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.

Table 43: Research and data (Element E): What would make it better

Category	What would make it better	Illustrative quotes
General	Focus on lived experience across research phases	“Right. So, you're an Autistic person. Tell me about this… you know, we need a lot more research on just what does it mean to be us? What does it mean to live our lives? What does that look like for us? What does the world look like for us? What are the spaces we inhabit look like for us? What our relationships look like?” (P63) “They need that they don't just come up with some sort of theory and hope for the best. Now they need it from the community” (P6)
	Include diversity of Autistic experience including children and young people	“There needs to be some kind of, you know, guidelines or insights around how do you keep yourself in check as an Autistic person, as a non-Autistic person. How do you make sure that the, the quietest voices among us are heard? …How do you make sure that people who have different ways of communicating are heard and engaged with.” (P63)
	Knowledge translation	“…making sure that they're engaging with up-to-date research… I would like to see it in the health care that like you have to do one hour on this, one hour on this… guided a little bit more in terms of like if you've been in the profession for 40 years, these are the areas that your knowledge is probably most outdated.” (P16) “…there needs to be some kind of like incentive for people to go and increase their learning [around current research / best methods] especially for people who graduated more than eight years ago.” (FG4) “…more businesses were more accepting of it and then they would promote like research.” (P52) “…if the research bodies like themselves or whatever the universities actually could promote it amongst like the medical professionals and they sort of can promote it or recommend people.” (P52)
	Knowledge translation through systems, universities, and social media	“…there needs to be a whole health approach…where there's somewhere to feed it in and it gets fed down because it certainly doesn't work being at the bottom of the pile and trying to feed it up through a system…it needs to come from a centralised point…maybe that's what the national autism strategy can actually offer, is being somewhere where you can go to get good information around supporting Autistics or looking at how can the Australian health system adopt some of those guidelines that have already been developed overseas.” (P26) “promoting [research] like through Facebook.” (P52)

Category	What would make it better	Illustrative quotes
Priority areas for future research	Autistic burnout	"It was a talk about burnout, and she had only found four studies that have been done ever on Autistic burnout. And the earliest one was like 2018, 2020." (P1)
	Community bias	"Community and social societal biases that prevent people from being able to access diagnosis and support." (P1)
	How to break stereotypes and stigma	"You know, you know, real men don't cry, et cetera, et cetera. All of these cultural forces could be, could actually be improved by understanding how we could better tailor emotional education to all people." (P54)
	Intersectional identities and experiences	"How can Aus[tralian] gov improve our mental health - fund research on AFAB [assigned female at birth] Autistic - topics - menopause, pregnancy, childbirth, mumming Autistic kids, returning to work after maternity leave." (FG1) "So, the other thing I'd like to add is I know that there's increasing research awareness in say, the strong association between neurodivergence and being queer." (P54)
	Need for consensus on priority areas	"…the first thing we need to do is to get the autism sector to understand and to come up with a position…The process needs to bring the community together and to sort of work it out; we need to define the problem …I don't think we're doing that. We are not defining the problem. We are running around like headless chooks, trying to find solutions when we don't know what the problem is. We can solve problems that we have not defined. And the first thing that needs to be done is to actually say, this is the problem or these are the problems that we need to solve and start thinking about when it's solved, how will we know? And the whole sector has to do this because at the moment, everybody has a different idea about what the problem is. And if that's what you've got, then there will be no agreement on solutions. But it's actually easier to agree about what the problem is…" (P50)
	Research that improves quality of life	"… research on harms cause marginalisation discrimination …so why not focus on the good things that they can do that make their lives at least bearable. Like, you know, some funders will go, okay, fair enough. Like we can't cure the world. You're not trying to promise us, cure the world. but you can, you know, sort of help us find out what might, might make my people's, people's lives bearable." (P63)
	Understanding heterogeneity and intersectionality	"Allocate resources for research on the intersectionality of autism and deafness to better understand the specific needs and challenges of this population. This research can inform evidence-based policies and practices to improve health care outcomes." (P57)

Table 44: Research and data (Element E): What would make it better – Group comparison

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Heterogeneity	Include diversity of Autistic experience including children and young people	B	B	B	B	B	B
Knowledge translation	Knowledge translation	A	A	B	B	A	A
	Knowledge translation through social media	A	A	A	B	B	B
	Knowledge translation through system-levels and companies	A	A	A	B	B	B
	Knowledge translation through universities	A	A	A	B	B	B
Priority areas	Autistic burnout	B	A	A	A	A	B
	Breaking stereotypes/stigma	A	B	B	A	A	A
	Community bias	B	A	A	A	A	B
	Consensus on problems to address	B	A	A	A	A	A
	Intersectional identities and experiences	B	C	B	B	B	B
	Late diagnosed autism	B	A	A	A	A	B

Legend

Percentage of participants per group raising idea	0%	Up to 24.9%	25-74.9%	More than 75%
Band	A	B	C	D

Area	Issue (Code)	High/complex disability needs	Culturally and linguistically diverse	LGBTIQA+	Women and girls	Rural and remote	Low socio-economic status
Priority areas	Lived experience	B	A	B	B	B	A
	Research that improves real-life outcomes	B	A	B	B	B	B
	Understanding heterogeneity	B	B	B	B	A	B

5. What happens next? Limitations and future directions

These data will inform development of a final report that synthesises information across all phases to inform the Roadmap. Consideration of alignment of what is working well, what is not working well, and ideas for what would make each element better in this report provide important insights that can be used to inform the Roadmap. Exemplars of positive practices can be used to mitigate areas of negatives identified, and where ideas for future changes have not been discussed, be used for key areas for discussions and problem-solving. While not intended to generalise to all Autistic people, these findings yield important insights and ideas from priority group members. However, limitations in the current community engagement are acknowledged and should be considered in next steps of Roadmap development and recommendations moving forward.

First, there was limited representation of Autistic First Nations people within this sample which precluded analysis of the specific needs of this priority group. It is important to acknowledge that the community engagement activities of the Roadmap coincided with other Government consultations and processes, such as the referendum. Consequently, it was deemed 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.

Second, due to the paucity of data on Roadmap Implementation (Element F) this element was not included in this overview of results due to participants rarely commenting on this element. This however, likely flowed from it being difficult to comment on implementation without knowing details or plans for the Roadmap. As such, it is recommended that community consultation regarding implementation is conducted following public release of the draft Roadmap to inform its implementation.

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

f X ▶ in autismcrc.com.au