Children's Hospital of Philadelphia™
PolicyLab

Improving Equitable Identification of Developmental Delays and Autism Spectrum Disorder

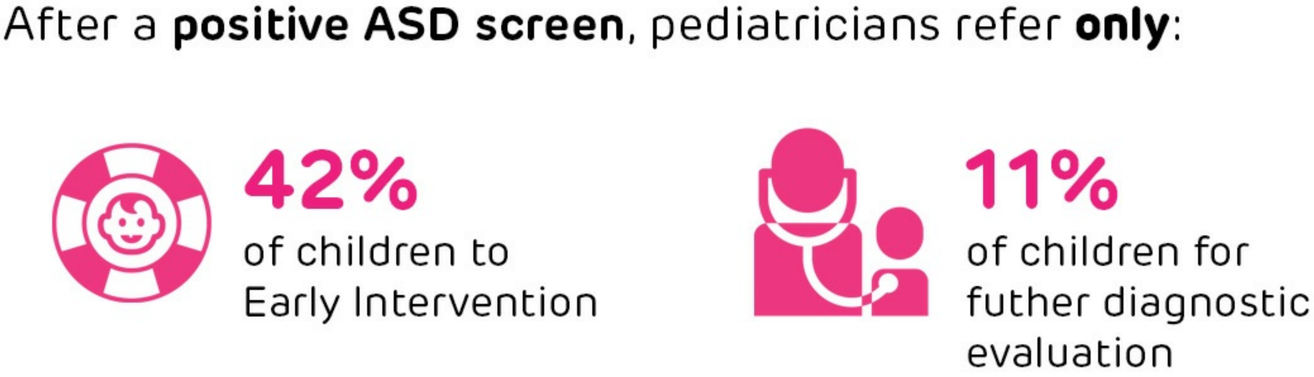
Statement of Problem

According to the Centers for Disease Control and Prevention, an estimated 1 in 59 children have autism spectrum disorder (ASD). Despite the high prevalence, significant disparities exist in identifying ASD and other developmental disabilities in young children from ethnic/racial minority backgrounds, as well as girls. Early identification of ASD, which allows for the earliest possible intervention, helps children to be their healthiest selves, yet children of color and girls are more likely to be identified at later ages—if at all. They are also under-represented in early intervention (EI) services—including speech/language therapy, occupational therapy and special education—for developmental delays. In turn, these disparities in identification and access to services can prevent vulnerable populations from receiving necessary autism-specific interventions.

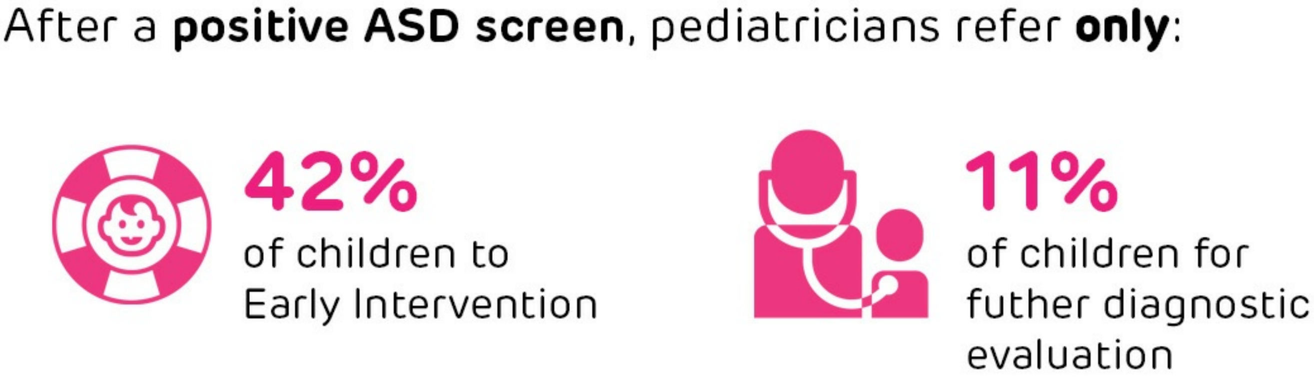
Description

Improving Equitable Identification of Developmental Delays and Autism Spectrum Disorder

Image



Image



Pediatricians were more likely to refer children who are white, male and from an English-only speaking home. These findings suggest that differences in referrals may impact children’s access to diagnostic and intervention services and may contribute to disparities in ASD diagnosis.

Pediatricians are tasked with discussing developmental concerns with caregivers (known as developmental surveillance) and with screening children for developmental delays and ASD at specified doctor’s visits using standardized screening tools. The goal of this body of research is to determine if the process of surveillance and screening may contribute to disparities in ASD identification, and if we can modify this process to promote equity in detection and referral for intervention.

First, Dr. Wallis and her team examined pediatricians' adherence to guidelines for referral to services after a young child screens positive for ASD. Using data from the electronic health record, the researchers found that **pediatricians refer 42% of children to EI after a positive ASD screen, but only 11% for a further diagnostic evaluation, as guidelines ask them to do.** Additionally, they are more likely to refer children to EI who are white, male and from an English-only speaking home. **These findings suggest that differences in referrals after a positive screen may impact children's access to diagnostic and intervention services and may contribute to disparities in ASD diagnosis.** There is room for improvement for all children to access evaluations after a positive screen.

Through that work, Dr. Wallis also noted that **pediatricians referred about one-fourth of children to EI even before their positive ASD screen**, which suggests that some children have developmental concerns identified very early and can benefit from services at a young age. She also found that **children who are white, Hispanic or from an English-only speaking home are more likely to be involved with EI prior to a positive ASD screen**. These findings emphasize that early initiation of EI may be related to disparities in ASD identification.

To further explore the identification process of ASD and developmental disabilities in pediatric primary care, Dr. Wallis sought to understand how doctors and caregivers discuss how a child is meeting developmental milestones and learning new things. Asking caregivers about any concerns in regards to how the child is developing is part of the process of developmental surveillance. She collected audio recordings of pediatricians and caregivers during well-child visits for young children between 15 and 36 months. After analyzing these recordings using a standardized coding scheme—the Roter Interaction Analysis System—the researchers found that **all well-child visits included some discussion of development. Few parents asked developmental questions, but they were willing to provide information about their child's development**. These findings suggest there are areas for improvement to engage parents in these discussions.

Next, Dr. Wallis and her team decided to run similar analyses to evaluate which children pediatricians referred early to EI, prior to screening positive on a general developmental screen or on the day of a positive developmental screen. Using data from the electronic health record, Dr. Wallis found that children who pediatricians referred early—even before the screen took place—were more likely to be white and male, or have public insurance. Children who pediatricians referred to EI on the day of the positive developmental screen were more likely to be black versus white and have a lower household income. These findings suggest that **screening may aid in identifying and referring children who otherwise may not have had access to EI services at a young age**.

Dr. Wallis has two additional studies that are related to this body of work:

- Dr. Wallis collaborated with Children's Hospital of Philadelphia's Center for Autism Research to conduct the first real-world study on universal screening for ASD. They found that the M-CHAT/F, a widely-used screening tool, is less accurate than previously shown for identifying children with ASD, especially those who are non-white, lower income and from non-English speaking homes, but is still a valuable tool.
- Dr. Wallis contributed to a systematic review that focused on the availability, translation and cultural validation of screening instruments to detect developmental concerns in U.S.-based Hispanic populations. The findings suggest that translation into Spanish alone is insufficient, as there may be cultural differences that impact the validity of screening between non-Hispanic and Hispanic populations, which can impact how pediatricians identify developmental issues in children with Spanish-speaking families.

Next Steps

Through these various studies, Dr. Wallis and her team are gaining an understanding of the processes that may be contributing to disparities in ASD identification among children of color, low-income children and girls. While we have known for many years that ethnic/racial minority and low-income populations and girls are more likely to be diagnosed with ASD at later ages, if at all, these studies inform our understanding of some of the mechanisms by which delayed identification occurs.

Dr. Wallis aims to use these insights to develop strategies for bettering the process of developmental surveillance and screening, improving developmental outcomes for all children, and bridging gaps in identification and care for low-income and ethnic/racial minority children and girls with developmental delays and ASD.

This project page was last updated in March 2020.

Suggested Citation

Children's Hospital of Philadelphia, PolicyLab. *Improving Equitable Identification of Developmental Delays and Autism Spectrum Disorder* [Online]. Available at: http://www.policylab.chop.edu. [Accessed: plug in date accessed here].

PolicyLab Leads

Kate Wallis
MD, MPH
Faculty Member

Team

Marsha Gerdes
PhD
Senior Psychologist (retired)

Whitney Guthrie, PhD

Judith Miller, PhD, MS

Amanda Bennett, MD, MPH

Susan Levy, MD, MPH

David Mandell, ScD

Funders of Project

Academic Pediatric Association, Bright Futures Young Investigators Award

Project Contact

Kate Wallis

WALLISK@EMAIL.CHOP.EDU

Related Tools & Publications

- How Developmental Screeners for Spanish-speaking Children Help with School Readiness in 200 Words
  Blog Post
  Sep 05, 2019

- Closing the Gap: Creating More Equity in Diagnosis of Autism Spectrum Disorder
  Blog Post
  Feb 18, 2020

- Supporting Families of Children with Special Educational Needs Amid COVID-19
  Blog Post
  Jun 08, 2020

- No More Watchful Waiting for Developmental Delays
  Blog Post
  Apr 01, 2022

- Rates of Autism Increase, but Numbers Don't Paint the Full Picture
  Blog Post
  Jan 18, 2023

- Psychometric Properties of Two Developmental Screening Instruments for Hispanic Children in the Philadelphia Region
  Article
  Oct 2018

- Distinguishing Primary and Secondary Early Intervention Programs: Implications for Families, Clinicians and Policymakers
  Article
  Nov 2018

- Accuracy of Autism Screening in a Large Pediatric Network
  Article
  Sep 2019

- Screening Instruments for Developmental and Behavioral Concerns in Pediatric Hispanic Populations in the United States: A Systematic Literature Review
  Article
  Oct 2019

- Adherence to Screening and Referral Guidelines for Autism Spectrum Disorder in Toddlers in Pediatric Primary Care

Article
May 2020

- Accuracy and Equity in Autism Screening, Identification and Referral
  Research at a Glance
  May 2020

- Identifying Autism Spectrum Disorder in Real-world Health Care Settings
  Article
  Jul 2020

- Provider Responses to Positive Developmental Screening: Disparities in Referral Practices?
  Article
  Sep 2020

- Insights from Behavioral Economics: A Case of Delayed Diagnosis of Autism Spectrum Disorder
  Article
  Sep 2020

- USPSTF Request for Public Comment: Screening for Autism Spectrum Disorder in Young Children
  Tools and Memos
  Apr 2021

- The Roadmap to Early and Equitable Autism Identification
  Article
  Jul 2021

- Missing Ethnicity and Language Information in Health Care Records of Patients from the Asian Diaspora
  Article
  Jul 2024

Related Projects

Improving Screening and Referral for Developmental Issues among Young Children in Urban Primary Care Sites
Behavioral Health

Improving Developmental and Behavioral Screening for Spanish-speaking Children
Behavioral Health