More Children Diagnosed with Autism: Policies to Help Philadelphia Families Access Services

Population Health Sciences

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In my most recent blog post, I wrote about the new Centers for Disease Control and Prevention (CDC) prevalence estimates for autism spectrum disorder (ASD) and the systems in place in Philadelphia to provide care for children with ASD. In this follow-up post, I write about the top policy implications of these new prevalence counts.

Across the 11 states included in the CDC analysis, an estimated 1 in 59 children is estimated to have autism, an approximate 15 percent increase from the last estimates in 2016. However, I believe the small increase likely reflects improvements in screening and diagnosis, rather than a true change in risk. Yet, these new numbers come at a time when access to health care coverage and services continue to be hotly debated in our halls of government. If we are to ensure that children with autism are receiving the right care, at the right place, at the right time, our policies must not only reflect these new numbers, but strengthen our systems to provide comprehensive, coordinated care to all children with autism and their families.

Providing Culturally Sensitive Care

One of the most likely explanations for the small rise in ASD prevalence is improved recognition of populations previously under-identified with ASD, including children from black and Hispanic backgrounds. There are no biologic differences that explain why ethnicity or race affects autism risk, but for many years children from non-white backgrounds were under-identified. The recent CDC study found that the gaps have narrowed, with more black and Hispanic children identified compared to prior prevalence estimates.

Recognizing the racial, ethnic, linguistic and cultural diversity of children affected by autism implores us to ensure that our systems are sensitive to each child's unique needs. At the very least, interventions and therapies should be made available in a variety of languages. Because children with autism often have difficulties generalizing the skills that they learn, children who receive speech/language therapy in English rather than in a family's preferred language may have difficulties learning to speak with their parents. Ensuring a diverse workforce of providers and therapists can help to promote delivery of culturally sensitive care.

Ensuring Access to Quality Public Insurance Options

Children in Pennsylvania with a diagnosis of autism qualify for supplemental Medical Assistance (MA), a public insurance benefit, regardless of family income. MA can be used to help families with medical co-payments, and children with MA can receive Behavioral Health Rehabilitation Services (BHRS, previously called WrapAround therapy) including home-based behavioral therapy. Medical Assistance also helps to pay for therapies in school, such as occupational or physical therapies. Even families with private insurance often rely on Medical Assistance as the primary way to access ASD services for their children.

In our ever-changing health care landscape, policymakers must recognize the vital importance of Medical Assistance in providing care for children with ASD. Changing the qualifications or funding for Medicaid would have enormous ramifications for a child's ability to access care in multiple settings: the medical office, schools and at home. With an estimated 1 in 59 children affected by ASD nationwide, policymakers should consider the needs of this large population when reviewing legislation that may affect Medicaid and these inter-dependent systems.

Building and Maintaining the Necessary Medical Workforce

While nearly every pediatric subspecialty sees children with autism developmental-behavioral pediatricians (DBPs) have additional training to diagnose and provide ongoing care for these children. However, the DBP workforce is expected to be increasingly unable to meet the needs of the growing population of children with ASD. A recent study found that the DBP workforce is insufficient to meet current demand, and approximately one-third of DBPs are expected to retire within the next five years. The new prevalence data can be used to educate policymakers about the looming shortage in trained DBPs. Additional support for fellowship training programs can help to address this gap. Furthermore, we should consider increasing reimbursements for care provided and novel ways to improve the efficiency of clinical care.

Strengthening Community Agencies to Support Demand

Community agencies are facing long waitlists to complete evaluations and provide staffing for children who qualify for services. As the population with diagnosed ASD grows, the strain on community agencies is likely to increase. In Philadelphia, my patients often wait several months to receive behavioral therapy, the hallmark for treating ASD, through community agencies. These delays in receiving crucial therapies can have negative effects for children and their families. Having an accurate estimate of the population with autism can help insurance providers anticipate the number of agencies they need to contract with, and can help agencies determine the number of therapists required to meet the need for all children with autism.

Ensuring Caregivers Have the Supports They Need

Parents and caregivers comprise the largest segment of the workforce caring for children with autism. Caregivers provide care around-the-clock to meet their child’s above-average needs. In addition, they engage children in therapies throughout the day to reinforce the skills learned during home-based or center-based therapy sessions. Many therapies utilize parent training to deliver the intervention to children, including one developed by the World Health Organization.

With more families affected by autism, policymakers should recognize the efforts of caregivers by supporting them with policies such as expanded access to paid family leave, flexible work schedules and respite care services. The needs are vast, but armed with data about the number of children and families affected by autism, we can make sure that services and support are adequate to help these children reach their optimal potential.

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