



Advancing HEALTHCARE

An Autism New Jersey Initiative



About Our Timely Diagnosis Project

Goal

To decrease wait times for autism diagnostic evaluations

Problem

Early identification and diagnosis of autism are crucial to optimal outcomes and quality of life.

- American Academy of Pediatrics (AAP) recommends developmental surveillance at 9, 18, and 30 months of age and periodic screening for autism at 18 and 24 months of age by general pediatricians.
- Typically, general pediatricians refer families to a specialized provider, such as a developmental behavioral pediatrician when there are concerns for autism.

In a 2021 Community Report, the CDC highlighted concerns about the delay between initial developmental concerns and official diagnosis of autism.

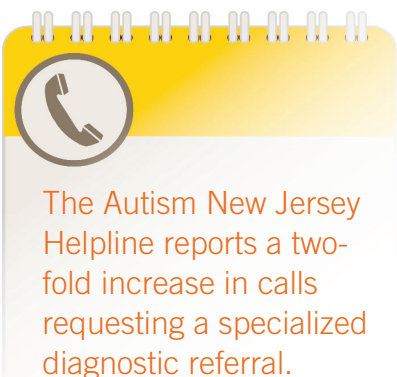
- While 85% of children with autism had developmental concerns documented prior to age 3, only 42% received that diagnosis by age three. 39% did not receive the diagnosis until after the age of 4.
- The average age at diagnosis is 4 years, 4 months.

One cause of this delay from initial concern to diagnosis is unacceptably long wait times for a diagnostic evaluation.

- Increased surveillance by general pediatricians, the increasing prevalence of Autism, a shortage of specialized providers, and the lasting impact of COVID-19 closures have all impacted these wait times.
- Developmental pediatricians in New Jersey report anywhere from 9 month to 2 year waiting lists for an initial diagnostic evaluation appointment.

An official autism diagnosis is required to access ABA therapy, the gold standard in treatment for autism.

- Early intensive behavioral intervention is key to improving communication, social skills, and other adaptive skills.
- These delays to a diagnosis and resulting delays to treatment could have a drastic and lasting negative impact on the quality of their lives.



Plainly stated, there simply aren't enough developmental pediatricians to meet the demand, and pediatricians lack clarity on their role in diagnosis.

Description and Scope

This work will focus primarily on the clinical and operational activities needed to increase the number of general pediatricians who are competent to diagnose autism. This includes:

- The didactic and experiential activities recommended prior to diagnosing
- The ongoing clinical oversight or support recommended
- The operational education and support to ensure adequate documentation and billing practices
- Advocacy to ensure payor acceptance of general pediatrician diagnosis for medical necessity billing

Autism New Jersey will initiate, coordinate, and support an in-depth analysis of current developmental behavioral pediatric operational and clinical practices at large diagnostic centers across the state and research insurance-related factors and clinical best practices for general pediatricians. Based on that analysis, Autism New Jersey will make recommendations regarding didactic and experiential activities for general pediatricians, offer suggestions for operational and clinical best practices at diagnostic centers, and advocate for any needed systemic and payor modifications.

Out of scope in the first phase, but will be considered moving forward, is the use of other healthcare professionals, such as APNs, to increase access to timely autism diagnostic evaluations.

Activities and Timeline

Current Steps

- Initiated developmental pediatricians outreach
- Established developmental pediatricians workgroup
- Responding to pediatrician inquiries

Next Steps

- Explore collaboration with various state healthcare professional associations
- Connect with more pediatricians
- Summarize issues for public and private payors

Outcome Measures

1. Decrease wait times by 50% for patients under age 5. Measured by self-report from large diagnostic centers and 800.4.AUTISM Helpline contacts.
2. Maintain diagnostic fidelity and patient satisfaction. Measured by differing second opinions, any already established patient satisfaction surveys in use at general pediatrician offices and diagnostic centers, and 800.4.AUTISM Helpline contacts.
3. No increase in insurance denials for treatment due to diagnostic provider type. Measured by provider self-report and 800.4.AUTISM Helpline contacts.