

TOOLBOX

Survey assesses well-being in adults with autism

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A brief questionnaire written with guidance from people with autism is the first of its kind to assess quality of life among adults with the condition.

The new assessment features nine autism-specific questions intended as an add-on to a general quality-of-life instrument. The original was developed by the World Health Organization and is called the WHO Quality of Life-BREF (WHOQOL-BREF).

The new questions and scoring framework are **available online**, and could help scientists and clinicians judge the effectiveness of treatments.

The questionnaire addresses gaps and ambiguities in the original that researchers identified after consulting with adults on the spectrum.

For example, one question from the original reads, "How well are you able to get around?" People with autism are likely to interpret this question as referring to barriers in the environment that prevent their movements rather than to impairments to their physical mobility.

The tailored questions cover the same ground as the original in a way that is clearer to people on the spectrum.

The initial discussions with the adults with autism yielded 11 new questions that a separate team of scientists reviewed for clarity and ranked in order of importance. The researchers then sent the questions to a second group of people with autism for review, and narrowed the list of questions to nine.

The final set also covers issues that are not addressed in the original, such as problems with sensory responses, friendships, finances and identity, and difficulties accessing healthcare and other services. Participants use a 5-point scale to indicate whether each question reflects their experience over the previous two weeks.

The researchers administered the nine questions along with the original questionnaire to 309 adults with autism in the United Kingdom. About half of the respondents are women. Most of the adults said they had read and answered the questions themselves; 31 reported that they had help filling out the questionnaire, and 14 were represented by a caregiver.

The scores revealed that people with autism report a lower quality of life than typical people do. More than half of the people with autism have a quality-of-life score that is more than one standard deviation below the norm. The findings appeared in November in the *Journal of Autism and Developmental Disorders*.

The results suggest that the original assessment provides a fair measure of quality of life in people with autism, but the new questions improve its accuracy in this population.

REFERENCES:

1. McConachie H. *et al. J. Autism Dev. Disord.* Epub ahead of print (2017) [PubMed](#)