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

Appendix A:

Reimagining health and mental health services co-design

March 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

Appendix A:

Reimagining health and mental health services co-design

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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*. Autism CRC.

Copyright and disclaimer

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Autism CRC

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

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

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

autismcrc.com.au

A note on terminology

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

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

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1. Report summary

1.1 Why we did this work

The Australian Government has committed to the development of a National Roadmap to Improve the Health and Mental Health of Autistic Australians (the Roadmap). The aim of the Roadmap is to address issues faced by Autistic people in the health care system and outline actions to improve outcomes. This is being informed through a collaborative research, co-design and community engagement process. This report provides an overview of and discusses the findings from the "Reimagining health and mental health services" co-design workshops.

1.2 What we did

Autism CRC facilitated a series of co-design workshops to explore people's challenges, experiences, and ideas for change to improve health and mental health services.

Six workshops were conducted from the 20th of November 2023 to the 17th of January 2024. The workshops were two to three hours in duration, and all workshops were co-facilitated by an Autistic team member. With the consent of participants, workshops were video recorded and transcribed for the purposes of data analysis. Participants were invited to engage in their preferred way, including having the camera on or off, using the chat function instead of speaking and providing opportunity for follow-up input.

1.3 Who we engaged

There were **51** stakeholders in the Reimagining health care service co-design. This included **30 Autistic** people.

Of the 51 stakeholders, 16 individuals were parents, carers or guardians of Autistic people including at least 14 parents, carers or guardians of Autistic people also identified as Autistic. Thirty individuals were practitioners and/or disability professionals who work with Autistic people, 9 of these were Autistic.

Participants were aged 18 and above, and all States and Territories across Australia were represented. Specifically, New South Wales (n=12); Victoria (n=13); Queensland (n=6); South Australia (n=7); Western Australia (n=5); Tasmania (n=4); Australian Capital Territory (n=3) and the Northern Territory (n=1).

Table 1:   Co-design workshop participants by priority group

Priority group	Number
People with high or complex needs and/or co-occurring health conditions that impact daily life	16
High communication needs	-
High behaviour support needs	-
People in residential settings	-
People with intellectual disability	1
Non-speaking/unreliably speaking	-
First Nations people	2
Culturally and linguistically diverse (CALD) people	8
LGBTIQA+ people	10
Women and girls	37
People living in rural and remote areas	13
People from low socio-economic backgrounds	-

NB: Co-design participants were not asked about their socio-economic background, communication or behaviour support needs. Most participants identified with more than one priority group.

1.4   What we found

Participants in the co-design process shared their thoughts, actions, challenges, and emotions, which were identified at every stage of the health care journey - from awareness of the need to seek help or care to continuing care, as summarised in Figure 1. This revealed that for Autistic individuals, the health care experience is marked by significant stress, anxiety, confusion, and overwhelm which starts well before an appointment, even before interacting with a health or mental health professional.

1.5   What this informed

The insights from the workshops informed our thinking about concurrent community engagement activities in the broader Roadmap co-design, research and community engagement. We considered the insights from the co-design as we formulated the questions for the targeted focus groups and interviews, fostering a richer understanding of Autistic people's, families and carers, experiences with health and mental health care.

Additionally, these insights influenced the creation of the overarching questions and prompts for the National Health and Mental Health Community Co-design Summit which brought together 69 Autistic people, professionals in health, mental health, allied health and disability fields, including Autistic and non-Autistic practitioners. This provided opportunity for a deeper discussion, exploration, and testing feasibility of potential solutions and ideas for change as we worked together to start creating a **reimagined health and mental health service** experience for Autistic people, health and mental health providers.

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Autistic peoples' current health care journey

Awareness

Becoming aware of need to seek help or care

Thoughts and actions

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

Challenges

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

Feeling anxious, stressed

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

Contemplation

Understanding available options and what is required

Thoughts and actions

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

Challenges

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

Feeling overwhelmed, self-doubt, dread, concern

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

Access

Knowing who to contact and making an appointment

Thoughts and actions

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

Challenges

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

Feeling anxious

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

Delivery

Health care interaction with a professional

Thoughts and actions

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

Challenges

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

Feeling worried, unsafe, low, disappointed, confused

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

Continuing care

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

Thoughts and actions

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

Challenges

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

Feeling stressed, overwhelmed, confused

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

2.   The co-design journey mapping process

2.1   What is co-design?

Co-design is an investigative and creative process that brings together a diverse group of people with lived experience and skills to explore problems and potential solutions. It aims to empower and put people with lived experience at the centre of the design process. Co-design is an exploratory process and does not result in a group consensus but rather serves as an input for further development and future work.

2.2   What is a journey map?

A journey map is a visual story of the steps someone takes to complete a particular process. In the context of the Roadmap co-design, the journey mapping process was used to explore and document people's experiences accessing health and mental health care services.

The journey mapping process sought to first develop a *current* journey map of health and mental health care services exploring the experiences that people currently have when accessing health and mental health care services. Then the groups focused on developing a *future* journey map of health and mental health services, with ideas on how people would like health and mental health services to be different in the future.

To structure and focus the conversation, we explored each of the stages in the health care journey for each journey map. These are detailed below and illustrated in Figure 2.

Figure 2: Stages in the health care journey

1.   **Awareness:** Experiences people have when they first become aware of their need for a health or mental health service, or when supporting others to identify a need to see a health or mental health professional
2.   **Contemplation:** How people make decisions and choices about the health or mental health care services or support they may need, or how professionals support others to make informed decisions and choices
3.   **Access:** Experiences people have when trying to access a health or mental health service or support, or when enabling access for others
4.   **Delivery:** Experiences people have as they are receiving or delivering health or mental health service or support
5.   **Continuing Care:** Experiences people have after they have received the initial service or support, or when helping others to manage their ongoing care.

In each stage during the *current* journey mapping activity, participants were asked to reflect on:

- **Actions:** the actions people do in each stage
- **Challenges:** the things that cause people frustration or anxiety
- **Thoughts:** what someone is thinking during the journey
- **Feelings:** how someone feels during the journey
- **Opportunities:** what might help make things better at that time.

2.3   Data Analysis

Data from the co-design workshops was analysed using thematic analysis.

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3. What we found

3.1 Awareness

Table 2: Summary of actions, challenges and potential solutions in the Awareness stage

Actions	Key challenges	Potential solutions
Autistic people rely on GPs or peers to identify symptoms and raise concerns	Not trusting their evaluation of having a health or mental health concern	Sources of health and mental health information
Autistic people are seeking external validation of their health or mental health concerns from peers and health professionals	Lack of access to external sources of validation	Increasing people's health literacy
Autistic people are researching and becoming informed about their health or mental health concerns	Interoception and not being aware of symptoms or being in need of support	Autistic people having self-awareness of their body and experiences
Autistic people are reflecting on and processing their experiences and symptoms	Knowing what a cause for concern is or when to seek health and mental health care	Increasing parents' awareness of their Autistic child's needs
Health professionals are supporting Autistic people and families' awareness through growth coaching, and awareness building	Communicating and describing their awareness of concerns to other people	Information to support recognising a health or mental health need and when to seek help
Health professionals are building patients capacity to communicate and self-advocate their health and mental health needs	Pre-existing symptoms and conditions make it harder to identify a need	The role of health practitioners and others in supporting early awareness and identification of concerns and needs
		Opportunities for validation of health and mental health concerns
		Self-advocacy and communicating awareness of needs and concerns

3.1.1 Actions

The health care journey for everyone begins when they first become aware of a need for health or mental health services or support. For Autistic people, we heard that this stage involves relying on other people, most often their General Practitioner, to identify symptoms and raise concern about their health or mental health. For this reason, people reported pre-booking appointments for future check-ins. Similarly, they reported seeking external validation of their concerns, by checking in with others and calling helplines for a second opinion. During the awareness stage, they are logically and interoceptively reflecting on and processing their experiences and symptoms. They are becoming informed through researching and learning about their health or mental health concerns.

Health professionals report supporting Autistic people's awareness of health and mental health needs by suggesting potential health concerns to investigate, as well as engaging in growth coaching and awareness building activities to assist their patients/clients and their families to recognise when they are sick. We heard that they also work to build the Autistic persons self-advocacy skills and capacity to communicate their health and mental health concerns, by developing health passports, and writing letters or scripts with key information about their health care, or needs, that can be used with other professionals.

3.1.2   Key challenges

3.1.2.1   Not trusting their evaluation of having a health or mental health concern

Autistic people shared experiences of being dismissed, not believed, not listened to, not taken seriously, or understood by health professionals, that lead to difficulty trusting themselves and their evaluation of health or mental health concerns. We heard this often results in the individual internalising symptoms as their fault or needing to rely on external validation.

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

We heard similar from health professionals who indicated that it can be hard to support Autistic people's awareness of a health or mental health need when they distrust themselves.

3.1.2.2   Lack of access to external sources of validation

Autistic people told us that having a reliance on external validation can also be challenging when there is a lack of access to sources of validation, either due to temporary absence, being socially isolated or having a lack of family support.

3.1.2.3   Interoception and not being aware of symptoms or being in need of support

Autistic people reported experiencing differences in interoception including sometimes not being aware that they are unwell, are experiencing physical changes or decline, or not being aware of where they are experiencing pain. They described the awareness process as being "too hard", and as requiring several appointments with a health professional to achieve. Similarly, health professionals noted that interoception differences, alexithymia and undiagnosed autism can impact on an Autistic person's awareness of their health and mental health needs. An additional factor raised was that when a person loses touch with services, this too can impact on them becoming aware of needing support.

> *"Interoception issues are things we live with as Autistic people and we don't necessarily know what is wrong. So we might feel out of sorts or not quite right and go to a GP. And I remember a conversation with the doctor who asked me, 'so what brought you here then?' And I said 'my wife, she drove me in the car' and there was a quite a bit the silent treatment. And then she said, 'no, I mean why have you come to see me?' I said 'because I need to see the doctor', she said 'well why do you need to see the doctor?' 'I'm just not right, I'm not well', 'what's wrong?' I said, 'I don't know. I'm hoping that you would be able to tell me'. So having General Practitioners understand how hard it is for Autistic people to identify, narrow down areas that are uncomfortable for us…it can take a bit of time… sometimes even harder for older Autistic people."* *(Autistic participant)*

3.1.2.4   Knowing what a cause for concern is or when to seek health and mental health care

Autistic people shared challenges with not knowing that they are in need of a service or support, being able to recognise the seriousness of a need and not knowing at what point to seek help. They also described difficulties with not knowing what is deemed a health issue, what are symptoms and what are appropriate bodily responses which requires previous knowledge. We heard, from health professionals, reports of parents of Autistic children not knowing what symptoms are for their child and Autistic people and parents ignoring, adapting to or normalising symptoms.

3.1.2.5   Communicating and describing their awareness of concerns to other people

Autistic people reported finding it difficult to communicate to others their awareness of a health or mental health concern, including describing their symptoms and being able to understand pain scales.

> *"The fact that I don't feel it the same way as you and/or I can't describe it in the same words as you, doesn't mean my pain or medical issue isn't real and in need of understanding and treatment"* (Autistic participant)

3.1.2.6   Pre-existing conditions make it harder to identify a need

Autistic people described the impact of pre-existing conditions making it harder to identify new symptoms or concerns. These included complex health needs, anxiety and depression, the normalisation of concerns that occurs within undiagnosed families and when they become used to feeling the way that they do. From health professionals, we learned that this impact extends to a person's behaviour in terms of hiding medical issues. We also heard that a pressure to diagnose autism can take the focus away from identifying underlying health or mental health concerns.

3.1.3   Potential solutions

Table 3:   Summary of potential solutions and direct insights in the Awareness stage

Potential solutions	Direct insights
Sources of health and mental health information	• Health information in easy English • National source of evidence based and peer reviewed information • Information about medications, interoception, mental health and suicide
Increasing people's health literacy	• Health literacy building via social media • Increasing health and mental health literacy • Knowing where and how to find health related information
Autistic people having self-awareness of their body and experiences	• Interoception training and resources for Autistic people • The person having an increased awareness of what is going on for them • Increased awareness and understanding of one's body and their "normal"
Increasing parents' awareness of their child's needs	• Educating parents to become aware of their Autistic child's health needs • Schools to support parents to become aware of their child's health needs
Information to support recognising a health or mental health need and when to seek help	• Information and education about when to seek help • Information about the typical human body and what is normal and not • Information and education about how to recognise the severity of issues
The role of health practitioners and others in supporting early awareness and identification of concerns and needs	• Pre-booked appointments for "check-ins" • Other people to prompt, and 'check in' with Autistic people • Social connections • Supportive health professionals who ask the "right" questions
Opportunities for validation of health and mental health concerns	• External sources of validation • Help or health lines for validation
Self-advocacy and communicating awareness of needs and concerns	• Scripts and letters for people to use to communicate their awareness of a need • Health passport • Autistic people telling others that they have interoception differences • Developing self-confidence and speaking up

3.2   Contemplation

Table 4:   Summary of actions, challenges and potential solutions in the Contemplation stage

Actions	Key challenges	Potential solutions
Autistic people are considering the waitlists, delivery modes and affordability of services and health professionals	Cost influences the consideration of options for services and supports	Increased availability of familiar and preferred options to consider
Autistic people are making the decision to avoid services or to delay accessing services or support	Shortage of suitable and available options to consider	Directory or database of health professionals
Autistic people are researching and seeking recommendations for services and supports	Past experiences with services and supports influence future consideration	Requirements for services and practitioners to publish and communicate information about their clinic
Autistic people are seeking neuro-affirming or Autistic health professionals and those with experience in specific conditions or disability	Prioritising health care against competing life demands	Level 'playing ground' for access and affordability
Health professionals are educating, planning and making decisions with patients and families	Identifying and finding the most suitable option for a service or health professional	Services and support to explore and find potential options
Health professionals are utilising directories, maps or lists of health professionals and services to make decisions	Delaying or avoiding health care	Lists of neurodivergent and neuro-affirming services and practitioners
Health professionals are referring to suitable specialists	Reliance on health professionals to inform and educate about services and supports	Knowledge and understanding of different health professions and options
	Professionals not being able to help and finding it hard to cease service provision	Knowing where and how to locate services and health professionals
		Neuro-affirming care training and accreditation
		Peer support and social connection

3.2.1   Actions

During the consideration stage, Autistic people shared that they are having to make the decision to either seek care or to delay or avoid it. We heard that Autistic people are avoiding services, health professionals and environments that they have had negative experiences with, including dentists, General Practitioners, hospitals, and those that are sensory overstimulating. Moreover, they told us that they are instead seeking health professionals who are bulk-billing and offer telehealth (sometimes overseas), are Autistic or neuro-affirming, have expertise in disability or specific conditions, and/or work holistically. They shared that they achieve this through peer support, seeking recommendations from peers and trusted health professionals and contacting and researching health professionals and services, to better understand their waitlists, modes of delivery and contact, and how they operate.

For health professionals, we heard that in the consideration stage they work to support Autistic people and families to explore and to make decisions about services. This includes educating families about options.

We heard that health professionals can become the main source of support for Autistic people, engaging in informed decision-making and developing plans - including a breakdown of the tasks they need to undertake to access care. When considering options for supports for their Autistic patient or client, they reported to referring to known suitable specialists or utilising maps, lists and directories to inform their decision of which professional or service to refer people to.

3.2.2   Key challenges

3.2.2.1   Cost influences the consideration of options for services and supports

For many Autistic people, they told us that services and supports are too expensive – including with subsidised services and co-payments and noting a lack of bulk-billing options – leading to them delaying accessing care or only having limited affordable options to consider. The lack of consensus whether a service is the responsibility of NDIS or the health system was also reported as a challenge. We heard from health professionals of the inequitable affordability of services for Autistic people, including the high cost of private options.

> *"Do I feed myself, or do I access health care?"* (Autistic participant)

3.2.2.2   Shortage of suitable and available options to consider

We heard that there are waitlists and a shortage of suitable and available options for Autistic people to consider, leaving people having to prioritise reduced wait times over quality of services. For people who live rural and regional this problem is exacerbated. A lack of neuro-affirming or Autistic clinicians was reported to be attributed to Autistic practitioners being unable to disclose and the term 'neuro-affirming being a buzz word. Health professionals agreed that there is a shortage of options, in particular a lack of autism specific services and for people who live rural being unable to access specific services.

3.2.2.3   Past experiences with services and supports influence future consideration

Autistic people reported that past negative experiences and interactions with services, practitioners, and clinical environments, led them to avoid these in the future, and to be less likely to seek help. For other people, it can be a challenge to not return to a service that was unsuitable.

3.2.2.4   Prioritising health care against competing life demands

We heard that it was challenging for Autistic people to make the decision to prioritise accessing health care against other life demands. This included work, competing health needs, paying bills, needing to consider the time that it takes to access care and the 'spoons' or mental and physical energy that will be required.

3.2.2.5   Identifying and finding the most suitable option for a service or health professional

Autistic people described the process of finding and knowing what the best option for support is, and knowing what the most suitable health profession would be for a particular need, as challenging. It was reported to be time-consuming and made more challenging by difficulties with accessing and finding information about services and professionals. This included people being unable to make enquiries prior to booking an appointment or being unsuccessful in seeking recommendations either due to being socially isolated or only hearing of people's negative experiences.

Health professionals reported a significant gap between what is available and what Autistic people and families are aware of, including people having little understanding of the roles of different health professionals. We heard this is further complicated by Autistic people being told that they require services and supports based on their autism diagnosis, irrespective of need. Another factor reported was Autistic people utilising unsuitable options due to their familiarity, as they are unlikely to try unfamiliar options when unwell. We heard that people not knowing the most suitable option can also be challenging for health professionals, when allied health professionals have no influence on referrals or when Autistic people don't 'fit' within any particular service. It was identified that this sometimes leads to a pressure on General Practitioners to have expertise and knowledge in areas they are not trained in.

> *"So, I guess around those considerations in knowing who can help, the health professionals have some responsibility there in being more explicit in what we can and can't do."* (Health professional participant)

3.2.2.6   Delaying or avoiding health care

Health professionals told us that when the recommended steps to take are not within the Autistic persons capacity, that this can also result in them avoiding or delaying health care.

3.2.2.7   Reliance on health professionals to inform and educate about services and supports

Health professionals reported that there is a reliance on them to make people aware of services and supports.

3.2.2.8   Professionals not being able to help and finding it hard to cease service provision

Health professionals shared that a challenge for them in the consideration of services and supports is when compassion and professional integrity prevents them from ceasing service provision when they can no longer help, not wanting to give up on families, and that it can be hard to say, "I can't help you".

3.2.3   Potential solutions

Table 5:   Summary of potential solutions and direct insights in the Contemplation stage

Potential solutions	Direct insights
Increased availability of familiar and preferred options to consider	• Availability of familiar options • Autistic clinicians • Autistic clinicians being able to disclose
Directory or database of health professionals	• Directory or database of health professionals • Advising others of who can and can't help • Peer developed database with recommendations from the Autistic community
Requirements for services and practitioners to publish and communicate information about their clinic	• Accreditation requirements for services to have accessible information, websites and contact methods • Practitioners being explicit about their scope • Published waiting lists with notification systems for clinicians • Communication access accreditation
Level 'playing ground' for access and affordability	• Level 'playing ground' for access and affordability of services
Services and support to explore and find potential options	• Care navigators and coordinators that are independent • Coordinators who coordinate all government services • Clear goals and prioritising services and supports • Supportive health professionals and services
Lists of neurodivergent and neuro-affirming services and practitioners	• List of neuro-affirming practitioners • List of neurodivergent practitioners • List of neuro-affirming 'tick of approval' practitioners
Knowledge and understanding of different health professions and options	• Raise awareness of available supports by educating schools, childcare and early childhood services about "who can help" • Educating General Practitioners about "who can help" • Information and awareness about available supports and services • Government website about available supports and services with prompts to find suitable options • Information about different health professionals and what they do • Information about the different types of therapies • Information about what is ethical vs not
Knowing where and how to locate services and health professionals	• Better understanding of the Australian Health Practitioner Regulation Agency (AHPRA) registration process • How to find information about health professionals and services • Knowing how to google and where to look for information
Neuro-affirming care training and accreditation	• Neuro-affirming clinicians • Minimum neuro-affirming care training requirements • Neuro-affirming accreditation • Neuro-affirming tick of approval • Neurodivergent safe spaces • Peak body for neuro-affirming providers
Peer support and social connection	• Social and peer connections • Peer support and support groups

3.3   Access

Table 6:   Summary of actions, challenges and ideas for change in the Access stage

Actions	Key challenges	Potential solutions
Autistic people are preparing for the intake process	Having to prepare for the appointment	Accessible methods of contacting and booking services and supports
Autistic people are booking the appointment by themselves or with support	Referral pathways and systems	Training, awareness and understanding of autism within the system
Autistic people are assessing and organising finances	Availability and affordability of services and supports	Services and support for navigation and access
Autistic people are organising transport and making travel arrangements	Engaging in the intake processes	Accommodations and accessibility
Autistic people are preparing for the appointment	Refused or denied access to services	Understanding of intake, referral and service processes
Autistic people are finding alternative options for services or supports	Support, travel and transport arrangements	Promoting an inclusive, respectful and accepting environment
Health professionals are preparing Autistic people and families for the intake process and appointment	Reception staff, waiting rooms and wait times	Preparing for the appointment and knowing what to expect
Health professionals are managing waitlists and triaging		Reformed triage processes
Health professionals are utilising diverse options for bookings and communication		Reformed policies and legislation

3.3.1   Actions

In the access stage, Autistic people told us that they prepare for the intake process by learning the 'right' words to use to access the service or support. They then engage in the process of booking the appointment either via email, online booking systems, noting that doing so is only possible when they feel that they can be assertive or have the 'spoons' required. Others told us that they access support to make appointments, including having other people make it for them, specifically support coordinators. They spoke about preparing for the appointment as requiring assessing and organising their finances and organising transport and necessary travel arrangements, including accommodation. Further, preparing for their appointment by writing lists, scripting what they want to say, carrying copies of medical documents and contacting the service to check the current wait time for their appointment. We also heard that it is during this stage, that people are also finding alternative options for services or supports.

For health professionals supporting people during the access stage, we heard that it involves working with families to prioritise their needs and preparing Autistic people and families for the intake process by providing them with information, including the steps they will need to take and what to expect.

For intake processes, health professionals shared that they use online booking systems, with some also reporting to accept any form of intake received. We also heard examples where communication and reminders with Autistic people and families is done via email and text message. To manage waitlists administrative staff are required to triage appointments and health professionals report utilising a time limited model of care.

> *"So, it's a complicated system for people to understand, I think as well, that's and even for health professionals, not just families."* (Health professional participant)

3.3.2 Key challenges

3.3.2.1 Having to prepare for the appointment

The process of preparing for appointments was described by Autistic people as challenging. This included preparing information, mental preparation and sometimes studying pain scales.

> *"I would like an information booklet outlining exactly what I need to do or bring to prepare when going to see a doctor, i.e. what do they need me to tell them or ask them."* (Autistic participant)

3.3.2.2 Referral pathways and systems

Autistic people told us that referral pathways and systems serve as barriers to accessing care, due to their dismissal or lack of authority. Referrals also create uncertainty when people are unsure which doctor they will see.

Health professionals also reported referral pathways as being problematic when access to particular professionals is difficult, when multiple referrals are required for access or when referrals to hospital and mental health services are refused and Autistic people are sent back to autism specific clinics.

3.3.2.3 Availability and affordability of services and supports

We heard from Autistic people that there are financial barriers to accessing health care, including inadequate Medicare subsidies, people's medical needs not being funded by NDIS or having to pay for appointments in advance.

When attempting to access services, Autistic people reported being told that books were closed or that specific clinics were not accepting particular age ranges. They noted there are telehealth restrictions, a lack of options, long waitlists, health professional shortages and poor availability of days and times for appointments. This results in Autistic people unable to access their preferred method of service delivery, having their appointments cancelled at short notice, and having to take unsuitable or last-minute appointment times. This is all the more challenging when there are pre-existing conditions that escalate and when having to choose quality over urgency.

Health professionals attributed poor availability to a lack of incentive to provide services, high staff turnover, and the system not utilising health practitioners' full scope of practice. Poor availability for people living rural means that sometimes there are no services to access, particularly when the person requires a face-to-face appointment which are not always available. Waitlists were reported to attract numerous challenges for health professionals, including the administration that is required to manage, frequent cancellations and people not having the capacity to access a service at the time of appointment availability. We heard that the absence of discharge systems for patients results in counterproductive and growing waitlists for services, with people sitting on multiple waitlists.

3.3.2.4 Engaging in the intake processes

Autistic people described intake processes as difficult and confusing, with reports of the system not being designed for patients and leaving people not knowing what to do or what the 'right' words to use during booking are. People told us that forms can be unclear. Additional barriers encountered during intake processes include cultural and language barriers, and reports being made to child protection. We heard of the many challenges associated with phone calls during intake processes. These included having to make, wait for and receive phone calls, with people noting that phone calls are exhausting, require energy, time, and result in needing time to recover. For people that require support to make phone calls, they told us that they needed the financial means [NDIS] to access help or needing to organise for someone to mind their child.

For health professionals, online booking processes were reported as not always being practical. They also described getting timely responses from public guardians as being challenging. We heard that there is no NDIS funded capacity building for parents to navigate systems and services.

3.3.2.5 Refused or denied access to services

We heard that there is a perception that Autistic people are "too hard", with Autistic people reporting being refused or denied access to services and supports, sometimes due to services not accepting people due to being Autistic or being a NDIS participant, or the existence of pseudo blacklists. Noting that it is harder to get services without an intellectual disability, health professionals also reported similar experiences, in addition to Autistic people being denied access due not meeting a certain criteria and people being excluded from both mainstream and NDIS services.

3.3.2.6 Support, travel and transport arrangements

Needing to make support, travel and transport arrangements in order to access services and supports was also identified as a challenge by Autistic people, particularly for Autistic parents who require someone to mind their child, people who have to travel and need to book accommodation or people who rely on others for transport and have to schedule appointments around other people's commitments.

3.3.2.7 Reception staff, waiting rooms and wait times

We heard that the waiting room and process of waiting for their appointment is difficult for Autistic people. This includes the anxiety of waiting rooms, sometimes having to wait all day for their appointment, and the sometimes negative interactions with reception staff, including being asked too many questions and having to divulge a lot of information.

3.3.3   Potential solutions

Table 7:   Summary of potential solutions and direct insights in the Access stage

Potential solutions	Direct insights
Accessible methods of contacting and booking services and supports	• Online booking systems with prompts and the ability to ask questions • Alternative communication with services, including email and live chat • Online booking systems built for end user
Training, awareness and understanding of autism within the system	• Training of reception staff • Upskilling intake staff that autism is not a child protection issue • Cultural shift in the system • Autistic cultural model • Changing the perception of what autism looks like' through community awareness of autism and the diversity of the community
Services and support for navigation and access	• Care coordinators • People being more health literate • Advocacy services • Navigators • Peer workers • Supportive health professionals • Assistance from others to book appointment
Accommodations and accessibility	• Educate Autistic people and practitioners about legislation and reasonable adjustments • Call back function for people waiting for appointments • Alternatives to waiting rooms • Consider the sensory environment of the reception and waiting room • Implementation of Sunflower lanyard initiative • A notification on the computer system that a patient is Autistic.
Understanding of intake, referral and service processes	• Communicate and provide information about waitlists, how the service works and contact methods • Having familiarity of the process • Knowing the referral processes • Support to know how to book appointments
Promoting an inclusive, respectful and accepting environment	• Not using problematic signage in clinic • Using preferred language and terminology of the Autistic community • Using people's preferred methods of communication

Preparing for the appointment and knowing what to expect	• Visuals and social stories • Videos of procedures • Being notified of appointment changes in advance • Improved wayfinding, including maps, videos, photos and directions • Templates, information or booklets about what to expect and how to prepare for appointment • Pre-appointment introductions with practitioners • Pre-appointment clinic visits or tours • Ability to provide information in advance to health professionals pre-appointment • Filling in forms in own time • Timely service delivery • Text message confirmation including before telehealth phone calls
Reformed triage processes	• While-you-wait services • Decision of whether triage is about directing people or a step towards the next stage • Upskill General Practitioners to take on less complex cases to triage more complex patients
Reformed policies and legislation	• Bulk billed services • Card for cheaper medication • Increased subsidised sessions, including Mental Healthcare Plan • Reduce Medicare threshold • Co-produced policies and funding • Improved referral pathways • Expand telehealth rules • Increased availability of services

Report on research, co-design and community engagement to inform the National Autism Health Roadmap
Appendix A: Reimagining health and mental health services co-design

3.4   Delivery

Table 8:   Summary of actions, challenges and potential solutions in the Delivery stage

Actions	Key challenges	Potential solutions
Autistic people are considering and making the decision whether to disclose	Negative health care experiences, environments, and interactions with professionals	The use of artificial intelligence (AI) during service delivery
Autistic people are bringing a support person to accompany	Needing to behave and engage in the 'right' way	Supporting patients to be informed and engaged during appointment
Autistic people are reacting positively to being believed and listened to	The mental and physical toll of the appointment	Consideration and provision of accommodations and accessibility requirements
Autistic people are feeling experienced in the process of service delivery	Lack of training, education and awareness of autism	Building people's capacity to effectively communicate and self-advocate
Health professionals are advocating on behalf of the patient	Gaps and barriers in diagnoses, care and treatment	Services and support during delivery
Health professionals are considering and providing for the sensory and support needs of patients	Providing information and communicating concerns	Flexible service delivery
Health professionals are educating, preparing and making decisions with people	Not being informed and having choice, control and autonomy	Health professionals making people feel respected, believed, validated and listened to
Health professionals are utilising telehealth	Lack of consideration and provision of supports and accommodations to patients	Support for health practitioners and students
	Challenges with telehealth delivery	Training, education and awareness for health professionals
		Improved data reporting requirements
		Dedicated services and funding streams
		Approaches to service provision, treatment and care

3.4.1   Actions

During the delivery stage, Autistic people often bring a support person with them to appointments, even if they feel they are experienced in the process. This is the stage of the journey where they begin to contemplate whether to disclose that they are Autistic. When they are listened to and believed by health professionals, they are sometimes brought to tears.

In the delivery stage, health professionals told us that they are often utilising telehealth and are engaging in various activities to support Autistic people. We heard reports of health professionals supporting patients to disclose and advocate for their support needs, by wearing sunflower lanyards or Autistic health professionals wearing an Autistic ID badge. They continue to consider the support needs of patients by additionally using visual supports and ensuring that clinics are sensory friendly. Health professionals are also working with Autistic patients to prepare them for medical interventions, using graded exposure and supporting them to engage in self-care. We heard that they educate Autistic people on where to find health information and engage with them in supported decision making. Sometimes, health professionals find themselves advocating for the Autistic person, for example writing to other health professionals to advise them of their support needs.

3.4.2   Key challenges

3.4.2.1   Negative health care experiences, environments, and interactions with professionals

We heard that the system, based on the medical model, is not always understanding of people's needs and preferences, with health professionals not being neuro-affirming and clinical environments not being sensory friendly. Negative health care experiences were commonly reported by Autistic people, including experiences of medical distress, mistreatment, trauma, abuse and neglect. They also shared experiences of being gaslit, dismissed, not believed, not being taken seriously or listened to, or understood by health professionals. Experiences of racial discrimination, sexism, and stigma and stereotyping of autism and other conditions was also encountered. Other people experienced being seen as tricking health professionals or being labelled as an attention seeker or hysterical. Upon learning that patients were Autistic, some health professionals began to talk down to patients, infantilising them or weaponising their diagnosis. For Autistic parents, they reported finding it difficult having health professionals talking negatively about them or their child in front of them and their children.

Health professionals reported that some health professionals do not want to work with Autistic people, and shared occasions where their medical trauma, fear and anxiety was minimised or misinterpreted, or they were labelled as rude or uncooperative. We heard that Autistic people do not disclose due to fear of discrimination or diagnostic overshadowing. For Autistic health professionals, service delivery can be particularly challenging due to experiences of discrimination and stigma in the workplace, in addition to the distress of seeing their Autistic peers experiencing negative health care interactions.

3.4.2.2   Needing to behave and engage in the 'right' way

For Autistic people they expressed feeling the need to behave and engage in the 'right' way during appointments, including masking and succumbing to a perceived pressure to appear confident, competent, smart and articulate. People reported needing to pay attention to how they were being perceived and were having to be careful with their words and their honesty, particularly to avoid hospital admissions.

> *"For me it is also important to know that it is ok to say anything. I think doctor's appointments would greatly benefit from an intro similar to a psychology session - of this is a safe space. Please discuss your issue freely. You won't be judged here"* (Autistic participant)

3.4.2.3   The mental and physical toll of the appointment

Due to the exhausting and stressful nature of appointments, we heard that they take a physical and mental toll on Autistic people, and require recovery from, especially when they have to retell their story or internalise less than good outcomes as their fault. The time constraints of the appointment, including only being able to focus on one thing at a time, leave people feeling time pressured, rushed, and having to make quick decisions.

3.4.2.4   Lack of training, education and awareness of autism

We heard that often health professionals have little to no understanding of autism and Autistic people, which leads to assumptions, misconceptions and misperceptions about autism, stimming (including it being negative), Autistic people's presentations of distress, and of the capacity of non-speaking Autistic people to consent and understand. They also expressed concerns about health professionals' degree of understanding of Autistic health needs, including chemical and medication sensitivities.

We heard from health professionals that there is a lack of training and exposure for them, including no mandatory training for General Practitioners or training in neurodivergence. This can lead to a low awareness of the need to screen patients and results in a lack of consistency in services and varying levels of experience and expertise. Additionally, the lack of data reporting requirements results in disaggregated data across the systems.

3.4.2.5   Gaps and barriers in diagnoses, care and treatment

Autistic people shared experiences of misdiagnosis or undertreatment, in addition to being denied or refused care, treatment or diagnoses, and health professionals being hesitant to diagnose or record diagnoses. Diagnostic overshadowing of autism and mental health conditions was also encountered, with some health professionals reporting other professionals as having little understanding of autism and the health and mental health needs of autistic people.

3.4.2.6   Providing information and communicating concerns

Autistic people shared that it was hard to advocate, to ask for help, to retell their story, remember everything needed to say, and provide a lot of information. They described other challenges including "*having to communicate the 'right way',*" or effectively, having to work out how to communicate, and finding it hard to describe symptoms. Communication was noted as being especially hard when masking or experiencing delayed processing, sensory overloaded, tiredness, or distress. They told us that they fear being misunderstood and do not know what is important, relevant or what they need to describe. This results in people over explaining, downplaying symptoms, having to work hard to convey seriousness and to show their symptoms. Health professionals shared that rating pain using pain scales can be difficult for Autistic people.

3.4.2.7   Not being informed and having choice, control and autonomy

Autistic people reported not being involved in decisions and that attempts at becoming informed through health research is often interpreted as health anxiety, with their overpreparation and question asking being off-putting and not liked by health professionals. The experience of service delivery was described as confusing for Autistic people, including understanding the interaction dynamic and what they are being told by health professionals, particularly when it is not presented in any accessible way. The presence of support people can mean that they unhelpfully intervene or are spoken to by the health professional instead of the Autistic person. We heard from health professionals of occasions where Autistic peoples' consent and assent were ignored, or in the interests of time, made quick decisions on an individual's behalf, rather than supporting the individuals' informed decision making.

> *"I think communication in multiple forms and also communication in a way that empowers the person to educate themselves. Due to ableism, people can often try and take control of an Autistic person's health for them, but this does not lead to good long-term outcomes nor is it rights based. So for example, providing Autistic people with information in a way that works for them - whether in video form, handouts, easy read, verbal communication etc..."* (Health professional participant)

3.4.2.8   Lack of consideration and provision of supports and accommodations to patients

We heard that the hospital environment is "*not set up for Autistic people*". Health professionals indicated a lack of time, capacity and limits and restrictions as barriers to being able to provide comprehensive and appropriate care, and to consider and provide accommodations and sensory support. This includes the supports required for service delivery to Autistic children and the use of artificial intelligence (AI) for service delivery.

3.4.2.9   Challenges with telehealth delivery

From the perspective of health professionals, telehealth is not always practical and presents additional challenges for them. This includes it being more difficult to write notes, adding extra time resulting in less time for other patients, being reliant on stable internet connection and the patient having digital literacy skills.

3.4.3   Potential solutions

Table 9:   Summary of potential solutions and direct insights in the Delivery stage

Potential solutions	Direct insights
The use of artificial intelligence (AI) during service delivery	• Using AI to summarise consultations • AI legislation including opt in requirements for patients
Supporting patients to be informed and engaged during appointment	• Invite people to share their communication preferences • Communicating important information to patient • Provide a care plan • Film the person engaging in self-management of their condition • Emailing information to people • Diverse ways of conveying information, including written, visuals, drawings and diagrams • Longer appointments and reminders of length • Give patients time to plan, process and identify that something is wrong • Asking questions such as "what do you need from me?" • Being direct
Consideration and provision of accommodations and accessibility requirements	• Increasing capacity of services to provide accommodations and supports • Invite people to share their sensory needs • Adjustments and accommodations for people • Disclosure of shared identity between patient and health professional • Build disclosure safety • Show that it is a safe space • Accreditation standards for hospitals
Building people's capacity to effectively communicate and self-advocate	• Script for people to use to communicate • Universal health passport • Knowing how to communicate what is going on in the body • Knowing how to advocate, inform of and ask for accommodations • Knowing how to communicate during appointment • Knowing the 'right' way to describe symptoms • Knowing what to say during appointment • Education about how people can have a successful appointment • Alternatives to pain scales
Services and support during delivery support	• Autistic health professionals • Autistic health workers • Peer workers, including Autistic • Support people
Flexible service delivery	• Provide telehealth • Hybrid service delivery • Health professionals being employed by schools

Potential solutions	Direct insights
Health professionals making people feel respected, believed, validated and listened to	• Answering questions • Prioritising people • Having empathy and compassion • Being constructive, receptive and working with patients • An appreciation of human diversity, reducing stigma and non-judgemental • Making the appointment a safe space • Relationship and trust building, including transitioning people to have medical procedures
Support for health practitioners and students	• Support, networking and collaboration with peers for health practitioners • Clinical placements and bursaries for Autistic health students • Support for Autistic health professionals and health students
Training, education and awareness for health professionals	• Ongoing professional development • Tiered training that is incentivised and mandatory • Training that challenges the medical model, is affirming and trauma informed • Training to build sustainability and confidence to work with Autistic people • Autistic led, co-produced, co-designed and co-delivered training • Education of health and mental health needs, including pain, interoception and co-occurring conditions • Education about autism, the Autistic experience and culture, diversity, communication and stimming • Understanding of neurodiversity, and that everyone learns differently
Improved data reporting requirements	• Improved data reporting requirements
Dedicated services and funding streams	• Splitting mental health vs physical health funding • Separation from those with intellectual disability in service provision
Approaches to service provision, treatment and care	• Individualised, person and family centred care and treatment Holistic, strengths and evidence-based approaches

3.5   Continuing care

Table 10:   Summary of actions, challenges and potential solutions in the Continuing care stage

Actions	Key challenges	Potential solutions
Autistic people are engaging in administrative tasks for appointments	Building care teams and managing services and supports	Preventative care and early intervention across the lifespan
Autistic people are becoming informed and engaging in self-management	Managing ongoing health care needs and care	Services and support to navigate and coordinate services
Autistic people are becoming disengaged in follow-up care	Poor collaboration, communication, transitioning and transferring between services	Planning and communication of next steps
Autistic people are accessing support and becoming informed	Continuity of care	Communication and collaboration between services
Health professionals are referring to other professionals for follow-up care and ongoing care	Follow-up processes	Funding and referral policy reform
Health professionals are engaging with wider care team	System constraints, under resourcing and lack of availability and capacity	Ensuring continuity of care and access to ongoing care
		Health professionals building patients capacity to self-manage their conditions and after care needs
		Rights, information sharing and privacy

3.5.1   Actions

During the continuing care stage, we heard that Autistic people are engaging in administrative tasks for appointments, such as keeping track of the next appointment, documents and engaging in a back-and-forth process with referrals. They are again seeking support by finding peers with similar experiences, having their General Practitioner as their central person, bringing support people to follow-up appointments, and doing a 'download' with others to process information. They described taking leadership over their health, and becoming informed about their health and mental health, by learning more, and engaging in self-management techniques, including 'checking in with their brains' and using timers on their phone for reminders. For some, they become disengaged from follow-up or ongoing care, either through not prioritising their health and mental health needs or from simply slipping through the system.

In the continuing care stage, health professionals are referring to other professionals and engaging with the Autistic persons wider care team through team meetings and working closely with General Practitioners.

3.5.2   Key challenges

3.5.2.1   Building care teams and managing services and supports

We heard that it can be challenging for Autistic people to coordinate services and health professionals not only for themselves, but in some cases also those of their family members. They shared that there is an expectation that people are competent in navigating the system, with the onus being on the patient to do the job of a doctor, including the necessary administrative tasks. Instead, however, the process is difficult and unclear, leaving people not knowing what the next step is. Due to the limited number of services available to support Autistic people and their families, health professionals report often having to case manage.

> *"...but we should be in a place where we should be thinking how can we try and make that less complex and what levers do we have to make it less complex?"*
> *(Health professional participant)*

3.5.2.2   Managing ongoing health care needs and care

We heard from Autistic people that it can be hard to engage in follow-up care, as it often means having to start again and find new services and health professionals, including those who specialise in particular conditions. Autistic people shared of being not informed of why an appointment is needed, waitlists, the lack of follow-up or having to rely on services to do follow up. Being responsible for managing their care and engaging in ongoing care was reported as being difficult. Often having no help to manage their care needs, it leaves Autistic people feeling overwhelmed and in 'fight mode', particularly when there are no instructions given, and they are unsure or can't remember what they are meant to be doing. There are also time and financial barriers to engaging in ongoing care, including people having no time to manage their ongoing needs and care, the costs of multiple family members appointments and having to prioritise paying for health care vs's paying bills.

For Autistic parents, appointments are often a burden, needing to fit multiple into the week and in addition to juggling family and caring responsibilities. They mentioned balancing the management and advocating for the health and support needs of themselves and their family and children.

> *"Families can become burdened by the number of health services involved with them and family members. Then if they don't engage are seen as neglectful or not doing enough."* *(Health professional participant)*

Health professionals shared that there is low affordability and lack of Medicare item numbers for ongoing care. For health professionals, it can be hard to service Autistic people and their families that have become disengaged from ongoing care.

3.5.2.3 Poor collaboration, communication, transitioning and transferring between services

Autistic people shared examples where health professionals did not use My Health Record or there were contradictions and disagreements between treating health teams with regard to diagnoses and who should have responsibility. This then results in people engaging in overlapping therapies and patients often having to retell their medical histories.

Health professionals attributed the lack of communication and collaboration between health professionals to the privacy concerns of My Health Record, and the time-consuming nature of managing care teams and case conferences, which take time away from other patients. They reported wrap around care, information sharing and communication with other systems and professionals as being costly and not supported by the system, leaving health professionals having to do large amounts of unpaid liaising, particularly for Autistic children. They also noted the lack of oversight, particular for the adult system, which results in a siloed approach across systems.

3.5.2.4 Continuity of care

Autistic people reported an absence of continuity of care, due to waitlists, not being able to see the same professional or as a result of falling out of touch with seeing a particular health professional.

3.5.2.5 Follow-up processes

Autistic people shared examples of the challenges associated with the follow-up process, including them not occurring at the scheduled time, there being a lack of follow-up, and having to rely on services to do the following up, particularly when they use phone calls.

> *"...having to be the one who rings up and makes the appointment or checks that the referral has even been received, for example. Can mean that I really delay in doing that, longer than I should, because yeah, I'm the one who has to do it."* (Autistic participant)

3.5.2.6 System constraints, under resourcing and lack of availability and capacity

> *"My experience has been that both practitioners and families and individuals have had a poor understanding of the differences between what is available in the state and territory funded sector, both child and moving into more sort of grown-up area, but also what is available in the Commonwealth subsidised private sector."* (Health professional participant)

Health professionals described the system as not being designed for complexity, with there being a lack of focus on ongoing care, particularly for chronic conditions. This makes it challenging to know where in the system is best placed to deliver longer term or ongoing care and who's responsibility it is to provide base level continuing care. This results in a lack of and sometimes non-existence of resources and services to refer to, and a pressure on General Practitioners to do more work than they have capacity for, including overseeing adult care and managing complexity and ongoing care. We heard that referral systems further drive the pressure for General Practitioners and additionally result in patients requiring ongoing care being referred to under-resourced assessment clinics. We heard speculation that the lack of health professional availability is a result of professional burnout, high staff turnover, recruitment challenges and practitioners only working part time.

3.5.3   Potential solutions

Table 11:   Summary of potential solutions and direct insights in the Delivery stage

Potential solutions	Direct insights
Preventative care and early intervention across the lifespan	• Annual health checks • Screenings • Check-ups • Genetic testing • Care and support across generations, including Autistic parents • Care across the lifespan • Checklists of things for health professionals to consider and check • Inclusive and accommodating schools, results in less need for services • Early intervention • Holistic approach
Services and support to navigate and coordinate services	• Autistic peer workers • School nurses to coordinate care for children
Planning and communication of next steps	• Provide a personalised and individualised plan that is shareable • Information about follow-up options and pathways • Guide for what to expect • Collaborate with the person • Writing down and informing people about what happens • Opportunity for processing time and ability to seek clarity post appointment
Communication and collaboration between services	• Connecting services and pulling professionals together • Nomination of a primary health professional contact by people • Treating team collaborating, communicating, sharing, and holding Roundtables • Not shuffled around the system • Multidisciplinary clinic • Seamless and easier testing and transition process • Patient profile and history document • Professional booking the follow-up appointment
Funding and referral policy reform	• Increased funding for follow-up care • Better referral system including unlimited referrals and adding weight to referrals
Ensuring continuity of care and access to ongoing care	• Integration of state and territory services • Transition planning for child to adult services • Six-monthly appointments with specialists • GP managing care in between specialists • Upskill schools and school nurses to provide ongoing care • General Practitioners should be the focus and at the forefront of continuing care • Improved follow-up process • Continuity of care and seeing the same person

Health professionals building patients capacity to self-manage their conditions and after care needs	- Digital and paper resources - People having leadership over their health - People learning more about their health and mental health - Matrix for people to manage after care - List of do's and don'ts - Tell people the importance and why - Provide people with rules to follow - Protocol for people to manage their conditions - Upskilling people in managing their conditions, including keeping track of symptoms, checking in with self and monitoring behaviour
Rights, information sharing and privacy	- Knowledge of complaint processes - Simplify the complaint process - Being informed of rights - Being informed of what information is on file and how it is shared and used

4.   Next steps

As we work towards developing Australia's first ever National Roadmap for Improving the Health and Mental Health of Autistic People, there is enormous commitment from the Autistic community and stakeholders to help realise the potential of this landmark initiative.

By mapping people's experiences with health and mental health care, as well as their interactions and engagement with services and supports, we were able to pinpoint key issues and identify clear opportunities for change. Echoing throughout this co-design process, we heard of a shared desire and a commitment from Autistic individuals, their families, and the health sector to collaborate on developing a safe, appropriate, and interconnected health system.

Our values

Inclusion
Valuing lived experience

Innovation
Solutions for long term challenges

Evidence
Truth in practice

Independence
Integrity through autonomy

Cooperation
Capturing opportunities together

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Independent national source of evidence for best practice

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