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Commentary: Embracing innovation is necessary to improve assessment and care for individuals with ASD: a reflection on Kanne and Bishop (2020)

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In their thought-provoking editorial, Kanne and Bishop (2020) advocate that comprehensive, expertdriven, diagnostic models for ASD remain essential to maintain quality standards and optimally inform intervention. They recognize the need to grow system capacity but caution against premature adoption of new devices or processes due to risk of diagnostic misclassification, or otherwise substandard evaluations leading to negative consequences for children, families, and the service system. While acknowledging that, 'the field has not completely settled on a specific set of tools or procedures to diagnose autism, nor is the same set of tools feasible or appropriate in every case', they argue that the solution lies primarily in 'more expert providers' rather than 'inappropriately enabling nonspecialty providers'.

The reality is that the number of highly trained experts has not grown in parallel with ASD prevalence, nor does it seem likely that this will occur (Bridgemohan et al., 2018). Thus, many communities will continue to struggle to meet assessment needs if models do not change. Moreover, long-term outcomes hinge on care paradigms that serve not only to accurately identify and diagnose but also accelerate access to services that address related impairments at the earliest actionable timepoints. As such, transparent discourse and rigorous evaluation of new potential tools, care practices, and systems for intervention are needed. We laud Kanne and Bishop for cogently advocating for quality care for individuals with ASD and the value of in-depth assessments. At the same time, we propose that given the complex and heterogeneous nature of ASD -within and across individuals over time-developing suites of tools and innovative approaches for screening, risk-classification, formal diagnosis, and rich assessment of abilities and challenges may be of great value to families and systems of care alike.

Understanding and embracing heterogeneity

There is tremendous and dynamic phenotypic heterogeneity in ASD presentation regarding core

symptoms; cognitive, language, and adaptive skills; comorbid medical and psychiatric symptoms; as well as other skills, abilities, and interests. Given this heterogeneity, it is unlikely that a single diagnostic and assessment approach will be equally suitable for all. Differential diagnosis of ASD is complex, but arguably, not equally complex across the continuum of children identified for assessment. In fact, there is a growing empirical literature supporting the accuracy and potential benefit of professional triage of cases based on complexity (i.e., apparent clarity of symptoms) including models utilizing communitypediatrician leads (Mazurek et al., 2019; Swanson et al., 2014), brief targeted consultation by expert behavioral providers embedded within primary care settings (Hine et al., 2019), telehealth supported models (Stainbrook et al., 2019), and risk-based models informed by ASD screening within early intervention systems (Rotholz et al., 2017). Consistently, there appears to be a sizeable portion of young children for whom marked social communication impairments and restrictive and repetitive behaviors clearly indicative of ASD can be accurately recognized in a variety of community settings. In addition, these novel assessment models may be quite capable of identifying children who ultimately need more specialized assessments to resolve ambiguity, identified either on review of the initial referral or following a community evaluation (Hine et al., 2020; Mazurek et al., 2019). In these contexts, such expert evaluation can represent an important 'safety net' that can mitigate against misclassification.

'Getting it right': what constitutes assessment quality?

Certainly, an inaccurate diagnosis can have deleterious consequences. However, so can delays in diagnosis. Thus, there are potential trade-offs between the unique benefits of resource-intensive, expert-led comprehensive evaluations (which are in limited supply) as the sole option for ASD diagnosis, and resulting wait times. This may be particularly true for families whose access is limited by geographic distance or socio-demographic barriers. Indeed, beyond the phenotypic heterogeneity of ASD, there is considerable variability in terms of

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family, cultural, social, and economic circumstances. Increasingly, health service research emphasizes the need to focus not only on clinically defined outcomes, but also patient-centered outcomes that are meaningful and aligned with patient values. Like ASD itself, assessment quality does not exist along a simple continuum, but, rather, can be considered a multi-dimensional construct. As such, evaluating quality of assessment should take account of content as well as process, with a focus on how key endpoints (e.g., accuracy, communication of findings, access to services that enhance functioning) are achieved, and through the lens of family experience. To date, ASD diagnostic models have not been compared head-to-head in this regard, contributing to substantial variation in international guidelines (Penner et al., 2018). For many families, satisfaction with diagnostic experience derives mainly from clarity of communication and practical guidance regarding services, and negatively related to wait times (reviewed in Zwaigenbaum & Penner, 2018). There is limited empirical work examining how the duration, depth, or expertise of those participating in the assessment relate to these outcomes. Does having an 18-month-old child living in a rural area wait 12 months then drive 3 hrs with their family to participate in 8 hrs of testing (likely in a dysregulated state) inherently yield a high-quality assessment? What if this same family can participate in a telehealth assessment within their medical home where an expert provider can help triage concerns and mentor a previously trained community provider or team? What if they could then receive navigation support informed by knowledge of local evidence-based services and resources? From this perspective, services and tools developed to be delivered in the child's community may also achieve 'quality' and help reduce disparities associated with geographic isolation, cultural/linguistic diversity, and lower SES.

Can we structure meaningful systems of care?

There is little empirical support for the idea that comprehensive assessment is necessary to accurately identify all young children with ASD. In fact, there is emerging data that individual providers report ambiguity in diagnostic impression in only a minority of referred children. Indeed, McDonnell et al. (2019) noted that 60% of all young children referred for ASD assessment were identified with 'complete certainty' in a recent multi-site investigation. These children presumably would not fall into the 'very complex' differential diagnosis category that Kanne and Bishop describe. For these children, would not ideal systems of care be able to move forward with assessment without delay? Could tools be developed and deployed across varied community settings to enhance system capacity to accurately diagnose such children in a timely manner that

guides access to appropriate services? There is emerging evidence that training a variety of providers in an array of rapid and comprehensive assessment methods across levels of care may result in substantial improvements in early accurate identification and service access. For instance, Rotholz et al. (2017) reported that an interdisciplinary assessment training program deployed across community pediatricians, their early intervention system, tertiary providers, and the state's disability eligibility agency resulted in a system of care that quintupled the number of children deemed eligible for ABA resources with over-diagnosis of only 2% of referred children. We contend that novel tools, new ways of thinking about training, and engagement of a wide variety of providers across systems of care can facilitate accurate diagnosis and treatment across these systems. If 60% of referrals are triaged to such community pathways in order to receive initial help, the limited reserve of expert and comprehensive assessments can then be focused efficiently to serve the remaining 40%.

Education and training

For decades, a diagnosis of ASD was thought to be the right and exclusive domain of specialists in development and behavior (e.g., clinical psychologists, developmental pediatricians). Unfortunately, there are not enough of these providers to perform comprehensive ASD evaluations. Recent workforce surveys of developmental and behavioral specialists have suggested that current practice models are 'insufficient and unsustainable' and advocated for broad solutions to critical shortages including novel strategies to promote training and education of other providers (Bridgemohan et al., 2018). Training models have targeted community providers or developed learning collaboratives to enhance access to ASD care and demonstrated shifts in perceived competencies as well as numbers of children directly served (e.g., Mazurek et al., 2020; Swanson et al., 2014). However, to date these models target practicing clinicians rather than preclinical trainees and represent attempts to instill competency and practice behaviors well after formal learning opportunities. There may be further value in developing crossdiscipline training programs, as pediatricians, psychologists, speech/language pathologists, early childhood educators, school professionals, and home visitors/early intervention providers can all play a role in a system of care supporting of identification and diagnosis of ASD. For instance, innovative models for training pediatric medical residents (Hine et al., 2019) could provide similar levels of exposure and support to entire cohorts of professionals on a population level to the same tools found useful in shaping practice behaviors of what now amounts to a select few (Mazurek et al., 2020; Swanson et al., 2014).

It is sobering to be drafting this commentary in the midst of a global pandemic, which has had such a profound impact on all communities and has been particularly disruptive to children with ASD and their families. Despite the devastating impact of COVID-19, one small silver lining has been the examples of clinical teams that have been able to adapt care models to these challenging circumstances to maintain a lifeline of support to families, including innovations in diagnostic models, which inspires hope for further opportunities to better serve the diverse needs of this diverse population.

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