

OPINION, VIEWPOINT

Why it is critical to assess quality of life in people with autism

BY LAURA GRAHAM HOLMES, JUDITH MILLER

2 JUNE 2020

Who decides what it means to live ‘the good life’? According to the **World Health Organization**, we get to decide for ourselves. It defines ‘quality of life’ as “an individual’s perception of their position in life” in the context of their own culture, values, goals and standards.

It should be no different for people with autism, yet there is little research about how to assess quality of life in this population. A decade ago, autistic policy adviser **Scott Michael Robertson** asked researchers to focus more on helping neurodiverse people overcome barriers to life satisfaction¹. Autistic self-advocates and their families, too, have called for more investment in this topic². By focusing on quality of life, researchers can better support autistic people and evaluate treatments and outcomes more meaningfully.

As a first step, researchers and clinicians need brief, accessible and validated tools to measure quality of life in autistic people of all ages. One approach is to create a tool from scratch. In 2018, for example, researchers tested the World Health Organization’s **quality-of-life disability module** with autistic adults and, based on input from those adults, created a new autism module³.

Our team took the opposite approach. We adapted a measure designed for the general population and tested it with autistic children and adults of various ages. This approach makes it possible to compare quality of life between people with and without autism more directly.

Complete portrait:

We started with a measure called Patient-Reported Outcomes Measurement Information System (**PROMIS**), which provides a complete portrait of a person’s quality of life relative to an ‘average’ person. This tool captures all the components that inform someone’s quality of life: physical health, including **sleep** and **sexual function**; mental health, such as **depression**, **anxiety** and cognitive function; social health, such as family relationships and social isolation; subjective well-being,

including life satisfaction and sense of purpose; and overall health⁴. It includes scales for children and adults of various ages, and it is easy to complete and **freely available**.

We identified the **PROMIS scales relevant to autism**, reviewed each item and solicited input from autism experts as well as autistic people and their family members. After taking their feedback into account, we included 14 brief questionnaires on different aspects of quality of life that seemed most important and relevant for children and teenagers, and 19 for adults.

None of the domains covered in the questionnaires — subjective well-being, physical, mental or social health, and, for adults, issues such as self-efficacy — are medical. Nor do they measure societal milestones such as educational attainment, rates of full-time employment or independent living. Those omissions are deliberate. Neither autism traits nor societal standards are sufficient to tell whether someone is living their best life.

We recruited 856 autistic individuals, aged 5 to 65 years, to take the battery online. Parents completed the questionnaires for children and some teenagers; teenagers and adults who were able to do so completed their own surveys. We included adults with **intellectual disability**. Because the survey had to be presented the same way that it is for the general population, though, we were not able to include adults who needed intensive support to respond. Developing accessible measures for this group is a critical area for future research⁵.

Personal perspective:

Most of the participants reported that they could complete the questionnaires in about 20 minutes — and found it useful, thought-provoking and important. Some said that they have a good quality of life but, compared with the general population, we found that autistic people of all ages have a lower quality of life overall. Autistic women and girls reported having greater challenges in some areas, including sleep quality, anxiety and social isolation, than men and boys with autism.

The personal responses on the survey (along with follow-up interviews) highlight important concerns and preferences among people with autism. For example, one participant said working full time had been stressful and harmed her mental health, but that her mood improved dramatically when she switched to part-time work. This change allowed her to excel and be happy at work — an insight that might guide support and care for others on the spectrum.

Another autistic adult said that stable housing would significantly improve her quality of life. In particular, she wanted a place large enough to house her beloved collections, including books, card decks, puzzles and fidget toys. An older participant reported that she hates social groups but would like to befriend one other autistic person she could talk with by phone. One older man wrote about loneliness and his desire for a romantic partner.

As we had hoped, our questions elicited answers that reveal the extent to which people's

circumstances fit their needs, desires and abilities. We think this type of assessment could jumpstart fruitful conversations among autistic people, clinicians, researchers and caregivers about how to help people with autism live their best lives, by their own definitions and on their own terms.

Laura Graham Holmes is a postdoctoral researcher at the A.J. Drexel Autism Institute at Drexel University in Philadelphia, Pennsylvania. Judith Miller is assistant professor of psychology at the Children's Hospital of Philadelphia.

REFERENCES:

1. Robertson S.M. *Disability Studies Quarterly* **30** (2010) [Full text](#)
2. Ne'eman A. *Disability Studies Quarterly* **30** (2010) [Full text](#)
3. McConachie H. *et al. J. Autism Dev. Disord.* **48**,1596-1611 (2018) [PubMed](#)
4. Cella D. *et. al. J. Clin. Epidemiol.* **63**, 1179-1194 (2010) [PubMed](#)
5. Nicolaidis C. *et al. Autism in Adulthood* **2**, 61-76 (2020) [PubMed](#)