

# 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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June 2023



# Designing Research Studies to be Inclusive for Autistic People with Complex Support and/or Communication Needs, White Paper

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**ISBN:** 978-1-922365-57-6

**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). *Designing Research Studies to be Inclusive for Autistic People with Complex Support and/or Communication Needs, White Paper*. Autism CRC, Brisbane.

This white paper is included in the *Quality of life and wellbeing of autistic individuals with complex support and/or communication needs* Final Report that can be downloaded from the Autism CRC website [autismcrc.com.au](https://autismcrc.com.au).

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# 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.

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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'.

## 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 well-being 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 well-being 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 well-being. 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 well-being 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 well-being 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 well-being. Autistic people with complex support and/or communication needs have a right to quality of life and well-being 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 well-being 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 well-being 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 well-being 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 well-being 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.

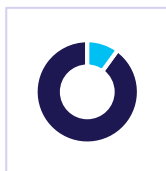
## Estimating the scale of the issue

A comprehensive search of the academic research published in the last 25 years identified 236 studies reporting on the quality of life or well-being of autistic people. We looked at every single study to see how it reported on the quality of life or well-being 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 was achieved by rephrasing questions or giving additional explanation to ensure the questions were 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 to be support; 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 taking into account 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 well-being 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 well-being 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 well-being 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 “well-being” in our search of the literature. Although this yielded 236 studies, studies that used other terms associated with quality of life and well-being (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 well-being 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 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 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 well-being 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.

## Our values



### **Inclusion**

Valuing lived experience



### **Innovation**

Solutions for long term challenges



### **Evidence**

Truth in practice



### **Independence**

Integrity through autonomy



### **Cooperation**

Capturing opportunities together



# AutismCRC

Independent national source of evidence for best practice



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