

Quality of life and wellbeing of autistic individuals with complex support and/or communication needs

Executive Summary

Kate Simpson, Larah van der Meer, Dawn Adams, Rachael Bowen, Hem Sid Chandran, Alison Gable, Robyn Garland, Melanie Heyworth, Helen Heussler, Gabrielle Hogg, Chanelle Moriah, Lee Patrick, Jessica Paynter, Marleen Westerveld

June 2023



Quality of life and wellbeing of autistic individuals with complex support and/or communication needs

A systemic review of how quality of life and wellbeing is measured in autistic individuals with and without complex support and/or communication needs.

Kate Simpson

Griffith University

Larah van der Meer

Autism New Zealand | Victoria University of Wellington

Dawn Adams

Griffith University

Rachael Bowen

Giant Steps

Alison Gable

The Sycamore School

Robyn Garland

Griffith University

Melanie Heyworth

Reframing Autism

Helen Heussler

Children's Health Queensland

Gabrielle Hogg

Autistic Expert

Chanelle Moriah

Autism New Zealand

Lee Patrick

Autism New Zealand

Jessica Paynter

Griffith University

Marleen Westerveld

Griffith University

ISBN: 978-1-922365-56-9

Citation: Simpson, K., van der Meer, L., Adams, D., Bowen, R., Chandran, H., Gable, A., Heyworth, M., Heussler, H., Hogg, G., Patrick, L., Paynter, J. & Westerveld, M. (2023). A systematic review of how quality of life and wellbeing is measured in autistic individuals with and without complex support and/or communication needs. Autism CRC, Brisbane.

Copies of this report can be downloaded from the Autism CRC website autismcrc.com.au.

Copyright and disclaimer

This report has been published by Autism CRC to assist public knowledge and discussion to improve the outcomes for autistic people through end-user driven research. General use of any or all of this information in the report should give due acknowledgement to its source. You should seek independent professional, technical or legal (as required) advice before acting on any information contained in this report. Autism CRC makes no warranties or assurances with respect to this report. Autism CRC and all persons associated with it exclude all liability (including liability for negligence) in relation to any opinion, advice or information contained in this report or for any consequences arising from the use of such opinion, advice or information. Copyright in this report and all the information it contains vests in Autism CRC.

Acknowledgements

The authors acknowledge the financial support of Autism CRC. Staff and non-staff in kind were provided by Autism CRC members – Autism NZ and Griffith University, affiliates – Children’s Health Queensland, Reframing Autism, and community organisations – Giant Steps. Research assistants were Gabriel Blair, Annette Carroll, Yixuan Liu, Libby MacDonald, Daniel Malone, Kendal O’Connor.

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.

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

Executive summary

Introduction

Autism is a heterogeneous presentation of characteristics including social communication differences and behaviours that are present across the lifespan (American Psychiatric Association, 2013). This means that each individual has their own unique profile of strengths and challenges; they may think differently, process and experience their senses differently, communicate differently and/or socialise differently. In addition, autistic people are often reported to have co-occurring conditions including intellectual disability, language impairments, mental health conditions, and medical conditions (Lai et al., 2019; Maenner et al., 2023; Tager-Flusberg & Kasari, 2013). Although there is no agreed definition for “complex needs”, the constellation of core and associated features can lead to greater, more complex communication and support needs for some individuals. It should be noted, however, that these needs are not conceptualised as static and may fluctuate, dependent on the levels of support in the environment.

Being able to enjoy a good life and wellbeing is viewed as a right for all people (United Nations, 2007, 2022). However, outcomes in this area for autistic people are frequently reported as below those of the non-autistic population (Ayres et al., 2018). The Select Committee on Autism (2022) was a committee established to investigate supports and life outcomes for autistic people in Australia. Following accounts from the autistic and autism community, the committee concluded that life outcomes (education, work, health, wellbeing) for autistic Australians are “unacceptably poor”.

The committee suggested that autistic individuals with complex support and communication needs are likely to have even poorer life outcomes than many autistic people due to more frequent and/or more significant barriers to education, community, and work inclusion.

There is ongoing discussion of what constitutes wellbeing or quality of life in autistic individuals and whether definitions or measures developed for neurotypical individuals are applicable or appropriate. This may be particularly pertinent to individuals with complex needs whose priorities, preferences, and abilities may differ, such as in vocational engagement, independent living, or socialisation, which are often embedded in measures of quality of life developed by or for neurotypical individuals.

What we did

Engaging with the autistic and autism communities, we developed a research protocol and conducted a systematic search of the research literature, with the aim to identify:

- Methods used to describe and measure the quality of life and/or wellbeing for autistic people with complex support and/or communication needs; these findings would be presented as a white paper report.
- Whose quality of life and/or wellbeing is being reported and who is reporting this.

A key focus of the research project was to understand the methods used for autistic people with complex support and communication needs. For the purpose of this project, we defined autistic people with complex care, support and/or communication needs as autistic people with co-occurring conditions (e.g. physical, intellectual, psychiatric, sensory, neurological, language or learning disability). This definition was co-developed with the autistic and autism communities.

We adopted a broad definition and acknowledge not all autistic people with co-occurring conditions would identify themselves as having complex care and/or support needs.

What we found

We identified 236 research studies that investigated the quality of life and/or wellbeing of autistic people (aged 3–83 years). Studies were predominantly located in the United States (33.6%), with 10% of the studies conducted in Australia and only one study conducted in New Zealand. We identified a growing interest in this area, with over 50% of the studies published in the last 5 years. When we looked at who is reporting on the quality of life or wellbeing of autistic people, we found that:

1. **Proxy informants provided information in over 30% of the studies.** Proxy is when the quality of life and/or wellbeing of the autistic person was reported by others. Most of these (83%) reported on the quality of life and/or wellbeing of children. Over 50% of the studies did not identify if the children had a co-occurring condition. Proxy reports were predominantly based on the use of questionnaire(s)/survey(s)/closed question interviews. Thirty-six different measures were reported in the studies, only three of which had been designed to measure the quality of life of autistic people and these reported preliminary findings about the measure. Proxy informants were often used when autistic people were not viewed as capable of participating in the research.
2. **Autistic individuals without any reported co-occurring conditions provided information in 31% of the studies.** In almost one third of the studies, an autistic person with no reported co-occurring condition/s was an informant in the study. This included studies where co-occurring conditions were not reported or were specifically excluded. As such, we recognise that these studies may have included autistic people who have complex support and/or communication needs. The majority of autistic informants in these studies were adults. Again, the most common method used to obtain the views about the quality of life and/or wellbeing was questionnaire(s)/survey(s)/closed question interview. Over 40 different measures were reported in the studies, with the World Health Organization Quality of Life (WHOQOL-BREF; The WHOQOL Group, 1998), the most frequently used measure. An autism-specific measure—Autism Specific Quality of Life module (ASQoL; McConachie et al., 2018)—was used in three studies with autistic adults. This measure is designed to be used in conjunction with the WHOQOL-BREF.
3. **Autistic individuals with a co-occurring condition provided information in 34% of the studies.** However, the co-occurring conditions that the autistic participants had varied significantly and even within these studies, autistic people with specific co-occurring conditions were sometimes excluded. For example, we found that in 10% of the 236 studies individuals with an intellectual disability were excluded from taking part in the research.

4. **Studies that did include autistic individuals with co-occurring conditions sometimes modified procedures or methods to be more accessible and inclusive.** Successful modifications or accommodations include:
- a) information about the project and task instructions provided in easy read language;
 - b) interview questions are provided beforehand;
 - c) questionnaire/surveys use clear unambiguous questions and provide examples, additional explanations and practice questions;
 - d) the use of visuals (e.g. symbols, pictures, artworks) to focus the discussion;
 - e) provide a range of different methods of response option;
 - f) option of having a support person;
 - g) environmental accommodations as required by the autistic person;
 - h) provide breaks and a flexible time period to complete the measures.
5. **Few studies reported using community involvement to design studies, which may then be impacting on accessibility.** Just over 10% of the 236 studies included some form of community involvement comprised of autistic people, community members, and/or autistic researchers contributing to the research beyond being participants in the research. The degree of involvement varied from consultation on the design of the study through to involvement at each stage of the project. Less than 10% of the 236 studies reported on adaptations made to support autistic people with complex support and/or communication needs. Again, the predominant form of collecting data was the use of questionnaire(s)/survey(s)/closed interview questions that may not support autistic informants and were not developed for autistic populations.

Limitations

The focus of this project was on autistic people with complex support and/or communication needs.

The lack of a clear definition of this term resulted in adopting a broad definition that could be systematically applied to screening the studies. This definition was based on reported diagnostic co-occurring conditions. Over 30% of the studies provided no information on the autistic informants having a co-occurring condition. These studies may well have included autistic people with complex support and/or communication needs but as this was not clear, and they were excluded from the white paper included in this report. As an aim of this project was to identify how autistic people's perspectives are gathered, studies that focused on groups of individuals who may have complex support and communication needs were excluded if they did not identify that autistic people were included, or if they did not identify the autistic informant respondents separately.

The search adopted in this project was restricted to research published papers, however current research methods may limit the participation of autistic people with complex support and/or communication needs. Furthermore, the search terms were restricted to "quality of life" and "wellbeing". However, autistic people with complex support and/or communication needs may use other descriptors to describe their life, for example, thriving, happiness, having a good life. Although 236 studies were identified, the findings need to be considered within the context of these limitations.

What next? Implications and recommendations for research and practice

This research has shown that 80 previous studies on quality of life and wellbeing have included autistic people that met our definition of complex support and/or communication needs. However, within these studies, few studies included autistic people with intellectual impairment or language impairment as informants. This highlights that this group of individuals are still largely excluded from the research about them. Within the studies, there were attempts to proactively design methods with amendments or accommodations to support participation. To ensure this designing for broader participation becomes standard practice in autism research and practice, changes need to be made. Based on the findings from this project and discussion with the autistic experts and autism community members involved in this project, the following implications and recommendations for both research and practice are made:

1. Always start with a mindset of presuming competence, respecting that every autistic person has the right to take part in all aspects of their life. Within research, when competence is presumed and the right for every autistic person to participate if they wish is respected, the onus moves to the researcher to co-develop methods that enable every autistic person to participate, including those with complex support and/or communication needs. If researchers do exclude autistic participants on the basis of their co-occurring conditions or their communication or support needs, the decision and lack of task design for inclusion needs to be comprehensively and clearly justified. The bias in the sample also needs to be made clear within the title of the work e.g., rather than just stating “autistic adults”, make it clear that it is “autistic individuals without an intellectual disability”.
2. Ensure that the autistic person has the opportunity to communicate using their preferred means of communication. This is likely to be different for every person and may require flexibility of presentation, time, processing, and response for each step with best practice accessibility principles. Within research this may mean focusing on inclusion over consistency by offering multiple response modes within a single study or being flexible with the time and pace of the process.
3. Appreciate that an autistic person’s level of support is not a static construct. The type and amount of support may vary across environments, people, and time. This requires describing people beyond broad diagnostic criteria, to include an autistic person’s level of support required in terms of communication and participation in daily activities from their perspective. For research, this means having more information in the participant demographics which could be defined within a co-developed *minimum reporting standards of autistic samples* (yet to be developed).
4. Ensure consistent and genuine participation with the autistic community, and with the autism community where appropriate, as partners at each stage of the study. Co-production between researchers and community members will help researchers and individuals conducting consultations to identify methods and measures which are relevant and appropriate for the participant group. Autistic people who contribute their time to the research through co-production or informing practices should be compensated financially at an appropriate rate for their expertise.

5. To ensure these key recommendations are implemented, strategic investment is required that allow the time and funding that inclusive, co-produced research demands, including building skills of researchers in co-production methodologies.

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



autismcrc.com.au