

Research to help make the Autism Health Roadmap: What we heard

Easy Read

March 2024



How to use this document



Autism CRC wrote this document.



We wrote this document in a way that is easy to read.

We use pictures to explain some ideas.



We wrote some words in **bold**.

Bold means the letters are thicker and darker.

We explain what the bold words mean.



This document is a summary.

A summary is shorter than the full report.

This means it only includes the most important information.



If you have any questions about this document you can email us at info@autismcrc.com.au

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What we heard about finding health care



It can be hard for Autistic people to make health care appointments.



It costs a lot of money to see health workers.



Health care buildings and rooms can be loud, bright and uncomfortable.



These things can make Autistic people not want to get health care.



It is important that health workers listen to Autistic people.



Health workers should always ask Autistic people for their permission before giving them treatment or care.



It is important that Autistic people have information about health care services and supports.



Sometimes information is not shared with other health workers at times when it would be helpful.



Autistic people feel that some health workers don't listen to them.

This makes Autistic people not want to get help.



It is hard for Autistic people to get help if they don't have a lot of money.



It is also hard for Autistic people to get help, if they don't know that they are sick.

What we heard about quality and safety



It is important for health workers to help people with different kinds of brains, genders, and sexualities.



Sometimes health care appointments are not long enough.

This can make it hard for Autistic people to get good care.



Autistic people feel pain differently.



Autistic people also communicate in different ways.

This can make it hard for health workers to give the right care.



Some Autistic people and their families find it helpful to get support from other people to explain their needs.



There are not enough health care workers to provide health care to Autistic people.

Sometimes health workers don't have enough time to give people the care they need.



It is important that health workers and Autistic people communicate with each other.



Mental health services should provide different types of care.



Sometimes people feel they don't get good, safe and helpful care from health care workers.

What we heard about connections and collaboration



Advocacy services are important. Advocacy means supporting people and helping to explain their needs.



It is helpful when Autistic people can tell health workers information before an appointment.

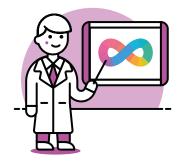


It is important for health workers and services to work together.



This will make sure that people get good help when they go to different services.

What we heard about training



Health workers would like training to learn how to help Autistic people.

The training needs to follow rules.



It could be helpful to everyone if health workers learn more about:



 Neurodiversity. Neurodiversity is the fact that everyone's brains are different



Autism



 How to make health services more comfortable for Autistic people and their families



 Intersectionality. Intersectionality is the idea that people have different experiences and challenges because of the different things about them, like race, gender, and disability



 How to help Autistic people who have had bad experiences that affect them in different ways



 How to understand how Autistic people feel pain



 How to help Autistic people who always need a carer to help with their daily living or health care needs.

What we heard about research and data



It is important that more research about autism is led by Autistic people.



People should do research about:



Neurodiversity



Intersectionality



 The health and mental health conditions some Autistic people have



 Autistic burnout. Autistic burnout is when Autistic people feel tired from acting like they aren't Autistic, or from not being supported



The different experiences that Autistic people have.

Next steps



Autism CRC gave this information to the government.



This information will help the government decide what should be in the Roadmap.

Word list

Advocacy

Advocacy means supporting people and helping to explain their needs.

Neurodiversity

Neurodiversity is the fact that everyone's brains are different.

Intersectionality

Intersectionality is the idea that people have different experiences and challenges because of the different things about them, like race, gender, and disability.

Autistic burnout

Autistic burnout is when Autistic people feel tired from acting like they aren't Autistic, or from not being supported.