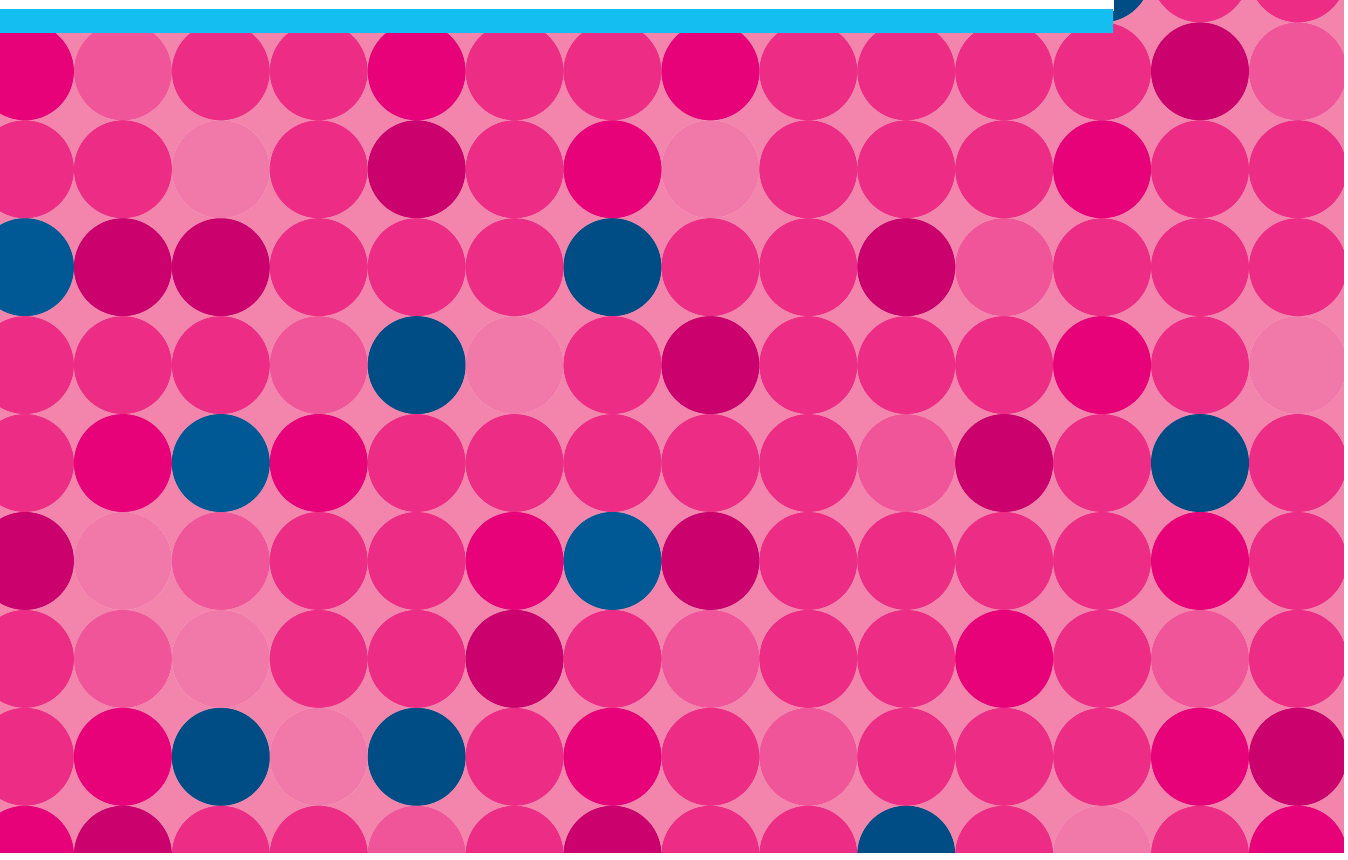
POLICYLAB

RESEARCH AT A GLANCE | SPRING 2020

A SYNOPSIS OF EMERGING POLICYLAB RESEARCH

ACCURACY AND EQUITY IN AUTISM SCREENING, IDENTIFICATION AND REFERRAL



Children's Hospital of Philadelphia℠
PolicyLab

policylab.chop.edu | *centerforautismresearch.org*

PRODUCED IN COLLABORATION WITH CHILDREN'S HOSPITAL OF PHILADELPHIA'S CENTER FOR AUTISM RESEARCH

WHAT IS THE PROBLEM:

Autism spectrum disorder (ASD) now affects at least 1 in 59 children. While we know that we can often detect ASD by age 2, the average age of diagnosis remains 4 years old and is even later for racial/ethnic minority, rural and low-income youth and girls.[1] This is concerning as early diagnosis can lead to earlier intervention, which is known to significantly improve outcomes for a child's health and well-being.

Given the prevalence of ASD and the importance of early detection, the American Academy of Pediatrics (AAP) recommends that physicians screen all young children for ASD at their 18- and 24-month well-child pediatric visits. The goal of universal screening is to identify children in need of an ASD evaluation as early as possible—potentially before parents or providers express concern about ASD—in order to diagnose them sooner. While we have recognized racial/ethnic, language-based, gender and socio–demographic disparities exist in ASD *diagnosis*, we know less about how *screening* may contribute to or mitigate differences in ASD diagnosis or about how those factors may affect the likelihood of referral to needed services after a screener shows positive signs of autism.

WHAT WE ASKED:

How accurate is the M-CHAT/F in detecting those children from different racial/ethnic and socioeconomic groups who were ultimately diagnosed with ASD?

Among children who do screen positive for ASD on the M-CHAT/F, are physicians equitably referring them for services?

WHAT WE DID:

In the first study, we analyzed data from about 26,000 patients seen at Children's Hospital of Philadelphia (CHOP), which by 2014 had implemented universal screening for ASD in accordance with the AAP guidelines. This was the first real-world study of the accuracy of universal screening using the Modified Checklist for Autism in Toddlers with Follow-Up (M-CHAT/F), a two-stage parent questionnaire. We followed patients from ages 16 months to 4 to 8 years, examining their initial screening results and following them through electronic health records to determine whether each child (including those who screened negative) was ultimately diagnosed with ASD.

With the second study, we sought to understand if children who screened positive for ASD were already receiving Early Intervention (EI) services—including speech/language therapy, occupational therapy and special education—or if they received referrals from their physician for EI services, or additional evaluation, on the day of a positive screen, as the AAP recommends. We then compared referral rates across children to understand if racial or socioeconomic disparities existed in which children physicians referred for evaluation or intervention.

WHAT WE FOUND:

While universal screening is the goal at CHOP, we found:

91%

of CHOP's primary care patients were screened for ASD in early childhood.

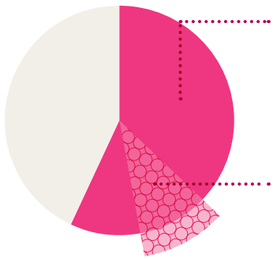
The **9%** *of children not screened for ASD were more likely to be children of color, from non-English speaking households, from lower-income families or insured by Medicaid. When the screen was completed in these populations, it was less accurate at detecting ASD.*

The M-CHAT/F detected only about 40% of children who went on to be diagnosed with ASD, but children with ASD who did screen positive on the M-CHAT/F were diagnosed

7 months earlier

than those who screened negative.

When it comes to referral to services:



57%

of children were referred to EI services prior to or on the day they screened positive for ASD, ***but only***

10%

of children left the doctor's office with both AAP-recommended referrals (EI and additional ASD evaluation).

Girls, children exposed to a language other than English, and black and Asian children were less likely to receive referrals than their peers.

WHAT IT MEANS:

While our research raises critical questions about the accuracy and equity of a widely used ASD screening tool, early screening has a positive effect on the age at which children are diagnosed with ASD.

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We need to improve adherence to physician guidelines around immediate referral to services following positive M-CHAT/F screens to help children access early diagnostic and intervention services.

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We have an opportunity to address biases and remove obstacles by modifying screening processes so young children with ASD can get the care they need as early as possible, when intervention is most effective.

STUDY METHODS

In the first study, we retrospectively looked at the electronic health records of 25,999 patients at Children's Hospital of Philadelphia who presented at a primary care site between January 2011 and July 2015 for a well-child visit between 16–26 months. We then followed these children through their health records until they were at least four years of age in order to identify the children who were later diagnosed with ASD.

We determined that a child had ASD if this diagnosis appeared in the electronic health record more than once or was provided by an ASD specialist.

In the second study, we observed 2,882 children ages 16–30 months who screened positive on the M-CHAT/F between January 2013 and December 2016 and who had also received the Survey of Well-being of Young Children (SWYC) developmental screener at a well-child visit. We reviewed patient records to determine whether the child was already receiving EI services, or if they were newly referred to EI or for additional evaluation during the visit with the positive screen.

RESOURCES FROM THE CENTER FOR AUTISM RESEARCH

ECHO Autism Teleconsult
centerforautismresearch.org/echo-autism-chop

A free, ongoing virtual learning network that offers medical and behavioral providers across the country access to an interdisciplinary team of autism experts. This innovative system allows professionals to increase their confidence in identifying and treating autism and expand their knowledge about treatments and solutions.

For additional resources, visit *centerforautismresearch.org*

RELATED POLICYLAB WORK

Children's Hospital of Philadelphia, PolicyLab. Improving Developmental and Behavioral Screening for Spanish-speaking Children [Online]. Available at: *https://policylab.chop.edu/project/improving-developmental-and-behavioral-screening-spanish-speaking-children*

Children's Hospital of Philadelphia, PolicyLab. Improving Screening and Referral for Developmental Issues among Young Children in Urban Primary Care Sites [Online]. Available at: *https://policylab.chop.edu/project/improving-screening-and-referral-developmental-issues-among-young-children-urban-primary*

Children's Hospital of Philadelphia, PolicyLab. Using Health Information Technology (HIT) to Improve Early Screening and Connect Children to Community Services: The CHIPRA Quality Demonstration Grant in Pennsylvania [Online]. Available at: *https://policylab.chop.edu/project/using-health-information-technology-hit-improve-early-screening-and-connect-children*

PUBLICATIONS

Guthrie W, Wallis K, Bennett A, et al. (2019). Accuracy of autism screening in a large pediatric network. *Pediatrics, 144(4)*, e20183963. doi:10.1542/peds.2018-3963

Wallis KE, Guthrie W, Bennett AE, et al. (2020) Adherence to screening and referral guidelines for autism spectrum disorder in toddlers in pediatric primary care. *PLoS ONE 15(5)*: e0232335. doi:10.1371/journal.pone.0232335

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1. Baio J, Wiggins L, Christensen DL, et al. Prevalence of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *MMWR Surveill Summ* 2018;67 (No. SS-6):1–23. doi: 10.15585/mmwr.ss6706a1

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Center for Autism Research

The mission of PolicyLab at Children's Hospital of Philadelphia (CHOP) is to achieve optimal child health and well-being by informing program and policy changes through interdisciplinary research. PolicyLab is a Center of Emphasis within the Children's Hospital of Philadelphia Research Institute, one of the largest pediatric research institutes in the country.

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