

Measuring What Matters in Autism Research and Practice

Teal W. Benevides, PhD, MS, OTR/L,¹ and Sarah A. Cassidy, PhD²

TRADITIONALLY, DECISIONS ABOUT what is important to measure in autism research have been made by researchers and funders of research, rather than by autistic people or those who support them. This has meant that *what* we measure and *how* we measure it has not necessarily captured the important or relevant outcomes to the autistic community, or in an accessible way. Advancing measurement to increase our understanding of autism in adulthood has therefore reached a crossroad, in which the autistic adult community, clinical providers, researchers, payer systems, and research funders must work together to identify those outcomes that are essential to measure, and how best they should be captured.

In this Special Issue of *Autism in Adulthood*, we have aimed to collate emerging and ongoing international work related to advancing measurement in autistic adults, with a particular focus on meaningfully involving autistic adults in deciding what we measure and how we measure it. Importantly, this topic of “measurement” received such international interest that we have two back-to-back issues dedicated to this topic. In this editorial for Issue 1, we aim to discuss the importance of advancing measurement, the current state of the evidence, and why this Special Issue fills an important gap in the existing literature. We also reflect on what is needed in terms of funding and infrastructure to support development of meaningful partnerships between the autistic community, researchers, clinical providers and research funders, drawing on examples from exciting recent international developments.

What Is Important to Measure?

Research has shown that the priorities of researchers and clinicians differ from the priorities of autistic people and their families.¹ In health and education systems, there is also a frequent lack of agreement between providers, systems, and clients regarding what is most important to measure. The autistic adult community has therefore called for more work and efforts to promote health and well-being through measurement of meaningful life outcomes. Hence, funders of research and research teams have begun to work collaboratively with the autistic community to identify research priorities²⁻⁴ and to measure outcomes such as employment,

independent living, mental and physical health, and quality of life. Early work to understand autistic adult priorities reveal that addressing the need for validated tools for adult diagnosis, particularly among women, is important.² Mental health outcomes are a second area in which better measurement are needed to understand the experience of depression, anxiety, self-harm, suicidal thoughts and behaviors, and, conversely, positive affect.²⁻⁴ Lastly, greater attention to measuring well-being and quality of life, based on a personalized definition, is essential for ensuring that measurement practices address what is important for individuals, rather than what are normatively expected to be “good” versus “poor” outcomes by non-autistic people.³ The measurement of autistic adult outcomes remains in its infancy, with few valid and reliable measures, and a reliance on utilizing standardized measures validated for other non-autistic groups in research and practice.^{5,6} Autism research has also historically neglected to meaningfully involve all autistic adults in research, such as those with an intellectual disability or those who speak few or no words,⁷ although leaders in the field have paved the way for these efforts. Advancing measurement to understand autism in adulthood will require new measurement methods appropriate and validated for all autistic adults.

How Can We Advance Measurement?

One of the top priority areas identified by autistic adults, mental health and quality of life, is presented in this issue, with three papers focused on measuring outcomes that matter. McConachie et al. report that autistic adults across four countries identified unique aspects of autistic quality of life that are not captured in a quality-of-life measure developed for the general population (the WHOQOL-BREF). Specifically, autistic quality of life included autistic identity, other people’s lack of understanding of autism, sensory issues, and autistic people’s contributions to society. McDonald presents validation and comparison data for a self-report measure that captures positive autistic identity: the Autism Spectrum Identity Scale (ASIS). Results suggest that the ASIS captures the same construct in adults diagnosed autistic and those self-diagnosed as autistic, and both groups are similar in self-reported stigma, self-esteem, quality of life, and ASIS fac-

¹Department of Occupational Therapy, Augusta University, Augusta, Georgia.

²School of Psychology, University of Nottingham, Nottingham, United Kingdom.

tors. Our final article on mental health by Rodgers et al. addresses measurement of anxiety, which is frequently reported as a co-occurring experience for autistic adults. Few tools have been developed to understand anxiety specifically in autistic people. Rodgers et al. adapted and modified a self-report screening tool for anxiety among autistic adults to fill this gap. Although this tool is in the preliminary stages of evaluation, these authors found that a general anxiety factor, as well as three underlying sub-factors (social anxiety, uncertainty, and anxious arousal), are present when measuring anxiety in autistic adults. Future evaluation to understand the measurement properties of this tool are indicated.

Diagnosis and the experience of diagnosis among autistic adults is an area that has languished in favor of screening and diagnosis in children. In this issue, Wigham et al. describe the initial participatory approach to develop and create the Autism Clinical Interview for Adults (ACIA). This tool, designed to capture elements of DSM-5 diagnosis for autism through both self-report and interview, and informant interview, is in the early stages of evaluation. The tool has established face and construct validity, and the early research is promising. Clinicians and autistic individuals have been asking for a valid and reliable tool to establish adult diagnosis of autism, and this tool warrants attention. McDermott et al. evaluate two tools typically used to capture repetitive behaviors during the diagnostic process, and evaluate the contributions each of these make to adult measurement. Lastly, the experience of diagnosis is as yet poorly understood but has implications for clinicians and undiagnosed autistic individuals. In this issue, Arnold et al. evaluate the measurement properties of the Impact of Diagnosis Scale-Preliminary Revision (IODS-PR). The revision of IODS, in collaboration with a team of autistic advisors, resulted in a new tool with three factors related to the experience of diagnosis in autistic adolescents and adults: service access, being understood, and self-acceptance and understanding. The experience of autistic diagnosis was felt by respondents, in early evaluation, to be a positive and life-changing event. This perspective is pivotal for caregivers, clinicians, and other service providers to understand in their work with autistic individuals.

In this issue, we are excited to share advances in measurement methods to capture a range of outcomes in autistic adults, including those traditionally excluded from research. In this issue, Nicolaidis et al. discuss lessons learned from six participatory research studies that have adapted survey instruments for autistic adults and people with intellectual disability. They make a number of useful recommendations to ensure that instruments are accessible to a wide range of autistic participants, and caution against using “standardized” tools without further adaptation and testing in autistic adults. Crompton et al. describe how they worked in partnership with autistic people to develop a new interview schedule in order to capture the experiences of older autistic adults in residential care. Ricco et al. describe how their participatory group of autistic and non-autistic researchers co-produced a picture-based measure to support autistic people to describe how they feel about topics such as edu-

cation and service delivery. Initial evidence supports the usefulness of this tool to help autistic people who prefer to use visual methods to communicate their emotions. These tools show promise for ensuring that validated tools are used to capture outcomes in all autistic adults, including those who have been traditionally excluded from research. We hope that the availability of such tools will reduce researchers’ and practitioners’ reliance on “standardized” measures developed for other groups, without additional adaptation and testing, in order to ensure that they are validated for autistic people.

What Does the Future Hold?

It is clear that across the studies presented in this special issue, meaningful partnerships with autistic people have advanced the field of measurement at a much faster pace than would have been possible without any autistic partnerships. However, we recognize that the collated articles represent new and emerging tools or measures, and that future work to extend or evaluate these measures is necessary for advancing the state of measurement. Further advancing measurement, in partnership with autistic adults, will require dedication from researchers and the autistic community, together with support and infrastructure from organizations and research funders. Examples of successful participatory research studies and wider programs are presented in this special issue. Furthermore, it is also important to highlight other excellent initiatives. For example, the leading autism research charity in the United Kingdom, Autistica, launched the Discover network, to facilitate connections between researchers with over 10,000 autistic people and those who support them. Funders, such as the National Institute for Health Research (NIHR) in the United Kingdom, also require all funding applications to include strong evidence of meaningfully involving patients and the public in developing the proposal. In the United States, the Patient-Centered Outcomes Research Institute (PCORI) funds studies that specifically include meaningful engagement of stakeholders as part of the research team, which is essential for development of results that matter. Other U.S. funders, both private and public, are beginning to reorient strategic plans to allow for funding critical adult studies. We call on researchers, the autistic community, clinicians, and funders to continue to work together to measure what matters to autistic adults.

References

1. Pellicano E, Dinsmore A, Charman T. What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*. 2014;18(7):756–770.
2. Autistica. Your questions: shaping future autism research. Available at: <https://autistica.org.uk/downloads/files/Autism-Top-10-Your-Priorities-for-Autism-Research.pdf> (accessed February 27, 2020).
3. Cassidy SA, Robertson A, Cogger-Ward H, Goodwin J, Rodgers J. Autism community priorities for suicide prevention. Available at: <https://sites.google.com/view/mentalhealthinautism/projects/insar-policy-briefing> (accessed February 27, 2020).

4. Benevides TW, Shore SM, Palmer K, et al. Listening to the autistic voice: mental health priorities to guide research and practice in autism from a stakeholder-driven project. *Autism*. 2020 (in press). DOI: 10.1177/1362361320908410.
5. Cassidy SA, Bradley L, Bowen E, Wigham S, Rodgers J. Measurement properties of tools used to assess depression in adults with and without autism spectrum conditions: a systematic review. *Autism Res*. 2018;11(5): 738–754.
6. Cassidy SA, Bradley L, Bowen E, Wigham S, Rodgers J. Measurement properties of tools used to assess suicidality in autistic and general population adults: a systematic review. *Clin Psychol Rev*. 2018;62:56–70.
7. Autistica. A review of the autism research funding landscape in the United Kingdom. Available at: <https://www.autistica.org.uk/downloads/files/Autistica-Scoping-Report.pdf> (accessed February 27, 2020).

Address correspondence to:
Teal W. Benevides, PhD, MS, OTR/L
Department of Occupational Therapy
Augusta University
987 St. Sebastian Way, EC-2324
Augusta, GA 30912

Email: tbenevides@augusta.edu

Sarah A. Cassidy, PhD
School of Psychology
University of Nottingham
Nottingham
NG7 2RD
United Kingdom

Email: Sarah.cassidy@nottingham.ac.uk