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A parent-centered approach to autism diagnosis in early childhood
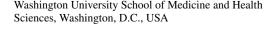
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The prevalence of autism spectrum disorders in the United States is estimated to be approximately 1 in 68 children (though the World Health Organization estimates a global prevalence of just 1 in 160 children) [1, 2]. The average age of the initial diagnosis is estimated to be 4 years of age [3], though research has shown that signs of autism can be observed by the first birthday, and possibly before [4, 5]. Early identification of autism is vital to prognosis, as studies have consistently shown that children who receive treatment at a younger age have better outcomes [6]. Even with the right treatment, however, the degree to which caregivers are invested in the therapeutic process serves as a mediating factor [7]. For this reason, an autism-specific evaluation should aim not just to provide a diagnosis, as appropriate, but also to allow caregivers to participate in the diagnostic process in a manner that educates and empowers them.

Most autism-specific evaluations are administered from a "child-centered" approach, as the goal of a developmental evaluation is to try to understand the child—who the child is, how the child perceives and relates to his or her environment. Indeed, the first step of an autism-specific developmental evaluation is to try to understand the child personally and clinically. However, as the inevitability of an autism diagnosis becomes increasingly clear, the focus of the evaluation shifts from the child to the parents/caregivers, as the goal of the evaluation shifts from ascertaining the diagnosis (i.e., answering the diagnostic question) to helping the parents understand the diagnosis and how it pertains to their child.

The Child Development Clinic at Children's National Medical Center provides developmental evaluations for children from birth through 3½ years of age. My colleagues and I assess many children who are at an elevated risk of developmental challenges, including former preemies and children with complex medical histories, many of whom we initially evaluate in early infancy. We also have many patients whom we first evaluate in toddlerhood and, starting around 18 months of age, many of the referrals from pediatricians, therapists, teachers, and parents are based on concerns about potential autism. Our goal in these autism-specific evaluations is not only to answer the diagnostic question, but also to look at the child's development more broadly—how is the child doing across all domains, what are the biggest challenges, and what domains seem to be lagging behind others. We start with comprehensive developmental measures (i.e., the Bayley Scales of Infant and Toddler Development) based on the principle that before assessing a child's social development, you must first have a sense of their broader level of development. (You cannot expect a child to function socially at a level that is higher than his or her developmental level.) Our goal with the Bayley is not solely to obtain precise standard scores or age equivalents, but instead to look at the child's strengths and weaknesses and to help the parents get a clearer sense of what seems to be the primary or foundational issues affecting the child's development. For example, although parents generally express concerns about walking and talking (i.e., during infancy and toddlerhood, respectively), our goal is to direct parents' attention to more foundational issues, such as challenges in terms of cognitive development, attention/self-regulation, and social/emotional development.

Working in a diverse and multicultural metropolis such as Washington, D.C., we see children from a range of backgrounds. Our population varies widely in terms of language, culture, parental education history, and socioeconomic status. We see parents who have never heard of autism, and we see parents who have "googled" every potential symptom and are anxiously expecting to confirm the diagnosis. Some parents spontaneously express concerns about autism, and some parents assume that their child simply has a speech delay that will resolve in due time. The parents' starting

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point dictates how the clinician approaches and addresses the "parent-centered" aspect of the evaluation.

As the diagnosis of autism becomes increasingly clear, the goal of the evaluation shifts from being focused on the child (and on the diagnostic question) to focusing on assessing the parents' understanding of the clinical concerns and of the diagnostic picture. The parents' knowledge of, and emotional/psychological readiness to discuss, autism and how it pertains to their child varies widely. Instead of directly asking about autism or autism-specific concerns, the clinician starts by trying to gain a clearer understanding of the parents' perspective: What are their concerns? What do they see as the primary issue? The clinical interview starts with their concerns and branches outwards, perhaps focusing on expressive language deficits, at first (i.e., parents who initially describe concerns that the child is not speaking) but then pivots towards deficits in terms of social communication. We ask broad, open-ended questions. Rather than specifically asking about eye contact and gesture use, for example, we ask about how the child gets his or her needs met. As the developmental evaluation and clinical interview progress, the questions become increasingly specific and the examiner is tasked with completing the interview while simultaneously observing the child (or while administering play-based measures). Even when the diagnosis is exceedingly clear, we proceed with play-based testing items as a means to target and clarify the social/social communication deficits, both for information-gathering purposes and so that the parents have the opportunity to observe these deficits. It can be helpful to administer the clinical interview and the testing items simultaneously such that the clinician can target the skills/deficits that the parents are reporting with the goal of providing the parents with deeper insight into these skills/deficits. For example, if parents express uncertainty about whether the child coordinates eye contact with a pointing gesture, the clinician attempts to elicit a point with coordinated eye contact as a means to both assess the child's skill and instantiate potential deficits for the parents' sake.

As testing progresses, it becomes clearer whether the parent report and the child's presentation are consistent. Some parents report higher functioning or more consistent social/ social communication skills than we readily elicit during testing and it is the clinician's responsibility to attempt to reconcile the discrepancy. Are the child's social struggles mainly due to the novel environment and/or unfamiliar examiner? Are the parents having difficulty answering specific questions about social communication due to a lack of attention to these specific skills or limited broader experience with young children? (It is not uncommon for parents— especially first-time parents—to lack a baseline to which they can compare their child's social skills.) As we gain a better understanding of the parents' perspective, attending to potential defensiveness, the clinician's role and goal shift to align with the parents' needs. It then becomes the clinician's job to not just elicit information from the parents, but also to show the parents, through the interview questions and through the interactions with the child, examples of the child's social deficits. With some parents, the clinician needs to be more direct to assure that the parents recognize the social challenges.

A parent-centered approach to testing is based on the objective that, by the end of the developmental evaluation, the parents and the examiner should be able to come to a common understanding about the child's developmental challenges. Whereas the parents may start off expressing concern solely about speech or behavioral challenges, for example, the interview and the play-based testing items can help draw the parents towards the understanding that the social deficits are the primary, foundational issue. The clinician's job is not only to clarify and provide the diagnosis; it is our job to also assure that the parents understand and, ideally, agree that the diagnosis is appropriate.

When I start feedback with the family, I first start by talking about the goals of the developmental evaluation—to assess a child's developmental levels but primarily to evaluate the child's strengths and weaknesses. I describe our goal of not just assessing speech delays, for example, but also looking at the underlying skills that affect language development, including nonverbal problem-solving skills, receptive language development and, perhaps most importantly, social development. I describe how, in their child's case, it is not the lack of language that concerns me but instead the lack of underlying social and social communication skills that form the foundation of language development. I discuss how, when we see deficits not just in language but also in these social foundations of language (e.g., eye contact, gesture use, imitation, joint attention, social referencing), it arouses concerns about potential autism spectrum disorder. I allude to the restricted and repetitive behaviors that round out the autism diagnosis. After mentioning the diagnosis (particularly, if it is the first time that autism has been mentioned), I take time to "check in" with the parents and more directly assess their understanding of autism, trying to get a sense of what autism means to them. Only then do I describe specific symptoms of autism as they pertain to their child. I provide a simplified version of the diagnostic criteria: deficits in social communication, deficits in social interest, and restricted and repetitive behaviors (I combine *deficits in social-emotional reciprocity* and *deficits in developing relationships* into *deficits in social interest* for simplicity's sake and because these criteria overlap in toddlerhood). I provide the family with examples of each diagnostic criterion, making sure to use both examples of behaviors that I have seen during testing as well as examples from the parent report of the child's behavior at home. The parents need to truly believe that we are making the diagnosis not just on what we have seen over

the course of the two hours of interacting with the child, but that the diagnosis is largely based on the parents' concerns and the parents' report of what the child is like on a daily basis and in a familiar environment with familiar people.

The type of language I use during feedback also depends on the parents' readiness and awareness of autism. By the time feedback starts, some parents have already expressed concerns about autism and are fully ready to receive the diagnosis, sometimes experiencing the diagnosis as a relief or, at least, a confirmation of their concerns. Some parents are familiar with autism but believe that it only refers to children with cognitive deficits (autism does not refer to cognitive functioning). Others are under the impression that autism is a term that cannot refer to a child with age-appropriate language (it can) or a child who shows some degree of social interest (it can). Most parents need to be eased into the diagnosis, they need to be walked through the diagnostic criteria so that, ultimately, they are not receiving the diagnosis, they are also making the diagnosis. We may be the "experts" on autism and early childhood development, but nobody knows the child as well as the parents; and if our diagnosis relies on parents' report (as an autism diagnosis should), then the provision of our diagnosis should similarly aim to obtain parents' accord.

The goal of a developmental evaluation is not solely to assess a child's development or clarify the diagnosis; it is also to assure that the child gets the help that he or she needs. If parents do not agree with the diagnosis, it is less likely that the child will receive that help. The parents will be the child's primary advocate, and services could be impacted if the parents do not believe that the child is on the autism spectrum. More importantly, perhaps, if the parents do not agree with the diagnosis, it is less likely that they will adjust the home-based routines based on these social concerns (such as by limiting screentime).

The developmental evaluation is, in many cases, the first formal evaluation that the child has undergone and, for many families, it is the first in a long line of neuropsychological and psychoeducational assessments that the child and family will endure. Our goal is to provide as positive an experience as possible, even if the diagnosis causes emotional distress for the parents, and we aim to make parents active participants in that process. Providing a family with an autism diagnosis requires a delicate balance: empathy with strength, warmth with assuredness, compassion with confidence about next steps. The family needs to know that we have seen such challenges before, that we have counseled families through the process, and that, in many cases, children make progress.

Compliance with ethical standards

Ethical approval Not required for this personal viewpoint.

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References

1. Autism and Developmental Disabilities Monitoring Network Surveillance Year 2008 Principal Investigators, Centers for Disease Control and Prevention. Prevalence of autism spectrum disorders—Autism and Developmental Disabilities Monitoring Network, 14 sites, United States, 2008. MMWR Surveill Summ. 2012;61:1–19.
2. Christensen DL, Baio J, Van Naarden Braun K, Bilder D, Charles J, Constantino JN, et al. Prevalence and characteristics of autism spectrum disorders among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States 2012. MMWR Surveill Summ. 2016;65:1–23.
3. Zwaigenbaum L, Bryson S, Garon N. Early identification of autism spectrum disorders. Behav Brain Res. 2013;251:133–46.
4. Zwaigenbaum L, Bryson S, Rogers T, Roberts W, Brian J, Szatmari P. Behavioral manifestations of autism in the first year of life. Int J Dev Neurosci. 2005;23:143–52.
5. Werner E, Dawson G, Osterling J, Dinno N. Brief report: Recognition of autism spectrum disorder before one year of age: a retrospective study based on home videotapes. J Autism Dev Disord. 2000;30:157–62.
6. Reichow B, Barton EE, Boyd BA, Hume K. Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). Cochrane Database Syst Rev. 2012;10:CD009260.
7. Estrada AU, Pinsof WM. The effectiveness of family therapies for selected behavioral disorders of childhood. J Marital Fam Ther. 2010;21:403–40.