More Children Diagnosed with Autism: What Services Can Philadelphia Families Access?

Population Health Sciences

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Recently, the Centers for Disease Control and Prevention (CDC) released new estimates for the prevalence of autism spectrum disorder. In the 11 states included in the study, 1 in 59 school-age children is estimated to have autism. Rates have increased slightly from data released in 2016, which estimated that 1 in 68 children had autism. However, I believe the small increase likely reflects improvements in screening and diagnosis, rather than a true change in risk. After decades of rapidly increasing rates of autism that contributed to fears about an "autism epidemic," the rate is relatively stable.

These numbers show that autism touches many families, as well as medical, educational and community systems. So how can we use these numbers to ensure that children with autism in Philadelphia have access to the care that they require? In this first post of a two-part series, I'll examine how children are diagnosed with autism and the interconnected systems that are responsible for their care. In the second post, I'll detail how these systems may be vulnerable to public policies that do not account for these new prevalence rates.

What is Autism Spectrum Disorder?

Autism spectrum disorder (ASD) is a neurodevelopmental condition, defined by differences in how a child experiences the world around him or her. Because it is a spectrum, each child with autism can have a unique presentation, and there is a range in the severity of impairments.

Autism is diagnosed when a child meets clinical criteria for having significant difficulties with social communication and is demonstrating restricted or repetitive behaviors. Deficits in social communication include difficulties in the way that a child uses words, eye contact and body language to communicate with other people in a back-and-forth way. Restricted and repetitive behaviors can include differences in how a child moves his or her body (such as by flapping his or her hands) or experiences sensory input, the unexpected way that he or she plays with toys or in how focused a child becomes on a particular object or topic at the exclusion of others. Many children may have one or more of these differences. But when a child has multiple and significant difficulties in both categories, a diagnosis of ASD is appropriate. While these difficulties impair a child from learning from the people and environment around him or her, therapies can help them progress.

Who Cares for Children with ASD in Philadelphia?

Role of Medical Providers in Diagnosis and Management of ASD

Primary care providers, including pediatric or family medicine doctors or nurse practitioners, are well situated to identify early developmental concerns, including autism, because of their frequent contact with children under the age of two, when symptoms of autism emerge. Pediatricians can either make a diagnosis of autism, or can refer a family to a specialist (such as a developmental-behavioral pediatrician, psychiatrist, psychologist or neurologist) for an evaluation. At Children's Hospital of Philadelphia (CHOP), primary care providers can refer children to the Autism Integrated Care Program for ASD evaluations. Children who participate in studies in CHOP's Center for Autism Research may also be eligible for assessments.

Simultaneously, while a child is waiting for additional evaluation, the American Academy of Pediatrics encourages pediatricians to refer the child to intervention services. Once a child has been diagnosed, primary care providers continue to provide routine care, and they can identify and manage other conditions that are more common in children with autism, such as sleep problems, obesity and gastrointestinal issues.

Role of the Education System in Providing Services for Children with ASD

Depending on his or her age, a child in Philadelphia with a developmental or autism-specific concern can be referred to a provider within the educational system: Early Intervention Services (up to three years), Elwyn (three-five years) or the school district (five years and older). Anyone can make a referral to Early Intervention, and families can even self-refer when they are worried about how a child is developing. The education system will conduct its own evaluation of the child and determine what services the child requires, although the team often takes into account prior medical evaluations. Through the education system, children can access specialized classrooms or instruction, as well as interventions such as speech/language, occupational and physical therapies.

Role of Community Behavioral Health Agencies

Children with autism are often referred to behavioral health agencies for evaluation and behavioral intervention, including Applied Behavioral Analysis, or ABA. ABA is the most-studied behavioral intervention for children with autism, although it's not the only form of behavioral therapy that is helpful for kids with autism. ABA and similar therapies help teach children foundational communication skills, work on their social interactions and increase a child's flexibility when approaching new situations. In Philadelphia, Community Behavioral Health provides behavioral therapy to patients insured through Medicaid, or Medical Assistance (MA). MA plays an important role in helping families access behavioral therapy services for their children. Even for families with private insurance, supplemental MA can often be the primary means for accessing behavioral therapy, but families can also call their insurance company to find other agencies that provide this care.

Interconnected Systems of Care

Using accurate and up-to-date estimates of the number of children with autism we can educate policymakers about the number of families affected by ASD and the complex systems that they must navigate to access

diagnostic and intervention services. By improving the coordination of care across medical systems, schools and community agencies, we can ensure that kids with ASD get the care they require more quickly and more easily.

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