

VIEWPOINT

How to help underserved groups gain access to autism care

BY LISA SHULMAN

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Professionals who specialize in autism diagnosis and treatment often set up shop in specialty clinics or autism centers, typically in children's hospitals or major medical centers. They tend to wait for children with autism to come to them, usually referred by pediatricians or concerned parents.

But this system favors families who are regular consumers of healthcare, are able to make it through the doors of specialty clinics and know how to make their voices heard. These families tend to have means and good health insurance. Appointments are booked months out, so even they have to wait for specialists who can administer a gold-standard diagnostic test, such as the Autism Diagnostic Observation Schedule (ADOS). The process is even more difficult for families with fewer resources: It may be complicated by lack of awareness and information about autism, language barriers, lack of parental empowerment to share concerns, reluctance to question a doctor's recommendations, providers who dismiss parents' concerns or give alternative diagnoses, and a complex and slow diagnostic process¹.

There are more efficient, and equitable, ways to help underserved communities gain access to autism diagnosis and care.

I'd like to introduce some ways of doing so that have worked at my center in the Bronx, New York. Our facility, the Rose F. Kennedy Children's Evaluation and Rehabilitation Center, has had success in increasing access for families of low socioeconomic status. We regularly diagnose children with autism before 2 years of age, when interventions are likely to be most helpful.

Our population in the Bronx is among the poorest, most diverse and youngest urban population in the United States. It is 55 percent Hispanic, 43 percent African-American and 32 percent foreign-born, according to the last U.S. census. Nationwide, African-American and Hispanic children are **less likely than white children** to be identified as having autism before school age^{1,2,3,4}.

When I present data from our clinic at conferences, people often ask: How did you get this group of children diagnosed so early? They also want to know how we get them to participate in research. Here's how.

Community care:

First, plop your diagnostic program down in the middle of the community and stay for a long time so you become a known and trusted resource.

Our center sits in the heart of the Bronx and provides multidisciplinary diagnostic evaluations and services to children with developmental disabilities in the community. We've been here for more than 60 years. Each year, we see about 7,000 children, diagnose about 300 with autism and see about 1,600 children with autism for therapy, medication management or developmental follow-up.

Second, reduce the barriers to entry. Eliminate the need for physician referral. Address language and cultural hurdles, and tackle insurance-related barriers.

Meet P., an African-American boy who is 28 months old. (Throughout this piece, I'm using only the first letter of children's names to protect their privacy.) His mother led him into the clinic by the hand, and he was screaming so loudly I could hear him from down the hall. The registration secretary at the front desk told me that the mother had reported that a lady on the bus told her to bring her little boy here, and that we would know what to do to help him speak. We did.

Our center accepts Medicaid of all varieties, and we do not require a referral from a primary-care provider. That means families can refer themselves, removing a significant barrier to access. Also, we have a full complement of bilingual Spanish-speaking clinical and administrative staff.

Wide net:

Third, cast a wide net and bring your autism expertise to the front door. That means looking at every child who comes in for any reason or concern and being ready to identify autism.

Meet D., a 22-month-old Hispanic toddler who has not yet started to speak. His mother doesn't see this as a problem because she knows that her son is smart and independent. When he is hungry, he goes to the refrigerator on his own and brings her the gallon of milk. D. is an 'easy baby' who can entertain himself for long periods of time. The mother brought D. in because he tends to walk on his tiptoes, and she thinks he may need special shoes. She also wants to get his

hearing checked because he doesn't always respond when she calls his name.

Both P. and D. have clear signs of autism. Neither child was referred to our center to be evaluated for autism; neither parent mentioned it as a concern. In fact, it is extremely rare that we see young children who are referred because they failed the **Modified Checklist for Autism in Toddlers** (a screening tool for autism in toddlers) in their pediatrician's office. Rather, parents bring their children because of a more general concern (not talking) or a different concern (toe-walking).

At our center, we like to say that we bring our autism expertise to the front door. We're proud of this capability, because children who might otherwise be overlooked get an early diagnosis.

On the spot:

Fourth, do as much as you can the first day a person comes in. Treat an early autism diagnosis as an emergency.

Don't make a family wait months for an evaluation with the ADOS when you can see that the child clearly meets **the criteria** for autism. Instead, use a diagnostic instrument that can be used on the spot, such as the **Child Autism Rating Scale**; talk with the parent regarding her concerns and yours; and move ahead with a plan the family is comfortable with.

Why? Because you never know when that family will come back. At our center, we have a high no-show rate for appointments. Our families tend to have many other stressors in their lives, so we rush to get a diagnosis that facilitates getting autism-specific early-intervention services in place, either at home or at the center.

When you heed these four principles, you form a partnership and a lifelong relationship with the people you serve. As a bonus, you won't have any problems getting your community partners to **participate in research**.

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