

NEWS

Checklist of abilities opens window onto lives of people with autism

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A new catalog aims to help clinicians evaluate the daily challenges people with autism face, and the environment in which they live¹.

The catalog is the result of an intensive international effort, initiated in 2012. It could lead to accommodations and treatments tailored to individuals on the spectrum.

Most clinicians diagnose autism based on criteria in the “Diagnostic and Statistical Manual of Mental Disorders” (**DSM-5**) or the “**International Classification of Diseases**” (ICD). Both manuals define autism using a checklist of features, such as problems with social skills and restrictive and **repetitive behaviors**.

But neither manual includes factors that detail **how people on the spectrum may fare** in their daily lives.

The new catalog aims to fill this gap. It comprises more than 100 ‘core sets,’ or categories, of behaviors, abilities and environmental factors. These include sleep habits, hygiene practices, family support and access to education or employment.

Some of the core sets for autism also highlight abilities such as an exquisite memory for detail.

“There is at least a large minority of [people with autism] who have strengths,” says lead investigator **Sven Bölte**, professor of child and adolescent psychiatric science at the Karolinska Institutet in Stockholm. “In the long run, [the core sets] give a little bit more balanced picture of the phenomenon.”

The catalog does not replace the DSM-5 or ICD but rather complements them.

“There is now this more concise and international description that focuses more on function,” says **Mayada Elsabbagh**, assistant professor of neurology at McGill University in Montreal, who was not involved in the study. “It’s about time.”

The autism core sets add to the “**International Classification of Functioning, Disability and Health**” (ICF), a growing list of function-based descriptions of conditions such as cerebral palsy and depression. The ICF is compiled by the World Health Organization.

Common ground:

Bölte and researchers from 43 countries homed in on the core sets relevant to autism in stages. They conducted a literature review of studies of daily living skills and outcomes in people with autism. Next, they surveyed 225 autism experts about these factors.

The team then interviewed 90 people with autism and their caregivers. Finally, they studied the daily living skills of 122 people with autism from 10 countries.

In September 2016, 20 autism researchers and health professionals representing 11 countries met

in Stockholm to review the data.

They agreed on the ‘master list’ of 111 functions. The list includes cognitive skills such as memory and attention, the ability to perform everyday tasks such as housework, and environmental factors that might influence well-being, such as family support and social norms in the country of residence. The results appeared 29 January in *Autism*.

The new catalog gives researchers and clinicians a common vocabulary to describe how people with autism fare in their lives, says **Megan Farley**, senior psychologist at the University of Wisconsin-Madison’s Waisman Center, who was not involved in the research.

This shared vocabulary is especially important for research on people’s living conditions, such as availability of support from family members, that have not been described systematically, she says.

For example, two people with autism might score similarly on standard measures of cognition. “One might be really impaired, and the other one might not be because of things that are happening in their environment that allow them to function and be really successful,” Farley says.

Help wanted:

The researchers at the Stockholm meeting also created an abbreviated list of 60 categories — and separate lists for preschoolers, adolescents and individuals over age 17.

The adult version does not include a **sensory sensitivity** category, which is a shortcoming, says **Helen McConachie**, emerita professor of child clinical psychology at Newcastle University in England, who was not involved in the work.

“In the work I’ve been doing with autistic adults, the sensory environment and the distractions and distress that can be caused by the sensory environment are very important,” she says. The researchers should have also included adults with autism in their working group, she says.

Still, the catalog may guide the selection of treatments and accommodations for many on the spectrum.

For instance, Bölte says, the categories might reveal that a child is overwhelmed by the noise in his school lunchroom. Giving the child the chance to eat lunch in a quieter room might dramatically improve his functioning.

Clinicians do not yet have guidelines on how to use the core sets, however.

“As a clinician, I wouldn’t really know what to do with the core set,” says McConachie. “The ways that the categories are written in the ICF, they’re just terribly broad and it doesn’t really guide you

as to how to ask some really key questions about people's lives.”

Bölte says he is confident the catalog will gain acceptance over the next few years. He and his colleagues plan to design software to help clinicians use the core sets.

REFERENCES:

1. Bölte S. *et al. Autism* Epub ahead of print (2018) [PubMed](#)