

# **An Integrative Literature Review on Pediatric Primary Care Provider Knowledge and Practice Gaps in the Early Identification of Children with Possible Autism Spectrum Disorder**

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## **Background:**

As reported by the CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network, it is estimated that 1 in 44 children have been identified with an autism spectrum disorder (ASD), occurring in all racial, ethnic, and socioeconomic groups (CDC, 2021). The American Academy of Pediatrics (AAP) recommends that children who score at risk or do not pass autism screening tests be referred for diagnostic and early intervention evaluations and services (Hyman et al., 2020). The timing of early intervention referrals is essential as referrals made at the time of positive screening can vary vastly from the time to formal diagnosis (Monterio et al., 2019). Wait times for autism diagnostic assessment can be six months to upwards of one year for a formal diagnosis (Monterio et al., 2016). This problem is significant because early and intensive behavioral and supportive interventions for autism are associated with improved developmental outcomes (Ahlers et al., 2019).

## **Purpose & Objective:**

This integrative literature review aims to identify pediatric primary care provider knowledge and practice gaps in the early screening, identification, referral, and intervention of children with possible autism spectrum disorder.

## **Methodology:**

With assistance from a health sciences librarian, an integrative literature review was conducted within the online PubMed and CINAHL databases.

### **CINAHL:**

MH "Autistic Disorder" AND (MH "Primary Health Care" OR MH "Physicians, Family" OR MH "Pediatricians" OR MH "Family Nurse Practitioners" OR MH "Pediatric Nurse Practitioners+" OR MH "Physician Assistants") AND (MH "Clinical Competence+" OR MH "Professional Knowledge+")

- Title/Abstract: 28/28
- Full Text: 20/28
- Included: 5/28 (3 duplicates with PubMed)

### **PubMed:**

“Autism Spectrum Disorder” [Mesh] AND (“Physicians, Primary Care” [Mesh] OR “Primary Care Nursing” [Mesh] OR “Primary Health Care” [Mesh] OR “Pediatricians” [Mesh] OR “Family Nurse Practitioners” [Mesh] OR “Pediatric Nurse Practitioners” [Mesh] OR “Physician Assistants” [Mesh]) AND (“Clinical Competence” [Mesh] OR “information needs” OR knowledge OR decision making)

- Title/Abstract: 70/70
- Full Text: 22/70
- Included: 8/70 (3 duplicates with CINAHL)

#### **Study Designs:**

- Quantitative: 6
- Qualitative: 2
- Mixed Methods: 1
- Clinical Report: 1

#### **Themes & Findings:**

- Providers cited a lack of knowledge, education, and training in autism. These knowledge gaps led to decreased comfort and a desire for ongoing education to improve skills and abilities in identifying autism (Burka et al., 2014; Mazurek et al., 2020b; Nolan et al., 2016; Rizzolo, Smith, and McCall, 2019; Will, Barnfather, and Lesley, 2013).
- Providers reported knowledge gaps about ASD knowledge, treatments, community resources, and ambiguity regarding the pediatrician’s role in ASD care (Levy et al., 2016; Mazurek et al., 2020b).
- After participation in learning collaboratives, continuing education, intensive workshops, pediatric primary care providers demonstrated significant improvements in their pre-test to post-test knowledge, self-efficacy, and confidence scores in providing care to children with ASD (Burka et al., 2014; Mazurek et al., 2020a; Mazurek et al., 2020b).
- Post learning collaborative, providers increased, and sustained implementation and documentation of AAP recommended universal autism screening at 18 & 24-month well-child exams, this was also reflected in increased referrals for comprehensive ASD evaluations (Carbone, Norlin, and Young, 2016).
- Inconsistencies were found in how PCPs use screening results to guide diagnostic evaluation referrals. Some reported using a “wait and see” or “watch and wait” approach (Carbone, Norlin, and Young, 2016) and some hesitated to clearly indicate concern for ASD and documented broad developmental concerns instead (McNally Keehan et al., 2021).

#### **Recommendations:**

- Workshops, learning collaboratives, expert training, and continuing ASD education seem to be effective approaches to increase provider knowledge, comfort, and confidence in the early identification and ongoing care of children with possible or known ASD (Burka et al., 2014; Carbone, Norlin, and Young, 2016; Mazurek et al., 2020a, Mazurek et al., 2020b).

- Improving primary care screening, skills, and knowledge may improve the timeliness of diagnosis and initiation of early intervention therapies by identifying risk for ASD and providing a pathway in decision making in referral for evaluation (Carbone, Norlin, and Young, 2016; McNally Keehan, et al., 2021).
- Additional training and education in ASD during pre-professional academic education, residency programs, and throughout clinical practice would prove beneficial for primary care providers (Nolan et al., 2016; Rizzolo, Smith, and McCall, 2019).

**Limitations:**

- Small participant sample sizes limit the generalizability of findings (Burka et al., 2014; Will, Barnfather, and Lesley, 2013).
- Study samples may not be representative of the larger population of pediatric PCPs (Levy et al., 2016; Mazurek et al., 2020a).
- Convenience sampling or self-selection choosing to participate may indicate that participants had a strong desire for additional knowledge and higher motivation to make changes limiting generalizability (Burka et al., 2014; Mazurek et al., 2020b; Nolan et al., 2016; Rizzolo, Smith, and McCall, 2019; Carbone, Norlin, and Young, 2016).

**Conclusion:**

Pediatric primary care providers have cited lack of sufficient education and training in autism spectrum disorder leading to knowledge gaps in screening, early intervention, and referral for official diagnostic evaluations. Participating in workshops, learning collaboratives, expert trainings, and continuing education is an effective approach to improve pediatric primary care provider knowledge, comfort, confidence, and self-efficacy in the early identification of children with possible autism spectrum disorder.

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