Children's Hospital of Philadelphia
PolicyLab

Rates of Autism Increase, but Numbers Don’t Paint the Full Picture

Health Equity

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Image

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Headlines over the past 20 years have signaled ever-increasing recognition of autism spectrum disorder (ASD). Now, in a new article published in *Autism*, our team describes our own estimates of how many children across Children’s Hospital of Philadelphia’s (CHOP) Primary Care Network have been diagnosed with ASD. What we found highlights the importance of tracking and unpacking the numbers of diagnoses to identify areas for continued improvement. This includes improving data collection for communities—such as Asian American families—that have been excluded from other studies of autism prevalence or whose needs have been obscured when categorized as “other.”

What we found

We found that almost 1 in 31 children, or 3.2% of our population, met our diagnostic definition for autism. This number is higher than some national data, but in line with a more recent study published in the last year. The median age at which a diagnosis was documented was 3.93 years. We are encouraged that more than half of our population was diagnosed before age 4, as we know that early diagnosis, which can provide early access to needed supports, can help children learn new skills.

We were also encouraged that our team found fewer racial, ethnic and socioeconomic disparities in ASD diagnoses than we might have expected based on historical data. For decades, Black, Hispanic, and other minoritized racial and ethnic children, as well as children from families with lower incomes were known to experience delayed and missed diagnoses of ASD. We found that after adjusting for other factors, children who identified as Black, Hispanic, White, or had other or multiple races were diagnosed at the same rates and ages. Similarly, socioeconomic vulnerability did not affect rates or ages of diagnosis.

However, children who identified as Asian had higher rates of ASD diagnosis compared to children from other racial groups—5.4% of Asian children (or 1 in 19 children) were diagnosed with autism. As this was an exploratory study, there is much more to do to understand these results.

Race and ethnicity are psycho-social constructs. As such, history suggests that when differences in autism prevalence between racial or ethnic groups are found, or are found to change, it is due to differences in identification rather than in underlying biology. Thus, our differences in rates of diagnoses compared to historical findings could be due to differences in internal clinical processes or in the social influences of health. For example, children may have differences in how they access and use health care services, or in the care they receive.

It's important to view this data not as a conclusion, but as information we can use to ask the next right question as we continue to put equity at the forefront of our care.

What can our teams in research and primary care learn from this study?

First, the rates of ASD across the CHOP Care Network can be used to help ensure we have the capacity to meet the needs for this large group of children with ASD.

While our data on age of diagnosis is promising, we can do more to continue to improve early identification and access to services. A new model, known as the Autism Care Champions in Primary Care, seeks to train primary care providers at Care Network sites to diagnose patients in their own practices and facilitate next steps to help families access needed services. Providers in these practices can refer their patients for evaluation if they have a high suspicion for ASD and if those patients meet specific referral criteria. Families can then pursue those assessments in their familiar primary care office, which can increase their comfort and expedite care without having to see a specialist to make the diagnosis.

An extra advantage of this program comes in the form of bi-weekly sessions where the Autism Care Champions can present any challenging cases to an interdisciplinary team of experts for discussion and clarification, building on the successful ECHO models used in various settings.

This consistent and open communication between primary care providers and developmental specialists is instrumental in ensuring that the child is receiving the most comprehensive and up-to-date evaluation possible. As this model grows, our hope is to decrease the median age of ASD diagnosis to have the greatest impact on children and families, and to decrease time between initial referral by a primary care provider and the actual diagnosis. Currently this interval can be as long as 18-24 months, since many developmental specialists have wait lists that long. This model can shorten time to diagnosis to half that, if not sooner.

And finally, ongoing efforts need to continue to center equity. Processes that reduce diagnostic barriers for historically and contemporaneously underserved groups continue to be needed. Additionally, it is necessary to increase equity in access to services post-diagnosis to ensure that children's needs are being met in a just and equitable way. For example, half of Asian children and 41% of Latino children in the Philadelphia metro area have at least one parent with limited English proficiency. For these children, interpreting, translation and bilingual providers play a key role in service delivery.

They say that if you can't measure something, you can't improve it. This exploratory project to quantify rates and ages of ASD diagnosis can serve as a benchmark as we continue to strive to improve care. It also illustrates the importance of granular data on race and ethnicity. As we aim to seek novel solutions to better meet the needs of children and families with ASD, continuously measuring our impact on diagnostic ages and on racial and ethnic equity will be crucial.

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