

Addressing the Crisis in Access to Autism Care

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Over the past 20 years, the prevalence of autism spectrum disorder (ASD) has grown tremendously, from 1 in 150 children in the U.S. in 2002 to 1 in 44 children today. But while screening and diagnosis have become more accessible, the systems in place for providing quality, affordable care are not meeting the growing community need, leaving people with autism and their families with few options.

Poor access to necessary healthcare can lead to reactive crisis management rather than proactive care, with potentially dire effects on the health and well-being of autistic people and their loved ones. For some, this may look like aggression, self-injury and other severe and unsafe behaviors. For others, it may look like crippling anxiety, obsessive compulsive disorder (OCD) or depression that negatively impacts day-to-day functioning and participation in community life. In the face of these crises, many have no other choice than to seek care in the emergency room but these days, the Emergency Room is in a crisis of its own.

A Washington Post article recently illustrated the devastating impact of inadequate autism care in the ER and inpatient mental healthcare systems. The article shared a family's tragic story of losing their son Zach to a seizure after two extended stays in the ER while he awaited a bed in an inpatient facility equipped to provide care for his aggressive outbursts.

Zach's experience in the ER is not uncommon among people on the spectrum. Research shows that children with ASD are nine times more likely to visit the ER for psychiatric problems than children who don't have autism, and autistic adolescents are four times more likely to visit the ER than their peers. But despite the higher frequency of admission, autistic people who go to the ER demonstrate lower patient satisfaction and higher unmet healthcare needs related to physical and mental health.

A culmination of bottlenecks and failures at multiple levels of our healthcare system has made the ER a last resort for most families. One contributing factor is the lack of easy access to behavioral and mental health services for autism and its co-occurring conditions that could help prevent and manage the types of crises that drive families to seek urgent help. Other factors are limitations in insurance coverage for needed mental health

interventions and a lack of reimbursement for providers offering these services.

At Autism Speaks, we are implementing a multi-layered approach to improve access to care for people with autism and ensure that local community providers not just autism specialists have the knowledge and skills they need to effectively serve this population.

Much of this work happens through our Autism Care Network (ACNet), a partnership of 24 participating medical centers across the U.S. and Canada working to improve person and family-centered autism care through research and the use of quality improvement methods to deliver best practice care to children and adolescents with autism.

The Network has developed evidence-informed clinical pathways to improve the identification and treatment of attention-deficit/hyperactivity disorder (ADHD), anxiety and irritability in autism— three of the most common contributors to disruptive behaviors in autistic patients receiving care at ACNet sites. These best practices are currently being tested among select Network sites and will ultimately be disseminated to community providers, building capacity for primary care clinicians to deliver preventative care to reduce behaviors that could escalate into a crisis-level situation.

Autism Speaks, with the support of the ACNet, also recently published its *Clinician Guide: Program Development and Best Practices for Treating Severe Behaviors in Autism*, a resource for licensed professionals and healthcare systems offering detailed guidance to expand clinicians' understanding of severe behaviors in autism and help them develop programs that can effectively serve those with this intensive level of need.

Lastly, the Autism Care Network, in collaboration with ECHO (Extension for Community Healthcare Outcomes) Autism Communities, offers virtual, interactive training sessions for providers in the areas of anxiety and autism, behavioral crisis care in hospitals, mental health, Research Units in Behavioral Intervention (RUBI) parent training and a variety of other topics through the ACNet ECHO Autism clinics. With these trainings, we are increasing provider capacity and improving access to autism care, knowledge and resources in underserved and rural areas.

But we recognize that the work doesn't stop at the clinic. Because there are significant disparities in access to clinical care across the U.S., Autism Speaks is also working directly with families and caregivers to improve their knowledge of autism so they can better support their autistic loved ones. Family ECHO: Autism and the Caregiver Skills Training (CST) program are two critical programs through which we are reaching families and helping them develop the skills to recognize and limit crisis situations. We have also created a number of Tool Kits and Roadmaps for families, including a robust Challenging Behaviors Tool Kit. A new Roadmap to educate families about severe and distressing behaviors will be released in early 2023.

At Autism Speaks, we also know that coverage is not enough autistics and their loved ones need more accessible healthcare. To this end, we are advocating for state and federal enforcement of network adequacy and parity provisions, lower patient costs and networking with insurers that are more attractive for providers.

While we have taken significant steps forward in increasing access to quality care, there is more to be done if we are to fulfill our vision of a world in which all autistic people can reach their full potential. As we move forward, it is a time for optimism, growth and continued dedication to building a better world for all.