

Building Capacity for Community Pediatric Autism Diagnosis: A Systemic Review of Physician Training Programs

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ABSTRACT: *Objectives:* Training primary care providers to provide diagnostic assessments for autism spectrum disorder (ASD) decreases wait times and improves diagnostic access. Outcomes related to the quality of these assessments and the impacts on system capacity have not been systematically examined. This systematic review identifies and summarizes published studies that included ASD diagnostic training for primary care providers (PCPs) and aims to guide future training and evaluation methods. *Methods:* Systematic searches of electronic databases, reference lists, and journals identified 6 studies that met 3 inclusion criteria: training for PCPs, community setting, and training outcome(s) reported. These studies were critically reviewed to characterize (1) study design, (2) training model, and (3) outcomes. *Results:* All studies were either pre-post design or nonrandomized trials with a relatively small number of participants. There was considerable heterogeneity among studies regarding the training provided and the program evaluation process. The most evaluated outcomes were access to autism diagnosis and accuracy of diagnosis. *Conclusion:* Training PCPs to make ASD diagnoses can yield high diagnostic agreement with specialty teams' assessments and reduce diagnostic wait times. Current data are limited by small sample size, poor to fair quality study methodology, and heterogenous study designs and outcome evaluations. Evidence is insufficient to draw conclusions about the overall effects of training PCPs for ASD diagnostic assessments. Since further research is still needed, this review highlights which outcomes are relevant to consider when evaluating the quality of ASD assessments across the continuum of approaches.

(*J Dev Behav Pediatr* 43:44–54, 2022) **Index terms:** autism spectrum disorder, diagnosis, primary care providers, training models, evaluation.

Autism spectrum disorder (ASD) is a complex developmental condition, characterized by persistent challenges in social interaction and communication and by restricted and repetitive behaviors.¹ The estimated prevalence of ASD is between 1% and 1.5%, with relative consistency across studies internationally, making ASD one of the more common developmental disabilities.² Although evidence has highlighted that ASD can be reliably diagnosed by age 2 years,³ the average age at di-

agnosis continues to be greater than 4 years.^{4,5} This lag in diagnosis is even more pronounced for children from racial and ethnic minority backgrounds. Delays in ASD diagnosis lead to a missed window of opportunity for early interventions. Numerous studies have demonstrated the benefit of early intervention, such as improvements in social and communication skills,⁶ cognitive abilities,^{7–9} verbal abilities,⁶ adaptive behavior,^{9,10} and potential to reduce societal costs.¹¹ Therefore, to improve the long-term outcomes for patients with ASD, it is imperative to address the impediments to timely diagnosis.

Owing to its complex nature, most ASD diagnostic evaluations are conducted by multidisciplinary teams in tertiary centers. This presents a bottleneck for many patients because wait times commonly exceed a year.¹² There have been numerous innovative approaches aimed at enhancing early detection of ASD, such as initiatives to increase ASD screening, telehealth-supported models, and novel assessment models.^{13,14} Recent disruptions to standard care related to COVID-19 encouraged prioritization of strategies aimed at increasing overall diagnostic capacity and accessibility. One of the most promising approaches to improving access is training primary care providers (PCPs; e.g., family physicians or community pediatricians) to provide comprehensive assessments. Encouraging community-based assessments for less complex presentations of ASD is

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Received March 2021; accepted October 2021.

This research is supported by the Resident Trainee Research Grant by the Department of Pediatrics and Women and Children's Health Research Institute at the University of Alberta.

Disclosures: The authors declare no conflict of interest.

Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's Web site (www.jdbp.org).

PROSPERO registration number: CRD42020187169.

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supported by the most recent guidelines from the American Academy of Pediatrics and Canadian Pediatric Society.^{12,15} Although recent studies have evaluated whether PCPs, with appropriate training, could perform as reliable and valid an ASD diagnostic assessment as a specialist team, it remains unclear whether adding community assessment pathways will reduce wait times and improve access to early interventions. To address these questions and guide future training and evaluation efforts, we conducted a systematic review of all published studies of ASD diagnostic training for PCPs, with the aim of summarizing and critically assessing (1) the training models and how they were implemented and (2) the reported outcomes.

METHODS

An a priori review protocol was developed following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement and was registered with PROSPERO. Ethics approval was not required for this review.¹⁶

Search Procedures

A systematic search procedure according to the PRISMA guidelines was used to identify studies to include in this review. First, we searched in PROSPERO, a registry for ongoing systematic reviews, to ensure there was no ongoing review of the same topic. Searches were then conducted in 6 electronic databases including Ovid MEDLINE, Embase, PsycINFO, CINAHL, Education Resources Information Center, and Scopus. A gray literature search was also conducted in HSRProj, OALster database, and Google Scholar to capture conferences, presentations, or other unpublished data that meet our inclusion criteria. The reference lists of included articles were also reviewed, and additional relevant studies were included. We also reviewed all publications by the first authors and corresponding authors of each included study to identify other potentially relevant articles. Therefore, this review includes all peer-reviewed articles and gray literature published in English from all publication years up to and including March 27, 2020. Searches in each database were conducted using search terms related to autism, diagnosis, primary care, and training. The search terms used for all databases were very similar and presented in Supplemental Digital Content 1, <http://links.lww.com/JDBP/A339>.

Inclusion Criteria

To be included in this review, studies had to meet 3 criteria. First, the study had to include at least 1 participant who was a community-based primary care provider (PCP) who provided care to the pediatric population, such as family physicians or general pediatricians. Second, the study had to describe a community-based training model for autism spectrum disorder (ASD) diagnostic assessment in the pediatric population. Finally, the study needed to report at least 1

outcome related to an evaluation of the implemented training model, such as accuracy of participants' diagnosis for ASD, improvement in access to diagnosis, increase in confidence and knowledge, or family satisfaction. Review papers and commentaries were excluded from this systematic review. Studies that described a training model but did not evaluate any outcome measures were also excluded.

The first author independently reviewed titles and abstracts to identify potentially relevant studies. Once identified, full-text review was completed independently by the first and second authors to determine eligibility based on the inclusion and exclusion criteria. Disagreements were resolved through discussion with the third author.

Data Extraction

Each included study was summarized with the following data extracted: (1) participant characteristics, (2) training program features, and (3) outcome measures and findings. These data are summarized in Tables 1–3.

Risk of Bias Analysis

The methodological quality of the included studies was assessed using the National Institutes of Health Quality Assessment Tool for Before-After (Pre-Post) Study Checklist (NIH Checklist) and the Cochrane risk assessment tool.^{17,18} The NIH Checklist was used for the pre-post study designs, whereas the Cochrane risk assessment was used for the nonrandomized trial studies. The NIH Checklist includes 12 questions and assesses quality based on study objective, population, intervention, outcome measures, and statistical analysis. The Cochrane risk assessment tool includes evaluation of 7 different areas of bias. The risk of bias analysis was conducted independently by 2 of the coauthors, and discrepancies were resolved by discussion among all authors.

Intervention fidelity was assessed for each study using the Treatment Fidelity Assessment Grid.¹⁹ Treatment fidelity is a measure of the reliability and validity of the interventions relative to how it was created, implemented, and received. The Treatment Fidelity Assessment Grid assesses the fidelity for each study in 5 domains: study design, provider training, intervention implementation, intervention receipt, and intervention enactment. Two of the coauthors completed the assessment independently, and the results were discussed among all authors. For the purpose of this review, the ASD diagnostic training for PCPs was considered an intervention. Thus, "provider training" refers to training autism experts on how to train the PCPs in ASD diagnostic assessment to ensure autism experts will provide standardized training for PCPs. "Intervention implementation" refers to the delivery of the training. "Intervention receipt" refers to how well the PCPs understood the training material, and "intervention enactment" refers to how well the trained providers were able to apply the diagnostic assessment methods with their patients.

Table 1. Characteristics of Included Studies

Study (First Author, Year)	Study Design	Country	Settings	Participants (Training Recipients)	Number of Participants	Number of Patients Assessed by PCPs
Warren, 2009	NRT	United States	Community pediatric clinics in underserved geographic areas	General pediatricians	5	25
McClure, 2010	NRT	Scotland	Community clinics in the health region of Lomond and Argyll	General pediatricians, SLP, and psychologists	16	39
Swanson, 2013	NRT	United States	Community clinics in different geographic regions	General pediatricians	27	14
Harrison, 2017	Pre-post	United States	Behavioral/developmental access clinic within a tertiary care children's hospital	General pediatrician	1	63
Mazurek, 2018	Pre-post	United States	Community clinics in different geographic regions	General pediatrician, family physician, and nurse practitioner	18	47
Ahlers, 2019	NRT	United States	University developmental assessment clinics associated with the University of UT	General pediatricians with advanced training in ASD	Not reported	91

ASD, autism spectrum disorder; NRT, nonrandomized trial study design; PCPs, primary care providers; SLP, speech language pathologist.

RESULTS

Search Results

The search process identified 2138 studies; 428 duplicates were removed, leaving 1710 unique studies. The identified articles were imported to Covidence,²⁰ an online screening and data extraction tool used for systematic reviews. Titles and abstracts were screened in Covidence by the first author to identify studies that would potentially meet the inclusion criteria; 29 papers passed the primary screen. A further reference review, based on the name of the first author and the corresponding author of each included study, identified 9 additional papers. The full text of those that passed the

primary screen and the studies found from the reference review were independently reviewed by the first 2 authors to identify studies for final inclusion. The first author identified 7 studies for inclusion, whereas the second author identified 6 studies. Discrepancies were resolved by the last author after independent review, with final selection of 6 studies for the review (Fig. 1).

Study Characteristics

Study characteristics are summarized in Table 1. Two studies used a pre-post study design, whereas the other 4 studies were nonrandomized trials that included a comparison group. Five of 6 studies were conducted in the

Table 2. Training Programs Summary

Study (First Author, Year)	Warren, 2009	McClure, 2010	Swanson, 2014	Harrison, 2017	Mazurek, 2018	Ahlers, 2019
Format	Interactive workshops	Didactic teaching	Didactic workshops	Shadowing	Didactic lectures	Workshops
	Diagnostic assessment and feedback	Clinical mentoring	Case-based evaluations	Self-study	Case-based learning	Online training
			Ongoing training	Case-based discussion as needed	Ongoing training	Ongoing supervision
Initial training	2-d workshop	5-d course	2-d workshop	Not reported	1.5-d workshop	2-d workshop
Ongoing mentorship duration	4–6 practice assessments	10 wk of mentoring	3.5 yr of ongoing training	6 mo	Bimonthly 90-min meeting for 12 mo	NA
Training material presented to PCPs	MCHAT	ADOS	MCHAT	Early childhood development	ASD overview	ADOS-2
	STAT	ICD-10 criteria	STAT	Developmental disorders	STAT	STAT
	DSM IV criteria	History and interview	History and interview		History and interview	AMSE
	History and interview	Explaining results	DSM criteria	Diagnosis criteria		
	Differential diagnosis	Charting	Explaining results	Differential diagnosis		
	Explaining results		Code for reimbursement	Explaining results		
	Coding for reimbursement			Management and resources		

ADOS, Autism Diagnostic Observation Schedule; AMSE, Autism Mental Status Exam; ASD, autism spectrum disorder; MCHAT, Modified Checklist for Autism in Toddlers; NA, not applicable; STAT, Screening Tool for Autism in Toddlers.

Table 3. Outcome Evaluation: Increased Access to ASD Diagnosis and Accuracy of Diagnosis

	Increased Access to ASD Diagnosis				Accuracy of ASD Diagnosis					
	Method	Control	Sample Size	Outcome	Method	Control	Sample Size	Diagnostic Decision	Expert Team Diagnosis	Accuracy of Diagnosis
Warren, 2009	NR	NR	NR	NR	Pediatric providers referred selected cases for further evaluation. Initial result was blinded for assessment	Autism diagnostic clinic	21 patients	ASD vs not ASD: Rank certainty of diagnosis on a 5-point Likert scale (1 = highly uncertain to 5 = highly certain)	71% ASD (n = 15) 29% non-ASD (n = 6)	71% agreement overall. 74% (n = 19) when diagnosed as ASD and 50% when not ASD (n = 2). Agreement in the 4 pediatricians ranged from 57% to 100%
McClure, 2010	Retrospective chart review	AAT	38 patients	Wait time for local teams was 13 wk compared with 36 wk for specialists	Traditional team assessed video-recorded ASD histories conducted by trained providers while blinded to result	AAT	38 patients	ASD vs not ASD: Specific diagnosis within the spectrum	41% ASD (n = 16) 59% non-ASD (n = 22)	87% (33/38) full agreement on diagnosis; 92% agreement as to whether the child was on the spectrum
Swanson, 2014	Self-reported surveys	NA	22 PCP participants	Number of children diagnosed within practice by providers involved in this training increased by 85%.	Pediatric providers referred selected cases for further evaluation. Initial result was blinded for assessment	Comprehensive psychological assessments	14 patients	ASD vs not ASD: Rank certainty on a 5-point Likert scale (1 = highly uncertain to 5 = highly certain)	57% ASD (n = 8) 43% non-ASD (n = 6)	86% diagnostic agreement in forced-choice classifications and 93% agreement when uncertain cases were counted as agreement
Harrison, 2017	Retrospective chart review	Developmental pediatricians	63 patients	Wait time to see a developmental pediatrician was 327 d vs 159 d to see a GP. Wait time was 11 d for new referrals to the access clinic.	NR	NR	NR	NR	NR	NR

(Table continues)

Table 3. Continued

	Increased Access to ASD Diagnosis				Accuracy of ASD Diagnosis					
	Method	Control	Sample Size	Outcome	Method	Control	Sample Size	Diagnostic Decision	Expert Team Diagnosis	Accuracy of Diagnosis
Mazurek, 2018	Self-reported surveys	NA	15 PCP participants	80% of PCPs reported increase in the number of children with autism on their caseload. 73% reported accepting referrals for ASD assessments at the end of the program. Average of 173 miles of travel avoided for families	NR	NR	NR	NR	NR	NR
Ahlers, 2019	Retrospective chart review	Traditional assessment model	143 patients in traditional and 101 patients in alternative models (91 seen by general pediatricians)	Time to diagnosis was shorter for all children evaluated by trained pediatricians compared with the traditional assessment model (85 vs 152 d, $p < 0.001$)	Pediatric providers referred selected cases for further evaluation. Initial result was blinded for assessment	Traditional assessment model	18 patients	ASD vs not ASD: Rank certainty on a 4-point Likert scale (very likely, somewhat likely, somewhat unlikely, or very unlikely)	78% ASD (n = 14) 22% non-ASD (n = 4)	93% diagnostic agreement among pediatricians and psychologists when ASD was ruled in (n = 14) and 100% when ASD was ruled out (n = 4)

AAT, ASD assessment team; ASD, autism spectrum disorder; GP, general practitioner; NA, not applicable; NR, not reported; PCPs, primary care providers.

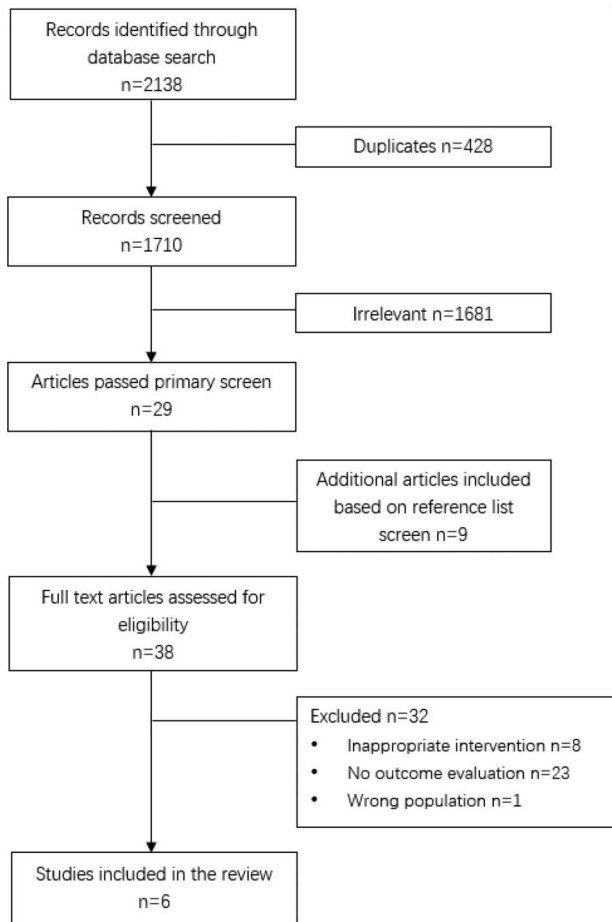


Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram of study selection.

United States, and 1 in Scotland. There was considerable heterogeneity among studies regarding the training provided and the program evaluation process.

Quality Assessment

The National Institutes of Health and Cochrane risk assessment protocols are summarized in Supplemental Digital Content 2, <http://links.lww.com/JDBP/A339>. Overall, the quality of the studies included in this review was rated fair to poor with these assessments. None of the studies included a randomized design or blinded outcome assessment, and participating trainees and patients were small in number. The lack of reliable outcome assessment was also common among the studies.

A summary of the fidelity assessment is presented in Supplemental Digital Content 3, <http://links.lww.com/JDBP/A339>. All studies described their general study design in detail, and 5 of 6 studies provided specific details regarding how the training was implemented. However, none of the studies took steps to ensure fidelity, such as developing a protocol to assess whether the trainers delivered standardized material consistently across different sessions. In addition, the studies did not describe how the expert teams were taught to conduct the training. Four of 6 studies reported steps to ensure intervention receipt, such as requiring trained primary

pediatricians to send in videotaped practice administration to demonstrate reliability.

Intervention Description

The included studies are summarized below with a description of participants trained and the diagnostic training program.

Participating Clinicians

The number of participants in the training programs ranged from 1 to 27 primary care providers (PCPs). Most studies trained the PCPs to conduct diagnostic assessments on their own, whereas 2 studies (Mazurek et al., 2018; McClure et al., 2010) trained the providers to make diagnosis in a team setting.^{21,22} Only 2 studies (Mazurek et al., 2018; Swanson et al., 2014) reported specific participant demographics.^{21,23} In these 2 studies, most participating clinicians were female (72%), White (83%), and general pediatricians (74%–78%). Detailed participants' demographics were not reported in the other studies. Four of the 6 studies reported on participants' level of training.^{21,23–25} Only 1 study (Swanson et al.,²³ 2014) reported years of clinical experience, which ranged from 2 to 39 years (average 17.6 years). In 2 studies (Mazurek et al., 2018 and Ahlers et al., 2019), most participants had previous formal autism spectrum disorder (ASD) training through their residency programs, webinars, or previous experience working in ASD clinics.^{21,24} By contrast, the training provided by Harrison et al. (2017) was targeted at general pediatricians with no formal training or experience in ASD.

Participating Patients

The number of patients assessed by trained PCPs through these training models ranged from 14 to 91 children (Table 1). Five of 6 studies only assessed patients younger than 5 years, whereas the sixth study (McClure et al.,²² 2010) assessed patients with the median age 8 years 9 months and had only 3 patients younger than 5 years. In the 4 studies that reported patient demographics, most (>70%) of the patients were male. Only 1 study reported the race/ethnicity of the patients, with 75% of them being White.²⁴ Most studies did not report how patients were referred or selected; only 2 studies mentioned that patients were young children with a query of ASD within the PCPs' own practices or had a positive autism screen.^{21,26} None of the studies provided details on what additional information was available to the PCPs, such as the patient's functional level or previous language assessments.

Training Program

Training Format and Duration

There was considerable variability among the training programs reported in the included studies presented in Table 2. The majority (5 of 6) included didactic lectures or workshops as part of the training. Four of 6 studies also included interactive case-based learning with individualized

feedback through videoconferencing or videotaped vignettes. Only 1 training program did not include any formal didactic teaching and was mainly based on "shadowing" (i.e., observing) developmental pediatricians with teaching provided as needed (Harrison et al.,²⁵ 2017). The didactic training portion ranged from 1.5 days to 5 days (median = 2 days). All training programs offered ongoing mentorship in different forms ranging from 10 weeks to 3.5 years. This included observed independent ASD assessment with personalized feedbacks, bimonthly clinics with expert teams for case discussions, or informal mentorship and consultation for challenging presentations.

Training Content

Four of 6 programs included training in administering a standardized ASD screening tool, either the Modified Checklist for Autism in Toddlers or the Screening Tool for Autism in Toddlers and Young Children (STAT).^{21,23,24,26} Two of the 6 programs provided training in administering and scoring the Autism Diagnostic Observation Schedule, an interactive assessment of autism signs.^{22,24} Two of the 4 studies required providers to submit video-recorded sessions of themselves interacting with a child to assess their reliability in administering the STAT.^{21,23} Four of 6 programs provided training on how to establish a diagnosis and how to communicate the diagnosis to patients and families.^{21,23,26} The diagnostic criteria differed between different training programs; 3 programs referred to the DSM criteria,^{21,23,26} and 1 program referred to the International Classification of Diseases criteria.²² Two of the 6 programs specified training for coding and billing for reimbursement.^{23,26} Only 1 of the 6 training programs provided training on resources for patients and families.²¹

Assessment Setting

The clinical settings of the training programs also varied. Four training programs aimed to implement autism assessment in community pediatrician clinics across different geographical areas, and 2 training programs focused on training PCPs to work in newly created diagnostic clinics associated with a tertiary hospital (Ahlers et al., 2019; Harrison et al., 2017).^{24,25}

Diagnostic Assessment

Assessments in most studies included interpretation of a screening instrument, diagnostic interview of caregivers, direct observation of patient, and delivery of the diagnostic decision. One of 6 training programs incorporated a structured diagnostic interview, whereas the others provided more general guidance to trainees on how to probe for ASD-related symptoms in their history-taking.²² Three studies specified assessment times, ranging from 60²⁶ to 90²⁵ to 120 minutes,²⁴ whereas the other studies did not estimate times.

Diagnostic Decision Making

Trained PCPs from all studies were asked to make diagnostic decisions on whether a child had ASD. In 4 of 6 training programs, providers were asked to make an ASD

diagnosis independently after evaluation. Three of these 4 programs had providers rate the certainty of their diagnosis on a Likert scale.^{23,24,26} In the other 2 programs, the diagnostic decisions were made through discussion with a team.^{21,22} The members on the team in 1 study included a pediatrician specializing in development and behavior, a clinical child psychologist, a child and adolescent psychiatrist, a social worker, a dietitian, a parent of a child with autism, and other participating PCPs, in the setting of bimonthly training sessions for 12 months.²¹ The members on the team in the other study included professionals from a range of disciplines, such as psychology, occupational therapy, speech and language therapy, and social work, who were also being trained to participate in the evaluation process.²²

OUTCOMES

Among the 6 studies evaluating models aimed at training primary care providers (PCPs) in autism spectrum disorder (ASD) diagnostic assessment, the most common outcomes evaluated were increased access to diagnosis, based on reduced wait times, and accuracy of diagnosis, comparing diagnostic decisions with blinded ASD expert teams. Five studies reported that training PCPs led to improved access in ASD diagnostic assessment, with reduction in wait time by around 50%. There was also a high degree of diagnostic agreement (71%–100%) between trained PCPs and traditional expert teams, as evaluated by 4 studies.

Increased Access to Autism Spectrum Disorder Diagnosis

Measures of access to diagnosis were reported by 5 studies (Table 3). Two studies evaluated the change in wait time before and after implementing the training program.^{22,25} These 2 studies compared the wait time to see an ASD specialist versus the wait time to seeing a trained PCP. Another study evaluated the change in time to diagnosis by measuring the number of days from receipt of the parent-completed intake package to the date the final diagnostic International Classification of Diseases code was entered.²⁴ All 3 studies reported the wait time to see a trained PCP was approximately 50% the length of the wait time to see the traditional assessment team. Two additional studies reported survey findings of the subjective increase in the number of ASD assessments by the trained PCPs.^{21,23} In 1 study, 73% of the trained PCPs reported they were accepting referrals for ASD diagnostic evaluation at the end of the program (Mazurek et al.,²¹ 2018). Another study reported the number of children diagnosed within the practice of these trained providers increased by 85% (Swanson et al.,²³ 2014). One study did not evaluate improved access to autism diagnosis as an outcome.²⁶

Accuracy of Diagnosis

Accuracy of diagnosis was reported by 4 of 6 studies (Table 2). Agreement of clinical diagnosis by PCPs was

assessed relative to the local multidisciplinary expert teams who provided the training. Expert teams independently assessed either the video recordings of the diagnostic interview or conducted independent in-person evaluations, blinded to the decisions made by the trained PCPs.^{22,24,26}

There was heterogeneity among the 4 papers on how the diagnostic decision was recorded. Warren et al. (2009) and Swanson et al. (2014) asked PCPs to make forced-choice decisions of ASD or non-ASD and rank their certainty of diagnoses on a Likert scale. Ahlers et al. (2019) asked participants to rank their certainty of diagnosis on a Likert scale. However, Ahler et al only reported the accuracy of diagnosis for which participating PCPs had a high level of certainty, likely inflating these rates and making them less comparable with those of studies that reported accuracy in the full sample.

A small number of patients were included in studies that reported accuracy ($n = 14$ –38). Diagnostic agreement between the trained providers and the expert teams ranged between 74% and 100%. Notably, each of these studies reported absolute agreement, without adjustment for chance agreement; the rates of ASD diagnosis by the expert teams ranged from 41% to 78%. The study (Warren et al., 2009) that reported the lowest mean absolute diagnostic agreement (74%) limited the diagnostic evaluation to 60 minutes and required the trained providers make a binary choice of whether the child had ASD. In that study, diagnostic disagreements often involved presentations with other clinically significant developmental concerns.

McClure et al. (2010) included the most patients ($n = 38$), but only 3 patients were younger than 5 years. PCPs reported their impression as to whether the child had ASD and stated the specific DSM IV diagnostic subtype. Full agreement between the trained PCP and the expert teams was 92% for the presence/absence of ASD and 87% for specific subtypes. Ahlers et al. (2019) reported the highest diagnostic agreement of 93% for children who were diagnosed as having ASD and 100% when children were diagnosed as not having ASD. Among the 4 studies that evaluated the accuracy of diagnosis, not all patients assessed by the PCPs were included in the analyses. The criteria and reasoning behind the patient selections were not provided or standardized in 3 of the 4 studies. The nonrandomized design for these studies increased the risk of selection bias. In these 4 studies, the expert teams were all blinded to the diagnosis made by the trained PCPs before the evaluation to ensure fidelity. However, the effectiveness of the blinding process was not assessed. In 3 of the 4 studies, it was unclear whether patients were informed of the PCP diagnosis before receiving the expert team's assessment.

Two of the 6 papers reported the complexity of behavioral presentation: 1 stratified the patients into 3 subgroups and a second excluded patients with significant medical complexity.^{23,27} No study reported the level of diagnostic agreement by complexity.

Provider Practice and Perception

Two of the 6 studies included self-reported changes in provider practice and perceptions.^{21,23} The first found that the providers' comfort level for discussing ASD diagnosis increased. They also noted a large, statistically significant shift in reports of practice behavior, with 68% of providers reporting that they were more likely to conduct ASD assessments within their practice at the end of the training program.²³ The second study reported an increased use of autism-specific screening tools (from 80% to 100%) pretraining to post-training.²¹ In this study, all providers reported improvements in relationships and interactions with patients with ASD and their families, and 93% reported that the program had a positive impact on their community.²¹

Family Perspectives

Only 1 of the 6 studies explored family perspectives as an outcome.²⁴ In that study, satisfaction surveys were completed by 14 parents of children evaluated by a trained PCP and 35 parents evaluated by the traditional expert team. Of these 14 parents, 90% of them were either "extremely satisfied" or "moderately satisfied" during the evaluation process. There were no significant differences in respect to parents' perception of shared decision making or family-centered care between the traditional model and the trained PCP model.

DISCUSSION

This review identified 6 studies evaluating training models aimed at preparing primary care providers (PCPs) to assess and provide autism spectrum disorder (ASD) diagnoses. Five of 6 studies demonstrated increased access to ASD diagnoses, with approximately a 50% reduction in wait times. Four studies assessed accuracy of diagnosis by comparing diagnostic decision with blinded ASD expert teams, and the degree of diagnostic agreement was as high as 71% to 100%. These studies have laid the foundational framework for ongoing research. As ASD assessment quality can be considered as a multidimensional construct, there are other important outcomes that should be further evaluated, such as family satisfaction and earlier access to interventions. For many families, satisfaction with the diagnostic experience was associated with clarity of communication and practical information around resources and services available and negatively associated with more professionals consulted and longer time to diagnosis.^{11,27,28} Diagnostic assessment training could include providing PCPs with practical guidance around navigating the service system and practical resources for patients and families, which was provided during training by 1 of the 6 studies. It is also important that future studies evaluate whether adding a PCP assessment stream to existing diagnostic programs leads to earlier access to intervention services.

Diagnostic wait times for ASD have reached a critical level.²⁹ The development of innovative approaches to address challenges will be of great value to families and systems of care alike.¹⁴ There are several barriers to developing and evaluating PCPs' training programs highlighted in the reviewed studies. First, ASD assessment by traditional multidisciplinary teams is very resource and time intensive. Having patients go through similar diagnostic processes twice, as part of the accuracy evaluation, would require significant resource investments and dedication from patient families. This may limit participation. One study video recorded the PCP's interview and assessments, enabling expert teams to form independent diagnostic impressions based on these recordings.²² This approach could reduce the required time commitment and travel for families for confirmatory assessments. Second, training programs are time intensive for PCPs. After training, community pediatricians may not have the time, resources, or infrastructure to incorporate the assessments into their clinical practices or to participate in evaluative studies. In addition, higher-volume and lower-complexity clinical activities may be better reimbursed for fee-for-service primary care physicians; thus, enhanced reimbursement and/or alternate payment models may be needed for sustainability of a PCP-based diagnostic stream. PCPs in these included studies may have had special interest in ASD and/or protected time for ASD assessments and may not be representative of all PCPs. Targeting "local champions" in the care of patients with ASD may be essential to building community capacity. Incorporating a task-sharing approach in primary care, whereby other nonphysician primary care workers (e.g., case managers, community health workers, or therapists) support PCPs' diagnostic assessments, is another strategy. There are also recent feasibility data on incorporating ASD diagnostic assessment into pediatric residency training, which may also enhance community capacity.³⁰ Furthermore, eligibility for supports and services may depend on including measures (e.g., adaptive skills or other relevant functional domains) that may be less accessible to PCPs than to specialized teams. Mitigating strategies are possible. First, PCPs could work in partnership with other community professionals to complete such measures. These assessments could provide the developmental context to inform differential diagnoses, consistent with current American Academy of Pediatrics practice recommendations.¹⁵ Second, leaders from ASD centers could work with decision/policy makers to ensure that requirements for specific measures are aligned with what is essential to inform care and not to inadvertently create barriers to diagnostic access. Ensuring the sustainability of improved access to ASD diagnosis related to PCP training is important. To date, there are no data to indicate to what degree trained PCPs maintain an active role in ASD assessment be-

yond the initial study period. Reimbursement models (as noted above) and other potential incentives, such as ongoing continuing education/case discussion opportunities, may be needed. Indeed, maintaining a longitudinal relationship to the specialized assessment team would be beneficial to provide PCPs with ongoing support as the clinical landscape and evidence base changes over time. These points argue for consideration of system-level issues and the need for longer follow-up when assessing strategies to increase access to ASD diagnoses.

This review identified solutions, as well as gaps, that can guide and inform future training model evaluation. Future evaluation efforts should aim to include patient and PCP demographics (e.g., age, sex, race, and ethnicity), how patients are referred, additional training and practice settings of PCPs, details of training material and training delivery, and rigorous and comprehensive assessments of outcomes. These outcomes should include family perspectives and timing of access to diagnostic and intervention services. Accuracy of diagnostic assessments should include a traditional expert consultant or team to cross-check the reliability and accuracy of diagnosis by the trained PCPs, the analysis of which should be corrected for chance agreement. Strict methodological standards should be applied to prevent overestimation or underestimation of the diagnostic accuracy. Patients selected for this process should be determined before assessment by either group to reduce selection bias. Although the reviewed training models were generally associated with high levels of concordance between diagnostic decision making by the trained PCPs and local specialty teams, clinical information available to the PCP about the children they were assessing did not generally include language, intellectual, and/or adaptive skill data. Information about the developmental level of the child is needed to inform clinical interpretation of behavioral symptoms, as recommended by clinical practice parameters internationally.¹² Future training efforts should ensure this aspect of differential diagnosis is understood by participating PCPs and ensure that assessment data including developmental level are made available. Finally, conducting future studies in settings that serve diverse patient populations such as race/ethnicity and rural/urban settings would be invaluable.

Comparability across studies would also be enhanced by incorporating standard definitions of access (e.g., wait time from referral to initial assessment, which could be compared across community and specialized teams) and total number of children assessed. A retrospective chart review would provide more objective data than self-reported surveys for these outcome measures. Future studies are needed to evaluate improved access to diagnosis to demonstrate that adding a community assessment pathway is not moving the problem downstream, delaying access to

intervention. Family experiences with trained PCPs and the expert teams should also be compared. A comprehensive framework for evaluating effectiveness should include a family-centered approach, continuity of care, and expertise pertaining to local resources. This discussion raises broader questions about how to evaluate the quality of diagnostic assessments, regardless of format and setting. A framework is needed that can be applied across the continuum, from traditional multidisciplinary center-based assessments to solo discipline, "virtual team" community assessments, and telehealth-based assessments. We should be working toward overall ASD assessment strategies that might involve multiple pathways within a single community.¹²

There are several limitations to this systematic review. We did not include studies that only targeted community-based psychologists trained as diagnosticians, which could be an additional strategy to increasing overall assessment capacity. The number of studies included is small, which made it difficult to assess publication bias. Study methodology for all the studies included was of low quality (e.g., before-after designs and nonrandomized trials), and none of the studies took steps to ensure fidelity. The diversity of training strategies and outcome assessments limited the ability of the review to compare programs and combine data across studies. The studies reviewed spanned the transition from DSM-IV to DSM-V, further complicating the comparison. As such, there is insufficient evidence from this review to draw conclusions about the effects of PCP training in the ASD diagnostic assessment or to recommend one approach over another.

In conclusion, training PCPs in ASD diagnostic assessment can lead to high levels of agreement with expert teams and potentially add capacity by increasing access. However, current data are limited and difficult to synthesize because of small sample sizes, variable quality of study methods, and heterogeneous study design and outcome evaluation. More rigorous training model evaluations addressing diagnostic accuracy, reduction in wait time, family satisfaction, and longer-term outcomes are needed. The potential to apply these training models on a larger scale holds great promise in improving access to ASD diagnosis, with the advantage of embedding diagnosis within the medical home for some children with ASD. This review also highlights important questions about which outcomes to consider when evaluating the quality of ASD diagnostic assessment, applied across the continuum of approaches, from traditional center-based teams to novel community-based models. Ultimately, evidence-based training processes could promote further uptake and increase capacity for high-quality community-based assessments. In combination with tertiary assessments, for patients with greater complexity, these approaches could move us forward toward a more flexible and integrated system of care.

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