

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

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## Final Report

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# 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.

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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.

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## 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'.

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# Executive summary

## Introduction

Autism is a heterogenous 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.

# 1. Introduction

## 1.1 Background

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 frequently have co-occurring conditions, with 95% of autistic children reported to have at least one co-occurring condition (Soke et al., 2018). Common co-occurring conditions include intellectual disability (37.6%, Maenner et al., 2023) and language impairments (see review by Kwok et al., 2015), with research indicating approximately 30% of autistic children not developing functional verbal language skills (Tager-Flusberg & Kasari, 2013). Furthermore, high co-occurrence has been observed with mental health conditions including anxiety, depression, and obsessive-compulsive disorder (Lai et al., 2019), as well as medical conditions including seizures and epilepsy (Liu et al., 2022) and gastrointestinal conditions (Wang et al., 2022). Although there is no agreed definition for “complex needs”, the collection of core and associated features can lead to greater, more complex 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.

Quality of life and wellbeing are seen as important life outcomes for all individuals (United Nations, 2022); however, outcomes in this area for autistic people are frequently reported as below those of the neurotypical population (Ayres et al., 2018). 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.

In terms of neuronormative definitions, one of the most common definitions of quality of life is from the World Health Organization: “Quality of life is defined as individuals’ perceptions of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO, 1996, p. 3). As such, quality of life is a multidimensional construct that includes subjective perceptions of the interactions of physical health, psychological state, level of independence, social relationships, and education/vocational satisfaction. WHO (1996) further described that this definition is focussed on perceptions of quality of life, differentiating it from wellbeing as a separate construct.

Most measures of QoL have been developed by and for neurotypical, and more specifically non-autistic individuals. However, recently, efforts have been made to create QoL measures to capture factors specific to particular populations. This has included extending items to include autism-specific features to the WHOQOL-BREF (McConachie et al., 2018) as well as revising an existing

measure (Patient-Reported Outcomes Measurement Information System [PROMIS-10]) for autistic individuals (Williams et al., 2023). This is an emerging area of research with McConachie et al. (2018) the first to validate a measure of quality of life with autistic adults.

Overall, quality of life has been found to be lower for autistic adults than for non-autistic adults when measured using tools designed for the general population (see review with 14 adult studies, Ayres et al., 2018). We highlight the inherent limitations of this approach in assuming autistic people value the same domains for QoL as non-autistic people; additionally, this approach does not capture potential individual differences among individuals in what constitutes quality of life.

Wellbeing may be viewed as a related, but separate construct to quality of life. Wellbeing has been conceptualised subjectively as well as objectively. Subjective wellbeing refers to the self-evaluation of one's emotional and cognitive wellbeing, including being engaged in interesting activities, experiencing frequent pleasant feelings and infrequent unpleasant feelings, and experiencing an overall subjective experience of life as satisfying (Diener, 1984). "This subjective definition of quality of life is democratic in that it grants to each individual the right to decide whether his or her life is worthwhile" (Diener, 1984, p. 34). Objective wellbeing "defines wellbeing in terms of the degree to which a person is fully functioning" (Ryan & Deci, 2001, p. 141), for example, through the activities they do/can do, or the amount of environmental social support.

The Select Committee on Autism (2022), following accounts from the autistic community, concluded that life outcomes (education, work, health, wellbeing) for autistic Australians, potential objective measures of wellbeing, 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.

The perspectives of autistic individuals with complex support and/or communication needs are not always the perspectives typically shared or heard, even within the autistic community. Consequently, little is known about life outcomes (objective) or subjective elements of wellbeing for autistic individuals with complex support and/or communication needs. In response, the Australasian Autism Research Council (AARC), who operate under the auspice of Autism CRC, identified this as a research priority area. This project aims to take the first step toward addressing this priority set by the AARC. The research team comprehensively searched the research literature to identify how quality of life and wellbeing are currently measured for autistic individuals with complex support and/or communication needs.

This project is a foundational step that aims to inform future research in this area, including identifying those whose perspectives are rarely included and identifying methods already successfully used to gain the perspectives of those with complex support and/or communication needs. For the purpose of this project, the co-developed definition of the cohort was autistic people with complex care, support and/or communication needs, and/or the presence of co-occurring conditions (e.g., physical, intellectual, psychiatric, sensory, neurological, or learning disability). This project informs future research into quality of life and wellbeing in autistic individuals to expand the perspectives reported, thereby ensuring the findings benefit all.

## 1.2 Objectives

Three specific objectives were identified.

- Perform a systematic search of the research on quality of life and/or wellbeing in autistic individuals with complex support and/or communication needs.
- Document the methods that have been used to describe or measure quality of life and/or wellbeing for autistic individuals with complex support and/or communication needs.
- Describe participant characteristics of studies on quality of life and wellbeing in autism and use the community advisory group to identify the characteristics of autistic individuals with complex support and/or communication needs that are currently unheard in the research literature.

## 2. What we did

### 2.1 General methods

Previous research has shown that autistic people with complex support and/or communication needs are often excluded in the research studies. This project is a foundational step towards changing that imbalance. It aims to find out the amount of research in a specific area (quality of life and wellbeing) that has included the perspectives of autistic people with complex support and/or communication needs to identify whose perspectives have been documented and whose may have been missed. It also aims to inform future research and work in this area by identifying studies in which the perspectives of those with complex support and/or communication needs have been included and identifying the methods studies used to hear such perspectives.

To address these aims, a systematic approach was adopted to comprehensively review the published research literature on the quality of life and/or wellbeing of autistic individuals. Following this, the identified papers pertinent to address the objectives of the study were examined and relevant information was extracted, discussed, and summarised. Based on the findings from this review, recommendations were provided for developing research and community consultation methods which increase the opportunities for autistic people with complex support and/or communication needs to share their perspective on issues that affect them.

### 2.2 Engaging with the autistic and autism community

#### 2.2.1 Autistic input to the project: autistic experts and autistic researchers

Throughout this project a flexible approach was adopted to enable meaningful participation of all members (i.e., autistic experts, advisory group, and research team). Following the investment being made from Autism CRC, to recruit autistic experts, an advertisement who those self-identified as having complex support and/or communication needs was created and shared. The advertisement used Easy English, had sufficient contrast between text and background, and had accessible tags (see Appendix A). The advertisement was shared through Autism New Zealand and end-user organisations.

Autistic people who expressed an interest in the project were contacted and more detailed information was then shared about the project and the roles of the autistic experts. This was done by creating a PowerPoint that included the information. Feedback on the PowerPoint was provided by one autistic expert, and changes were made, before this was shared with the other autistic experts and autistic researchers. Methods for sharing the PowerPoint were adapted for the needs of the individual (e.g., Microsoft Teams meeting with the PowerPoint being shared; PowerPoint embedded into a video presentation and the link shared via an email <https://vimeo.com/758990217/acc0b89e8e>). See Appendix B for the printout of the slides.

Two autistic experts (Gabrielle Hogg and Hem Sidharth Chandran) played an integral part in each stage of the project. Throughout this project, the presentation of the information was tailored to each expert's preferred methods of communication. Engagement with each autistic expert occurred on an individual basis, via e-mail and Teams. Time contributed by the autistic experts varied depending on the time required to complete the different activities (i.e., reading emails, looking at materials, formulating responses, and responding via email).

Recognising and respecting that it may take individuals different periods of time to complete activities is important for informing future research. The method of payment was negotiated with the autistic experts. The autistic experts co-designed the definition and search protocol, interpreted the findings, contributed to the collating of the results, and provided feedback on the final report and dissemination materials.

In addition, three autistic researchers (Lee Patrick, Chanelle Moriah, Yixuan Liu) were part of the research team and contributed throughout the project. They co-designed the definition and search protocol (LP, CM), reviewed the studies (LP, CM), evaluated the quality of the studies (YL), interpreted the findings (LP) and prepared the dissemination materials (LP, CM).

### **2.2.2 Autism community organisations**

Autism community engagement was an essential component throughout this project. An EOI was sent to four Autism CRC affiliates and two external organisations. The organisations were selected based on their work supporting autistic individuals with complex support and/or communication needs and their families. Two affiliates (Children's Health Queensland and Reframing Autism) and two external organisations (Giant Steps and Sycamore School) were selected based on their availability and willingness to participate in the project. They received honorariums as third parties.

Throughout the project a range of different communication methods were used, depending on availability of the advisory group (made up of people from the autistic and autism communities) and research team and the types of actions required. For example, Microsoft Teams meetings were used to discuss the project, define the research questions, and discuss and resolve issues arising in the project. Email was used to provide the group with updates and when summary documents required feedback and recommendations.

## 2.3 How we did it

### 2.3.1 Developing a systematic review protocol

The systematic review protocol details the plan for the systematic review. Once agreed upon, the protocol should be registered on a public register prior to the review being commenced.

This enhances the integrity of the work by promoting transparency, helping to reduce potential for bias and reducing the risk of unintended duplication of reviews. The protocol for this study was registered with the international prospective register of systemic reviews: “Whose voice is heard, and whose is missing, in research exploring quality of life and wellbeing of autistic individuals: A systematic review” (PROSPERO, 2022, CRD42022385357; see Appendix C).

A key component of developing the research protocol was identifying search terms to describe autistic individuals who have complex support and/or communication needs. We wanted to ensure that the review was comprehensive and that it captured autistic people who may be reported as a subgroup of participants in a broader study (e.g., quality of life in non-speaking people). The autistic experts shared words they would use to describe themselves, and words others used to describe them. These terms were included in the search terms. In addition, terms were identified by the autistic researchers, advisory group, and research team. Further, to ensure the search terms encompassed the broad range of autistic viewpoints, a post on the Autism Centre of Excellence, Griffith University Facebook page invited people to contribute their ideas of relevant terms.

The search terms were trialled with four databases. The terms were refined and then included in the protocol. The protocol was developed to align with the project and the research objectives outlined and distributed to the end-users and research team members via email for feedback. An area of concern raised in the feedback was the large number of results that would be generated using the umbrella terms for co-occurring conditions, and whether this would be feasible. This concern is acknowledged; however, to align with the project aims (i.e., to identify information on autistic individuals under-reported in the research) it was considered that these terms were important to include. Search parameters (i.e., inclusion and exclusion criteria) were determined by the advisory group and research team. The Principal Leader and Co-Investigator finalised the proposal.

### 2.3.2 Finding the relevant studies

Four databases covering a broad range of disciplines relevant to autism research were searched using the co-produced agreed terms from the protocol. Following the removal of duplicates, 36,458 records were identified for initial screening. This is an exceptionally large data search result compared to previous reviews conducted on autism and quality of life and/or wellbeing (e.g., Ikeda et al., 2014: 10,991 records; Sáez-Suanes & Alvarez-Couto, 2021: 1,009 records). The identification of the large number of records was due to the inclusion of quality of life and/or wellbeing as search terms, quantitative and qualitative research, the lifespan focus, and the broad and general terms used to maximise the potential to encompass autistic individuals who may be reported as a subgroup within studies focusing on other conditions.

Records were screened by a team of autistic and non-autistic researchers. This was led by the team from Griffith University, and reliability at each stage of the screening process was led by the team from Autism New Zealand. Instructions were provided detailing the inclusion and exclusion criteria. The instructions were developed within the team, tested, and clarified to improve reliability.

A systematic screening process was conducted at the title and abstract level and at full-text level. Key reasons for exclusion were as follows:

1. studies did not report on original research,
2. studies were on quality of life and/or wellbeing of another person connected to the autistic individual (e.g., parents, siblings, professionals), or
3. studies reported on another condition (e.g., people with developmental disabilities, intellectual impairments, psychological disorder) but did not report separately on the autistic people.

Due to the intersectionality between autism and other conditions, we felt it was important that the autistic perspective was reported separately as it could not be assumed their experiences were the same as the collective group. There were 38 studies that could not be retrieved through the standard methods. Requests have been made to obtain copies of these studies through Griffith University library services and directly from the authors via the ResearchGate online researcher social media platform.

### **2.3.3 Finding the key information**

To extract the data in a systematic way, a data extraction template was co-produced with the autistic experts, autism community, and research team. This co-production process helped to ensure that relevant data were extracted from the studies to answer the research questions. The data extraction template (see Appendix D) was tested and populated in Covidence (an online systematic review tool). Data collected included general information about the study (location, year, involvement of the autistic community, method of data collection), description of participants (who is reporting, who is being reported on), and key findings on quality of life and/or wellbeing. A list of included studies is in Appendix E.



## 3. What we found

### 3.1 General information about the studies

A community report summarising the project and findings can be found in Appendix G.

We found 236 studies that reported on quality of life and/or wellbeing of at least one autistic person. Studies were predominantly located in the United States (33.1%), United Kingdom

(14.8%), Australia (10.2%), the Netherlands (6.3%), and Canada (5.5%). One study was conducted in New Zealand. The studies were published between 1998 and 2023. Over 50% of the studies were published in the last 5 years. Less than 10% were published prior to 2010.

#### 3.1.1 Description of autistic people

##### 3.1.1.1 Number of autistic people

The number of autistic individuals reported on in each study ranged from 1 (i.e. a case study consisting of one autistic person) through to almost 5,000 (i.e. large database samples). The total number of autistic people reported on was almost 50,000.

##### 3.1.1.2 Age and gender

The quality of life and/or wellbeing was reported on autistic individuals across the lifespan (age range 3–83 years). Gender was reported for the autistic individuals in 84% of the studies. Binary gender was most frequently reported, with proportionally more males than females, consistent with reported ratios (Loomes et al., 2017). Fourteen studies investigated the quality of life and/or wellbeing in males only, and six studies in females only. Twenty-two studies (9%) identified gender diverse individuals, with one study specifically exploring quality of life in this population.

##### 3.1.1.3 Co-occurring conditions

More than half the studies included autistic people with co-occurring conditions. Almost one third of the studies made no reference to the autistic person having any co-occurring conditions.

Participants with co-occurring conditions were actively excluded from participating in the research in over 10% of the studies. Predominantly, they were excluded if their IQ was below average; however, in a small number of studies, people were also excluded if they had psychiatric, neurological, motor, genetic, or learning conditions.

## 3.2 What aspects of quality of life and wellbeing were reported on

Quality of life and wellbeing are complex concepts, with multiple definitions used across different studies. Within the 236 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 Organization, 1996, p. 3)
- “A multi-element framework, including domains of interpersonal relationships, social inclusion, personal development, physical wellbeing, material wellbeing, emotional wellbeing, and rights.” (Schalock, 2004, p. 205)

Overall, the most common factors being measured by quality of life and wellbeing research were physical wellbeing, emotional wellbeing, personal development, material wellbeing, self-determination, social inclusion, interpersonal relationships, and rights. Although these are universal domains identified in terms of quality of life and wellbeing, there has been emerging evidence suggesting that autistic people’s conceptions of quality of life and wellbeing may differ from these definitions, with other areas being more salient (Milbourn et al., 2022; Reframing Autism videos).

These perspectives are reflected in the move to create more autism-specific measures of quality of life and wellbeing. The inclusion of autism-specific measures occurred in less than 5% of the studies. One example of such measures is the ASQoL. This is a nine-question add-on intended to be used along with a more general quality of life measure. It covers support in making decisions and dealing with problems; barriers to health services and within official situations like work or benefit offices; financial security; satisfaction with friendships; sensory issues; being yourself around others; and being at ease with autism as part of the individual’s identity. A second example is the Quality of Life for Children with Autism Spectrum Disorder measure (QOLASD\_C), a measure that includes three domains of functioning viewed as pertinent for autistic children: interpersonal relationships, self-determination, and emotional wellbeing.

## 3.3 Who and how is quality of life and wellbeing measured

The focus of this work was on quality of life and/or wellbeing of autistic people with complex support and/or communication needs. For the purpose of this work, ***autistic people with complex support and/or communication needs were those who have at least one co-occurring condition (e.g., physical, intellectual, psychiatric, sensory, neurological, or learning disability).***

The studies were categorised based upon who provided the information on the autistic person’s quality of life. The three categories are:

- Proxy informants; described in section 4.3.1. In 83 studies, the quality of life and/or wellbeing of autistic people were reported by others (e.g., parent/caregiver, professionals). These included studies where proxy informants reported on the quality of life and/or wellbeing of autistic people with complex support and/or communication needs.
- Autistic informants with no reported complex support and/or communication needs; described in section 4.3.2. included 72 studies. These studies included at least one autistic person as an informant.

- Autistic people with complex support and/or communication needs; described in section 4.3.3. In 80 studies, at least one autistic person with complex support and/or communication needs was included as an informant. This section has been written as a white paper that can be extracted from this document.

The proportion of studies categorised under each heading is displayed in Figure 1. An autistic person self-reported in at least two-thirds of the studies. In one study, the data were extracted from measures completed in a database. The informant type was not reported and, therefore, this study is not included in this breakdown.

**Figure 1: Proportion of studies categorised under each informant**



### 3.3.1 Proxy informants

Of the 236 studies that met the inclusion criteria, in 83 (33.9%) the quality of life or wellbeing of autistic individuals was reported solely by proxy informants (e.g., parent/caregiver, professionals). The results for methods used and the description of the autistic population in these studies are reported in this section.

Only three of these 83 studies reported on community involvement. The community involvement contributed to the development and refinement of interview/survey questions, and provided feedback on the study invitation, instructions, and formatting of the survey to ensure usability, functionality, and interpretations of the findings.

#### 3.1.3.1 Whose quality of life/wellbeing is reported on by proxy informants

Most studies using proxy informants reported on the quality of life and/or wellbeing of autistic children or adolescents (see Table 1). In almost half of the studies the autistic person’s cognitive, language, and adaptive functioning, or co-occurring conditions, were reported. In three studies, co-occurring conditions were identified in the exclusion criteria for autistic children. In the studies that identified co-occurring conditions, the proxy informant reported on autistic adults with intellectual impairment nearly half the time. In contrast the proxy informant tended to report on children who had a range of co-occurring conditions.

**Table 1: Proxy informants***Description of whose quality of life or wellbeing was reported using proxy informants*

Condition	Total studies n = 83 % (n)	Children (Age < 18 years) n = 70 % (n)	Adults (Age > 18 years) n = 9 % (n)	Children and adults n = 4 % (n)
Multiple conditions	26.5% (22)	28.6% (20)	22.2% (2)	--
Intellectual impairment	13.3% (11)	8.5% (6)	44.4% (4)	25% (1)
Genetic conditions	1.2% (1)	1.4% (1)	--	--
Psychiatric conditions	1.2% (1)	1.4% (1)	--	--
Neurodevelopmental conditions	1.2% (1)	1.4% (1)	--	--
Cooccurring conditions excluded	3.6% (3)	4.2% (3)	--	--
Not reported	53.0% (44)	54.3% (38)	33.3% (3)	75% (3)

### 3.1.3.2 What methods were used to collect information on autistic people's quality of life/wellbeing from proxy informants

The methods used for proxy reporting on quality of life/wellbeing are summarised in Table 2. In 94.0% of these studies, data was collected using questionnaire(s)/survey(s) that were completed online, in writing, or during an interview. The predominance of questionnaire(s)/survey(s) as a method of data collection was evident across age groups.

**Table 2: Methods of data collection***Description of methods of data collection used by proxy informants*

Condition	Total studies n = 83 %(n)	Children (Mage < 18 years) n = 70 % (n)	Adults (Mage > 18 years) n = 9 % (n)	Children and adults n = 4 % (n)
Questionnaire(s)/survey(s)/closed question interviews	90.4% (75)	92.8% (65)	66.7% (6)	100% (4)
Questionnaire(s)/survey(s)/closed question interviews + observation	1.2% (1)	--	11.1% (1)	--
Questionnaire(s)/survey(s)/closed question interviews + semi-structured interviews	2.4% (2)	1.4% (1)	11.1% (1)	--
Semi-structured interview-social media messaging	6.0% (5)	5.7% (4)	11.1% (1)	--

**3.1.3.3 Questionnaire/survey/closed question interviews**

Thirty-six different measures were reported in the studies, with nearly 90% of these identified as measuring the autistic person’s quality of life. The PedsQL was the most frequently used measure across the studies. Twenty-seven of the measures were reported in one study only; seven studies included a survey or survey items developed for the specific study; and four studies extracted item data on quality of life and/or wellbeing from a broader survey.

Of the measures used, three have been designed to measure the quality of life of autistic people. The Quality of Life for Children with Autism Spectrum Disorder (QOLASD\_C; Cholesicki et al., 2019) was used in four studies which reported on the development of the measure and investigated the psychometrics of the instrument.

Both the Caregiver Evaluation of Quality of Life Scales (CEQOL; Brown, 2019) and the Caregiver-completed Evaluation of Quality of Life (CEQOL-II; Yetenekian, 2019) were developed as part of doctoral dissertations as a caregiver-reported quality of life measure for children on the autism spectrum. The CEQOL-II is a revised version of the unpublished CEQOL measure.

**3.1.3.4 Semi-structured interviews**

In seven studies, semi-structured interviews were conducted with parents/caregivers to obtain their views of the quality of life and/or wellbeing of autistic people, focusing predominantly on children. In two studies, semi-structured interviews were used in addition to a questionnaire or survey measure. Three studies provided the interview question protocol or example questions, and one study indicated that this could be obtained from the authors.

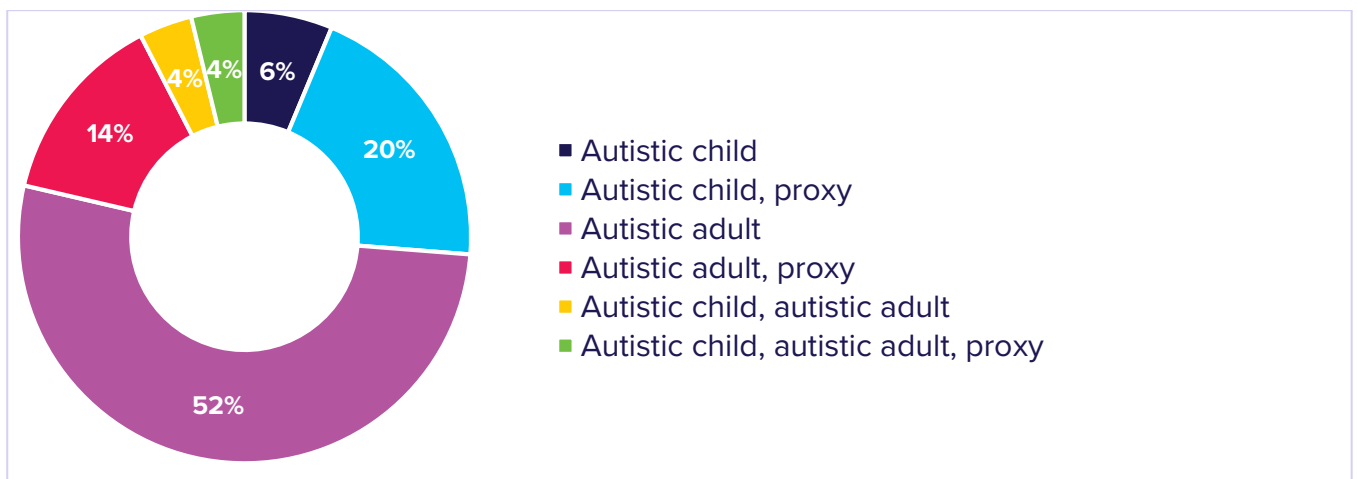
### 3.3.2 Autistic informants with no reported complex support and/or communication needs

Within the 236 studies, 72 involved autistic informants who were **not** identified as having a complex support and/or communication need. Most (89%) of these studies did not provide information on the autistic informants' co-occurring conditions. We acknowledge that some of these people may experience complex support and/or communication needs; however, as the presence or absence of complex support and/or communication needs was not reported in 65 of these studies, we could not confirm if this was the case. Only seven studies explicitly specified that the autistic informants did not have co-occurring conditions, or that autistic informants were excluded if they had a co-occurring condition.

#### 3.2.3.1 Who were the informants

In most cases, the quality of life and or wellbeing of autistic people with no reported co-occurring condition/s were self-reported, with less than one third of the studies including an additional informant (i.e., parent/caregiver). Two thirds of the studies included the perspectives of autistic adults and less than 10% included autistic children as sole informants.

**Figure 2: Proportion of studies categorised under each informant**





### **3.2.3.2 What methods were used to collect information on the quality of life and/or wellbeing of autistic people with no reported complex support and/or communication needs?**

#### **Questionnaire/survey/closed question interviews**

Over 40 different referenced measures were reported in the studies. Of these measures, 31 were used once. In addition, another six questionnaire/survey measures were developed by the research team and used solely in their studies. The majority (70%) were measures of quality of life. The WHOQOL-BREF assessment (The WHOQOL Group, 1998), was the most frequently used measure but was used in less than 20% of the studies. Several studies used multiple measures to provide a comprehensive overview of the autistic person's quality and life and their wellbeing. For example, Hosozawa et al. (2021) used four scales to capture the components they defined as psychological wellbeing (i.e., happiness, self-esteem, mood, self-harming behaviours).

Of the measures used, one (ASQoL; McConachie et al., 2018) had been designed to measure the quality of life of autistic people and was used in two studies with autistic adults with no co-occurring conditions. This measure is designed to be used alongside the WHOQOL-BREF (The WHOQOL Group, 1998). These studies investigated the development and assessment of the measure.

#### **Semi-structured interviews and focus groups**

Of the 72 studies that included autistic informants who were not identified as having complex support and/or communication needs, 19 used semi-structured interviews and one included focus groups. Most semi-structured interviews were conducted with autistic adults. Five studies incorporated photos provided by the autistic person. Drawings were also incorporated into one study conducted with autistic children.

### **3.2.3.3 Designing consultation methods for research studies to be inclusive**

#### **Adaptations and accommodations to the data collection process**

One third of the 72 studies described approaches offered to support the autistic person expressing their viewpoint on the questionnaires/surveys. In three studies, proxy respondents were allowed, with parents able to respond if their child was unable to answer the questions. In addition, supports were provided, such as having a support person present, rewording the questions for clarity, providing visual supports or picture response formats, checking explicitly to ensure the autistic person was provided a safe and supportive environment (particularly to address any sensory needs), and providing breaks during the research data collection. The use of alternate methods of completing the questionnaires/surveys and participating in the interviews was also identified, including responding by text message, email, or telephone, and the use of a timer in the focus group to ensure everyone had a turn to contribute.

#### **Community involvement to ensure respectful and relevant research**

Ten studies (of the 72 studies reported on within this category) identified some level of community involvement. Community involvement mostly consisted of providing feedback on the wording of questions or the selection of the type of measures to be used and development of the methods employed. Two studies identified community involvement across each stage of the research study. In one study this involved working with a community partner; in the other study, autistic young adults were an integral part of the decision-making throughout each stage of the project.

### **3.2.3.4 Recruiting methods**

Recruitment was conducted through multiple avenues. Community and service organisations, clinics, and education settings were most frequently used as an avenue for advertising the studies. In 30% of the studies, recruitment occurred through existing or previous studies and through database registries.

### **Adjusting the voluntary and informed consent process**

Only four studies specified the processes undertaken to ensure that the participants could make an informed decision. This involved an orientation session to introduce the researcher and research activities, the researcher explaining the aims and ethical considerations at the beginning of the study, and the provision of information sheets that used easy words and pictures.

The remaining studies stated that informed consent was provided by (a) a parent on behalf of the autistic person, (b) parent and the autistic person, or (c) the autistic person. Consent was provided in the form of verbal consent, written consent, or ticking a box on an online form. In two studies, ongoing consent was obtained across the study and was described in one study as passive consent (i.e., not indicating refusal to participate).

# Designing research studies to be inclusive for autistic people with complex support and/or communication needs

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## White paper

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## The context

Autism is a spectrum condition. 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 from a “norm” of typical development. Some autistic people may need significant help with their day to day lives, especially if they have additional co-occurring conditions, while others may need little or no help. The level of support may fluctuate depending on the autistic person and their environment and may change within different contexts and over time. Although there is great diversity in how each person experiences their autistic neurology, the recent Select Committee on Autism (2022) drew upon accounts from autistic people and the autism community with a wide range of strengths and support needs to conclude that educational, employment, health, and wellbeing outcomes for autistic Australians are “unacceptably poor”. Moreover, autistic individuals with *complex support and/or communication needs* (i.e., those who have at least one co-occurring condition, e.g., physical, intellectual, psychiatric, sensory, neurological, or learning disability) are likely to have even poorer quality of life and wellbeing outcomes, due to more frequent and/or more significant barriers to education, community, and work inclusion.

We agree with the Select Committee on Autism that this is unacceptable. Every single person should have the opportunity for good quality of life and wellbeing. If a person’s quality of life is poor, the Convention on the Rights of Persons with Disabilities recommends providing “reasonable accommodation” to ensure each person can enjoy their rights on an equal basis with others. However, providing reasonable accommodations requires an in-depth understanding of factors that can improve or reduce wellbeing and quality of life in autistic individuals. Given that autism is a spectrum condition, it is important that this in-depth understanding considers factors that influence the wellbeing or quality of life of autistic people with different strengths and different support needs. Unfortunately, autistic people with complex support and/or communication needs, especially autistic individuals who are non-speaking and/or have a co-occurring intellectual disability, are poorly represented in the research literature about autistic wellbeing. Autistic people with complex support and/or communication needs have a right to quality of life and wellbeing and have experiences to share that can advance our understanding in this area, ensuring “Nothing about us, without us”. It is vital to address unacceptably low quality of life reported in this population. To achieve this requires a commitment to providing ways that autistic people with complex communication and/or complex support needs can share these experiences with us.

## The issue

While there has been a significant increase in the amount of research funded and published internationally on autism over time (den Houting & Pellicano, 2019; Sweileh et al., 2016), the vast majority of autism research reports on individuals without intellectual disabilities or complex support/communication needs (e.g., Russell et al., 2019; Stedman et al., 2019). For example, Russell et al. (2019) reported that only 6% of studies they reviewed included autistic people with an intellectual disability. Furthermore, most research does not focus on autistic wellbeing or quality of life, with the majority of research concentrating on biology, causes, and genetics (e.g., den Houting & Pellicano, 2019). Those studies that do focus on autistic wellbeing and quality of life rarely include the voices, experiences, or desires of the full spectrum of the autistic community. This means that, at worst, we may be relying on research informed by non-autistic people, and at best on autistic people without complex support and/or communication needs to understand the factors that impact on the quality of life and wellbeing of autistic people with complex support and/or communication needs.

The voices of autistic people with complex support and/or communication needs is largely absent from research that is focused on them. For this to change, we need to address **this issue**:

How can we proactively design research and consultations that are accessible and inclusive for autistic individuals with complex support/communication needs?

This document addresses this issue by:

- Describing methods that have been successfully used in research to gain the perspectives of autistic individuals with complex support/communication needs on their wellbeing or quality of life.
- Providing recommendations for developing research and community consultation methods which increase the opportunities for autistic people with complex support and/or communication needs to share their perspectives.

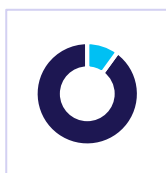
## Estimating the scale of the issue

A comprehensive search of the academic research published in the last 25 years identified 236 studies reporting on the quality of life or wellbeing of autistic people. We looked at every single study to see how it reported on the quality of life or wellbeing of autistic people with complex support and/or communication needs. As there is no widely accepted definition of complex support needs or complex communication needs, we co-developed a definition with the autistic and autism communities. This was: autistic people with complex care, support and/or communication needs, and/or the presence of co-occurring conditions (e.g., physical, intellectual, psychiatric, sensory, neurological, or learning disability). To put this in context, Soke et al. (2018) reported that 95% of autistic children have at least one co-occurring condition.

We found that:



Even using our broad definition of complex support and/or communication needs, **approximately one third of studies only (34%) included the perspectives of at least one autistic person with complex support and/or communication needs.**



**One in 10 studies specifically excluded** individuals with an intellectual disability from taking part in their research.



## **Current solutions used in research to address the issue of ensuring autistic people with complex support and/or communication needs can share their perspectives or experience**

In this section, we describe the methods used to date by research studies to promote the inclusion of autistic people with complex support and/or communication needs in their studies.

### **Designing Consultation Methods for Research Studies to be Inclusive**

#### **Community Involvement to Ensure Respectful and Relevant Research**

Only 5% of these studies included some level of autistic community involvement. This community involvement comprised of autistic people, community members, and/or autistic researchers contributing to the research beyond being participants in the research. In three studies the autistic community was involved throughout the study from the design of the research through to reporting the results. In the remaining studies, the level of community involvement varied. For example, in one study it was limited to consultation on the design of the study prior to ethical approval; in another study, autistic people were asked to provide feedback on language used in the information forms and questionnaires to ensure it was respectful and understandable; one study asked autistic people what adaptations they required to complete the questionnaire. Five studies included an autistic person as part of the research team and in three of these studies the autistic researcher contributed to the data analyses.

#### **Recruiting Methods That are Accessible**

To ensure autistic people with complex support and/or communication needs are included in research about them, it is key that they are aware of the research being conducted. Email, mailouts, and posters (electronic, hard-copy, easy read) were distributed using a range of contact methods. These included:

- Service and community agencies
- Education organisations
- Existing research projects
- Databases and registers
- Social media

#### **Adjusting the Voluntary and Informed Consent Process**

Research conducted with people requires clearance through Human Research Ethics Committees to ensure the approaches used are ethically acceptable. A key ethical consideration of every study is ensuring that the people participating in the research have informed knowledge of what they will be required to do, of their right to withdraw at any stage, and that they understand what will happen to any information collected during the project. The language used in documents approved by ethics committees may not be easily accessible for children, people with an intellectual disability, or people with complex communication needs. As a result, usually another person, often a parent/caregiver, will provide informed consent and the autistic person will provide assent. To ensure that the autistic person still had a say in whether or not they wanted to take part in the study, a number of studies made adaptations to the process. These included:

- Providing information about the research in an easy-to-read format
- Allowing consent through a person's preferred methods/modalities of communication, e.g., written, spoken, or communication through an AAC device/iPad or light-tech communication aid
- Relying on continued behavioural assent (e.g., observing to assess if the person taking part in the research is willing to participate)

## **Taking a Flexible, Individualised Approach to Data Collection**

Of the studies that included autistic informants with co-occurring conditions, less than one third reported on ways that they made adaptations to the study process to make it more accessible to autistic people with complex support and/or communication needs. The importance of a flexible, individualised approach with autistic people was also highlighted in some studies. Examples are:

- Allowing participants to prepare and practice: providing interview questions or practice questions in advance
- Designing questions to accommodate the communication styles and preferences of autistic people with complex support and/or communication needs. This can be achieved by rephrasing questions or giving additional explanation to ensure the questions are understood and clear; designing questionnaires for different levels of difficulty (e.g., Level 1 contained "yes/no" questions, to more complex questions); adapting response formats such as using visual symbols, pictures, and/or a visual scale based on facial expressions to facilitate responding; using flexible wording with pictorial responses; providing a range of formats for the information to be provided (e.g., face-to-face, online, providing written response, selecting pictures from the internet, photos, or drawings); minimal use of open-ended questions; questions read out to the autistic person; having the option of a support person to provide assistance with the interpretation of the questions, to be a communication partner OR support person; allowing respondents to return to previous pages in a survey to change answers
- Changes to structure of information gathering: allowing time to build rapport; ensuring frequent breaks between tasks and allowing time and space for sensory, behavioural, or communicative differences and considering individual needs and preferences; noise reduction and soft lighting; providing the opportunity to complete a survey over multiple sittings or unlimited time; and allowing the autistic person the opportunity to select the location and time to take part in the research.

## **Selecting Methods That Allow Autistic People with Complex Support and/or Communication Needs to Share Their Perspectives and Experiences**

The 80 studies that included autistic people with complex support and/or communication needs used four different ways to gather their perspectives. Predominantly questionnaires/surveys, that were not developed with and for the autistic population, were used to compare quality of life or wellbeing outcomes of autistic people with others, or to identify predictors of these outcomes.

Furthermore, not all these methods will be relevant for all autistic people with complex support and/or communication needs to share their experiences or thoughts on wellbeing and quality of life. Each is described in the Table 1 with some perceived strengths and limitations that were highlighted in the studies and discussed by our advisory group and autistic experts.

**Table 1. Summary of advantages and disadvantages of methods reported in the studies**

Method	Advantages	Disadvantages
<p><b>Questionnaire, surveys, closed question interviews</b></p> <ul style="list-style-type: none"> <li>Reported in 86.6% of the studies</li> </ul>	<ul style="list-style-type: none"> <li>Answers can be provided without spoken language</li> <li>Respondent may be able to complete the activity within their preferred surroundings (e.g. at home)</li> <li>Less time limits to complete the activity</li> </ul>	<ul style="list-style-type: none"> <li>Most measures are not specifically designed for autistic people</li> <li>Over 40 different measures identified with no measures designed for autistic people with complex support and/or communication needs</li> <li>Difficult to compare similarities and differences in findings across studies due to wide range of measures used</li> <li>A person's response is limited to the items listed on the questionnaire/survey</li> <li>Requires sufficient language and literacy skills to read and/or comprehend the questions and provide a response using the designated scale</li> </ul>
<p><b>Semi-structured interviews, focus groups</b></p> <ul style="list-style-type: none"> <li>Reported in 15.5% of the studies</li> </ul>	<ul style="list-style-type: none"> <li>The autistic person can discuss issues that are relevant and meaningful to them</li> <li>A diversity of perspectives can be reported</li> <li>Flexibility in how the participant can provide their responses</li> </ul>	<ul style="list-style-type: none"> <li>Discussions are limited by the interview guide/focus group topics</li> <li>The autistic person's experiences are interpreted by others (this can be mitigated if autistic people are included actively in the data analysis process)</li> <li>May not allow for participation of autistics who cannot access comprehensive AAC and/or have limited language output, through speech or other modalities of communication</li> <li>Marginalised and individuals who have experienced trauma are less likely to open up honestly with a stranger</li> </ul>
<p><b>Blog review (reviewing material already written and publicly available)</b></p> <ul style="list-style-type: none"> <li>Reported in 1.2% of the studies</li> </ul>	<ul style="list-style-type: none"> <li>The autistic person can express their views on issues that are important to them</li> </ul>	<ul style="list-style-type: none"> <li>Only includes the perspectives of those that have the language, literacy and digital literacy skills to share and resources available to them to post about their experiences</li> <li>Identifying blogs that are authentically written by an autistic person</li> <li>May be difficult for clarification and further elaboration of the information</li> </ul>
<p><b>Photovoice (modified technique)</b></p> <ul style="list-style-type: none"> <li>Reported in 2.4% of the studies</li> </ul>	<ul style="list-style-type: none"> <li>The informant can choose to take photos of things that are important and relevant to them</li> <li>Images from the web/existing photos can be used</li> <li>Support can be tailored to each informant</li> <li>Discussions can be tailored to each informant</li> <li>Discussions regarding images can be conducted with individual informants</li> </ul>	<ul style="list-style-type: none"> <li>Participant needs to be able to understand concepts of acceptable and non-acceptable images</li> <li>Resource requirements e.g. camera</li> <li>Discussion/use may be limited by communication ability</li> </ul>

Note: Total percentage is > 100 as a small number of studies included both questionnaires and semi-structured interviews.

## Limitations

The focus of this project was on autistic people with complex support and/or communication needs. In the discussions among the research team, the autistic advisory group, and autistic experts, it became apparent early in the project that there was no agreed definition to describe this group. As a group we found it challenging to develop an agreed definition due to the impact that context may have on the need for complex support for autistic people. As a result, a broad definition was adopted for screening based on reported co-occurring conditions. We acknowledge this as a limitation as it required the autistic person to be asked about and to report on any co-occurring conditions, and not every autistic person with one co-occurring condition may perceive themselves as demonstrating complex support and/or communication needs. It also makes assumptions; not every autistic person with a co-occurring condition would describe or perceive themselves as having complex support or communication needs. Over 30% of the 236 studies did not report if the autistic informant had a co-occurring condition. It may well be that this group did include autistic people who had complex support and/or communication needs; because of the project's parameters, their data were not incorporated in this white paper.

Studies that focused on a particular group (e.g., intellectual impairment, non-speaking participants) may have included autistic people but did not report this in their article. Because of the focus of this work, we had to exclude studies that did not explicitly state that at least one of their participants was autistic. This decision was made as it cannot be assumed that a non-speaking non-autistic person would have the same experiences as a non-speaking autistic person. As a result, some autistic people with complex support and/or communication needs may not have been included in this report.

This project was viewed as a foundational step to inform future research in this area. To accomplish this, the search of the literature was restricted to published research papers. However, it is recognised that the current methods of conducting research may exclude the participation of autistic people who have complex support and/or communication needs. We also recognise that autistic people who have complex support and/or communication needs may express their opinions about their quality of life and wellbeing through other forums and methods (e.g., blogs, books) that were not captured in this project.

We specifically used the terms “quality of life” and “wellbeing” in our search of the literature. Although this yielded 236 studies, studies that used other terms associated with quality of life and wellbeing (e.g., thriving, having a good life, happiness) were not included. As a result, studies providing a more nuanced approach to an autistic person's quality of life and/or wellbeing may have been excluded.

# Implications for research and practice

The findings from this project highlight a number of implications for both research and practice:

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 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 standard for 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 part 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 allows the time and funds that inclusive, co-produced research demands, including building skills of researchers in co-production methodologies.
6. An agreed definition (e.g., Delphi) for complex communication and support needs should be developed in the field to inform communication, research, and practice moving forward. This definition should be co-developed with autistic people.

## Key recommendations

Incorporating the approaches reported in the previous research, as described and critiqued above (Table 1), the following recommendations are made based on consultation between members of the autistic and autism communities and our research team to address the issue.

- There is no single way to conduct inclusive research. Each study will require specific considerations as to how to break down the barriers to participating for autistic people with complex support and/or communication needs. Researchers need to start with the mindset of presuming competence within participants. With that mindset, the onus is on researchers to consider participant group preferences and to co-develop methods to enable participation. This is a different mindset and approach from the more traditional way of starting with researcher preferences and presuming a lack of competence if participants are not able to participate in or respond to such methods.
- Ensure that each research or consultation (from initial conception through to analysis and dissemination) is in genuine collaboration with autistic and where relevant autism community partners. This co-production should be intrinsic to every part of a study and should preferably be with people who themselves have complex communication and/or support needs to ensure a relational ethics of care. All those who contribute to the co-production need to be paid with fair compensation (as opposed to “token” compensation that does not acknowledge time and expertise) and to be able to contribute in their own preferred way. This does not mean that one autistic researcher or collaborator or partner needs to do “all” jobs in co-production: paying some autistic people to comment on a lay abstract, or to contribute to knowledge translation, or to refine an interview schedule even if they don’t have capacity to commit to a complete project, is absolutely valid (perhaps more so) in terms of fulfilling co-production principles
- To be inclusive of those with complex support and/or communication needs, research or consultations need to offer flexibility of presentation, time, processing, and response for each step (i.e., everything from recruitment, to distribution of questions, to collection of data is done with flexibility, choice, and individualisation, and with best practice accessibility principles). For example:
- Quantitative data collection (typically through questionnaires or surveys that are analysed and reported statistically). This may include allowing participants to have the option of reading additional context around the questions, having an audio recording of someone reading the questions, having someone available to clarify or simplify the questions, allowing flexibility in being able to complete the measure over time, providing alternate modes to indicate a response, or the option to provide additional notes in case someone wants to further explain their answers.
  - Qualitative data collection (typically semi-structured interviews, focus groups providing descriptions of a person’s experience). This may include providing an Easy Language summary in the person’s preferred language spoken at home that is distributed prior to any engagement, introducing the researcher and the questions to be asked. There is also a need to offer participants choice in how they would like to respond, even within an interview, so that they can answer each question in a way that works for them. This might include written words, images, artworks, or poems, either instead of or as well as verbal answers. The data collection process needs to be set up so that these different methods

can be used with ease (e.g., if using videoconference, having the chat box and screen share proactively enabled, having a private video channel link set up so people can upload videos, completing the interview with a trusted communication partner rather than a researcher). Allowing flexibility with timing of data collection allow for fluctuations in day-to-day functioning and capacity.

- Co-production will help researchers or those running consultations to identify methods and measures which are relevant and appropriate for the participant group. This includes developing recruitment methods that are accessible to autistic people with complex communication and/or support needs. Before asking autistic individuals with complex support and/or communication needs to complete any measure, it is important to evaluate whether that measure is accurate and meaningful for autistic individuals with those needs. For example, with reference to the topic of the review in this white paper, can a small number of items on a questionnaire designed for neurotypical individuals accurately measure the entirety of “quality of life” in autistic people with complex support and/or communication needs? Question length, answer options, complexity of language, and the environment in which the participant is participating all need to be considered in relation to participant preferences and needs.
- To enable all the above points, there needs to be a strategic investment in research that allows the time and funds that inclusive, co-produced research requires, including building researchers’ capacity in co-production methodologies. This is essential to ensure that autistic people with complex communication and/or support needs have the human right for a say in decisions that impact them, with good quality of life and wellbeing key areas of national importance.
- Researchers can collaborate to facilitate the inclusion of autistic individuals with complex communication and/or support needs through sharing resources. Such initiatives can occur through some country-specific funders such as Autistica who have a “Complex Needs Study Group” (<https://www.autistica.org.uk/get-involved/take-part-in-research/autism-study-groups/complex-needs-study-group>). Ideally, such study groups should be led by autistic people, preferably those with complex support and/or communication needs. This could lead to the development of guidelines for research with autistic people with complex communication and/or support needs and identification of strengths and limitations of alternative data collection methods for particular users.



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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



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