Children's Hospital of Philadelphia
PolicyLab

Disparities in Autism Screening and Well-Child Care Persisted During the Pandemic, but Novel Solutions to Promote Equity Exist

Health Equity

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We are just beginning to understand the impacts of the COVID-19 pandemic on children over the last two years. Although children generally had lower risks of severe infection with COVID-19, they were not spared from its wide-ranging effects, including disruption in seeking and receiving routine well-child care. Even more concerning was that pandemic-related burdens were disproportionately experienced by children from racial/ethnic minority communities, children in families with low incomes and children with developmental disabilities.

In a new article in *Academic Pediatrics*, our team, in collaboration with the Possibilities Project, describes the impact of COVID-19 on well-child visits and on screening for autism spectrum disorder (ASD) in pediatric primary care. In this blog post, we'll break down our findings and discuss what they could mean for children who may have ASD.

What trends did we see in ASD screening during the pandemic?

Well-child pediatric care is vital for providing preventive care, such as vaccinations, and assessing family and child health, including child development. In the American Academy of Pediatrics Bright Futures "Periodicity Schedule," universal screening for ASD at 18- and 24-month visits is recommended to promote early detection and initiation of services for eligible children.

While visits for older children were often rescheduled during the height of the pandemic in spring 2020, well-child care was still prioritized and recommended for young children under the age of 2. However, we now know that not all children received preventive, primary, and behavioral health services at equivalent rates, and priorities for what was addressed during well-child care visits might have shifted during the pandemic.

A 2019 study found nearly universal screening of all children across Children's Hospital of Philadelphia's (CHOP) Primary Care Network, and as a follow up, we sought to identify and understand trends in screening during the COVID-19 pandemic. We examined and compared two groups of young children who received in-person well-child care at CHOP at 16-26 months: the COVID-19 group, which included 24,549 children who were seen between March 2020 and February 2021, and the pre-COVID-19 group, which included 26,779 children who were seen between March 2019 and February 2020. Knowing that there were existing racial, ethnic, and socioeconomic disparities in screening completion, positivity, and accuracy (which we discussed in detail in our 2019 paper), we wanted to know if the disparities widened, persisted or decreased during the pandemic.

Who missed out on well-child visits during the pandemic?

One of our most concerning findings was that well-child visits for 16-26-month-old children decreased by 8.3% during the pandemic, with the most pronounced declines among Black and publicly insured children. While our data do not offer insights into *why* these differences in well-child visits occurred, we know that Black children have experienced both historic and contemporaneous barriers to high-quality health care and also suffered disproportionately from COVID-19 in multiple ways. Such circumstances may have affected family decisions to

seek well-child care for their children.

These findings suggest that health care systems should engage in proactive outreach to families, especially those who are Black and publicly insured, to make sure that all children who missed well-child care during the pandemic receive catch up care.

Screening completion rates remained very high overall, with more than 85% of children screened at least once in both groups. However, in both groups, White, English-speaking, and privately insured children completed screening at higher rates than all other racial and ethnic groups, Spanish-speaking children, and publicly insured children, respectively.

In both cohorts, non-White, publicly insured and Spanish-speaking children were more likely to screen positive. A positive ASD screen does not always mean a patient is diagnosed with ASD, and the higher rates of positive screenings could be attributed to many reasons including misinterpretations of the screening tool. Additionally, families may have different cultural interpretations of the screening questions and perceptions of typical developmental milestones or may experience reading difficulties.

Overall, these findings highlight screening disparities and gaps in the accuracy of the ASD screening tool that existed even before the pandemic that should be addressed.

What does this mean for children who might have ASD?

We know that COVID-related disruptions in intervention services for children with developmental delays also compounded primary care-related delays in ASD identification and exacerbated existing disparities. Early intervention programs can aid in the recognition of ASD, so limited in-person services during the pandemic likely decreased ASD identification further. Additionally, for children who did have early signs or symptoms identified, this limited access to in-person intervention services likely impacted how children were supported to learn new skills, as many of our patients anecdotally have reported.

What can we do to help remedy these pandemic-related concerns?

Health systems should recognize that some children might have missed opportunities for early ASD identification either because they missed routine well-child visits or because they did not complete an ASD screen when they did receive care. Clinicians should be attuned to signs and symptoms of ASD and consider screening for ASD outside of the traditional screening ages to help identify children with developmental differences as quickly as possible. When ASD is considered, children should be referred for assessment and intervention services. Lastly, early intervention systems should consider catch-up services for children who missed out on in-person therapy during the pandemic.

More broadly, lessons learned during the pandemic may also help us think about population-based strategies for primary and secondary prevention of developmental delays. Universal access to high-quality early child care may help promote child developmental progress and school readiness. Moreover, in combination with screening at well-child visits, we should consider proactive outreach to families to help them complete ASD screenings and refer children flagged by the screening process for assessment and intervention services.

As the scope of the pandemic's impact on children continues to be revealed, we hope that our findings shine a spotlight on missed early well-child care, gaps in ASD screening and disparities. Ongoing attention to the specific needs of children and families is critical as we emerge from the COVID-19 pandemic. We should not only think about what was lost but critically evaluate the lessons learned from this pandemic through a creative and innovative lens, actively applying those lessons to promote child development and enhance equity.

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