

Representation of the autistic community in research on quality of life and wellbeing: Who is heard and who is excluded?

What is quality of life and wellbeing?

Quality of life and wellbeing are complex concepts, with multiple definitions used across different studies. Although there weren't any consistent definitions of wellbeing, it has been defined as:

“The internal state of mind that individuals adopt regarding their personal sense of satisfaction with life as a whole”. (Cummins, 2010)

Within the studies we looked at, the two most cited definitions of quality of life were:

“An individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.” (World Health Organisation, 1993)

“A multi-element framework, including domains of emotional wellbeing, interpersonal relationships, material wellbeing, personal development, and physical wellbeing.” (Schalock, 2004)

Overall, the most common factors being measured by quality of life and wellbeing research were:



Physical wellbeing



Self determination



Emotional wellbeing



Social inclusion



Personal development



Interpersonal relationships



Material wellbeing



Rights

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Autistic-specific measures

Only six studies used an autism-specific quality of life measure. Five used the Autism Spectrum Quality of Life measure (ASQoL), and one used the Quality of Life for Children with Autism Spectrum Disorder measure (QOLASD_C).

The ASQoL is a nine-question add-on intended to be used along with a more general quality of life measure. This covers:

- Support in making decisions
- Support in dealing with problems
- Barriers within official situations like work or benefit offices
- Barriers to health services
- Financial security
- Being at ease with autism as part of the individual's identity
- Satisfaction with friendships
- Being yourself around others
- Sensory issues

Five more studies worked on producing or validating autistic-specific quality of life measures.

- One investigated the validity of the ASQoL.
- Two studies reported on the development of the Quality of Life for Children with Autism Spectrum Disorder (QOLASD_C).
- Two studies developed autistic-specific quality of life measures (the Caregiver Evaluation Quality of Life Scale, and Caregiver-completed Quality of Life).

Outside of this review, there has been some research into autistic people's conceptions of quality of life or wellbeing.

- [Autism CRC's 2022](#) investigation into developing a quality of life assessment for autistic people identified several themes from autistic adults: activities and routines; relationships; socialisation and supports; mind and body; personal experiences; and the environment around them.
- [McConachie et al. \(2020\)](#) also identified themes that were particularly relevant to autistic people in terms of quality of life: a positive autistic identity; other people's understanding of autism (or lack of understanding); sensory issues; and contribution to society.
- Themes identified from [Reframing Autism's video series](#) on autistic wellbeing included: being understood, accepted, and supported; connection with other autistic people; having meaning and purpose to life; and a sense of achieving something.

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There is no widely accepted definition of complex support needs or complex communication needs. Even using our broad definition of complex support and/or communication needs, we found that:



Only about one third of studies had autistic people with complex support and/or communication needs report on their own quality of life.



One in ten studies specifically excluded autistic people with a diagnosis of intellectual disability from taking part in their research.

Limitations of this definition

Some co-occurring conditions, on their own, might not be viewed as a person having complex support and/or communication needs, but in combination, very much could do. Additionally, the impact of co-occurring conditions may vary in different people, different environments and at different times. There is limited consideration for the intersectionality of co-occurring conditions in each autistic person, and privilege of, or access to diagnosis.

This means that we are limited in our knowledge about the wellbeing and quality of life of autistic people with complex support and/or communication needs, and more research is needed which aims to include participants with this profile.

What did we do?

We completed a comprehensive review of the research literature and found 236 studies on the quality of life and/or wellbeing of autistic people published in the last 25 years. In reviewing these studies, we aimed to find out:

- Whose perspectives have been heard and whose are missing.
- How quality of life and wellbeing were reported and what was found.
- Ways to hear the perspectives of autistic people with complex support and/or communication needs.

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Why did we do this?

Autistic people often report that their life outcomes, such as education, work, health, and wellbeing, are poor. However, the perspectives of autistic people with complex support and/or communication needs are not always shared or heard.

This project identifies ways in which future research into quality of life and wellbeing in autistic people can expand on the perspectives reported, thereby ensuring the findings benefit all.

Who was involved?

The research team was made up of autistic and non-autistic researchers from Griffith University and Autism New Zealand, working with an advisory group, and autistic people who identified as having complex support and/or communication needs.

Research findings

Community involvement



Autistic involvement: Of the 236 studies we found that reported on autistic quality of life, **20** reported some form of autistic community involvement in their research.



Feedback: **2 studies** made significant changes to their questionnaires based on feedback from autistic people.



Autistic researcher: An autistic researcher or research assistant was part of the research team for **5 studies**.



Consultation with autistic people: **4 studies** consulted with autistic people throughout every stage of the study.



Design: **9 studies** involved autistic people in the process of designing the study.

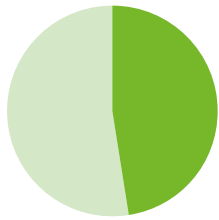


Consultation with the autism community: **4 studies** consulted parents of autistic children, professionals who worked with autistic people, and/or researchers in the autism field when designing their study.

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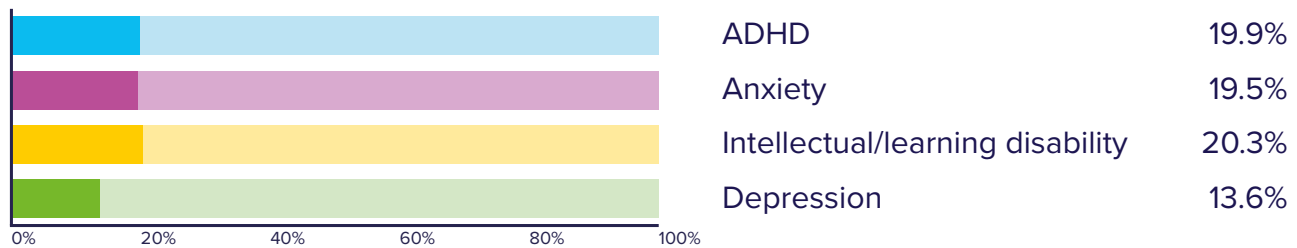
Participant characteristics

Co-occurring conditions



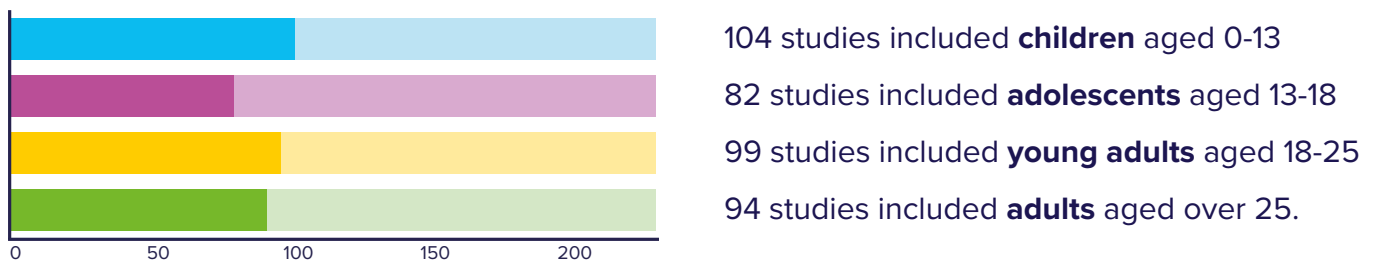
- Included co-occurring conditions:** Of our total 236 studies, 112 (47.5%) reported that some or all of their participants had one or more co-occurring conditions, in addition to being autistic.
- Didn't include co-occurring conditions:** The other 124 either did not report any co-occurring conditions, or specifically excluded participants with co-occurring conditions.

A wide range of co-occurring conditions were reported; with studies most commonly including the following:



Age range

There was a fairly even split across age ranges.



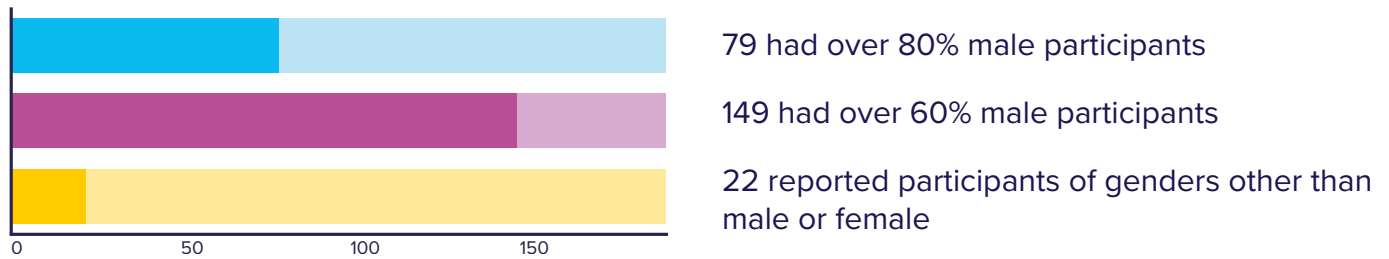
Gender



- Reported participants' genders:** Of our total 236 studies, 193 (81.8%) reported participants' genders.
- Did not report participants' genders:** The other 43 (18.2%) studies either did not report on their participants' gender or did not report on autistic participants' gender separate to the wider population being studied.

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Of the 193 studies that reported participant's genders:



Of the 22 studies that reported gender diverse participants:

- 21 had between 1-20% of their participants identify as a gender other than male or female.
- 1 specifically targeted gender diverse youth, and therefore, had the majority of their participants identify as a gender besides male or female.

Proxy report vs. self-report

Most of the studies reporting on autistic children and adolescents' quality of life used proxy reports (that is, someone else answering questions about the autistic child, usually a parent or caregiver), while most of the studies reporting on autistic adults' quality of life used self-reports (that is, autistic adults answering questions about themselves).

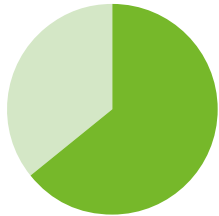
4 studies investigated the accuracy of proxy reports compared to self-reports.

- 1 found that caregivers' reports and autistic children's reports mostly or entirely agreed with each other.
- 1 found that proxy reporters consistently scored autistic young people's quality of life as better than the young people themselves did.
- 1 found large discrepancies between proxy reports from the mothers of autistic adolescents and self-reports from the adolescents.
- 1 found significant differences between proxy reports and self-reports from autistic adults.

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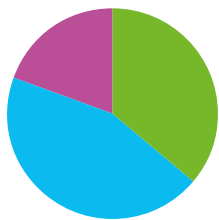
What were participants' quality of life and wellbeing?

56 studies compared quality of life between autistic people and populations with no reported neurodivergent or psychological conditions.



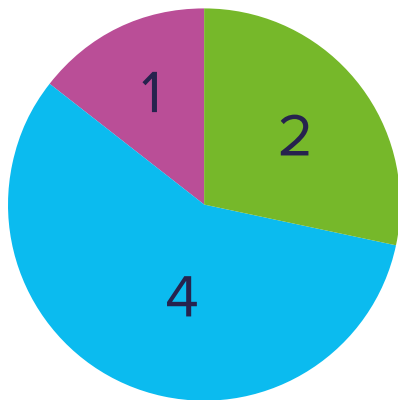
36 of these studies found that autistic people generally had worse quality of life than the general population.

These 36 studies were fairly evenly split in terms of who was reporting on autistic quality of life with:

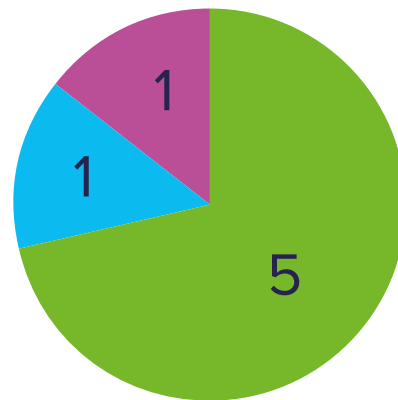


- 16 using proxy reports
- 13 using self-report
- 7 using a mixture

14 studies investigated and compared the quality of life of autistic people with the quality of life of people with other neurodivergent, psychological or physical health conditions.



7 found that autistic people had worse quality of life than those with other conditions.



7 found no difference.

Most of the self-report studies (5 out of 7) found no difference in quality of life.

Most of the proxy-report studies (4 out of 5) found that autistic people's quality of life was worse.

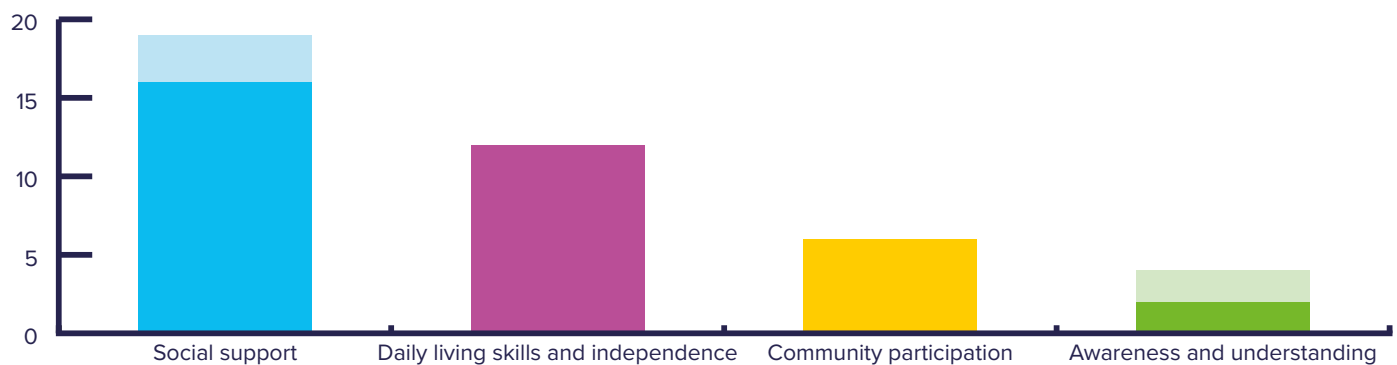
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Factors contributing to quality of life and wellbeing

Of the total 236 total studies, 95 identified factors contributing to quality of life and wellbeing.

Factors supporting a good life

41 studies identified factors that support a good life.



Social support

19 studies found that social support positively impacted autistic quality of life. Social support includes direct support from family, friends, and communities (but not formal support from professionals), as well as feelings of belonging and community.

3 of these studies had autistic consultation or involvement and reported that:

- Social stigma related to autism was associated with worse quality of life.
- Stronger feelings of social identification and belonging were associated with better quality of life.
- Community connectedness and school support were associated with better quality of life in autistic children.

Daily living skills and independence

12 studies found that higher daily living skills were linked to higher quality of life.

Community participation

6 studies investigated participation in organised or community activities, and all of these found that more available activities and/or more participation in one or more types of activities was associated with better quality of life.

Awareness and understanding

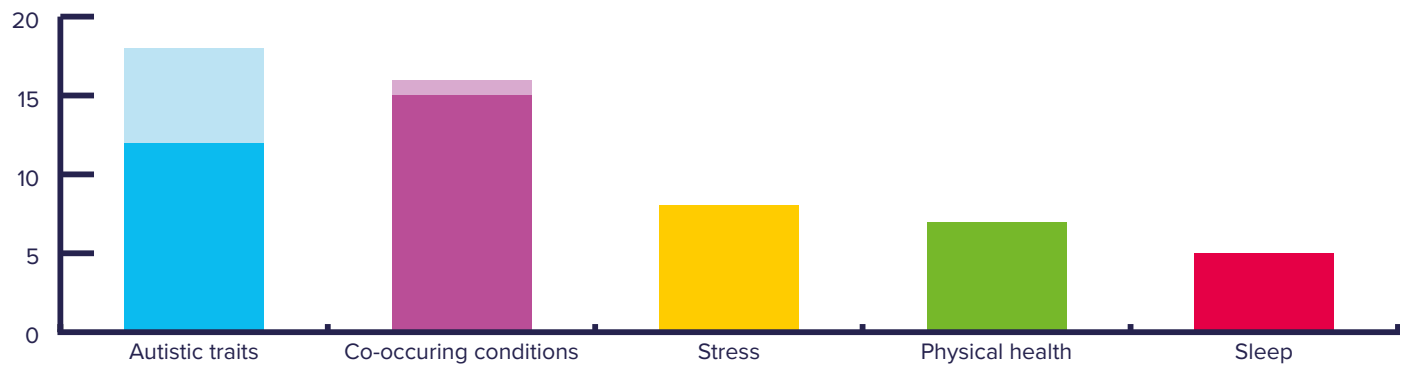
4 studies investigated other people's knowledge of autism.

- 2 of these found that higher awareness and acceptance of autism within schools was associated with better quality of life for autistic children.
- The other 2 found that carers' knowledge and understanding of autism was associated with better quality of life for the autistic adults they cared for.

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Factors hindering a good life

54 studies investigated factors that make having a good life more difficult.



Autistic traits

18 studies found links between quality of life and autistic traits.

Many of these studies used deficit-based measures and definitions. Most did not define terms like 'levels of autism' or 'negative symptoms', making it difficult to determine what they were measuring.

12 of these studies found that higher 'levels' of autism were associated with worse quality of life.

The remaining 6 studies isolated specific behaviours often referred to as challenging.

- 5 of these reported that higher levels of these behaviours were associated with worse quality of life.
- 1 of these 6 studies also reported that autistic adults with special interests generally had better leisure activity-related quality of life.

Co-occurring conditions

16 studies reported that co-occurring psychiatric conditions were associated with worse quality of life.

1 of these studies had autistic consultation or involvement and reported that mental health difficulties were consistent predictors of poor quality of life.

Stress

8 studies found that higher stress levels were associated with worse quality of life.

Physical health

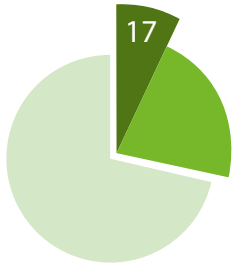
7 studies found that poorer physical health was associated with worse quality of life.

Sleep

5 studies found that sleep problems were associated with worse quality of life.

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How can we hear from autistic people with complex support and/or communication needs?



Of the 236 studies covered in this review, 68 (28.8%) used self-reported measures.

17 of these reported putting specific accommodations in place for participants.



Taking a break or completing the questionnaire over multiple sessions (7 studies).



Changing wording or questions to reduce vagueness and confusion (2 studies).



Clarification or prompts to help complete questionnaires (6 studies).



Removing sensitive questions from the questionnaires (2 studies).



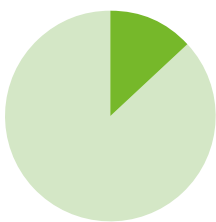
Allowing support people (2 studies).



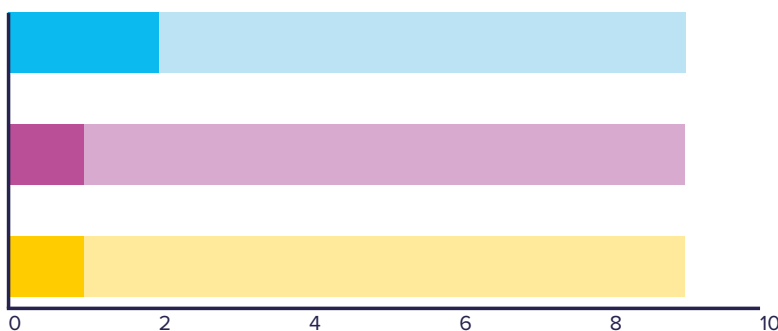
Environmental accommodations such as quiet rooms and/or soft lighting (3 studies).



Information and task instructions in Easy Read (1 study).



Of the 68 studies that used self-report measures, 9 had autistic consultation.



2 of these reported providing specific accommodations for participants.

1 provided Easy Read translations, noise reduction and soft lighting in the lab environment, and frequent breaks between tasks.

1 provided telephone assistance to read and complete the survey.

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What can we do in the future?

Factors contributing to quality of life and wellbeing

The most commonly used definitions of 'quality of life' and 'wellbeing' do not seem to align with factors that are important or relevant to autistic people. In general, there is insufficient research into what quality of life and wellbeing mean to autistic people, and what a good life looks like for autistic people with complex support and/or complex communication needs. Without this baseline, the studies we investigated may or may not be accurately measuring their autistic participants' subjective quality of life and wellbeing.



Further research needs to be done into what 'quality of life' and 'wellbeing' mean to autistic people as a whole, and into what these concepts mean to autistic people with complex support needs and/or complex communication needs.

Understanding complex support and/or communication needs

There is very little research into quality of life for autistic people with complex support and/or communication needs, and in fact some research specifically excludes them. This is a significant gap in current research.



Research needs to be done specifically on this population and their quality of life. Research about autistic people in general should include the entire community, including autistic people with complex support and/or communication needs.

Community involvement

Most studies did not have any input from autistic people into designing and doing the research.



More accurate results could be obtained by future research that is undertaken by autistic researchers or co-produced with autistic people. As well as helping to guide research in directions that are important and relevant to autistic people, this also helps to reduce misunderstandings and inaccurate data due to autistic participants potentially finding questions unclear or ambiguous.

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Accommodations

Only nine studies reported having researchers available to clarify questions or changing the language in surveys to reduce confusion in autistic participants. Only one reported providing an Easy Read translation of survey materials.



Future research needs to account for the fact that autistic people often interpret questions differently from non-autistic people or may be unable to parse questions that are too ambiguous. Research needs to make accommodations so that autistic people with more complex communication needs, lower reading levels, or learning disabilities are not self-excluded from the research due to being unable to complete the surveys.

Self-report

The majority of research into autistic quality of life relies on proxy reporting. Most research that used self-report measures provided very basic or no accommodations for the autistic participants. This could potentially exclude participants with more complex needs.



Future research should investigate ways to provide opportunities for participants with complex needs to self-report on their own lives.

Who did the research



Acknowledgements

We'd like to acknowledge our advisory group from: Reframing Autism, Giant Steps, The Sycamore School, and Children's Health Queensland. We'd also like to thank our autistic experts: Gabrielle Hogg and Hem Sidharth Chandran.

Where to go for more info

Download the full report, executive summary, and Easy Read summary at autismcrc.com.au/reports/quality-of-life.