

COMMENTARY**Rethinking autism spectrum disorder assessment for children during COVID-19 and beyond**

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Funding information

Autism Science Foundation; Stollery Children's Hospital Foundation; Canadian Institutes of Health Research Sex and Gender Science Chair, Grant/Award Number: GSB 171373; Eunice Kennedy Shriver National Institute of Child Health and Human Development, Grant/Award Number: R01HD093055; US National Institutes of Health, Grant/Award Numbers: R00MH10664, R01MH121416

Abstract

The COVID-19 pandemic has posed unique challenges for families and caregivers, as well as for autism-focused clinicians, who are faced with providing a thorough and accurate evaluation of children's specific needs and diagnoses in the absence of in-person assessment tools. The shift to telehealth assessments has challenged clinicians to reconsider approaches and assumptions that underlie the diagnostic assessment process, and to adopt new ways of individualizing standard assessments according to family and child needs. Mandates for physical distancing have uncovered deficiencies in diagnostic practices for suspected autism and have illuminated biases that have posed obstacles preventing children and families from receiving the services that they truly need. This Commentary outlines several considerations for improving diagnostic practices as we move forward from the current pandemic and continue to strive to build an adaptable, sustainable, equitable, and family-centered system of care.

Lay Summary

Physical distancing and the abrupt end to in-person services for many children on the autism spectrum has forced clinicians to examine the existing challenges with autism spectrum disorder (ASD) diagnostic assessment and consider things they want to keep and things that should be changed in the years ahead. New approaches such as telehealth both alleviated and exacerbated existing disparities, and brought into stark focus the importance of equitable and timely access to family-centered care. This commentary suggests ways of improving clinical practices related to ASD assessment to continue along this path.

KEYWORDS

assessment, autism, challenges, children, diagnosis, disparities, pandemic

Assessments for autism spectrum disorder (ASD) can have a profound effect on families, helping them understand their child's development and needs as well as providing information needed to advocate effectively for appropriately specialized services and interventions throughout their child's life. While ASD prevalence rates have increased steadily (Maenner et al., 2020), the number of professionals (especially those from diverse backgrounds) trained in conducting ASD assessments has not kept pace (Bridgemohan et al., 2018; Hsu, 2018), prompting discussion about potential strategies for increasing access (Kanne & Bishop, 2021; Zwaigenbaum & Warren, 2021). To date, the empirical literature on ASD assessment has focused primarily on the accuracy of specific measures, rather than the process of assessment and the range of various clinical models into which measures could be incorporated (Brian et al., 2019; Health, , 2011; Whitehouse, Whitehouse et al., 2018). Moreover, "best practice" is often conceptualized as a unitary construct, rather than a range of approaches that consider the individual child and family within their specific community and health service contexts. While this commentary focuses primarily on perspectives related to experiences within Canada and the United States, we also note implications for, as well as insights that can be drawn from, the global community.

The COVID-19 pandemic has superimposed profound disruptions to usual care pathways in already strained service delivery systems. Traditional face-to-face ASD assessments, which were associated with extremely long wait times before COVID-19, have become more difficult to access, or entirely untenable in some settings. Many clinical programs have adapted to these constraints, leveraging telehealth-based approaches that were developed pre-pandemic (Corona et al., 2021; Schrader et al., 2020) or adopting novel online "virtual" screening and assessment models (Berger et al., 2021; Jang et al., 2021). Positive aspects of telehealth models include easier access for some families living in remote locations or with complex schedules, as well as multiple opportunities to observe children in their familiar home environment with other family members such as siblings (Ameis et al., 2020; Wagner et al., 2020). However, the challenge of not being able to interact with children and families in person, amplified by

restricted access to, or closures of, community resources and supports, has forced many clinical teams to grapple with fundamental questions regarding the ultimate priorities and goals of diagnostic assessment. Families have also been trying to navigate this unusual and unprecedented time, which has disrupted not only diagnostic procedures but also the broader service delivery systems.

Access to ASD assessment and services is often exacerbated in low and middle income countries (LMIC), which have long experienced more basic issues, including knowledge gaps, the shortage of trained clinicians, the stigma of ASD, cultural differences of varying health care systems, lack of resources for treatment and support, and lack of culturally-sensitive and language-appropriate screening and diagnostic tools (Durkin et al., 2015). While telehealth has been useful in some settings (Franz et al., 2021), many LMIC face a "digital divide" by not having adequate or consistent internet access to deliver telehealth (Franz et al., 2017; Kumm et al., 2021). Such barriers have also been described within higher income countries, particularly in remote and rural areas (Fisk et al., 2020).

Now more than a year into the pandemic, we are presented with an opportunity to take a step back and review the principles that guide ASD assessment, so that novel, accessible, flexible, and sustainable practices can be developed. This commentary presents ideas generated by a panel that was convened by the Autism Science Foundation to discuss short- and long-term priorities for re-envisioning the diagnostic assessment process in light of pandemic-related experiences. Participants included senior clinicians (psychologists, psychiatrists, and pediatricians among whom there were individuals with general training as well as specialized ASD training and practices), researchers, and a professional parent-leader. While initially focused on technical adaptations of assessments in response to the COVID-19 pandemic, discussions quickly shifted to longer-term considerations. Structured dialogue was focused on questions related to ASD assessment frameworks prior to and during the pandemic, as well as potential implications for future practice. Three major themes emerged from the discussions: (a) the need to re-think the goals of ASD assessment, (b) the need to consider issues and opportunities related

to social inequity, and (c) the need to adopt and evaluate novel approaches to promoting systems-level change. Although the comments relate specifically to the needs of children and their families, there are broader implications for assessment and supports/services for individuals across the lifespan. Discussions primarily focused on issues faced in the United States and Canada, given the first-hand experiences of panel members. Similar opportunities for enhancing training and service delivery are likely to exist at a global level, although we acknowledge that pre-pandemic assessment models and contexts vary across countries, as do local assets and challenges.

RETHINKING THE GOALS OF ASD ASSESSMENT

Diagnostic assessment practices over the past three decades have evolved considerably (Rosen et al., 2021). As is still commonplace for other psychiatric/neurodevelopmental conditions, ASD assessment was originally conducted using a variety of approaches that relied heavily on expert clinical judgement, which could be idiosyncratic to each clinician. As the prevalence of ASD increased, calls for more standard practices for evaluating the presence or absence of ASD ensued, and the field shifted toward the development and use of standardized diagnostic instruments. Originally developed to guide ASD research, tools such as the Autism Diagnostic Interview - Revised, a parent/caregiver interview (Lord et al., 1994), and Autism Diagnostic Observation Schedule, a direct observation tool (Lord et al., 1989) provided a common language to describe behavioral characteristics and operationalize ASD symptoms. Over time, these research tools, particularly the ADOS and subsequently, the ADOS-2 (Lord, Petkova, et al., 2012), were incorporated into clinical practice, as they provided rich opportunities to systematically observe ASD-related behaviors. As the authors of these measures have emphasized, the ADOS and ADI-R were always intended to inform—rather than replace—clinical judgement (Lord et al., 1994; Lord, DiLavore, et al., 2012). In fact, clinical diagnosis by experienced clinicians based on DSM criteria was the criterion against which these research tools were calibrated, validated, and refined (Gotham et al., 2007; Lord et al., 1994; Risi et al., 2006). In addition, a comprehensive developmental history that takes account of behavior in multiple settings is an essential component of any diagnostic evaluation. However, to keep pace with growing numbers of referrals for ASD assessment, and to ensure some level of quality control in the assessment of a condition that is associated with substantial costs post-diagnosis, health systems in some jurisdictions have increasingly focused on scores and classifications from standardized diagnostic instruments for confirmation of clinical diagnosis. Concurrently, it has become tempting for payors within those systems

(e.g., insurance providers, school districts) to mandate the use of specific instruments as requirements for service eligibility and funding. This is not a universal trend, and some clinical practice parameters internationally have emphasized key functional domains (i.e., profiling “strengths and needs”), clinical decision-making and tailoring assessment to clinical presentation over specifics of measurement (National Collaborating Centre on Women’s and Children’s Health, 2011; Whitehouse et al., 2018).

The requirement that certain tests be used to determine an ASD diagnosis has generated questions about what constitutes the essential components of a diagnostic assessment, and how (and by whom) this should be determined. Over-reliance on use of particular measures leads to fragility in the care system, straining the already limited resources available to conduct specialized assessment. Requirement for the use of specific measures becomes a limiting step to service access, creating socioeconomic and professional barriers by: (a) undermining confidence in the validity of a clinical diagnosis (based on DSM criteria) derived by experienced clinicians not using the measure; (b) preventing experienced clinicians from employing flexible and individualized assessment protocols that are most efficient and appropriate for a given child (e.g., more tailored approaches that are often required for children with severe/profound intellectual disability (Soorya et al., 2018; Thurm et al., 2019), girls versus boys, those with vision, hearing, and/or motor impairments, as well as those that do not speak the same native language as the clinician); and (c) inadvertently adding to navigational challenges experienced by families through reduced access to “acceptable” diagnostic assessments when professionals using these tools are not readily available. These challenges may be especially pronounced in LMIC (and in lower resourced communities within higher income countries), where access to both trained clinicians and standardized instruments is severely limited and may exacerbate delays in assessment, diagnosis and later services to an even greater extent.

The unprecedented disruptions to standard care caused by the COVID-19 pandemic provide a unique opportunity to revisit the core values that guide diagnostic assessment for ASD and determine how to define “best-practices” moving forward. Critical questions to address include how training models can better foster high-quality assessment practices in an agile manner, and how specific measures (including newly developed measures) or combinations of measures can sustain diagnostic capacity across the continuum of family and environmental contexts. It is essential for clinicians involved in ASD assessment to understand the developmental constructs underlying the diagnostic criteria, and to learn more than the technical skills needed to administer, score, and interpret particular instruments. Regardless of the ultimate diagnosis, children referred for ASD assessment often present with delays or atypical developmental trajectories in cognitive, language, and adaptive skills, as well as co-

occurring behavioral and/or mental health symptoms. This makes differential diagnosis challenging and requires that clinicians have a deep and nuanced understanding of the developmental profiles that characterize ASD as well as other neurodevelopmental disorders (Havdahl et al., 2016; Thurm et al., 2019). Acquisition of such clinical expertise is an ongoing process that extends far beyond an initial period of training and certification and extends through across the career of the clinician.

Another critical consideration is the tension between prioritizing a categorical diagnosis versus determining a child's functional needs. In many service systems, a categorical diagnosis is often the gateway to accessing specialized services and interventions, while information about the child's profile of strengths and challenges forms the basis for identifying appropriate intervention goals. Thus, it is critical to parse out the full range of questions that families and clinicians are seeking to answer: Does the child have ASD, and to what degree of severity? Does the child have any other diagnoses? What does the child need right now, regardless of diagnosis? How can clinicians assist the child and family in getting what they need? Providing valid and meaningful answers to each of these questions (which, arguably, should be the benchmark for "best practices") may require different assessment methods and types of expertise. Therefore, moving forward, strong advocacy from stakeholder and professional groups will be needed to ensure greater alignment between systems providing ASD-specialized services pre- (e.g., at the assessment stage) and post-diagnosis across systems of care. Further, ASD advocacy efforts must directly consider how to secure necessary intervention services to children across the broad spectrum of neurodevelopmental disabilities (including ASD), based on individual needs, developmental level, function, and symptoms, rather than a formal categorical diagnosis per se (Bolte et al., 2021; Lord & Bishop, 2010).

As we grapple with finding optimal flexibility related to diagnostic assessment (and recognizing that "standardization" can apply to multiple levels of decision making and assessment processes, not just the scoring of a particular instrument), we must also consider potential differences in how researchers, clinicians, and families prioritize and value the various elements of the assessment process. For example, while the research literature tends to focus on accuracy of diagnostic classification as the primary consideration (Randall et al., 2018), parents tend to emphasize the importance of: (a) access to services (i.e., wait times, although delays in securing a diagnosis are often not the only bottleneck) (Moh & Magiati, 2012); (b) clinicians' communication, including provision of hope and a positive and strengths-based framework regarding questions about what the future holds (Brown et al., 2021; Edwards et al., 2017; Nissenbaum et al., 2002); and (c) the quality and clarity of the information provided (Hennel et al., 2016; Lappe et al., 2018). These complementary perspectives have

been embedded in current ASD practice guidelines, which prioritize tailored assessment processes that are responsive to diagnostic complexity as well as families' needs (Brian et al., 2019; National Collaborating Centre on Women's and Children's Health, 2011; Whitehouse et al., 2018). However, our collective experience is that these principles have not yet fully permeated the culture of clinical practice or training in ASD assessment across settings.

Revisiting the goals of the ASD assessment process, we cannot ignore the systems of care that are involved. Assessments inform decisions across the care pathway (e.g., from diagnosis to intervention) and across sectors (e.g., education and health). Experiences during the pandemic have been a poignant reminder of the fragmentation across systems of care (Brewer, 2018), to the detriment of children and families. It is essential to remove the silos between systems (medical, educational, behavioral health, community services, etc.) to foster coordinated, and person- and family-centered care across all service sectors. Moreover, the importance of communication and collaboration extends to other key partners and stakeholders such as public or private insurance providers, governmental administrators, and policy makers. For example within the US system, we need to work with payors to negotiate changes in reimbursement frameworks in parallel with changes in clinical best practices. Similarly, advocacy efforts directed toward policy-makers and licensing boards are needed to provide flexibility in offering services across jurisdictions (e.g., multiple states or provinces) now that virtual care makes this possible.

CONSIDERING SOCIAL INEQUITY IN ASD ASSESSMENT

Disparities in rates of detection and age of diagnosis of ASD related to race/ethnicity (Baio et al., 2018; Constantino et al., 2020; Daniels & Mandell, 2014; Mandell et al., 2009; Travers, 2018), socioeconomic status (Daniels & Mandell, 2014; Mandell et al., 2005; Roman-Urrestarazu et al., 2021) and sex/gender (Lai & Szatmari, 2020; McDonnell et al., 2020) are well documented. Families living in rural or geographically isolated areas often face a shortage of providers with ASD expertise and may be unable to manage the time and expense of traveling or taking time off from work to obtain a diagnostic assessment (Stahmer et al., 2019). The factors driving these disparities are multi-faceted and linked both to systematic under-identification and to the conventional service delivery model, which relies heavily on assessment in academic and tertiary care centers (Carbone, 2013; Ibanez et al., 2019). Innovative models that engage community-based professionals and/or technology-enabled assessments should be prioritized (Sohl et al., 2017; Zwaigenbaum & Warren, 2021). Enhancing access to quality ASD assessments will require a reimagining of existing processes to consider core

elements of the assessment, including a focus on professional expertise. Pre- and post-pandemic innovations in workforce development and technology-enabled models offer compelling opportunities to deconstruct the current system to build a more adaptive, agile framework to meet the demands. It is also important to acknowledge that there is global inequity in access to ASD diagnosis (and autism care more generally; (Franz et al., 2017) while at the same time, there are examples of clinical innovations from LMIC that could help inform service delivery to diverse and underserved communities within higher-income countries (de Vries, 2016; Duggal et al., 2020).

We must also anticipate and track how a shift to newer technologies and platforms could inadvertently magnify the cultural and socioeconomic disparities that currently exist (i.e., the “digital divide”) (Crawford & Serhal, 2020; Kumm et al., 2021; Smith et al., 2020). There will be new barriers related to technological capacity and literacy, as underserved families are likely to have less access to needed equipment (i.e., computer, smart phone, or tablet), limited or unreliable internet connection, and less comfort using the internet for healthcare services (Anderson-Lewis et al., 2018; Huh et al., 2018). Furthermore, families need to be comfortable with the level of exposure associated with clinicians venturing into their personal home setting, and with taking on the role of assessor in parent-led remote assessment (Corona et al., 2021; Talbott et al., 2020; Wagner et al., 2020). As such, this shift will increase the need for heightened cultural humility, competency, and awareness among providers (Olsen et al., 2007). The unique cultural and socioeconomic considerations that arise with tele-assessments underscore the need to train professionals on how to tailor the assessment experience to individual and family contexts.

Ideally, the development and adaptation of tele-assessment tools to meet the demands of the pandemic also provides an opportunity to create methods from the ground up that are equitable and have algorithmic parity across demographic characteristics (e.g., race, ethnicity, sex, gender), as well as feasibility across cultures (Dash et al., 2021; Franz et al., 2017). For example, the well-documented sex/gender differences in referral for ASD may in part be attributable to some females with intact language and cognition being “missed” by standard assessment methods (Lai & Szatmari, 2020), reinforcing the need for a comprehensive, multi-modal assessment by trained experts. Furthermore, studies do not typically report the accuracy of ASD screening and diagnostic tools by sex or gender, race or ethnicity, or linguistic diversity, making it unclear whether differential performance of currently available tools is actually contributing to disparities in detection rates (McCadden et al., 2020). We can capitalize on this “re-set” moment to build new tools that have functionality and performance (i.e., psychometrics) that are optimized to reduce disparities, by: (a) identifying activities (to be used in the assessment) that are culturally acceptable and using empirical

methods to ensure that scoring is invariant across diverse groups of children and families; and (b) ensuring that the development and validation process includes families from diverse backgrounds.

Professional training and workforce development for ASD assessment should also carefully consider these disparities and how they affect diagnostic practices, so as to increase clinicians’ awareness and minimize ascertainment and diagnostic biases. Another dynamic that needs to be addressed is the process of evaluating social-communication characteristics in children who have had less social exposure to peers and fewer learning experiences outside of the home due to the pandemic. Although the COVID-19 pandemic is currently shining a light on this issue, it is important to acknowledge that similar issues may arise with children who have experienced disruptions with primary attachments (including those raised in the foster care system), early institutionalization, and/or who are embedded within socially isolated and/or marginalized families (Levin et al., 2015). Ultimately, training in differential diagnosis is essential, and the intervention needs of all children with developmental and/or emotional-behavioral impairments must be addressed in a child- and family-centered and culturally-sensitive way, regardless of diagnosis.

ADOPTING NOVEL APPROACHES TO SYSTEMS-LEVEL CHANGE

The dramatic and sudden changes in the care landscape associated with the COVID-19 pandemic have demanded rapid adaptation and the need to evaluate, in real time, the effectiveness of new practices. Under these circumstances, quality improvement (QI) approaches offer some advantages over conventional research frameworks. For example, Learning Health Systems integrate quality improvement science with clinical practice as a collaborative method for addressing complex clinical challenges, including diagnostic practices (Satterfield et al., 2020). An essential element is the active partnering with patients and families in all aspects of work. Promising practices in this regard include the Extension for Community Healthcare Outcomes (ECHO) Autism model, which blends case-based tele-mentoring and guided practice to build community capacity for ASD diagnosis (Mazurek et al., 2019) and ongoing medical management (Mazurek et al., 2020) to complement what can be offered in specialty settings. Such partnerships might be helpful for fostering clinical expertise that is less tied to particular tools and has greater capacity to rapidly and effectively adapt to an evolving practice environment. Notably, community assessment should include other aspects of best practice (Hyman et al., 2020) including a medical and etiologic evaluation. An important caveat is that training in ASD assessment, whether in a primary care or specialty setting, traditionally occurs in the context of face-to-face, interactive assessments, access to which is limited

during a pandemic. The shift to fully remote evaluations may result in a cohort of trainees across disciplines with limited “hands-on” experience serving children with ASD and their families. Although there are several excellent tools and assessments available (Berger et al., 2021), clinical judgment based on observations from face-to-face assessments (integrated with parent/caregiver report) is paramount in ASD diagnosis. Ultimately, the impact of the shift to remote assessment over the last year on trainee development of clinical expertise remains to be evaluated.

CONCLUSION

Moving forward, we must continue to leverage clinical expertise to tailor assessments to accommodate the complexity of the child’s clinical presentation and families’ priorities, as well as to increase community capacity for effective diagnosis and treatment. This process will entail adopting and developing novel assessment practices (e.g., telehealth, community models including pediatrician training) that increase accessibility and build greater adaptability in the system to respond to a changing environment. It is important to acknowledge that in-person assessment may be required to establish a valid diagnosis, achieve an adequate understanding of an individual’s profile to identify appropriate treatment goals, and/or provide appropriate emotional support in communicating these findings. Moving forward, a hybrid service model (Jang et al., 2021) may be preferable to allow for the benefits of both online and in-person assessments. As part of this process, researchers and service providers across disciplines must work together with stakeholders with lived experience (Alexander et al., 2021) to assist in the conception and co-production of valid, yet flexible, methods for ASD assessment. All of these practices will benefit from ongoing funded roles for partners with lived experience, to provide navigational support and peer mentorship. Many of the priorities identified in this child-focused Commentary could be applied across the lifespan (e.g., training and ongoing mentorship of community professionals to improve access to ASD diagnosis), although the key partners would likely differ. Regardless of age group, special attention must be given to issues of diversity, intersectionality and inequity from the ground up, to address disparities in access and ensure that assessments are feasible and validated for the diverse populations with whom they are used. Finally, cultivating clinical expertise and nuanced understanding of typical and atypical development, attending to and addressing social inequity (locally, nationally, and globally), and actively partnering with children and families to advocate for systems-level change, should be put at the center of the professional training for the next generation of ASD clinicians.

ACKNOWLEDGMENTS

The Autism Science Foundation provided support for gathering of the co-authors. Lonnie Zwaigenbaum is supported by the Stollery Children’s Hospital Foundation Chair in Autism. Meng-Chuan Lai is supported by a Canadian Institutes of Health Research Sex and Gender Science Chair (GSB 171373) and an Academic Scholars Award from the Department of Psychiatry, University of Toronto. Meghan Miller’s efforts were supported in part by the US National Institutes of Health (R00MH106642 and R01MH121416), Amy Wetherby is supported by Eunice Kennedy Shriver National Institute of Child Health and Human Development under Award R01HD093055. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. We would like to sincerely thank Christy Kavulic, Cathy Lord and Joe Piven who provided input to this paper and contributed their expertise and thoughts to the conversations that informed this Commentary. We are also grateful to the many parents and Autistic individuals who helped shape our thinking about these important issues.

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How to cite this article: Zwaigenbaum, L., Bishop, S., Stone, W. L., Ibanez, L., Halladay, A., Goldman, S., Kelly, A., Klaiman, C., Lai, M.-C., Miller, M., Saulnier, C., Siper, P., Sohl, K., Warren, Z., & Wetherby, A. (2021). Rethinking autism spectrum disorder assessment for children during COVID-19 and beyond. *Autism Research*, 14(11), 2251–2259. <https://doi.org/10.1002/aur.2615>