

Q&A

Rethinking autism assessments in the time of COVID-19: Q&A with Bishop, Zwaigenbaum

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The COVID-19 pandemic has fundamentally changed how autism is assessed. Most clinical assessments, which are key to understanding, tracking and providing help for children with the condition, have moved online.

This transition to telehealth has made it easier for families with autistic children who live in remote areas to access some services. But it has also created a digital divide: Parents who aren't technologically proficient cannot take full advantage of virtual assessments and other autism-related services.

This and other stark reminders of social inequities in the autism community have prompted clinicians to ask fundamental questions about the nature of autism assessments: Who are they for? What are their main goals? And how do we devise clinical assessments that can reach those in underserved communities?

A **commentary** published in September in *Autism Research* attempted to answer these questions. *Spectrum* spoke to two of the commentary's authors — **Lonnie Zwaigenbaum**, professor of pediatrics at the University of Alberta in Canada, and **Somer Bishop**, associate professor of psychiatry at the University of California, San Francisco — about how they are rethinking autism assessments.

Spectrum: What got you interested in this particular topic?

Lonnie Zwaigenbaum: This commentary started off with a conversation between **Alycia Halladay**, chief science officer of the Autism Science Foundation, and **Sylvie Goldman**, assistant professor of neuropsychology at Columbia University, about the challenges of providing quality assessments

for autism during the COVID-19 pandemic. Alycia then invited Somer and me as well as other experienced clinicians and a parent who also works in a professional role with a service organization to discuss these issues in greater depth, in the context of patient- and family-centered care.

Somer Bishop: Our discussions initially focused mainly on how the pandemic had disrupted usual clinical practices, and the need for technical adaptations such as virtual care. However, these conversations led to the uncomfortable realization that our field was already grappling with some serious issues related to clinical service provision. The chasm between system capacity and needs was widening under the pressure of COVID, in part because there were already cracks in the foundation.

S: How has the pandemic affected clinicians' ability to assess children for autism?

LZ: The most obvious challenge is restrictions placed on in-person assessments, which include the need to wear personal protective equipment, physical distancing and, for some periods of time, closure of facilities where assessments take place. A related challenge has been the need to rapidly pivot to new or unfamiliar diagnostic assessment methods and measures to avoid complete disruption of assessment activity.

SB: On the positive side, many clinical programs have been able to incorporate at least some remote assessment approaches, using **telehealth-based tools** that were developed pre-pandemic, such as the video-based screener **TELE-ASD-PEDS**, or that were quickly adapted from existing measures, such as the **Brief Observation of Symptoms of Autism**.

S: What social and economic inequities in autism assessment has the pandemic revealed?

LZ: Even prior to the pandemic, we faced undeniable racial disparities in **rates of detection** and **age of autism diagnosis**. Structural racism **creates barriers to autism diagnosis**, including through bias and **discrimination experienced by families** and a **lack of diversity among clinicians**. Disparities in mortality and other health outcomes **related to COVID-19 infection** further reinforce the need to address systemic and pervasive inequities within the health system. An unequal **geographic distribution of specialists** also creates further structural barriers for minority families and for families who lack the financial resources, transportation or flexibility in work schedules to travel long distances to access autism assessment and treatment services.

SB: With the shift to virtual assessments, families are already experiencing new barriers. Reliance on newer technologies and platforms could inadvertently magnify the cultural and socioeconomic disparities that already exist — for example, through the 'digital divide' that has been **recognized in other health services**.

S: Your article says autism researchers need to rethink the goals of autism assessments for

children. What do you mean, and how might that be accomplished?

LZ: Until recently, the autism research literature has primarily focused on the classification accuracy of specific diagnostic measures. Accuracy is essential but not sufficient. Families bring a broader lens based on their experiences navigating the health system prior to and following diagnosis. Parents emphasize the importance of timely access to a diagnostic assessment, a **focus on the strengths** and potential of their autistic child when discussing what the future holds, and clear information about how to access services.

SB: These perspectives have found a voice in recent practice guidelines. However, given ongoing feedback from families and in recognition of the disparities already discussed, we have a long way to go in aligning our research and quality improvement efforts.

S: Moving forward, what are the best approaches researchers and clinicians can take?

LZ: None of us has all the answers, and the “best” approaches will vary depending on the particular clinical situation. While there has been progress in implementing new models of care, including virtual assessments and remote parent-mediated interventions, at some point we are going to need to catch our collective breath, reflect on how the service landscape has changed and continue the process of evaluating and improving new practices. It is also important to recognize that some of the challenges experienced by the broader community during the pandemic — isolation and limited access to assessments, interventions and support services — have been long-standing for many autistic people and their families.

SB: We must commit to ensuring that systems of care are just and equitable going forward and don't entrench or create new systematic barriers or disparities. We respectfully suggest that a **hybrid service model** may allow for the benefits of both online and in-person assessments, but there is considerable work to do to understand what combinations of approaches are going to be most effective and for whom. As part of this process, researchers and service providers across disciplines must **work together** with those who have lived experience with autism to assist in the conception, development and evaluation of valid yet flexible methods for autism assessment.

S: How does the autism community make sure these new approaches work for underserved communities?

LZ: **Lisa Ibañez**, research scientist at the University of Washington in Seattle and one of the commentary's co-authors, noted that we have a unique opportunity to capitalize on this 're-set' moment to establish new tools and practices that are valid and meaningful for the broad diversity of the communities we serve. It is essential that we engage families and clinicians from underserved groups in the development and evaluation process; for example, to ensure that the activities used within assessments are culturally acceptable and can be adapted as needed.

It is also critical to ensure that the validation process includes participants from diverse backgrounds so that we can gauge to what extent clinical judgement and scoring on a measure may be influenced by factors such as race, sex and gender.

SB: We must also pay greater attention to other aspects of diversity — for example, in cognitive and language abilities, which can drastically affect the validity of assessment tools. More importantly, we need to move evaluation practices beyond the narrow focus on the psychometrics of a particular measure. We need to instead evaluate assessment practices more programmatically with respect to access and empowering and preparing families to navigate the service system. We need to be vigilant and commit to addressing disparities with respect to all these outcomes — and ensure accountability by engaging with families and clinicians from underserved communities in the oversight and evaluation process.

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