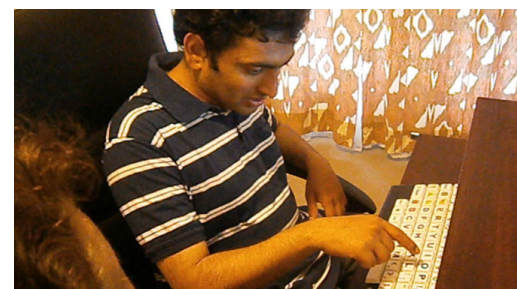


Research into autism: Who is listened to and who is left out?



What is this document about?



Autistic people often report poor life outcomes in things like:

- education / learning
- work
- health
- wellbeing / how they feel about themselves.

Autistic people have brains that work differently from the brains of people who are not autistic.

Their brains work differently:

- in lots of different ways
- in ways that are often different to other autistic people.



This Easy Read document is a **summary** of a **research** report written by Griffith University in Australia and Autism New Zealand.

A **summary**:

- is shorter than the full report
- tells you the main ideas.



Research is when we do work to:

- find things out
- understand what these things mean.



In this Easy Read document when we say **we** this means Autism CRC.

For this research we:



- looked at what other research reports said about **quality of life** of autistic people with **complex needs**



- wanted to know more about who is listened to and who is left out in research



- wanted to find ways that autistic people with complex needs can have their say about quality of their life.



Quality of life means how good your life is for you.



For this research when we say an autistic person with **complex needs** this means they are:

- autistic
- have at least 1 other **mental** or **physical condition**.



Mental condition may mean things like:

- depression
- anxiety disorders
- eating disorders
- schizophrenia.





Physical condition may mean things like:

- health condition
- disability.

Past research

We read a lot of research by other people to understand:



- if autistic people with complex needs were part of much research
- how other researchers **reported** on quality of life
- what other researchers found out.



Reporting is when someone writes down what they found out through doing research.



We used the research we read to find out the best ways to include autistic people with complex needs in our research.



We read a lot of studies from the last 25 years.



We looked at every study to see how other researchers reported on quality of life of autistic people.



Only a few of these studies had autistic people with complex needs tell researchers about their own quality of life.

Who did our research?



Our research team had researchers who are:

- autistic
- not autistic.



These researchers were from:

- Griffith University in Australia
- Autism New Zealand in New Zealand.



This research was funded / paid for by Autism CRC in Australia.



We also worked with an advisory group that was made up of people from services like:

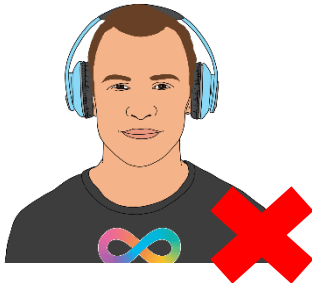
- Reframing Autism
- Giant Steps
- The Sycamore School
- Children's Health Queensland.



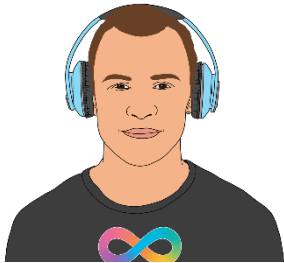
We also worked with autistic people with complex needs.



What we found out: quality of life



We found out that the way most researchers measured quality of life was not designed for autistic people.



Only 6 of the studies we read used a way to measure quality of life that was designed for autistic people.



We read some studies that looked at the quality of life of:

- autistic people
- people who are not autistic.



Most of those studies found that autistic people usually have a worse quality of life than people who are not autistic.



A good life for autistic people means things like:



- having social support
- having daily living skills like cooking
- doing things themselves
- doing things in their community
- planning to do things with friends
- other people knowing what autism is.



What we found out: who was included



Not many of the studies we read asked autistic people to help:



- work out how the research would be done
- do the research.



We think more autistic people need to be part of designing research so that:

- research is done about things that are important to autistic people
- autistic people are listened to
- autistic people are understood.



What we found out: accommodations



Some autistic people need **accommodations** so they can take part in the research.



An **accommodation** is something that will make it easier for someone to be part of a research project.



Some of the studies we read when researching accommodations used **self-reporting**.



Self-reporting is where a person answers questions about themselves as part of a research project.



Most of the studies with adult **participants** used self-reporting.



Participants are people who take part in a research project so that researchers can learn things.

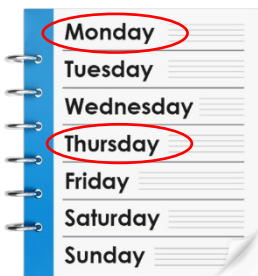


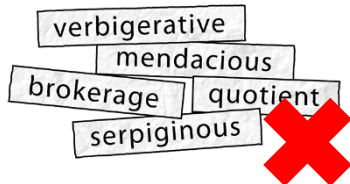
Only some of these studies said they had accommodations to make it easier for their participants.



Some of the accommodations were:

- participants taking a break between questions
- participants answering questions over 2 or more meetings.





Other accommodations were:

- participants having a support person with them
- changing the words of the questions so they were easier to understand
- taking away questions that might be upsetting
- a room that was comfortable for the participant like:
 - a room with soft lights
 - a room that was very quiet
- writing the information in alternate formats like:
 - Easy Read
 - Easy English.

What we think needs to happen next



We think what we have found out shows that more:

- research needs to be done to understand autistic peoples ideas about quality of life
- work needs to be done to include autistic people with complex needs in research projects.



Including autistic people with complex needs in research will mean they can have their say.

More information



You can read the:

- full report
- community report
- summary



at this **website**:

autismcrc.com.au/reports/quality-of-life



This information has been written by Griffith University and Autism New Zealand.

It has been translated into Easy Read by the Make it Easy Kia Māmā Mai service of People First New Zealand Ngā Tāngata Tuatahi.

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Our values



Inclusion

Valuing lived experience



Innovation

Solutions for long term challenges



Evidence

Truth in practice



Independence

Integrity through autonomy



Cooperation

Capturing opportunities together



AutismCRC

Independent national source of evidence for best practice



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