Approaches to Enhancing the Early Detection of Autism Spectrum Disorders: A Systematic Review of the Literature

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Background: A reliable diagnosis of autism can be made as early as 24 months, yet in many children diagnoses are made much later. A delay in diagnosis translates into a missed opportunity to provide early intervention services and to improve outcomes. The aim of the current study was to review the literature on early detection approaches in primary care and other community settings in the United States. **Methods:** A search was conducted of the peer-reviewed and gray literature to identify studies published from January 1990 through January 2013 testing approaches to enhance the early detection of autism in community settings in the United States. **Results:** The search identified 40 studies describing 35 approaches, which were grouped into the following categories: awareness (n = 4), routine screening (n = 21), and practice improvement to enhance screening (n = 10). Awareness approaches were associated with positive changes in knowledge of autism-related topics. Routine screening yielded high or increased rates of screening and referrals; however, few studies assessed the effect of screening on age at diagnosis or services enrollment. Practice improvement approaches resulted in increased screening and referral rates and highlighted the importance of adopting a multipronged approach to enhance early detection. **Conclusions:** Although studies that tested screening approaches in community settings found positive results, the effectiveness of such efforts on reducing time to diagnosis and services enrollment remains largely untested. The fact that few studies reported outcomes beyond rates of referral indicates the need for enhanced methodological rigor, particularly with respect to length of follow-up and quality of measures used. J. Am. Acad. Child Adolesc. Psychiatry, 2014;53(2):141–152. **Key Words:** age, autism, diagnosis, early detection, screening

Despite the ability to reliably diagnose autism in children as young as 24 months of age[1] and the existence of evidence-based early behavioral interventions,[2-4] the diagnosis remains delayed in many children.[5,6] The most recent prevalence study conducted by the Centers for Disease Control and Prevention (CDC) reported median ages at diagnosis for autistic disorder to be 48 months, and 53 and 75 months for autism spectrum disorder (ASD)/pervasive developmental disorder (PDD) and Asperger's disorder, respectively.[6] Children whose diagnoses are delayed may miss the opportunity to receive early intervention services to improve developmental outcomes and quality of life.

This article is discussed in an editorial by Dr. Connie Kasari on page 133.

A recent systematic review of studies examining age at ASD diagnosis identified myriad factors associated with delayed diagnosis at the child, family, and community levels, including greater symptom severity, lower socioeconomic status, racial/ethnic minority status, low levels of caregiver awareness of the early signs of autism, living in resource-poor settings, and visiting greater numbers of clinicians before diagnosis.[7] Furthermore, a number of ASD prevalence studies consistently identify a much lower prevalence among population subgroups such as African-American and Latino children,[6,8-11] despite a lack of evidence supporting true differences in population prevalence across racial and ethnic groups.

Recognition of disparities in early detection has spurred a number of efforts by federal agencies, such as the CDC,[12] professional associations, such as the American Academy of Pediatrics (AAP),[1] and local and state early intervention (EI) programs,[13] all with varying levels of success. In addition, the Interagency Autism Coordinating Committee (IACC) originally established by the Combating Autism Act of 2006 and represented by the US Departments of Health and Human Services, Defense and Education, has made early detection of autism a priority.[14] As a result of these efforts, the evidence base for effective approaches in early detection in community settings is gradually building. This review attempts to answer the following questions: What are the approaches to enhancing early detection of autism spectrum disorders and developmental delay in community settings in the United States? How do these approaches compare with respect to populations studied, intervention components, and outcomes?

METHOD

This study reports on findings from a comprehensive literature review of approaches to enhance the early detection of autism and developmental delay in children. A search for all peer-reviewed articles containing the following search terms was performed in PubMed, PsycINFO, CINAHL and Web of Science, Web of Knowledge: autism, developmental delay, developmental disorder (condition); community, day care, center, clinic, preschool, primary care (setting); approach, component, guideline, implement, intervention, model, plan, policy, practice, program, project, protocol, recommendation, strategy, standard (approach); and awareness, detection, diagnosis, referral, screening (outcome). The search was limited to studies published in English from January 1990 through January 2013. An additional search was conducted for studies and other gray literature containing the aforementioned key words in Google. Gray literature refers to information that is not commercially published (i.e., government reports) and does not undergo peer review.[15] In addition, references from all relevant articles were reviewed for studies that may have been missed during the initial search. One individual performed the initial title and abstract screens, and 2 individuals reviewed the remaining articles for final consensus on inclusion.

A study or report was included in this review if it met the following criteria: target population is children at risk for or diagnosed with ASD and/or developmental delay (DD); study is conducted in the United States; study describes approaches that target service providers, caregivers, and/or families; and study reports outcomes related to early detection. The initial search yielded a total of 4,975 studies (henceforth, "study" is used to describe peer-reviewed articles, dissertations, published reports), 36 of which met inclusion criteria for this review. An additional 3 studies were identified through the reference search and 1 from Google. A total of 40 studies describing 35 approaches met inclusion criteria for this review.

The 35 approaches were then grouped loosely into the following categories: increase awareness (n = 4); routine screening (n = 21); and practice improvement to enhance routine screening (n = 10). Awareness refers to studies that evaluated techniques to increase knowledge related to early detection; routine screening refers to studies that evaluated the implementation of screening only in community settings; and practice improvement to enhance routing screening refers to studies that supplemented screening activities with at least 1 additional practice improvement component, such as provider training.

RESULTS

Characteristics of the 40 studies are summarized according to the aforementioned categories in Table 1.[16-53] All but 4 studies were published after the year 2000. Study designs varied and included post only (n = 23), pre–post (n = 12), pre–post comparison (n = 3), and randomized controlled trials (n = 2).

Awareness

Four studies described approaches to increase knowledge of ASD and DD.[12,16-18] One evaluated a social marketing campaign ("Learn the signs. Act early."), comprising print and Web materials, public service announcements, and a 24-hour-a day, 7-days-a-week live call center, targeting parents, clinicians, and child care professionals.[12] Outcomes examined in this study included changes in autism awareness, knowledge and behaviors among parents and clinicians over time and reported positive changes in awareness over the 3-year study period. The 3 remaining studies tested the effectiveness of training providers to recognize autism or developmental delays in children. Two studies conducted didactic, in-person trainings,[17,18] and the third delivered training over the Internet.[16] Changes in mean knowledge scores pre–post were assessed in all 3 studies. The randomized controlled trial of in-person training found no group differences in knowledge measures,[18] whereas the remaining 2 studies reported increases in knowledge post-intervention.[17]

TABLE 1 Early Detection Approaches for Children With Developmental Delay and Autism Spectrum Disorders (ASD) (N = 35)

Study, Location	Participants	Design	Setting	Intervention	Outcomes
Awareness (n = 4)					
Daniel *et al.*, 2009,[12] National	Parents; health practitioners; early educators	Pre–post	Childcare; primary care practices	Social marketing campaign on importance of early detection of DD and ASD, over 3 years	Parents: increased awareness of milestones, early warning signs, benefits of early action; Clinicians: increased dialogue with parents, regular screening, confidence discussing cognitive development, referral and treatment resources, fewer 'wait and see' approaches
Elmensdorp, 2012,[18] California	30 Health care professionals	Randomized controlled trial	Primary care practices; residency program office	Brief didactic training on ASD in young children, study length unspecified	No differences in global knowledge; Differences in recognition of core symptoms, confidence in discussing concerns; High satisfaction
Kobak *et al.*, 2011,[16] National	30 Health care professionals	Pre–post	Web	Web-based training in early ASD screening, study length unspecified	Increase in mean scores; High satisfaction; Feasible training method
Nalven *et al.*, 1997,[17] Pennsylvania	49 Pediatric residents; 1,204 children, <6 years	Pre–post, comparison	Pediatric outpatient clinic	Brief didactic training on EI and special education, study length unspecified	SPR: 13%, no difference by educational strategy; Increase in mean scores; 1st year residents scored lower than 2nd and 3rd year pre and post
Routine screening (n = 21)					
Bruhn, Duval, and Louderman, 2008,[19] Illinois	2,164 Children, <36 mo	Post only	Regional screening offices	Centralized DD screening of foster care children, over 13.5 mo	SPR: 57%; SR: 77%; RR: 98%; 98% evaluation rate; Other: 93% enrolled in services
Earls, Andrew and Hay, 2009; Earls and Hay, 2006; Klein and McCarthy, 2009,[13,20,21] North Carolina	526 Children, 29–48 mo	Post only	Primary care practices	Routine DD screening at 6-, 12-, 18-, 24-, 36, 48- and 60-mo well-child visits project, over 28 mo	SPR: 19%; RR: 12% (all screened), 65% (screen positive); State-wide data: SRC: 34% (2000) to 66% (2002–2003); RRD (v. State Child Find): 6–8% vs. 3%; Other: age at EI referral 15 mo, 40% children <12 mo
Eddey *et al.*, 1995,[22] New Jersey	159 Children, <6 y	Post only	Classrooms	Multidisciplinary DD screening events, study length unspecified	RR: 32% (all screened); Other: Parent concerns included delayed speech, behavior issues, premature birth, prenatal drug exposure; High satisfaction
Grossman *et al.*, 2010,[23] New York	138 Parents and children, 6–36 mo	Post only	Pediatric emergency department	DD screening during emergency department visit, over 18 mo	SPR: 27%; Other: 21% no primary care doctor; Child age significantly associated with SPR

TABLE 1 Continued

Study, Location	Participants	Design	Setting	Intervention	Outcomes
Guevara *et al.*, 2013; Kavanagh *et al.*, 2012,[24,25] Pennsylvania	2,103 Children, <30 mo	Randomized controlled trial (screening, screening + office support, surveillance only)	Urban pediatric practices	Routine DD and ASD screening at the 9-, 18- and 30-month and 18- and 24- month well child visit, respectively, over 16 mo	SR: 81% (screening), 88% (screening +); SPRD: 27% (screening), 23% (screening +) vs. 13% (surveillance); RRD: 18% (screening), 20% (screening +) vs. 10% (surveillance), among all screened, 65% (screening), 86% (screening +) vs. 79% (surveillance), among screened positive; Other: EI eligible: 5% (screening), 7% (screening +) vs. 3% (surveillance); Screening resulted in shorter time to identification, EI referral, evaluation
Gura, Champagne, and Blood-Siegfried, 2011,[26] Southeastern city	99 Children, 18–24 mo	Post only	Community-based, private primary care practice	Routine ASD screening at the 18- and 24-mo well-child visit, over 7 mo	SPR: 4%; SR: 91%; Other: cost offset
Harrington, Bai, and Perkins, 2013,[27] Virginia	176 Electronic screens; 197 paper screens	Post only	Urban health clinic	Electronic routine ASD screening at primary care setting, over approximately 1.5 mo	SPR: 3% (electronic form), 10% (paper-based) with follow-up; Other: parent satisfaction
Hepburn *et al.*,[28] 2008, Colorado	7 Elementary schools; 60 teachers; 1,355 children	Post only	Large school district	Routine ASD screening using teacher nomination in general education classrooms, study length unspecified	SPR: 7% (ASSQ), 9% (teacher nomination); Other: high teacher-ASSQ agreement, time offset, feasible
Hix-Small *et al.*, 2007; Marks *et al.*, 2009,[29,30] Pacific Northwest	20 Health care professionals; 1,428 caregivers	Pre–post	Primary care practices	Routine DD screening at the 12- and 24-month well-child visit, over 12 mo	SR: 54%; RR 14% (all screened); RRC: 224%; Other: 38 (of 81) EI eligible; 44 follow-up evaluation; 25 did not qualify; Increase eligibility for special education; Low cost; Minimal time to administer
Jee *et al.*, 2010,[31] New York	261 Visits of children, 4-61 mo	Pre–post	Pediatric office	Routine DD screening of foster care children at well-child visits, over 20 mo	SPR: 58% (new to foster care); SR: 96%; SPRC: 29% vs. 58%; Other: Feasible to implement
King *et al.*,[32] 2010, National	15 States; 17 pediatric practices	Pre–post	Pediatric, primary care practices	Routine DD screening according to 2006 AAP policy guidelines, over 9 mo	SPR: 14%; SR: 80%; RR: 61% (screened positive); SRC: 68% vs. 86%
Mauch *et al.*,[33] 2011, Missouri	4 Hospitals; 55 physicians	Pre–post	Primary care practices	Routine DD and ASD screening; Development of state policy guidelines, study length unspecified	SR: 80–90%; SRC: 30% and 10% vs. 90% and 80% (DD and ASD, respectively): Other: Developed Web site; Distributed 6,000 guidelines

TABLE 1 Continued

Study, Location	Participants	Design	Setting	Intervention	Outcomes
McGookin and D'Sa, 2011,[34] Rhode Island	489 Children; 8 health care professionals	Post only	Primary care practice	Routine DD and ASD screening at the 9-, 15, and 24-month and 18- and 24-month well child visits, respectively, over 12 mo	SPR: 23% (DD), 5% (ASD); RR: 8% (DD), 3% (ASD), all screened, 34% (DD) and 60% (DD), screen positive; Other: 70% diagnosed with DD
Miller *et al.*, 2011,[35] Utah	990 Children, 14–24 mo	Post only	Community-based pediatric practice	Routine DD and ASD screening at all visits (sick and well), over 6 mo	SPR: 24%; SR: 80%; RR: 6% (all screened), 26% (screened positive); Other: 2% early signs of ASD; 32% screened did not receive well-child visit
O'Hara, Church, and Blatt, 1998,[36] New York	52 Children, <18 mo	Post only	Home	Home-based DD screening for foster care children, over 11 mo	SPR: 35%; Other: high foster parent satisfaction
Pierce *et al.*,[37] 2011, California	30 Offices; 133 pediatricians; 225 infants	Post only	Pediatric offices	Routine ASD screening at 1 year well-child visit, over 3.5 years	SPR: 13%; RR: 4% (all screened), 26% (screen positive); Other: 184 evaluated; 32 received provisional ASD diagnosis (72% diagnosed at 32-36 mo); Average age at treatment 17 mo; High provider satisfaction
Pinto-Martin *et al.*, 2005,[38] Pennsylvania	21 Children, 18-24 mo	Post only	Urban primary care practice	Routine ASD screening at 18- and 24- month well-child visit, study length unspecified	SPR: 14%; RR: 5% (all screened), 33% (screen positive)
Roux *et al.*,[39] 2013, California	2,845 Children, ages <60 mo	Post only	Phone	DD and ASD screening by telephone, over 26 mo	SPR: 28% (DD) and 21% (ASD) ; RR: 92%; Other: 45% (DD), 51% (DD) receiving services at follow-up; 40% loss to follow-up (among families initially indicating interest in screening)
Rybski and Wilder, 2008,[40] Missouri	4 Child care centers; child care providers; 95 children, <60 mo	Post only	Child care centers	Routine DD screening in urban child care settings, study length unspecified	SPR: 43%; Other: 10 previously identified, 14 identified at risk, 17 lost to follow-up; High reliability between provider and Denver II scores
Schonwald *et al.*, 2009,[41] Massachusetts	2 primary care practices; 616 children, 6 mo to 8 y	Pre–post	Primary care practices	Routine DD screening at all well-child visits, over 12 mo	SPR: 26%; SR: 61% (2-year-olds), 62% (3-year-olds); RR: 10% (all screened), 34% (screen positive); SPRC: 21% vs. 26%; RR: increase for 3-year-olds only; Other: increase in provider perceived abilities

TABLE 1 Continued

Study, Location	Participants	Design	Setting	Intervention	Outcomes
Thomas *et al.*, 2012,[42] Ohio	6 Health care professionals; 95 children, <24 mo	Post only	Primary care practice	Health surveillance and routine DD screening at the 9-, 18- and 24-month well-child visit, over 6 mo	SPR: 12% (surveillance), 16% (DD screening); Other: 67% of children who failed screen not identified by surveillance alone
Screening with practice improvement (n = 10)					
Allen *et al.*, 2010,[43] Illinois	16 Primary care sites; 350 + primary care providers; 25 children/site, 4–24 mo	Pre–post	Primary care practices	Statewide provider training, routine DD screening at 12-, 18- and 24-month well-child visits, over 3 years	SR: 85% (in 69% of sites); Other: 90% providers reported improved skills, confidence in screening; increase in intent to screen; 336 trainings at 164 sites for 2,873 participants
Bauer *et al.*, 2009,[44] Illinois	1 Primary care clinic; 32 pediatric residents	Pre–post	Primary care clinic; Medical school	Resident training, routine DD screening at well-child visits, over 12 mo	SRC: 11% vs. 100% (12-month), 0% vs. 88% (24 month); Other: increased knowledge of DD screening; No change in perceived ability to refer and manage
Honigfeld, Chandhok, and Spiegelman, 2012,[45] Connecticut	43 Primary care practices; 318 health care professionals	Pre–post, comparison	Primary care practices	Academic detailing module, routine DD and ASD screening, over 20 mo	SR: 71%; SPR: 12%; SRC: 0%-100% vs. 19%-100%; SRD: 71% vs. 46%; SPRD: 7% vs. 12%; Other: Increased billing to Medicaid; 93% trained clinicians intend to screen
Koegel *et al.*,[46] 2005, California	Not reported	Pre–post	Primary care offices; Autism Research and Training Center	Community outreach, DD and ASD screening, family support, over 2 years	RR: 57%; RRC: 36% (2003) vs. 57% (2004); Decrease in age at referral from 32 mo (2003) to 30 mo (2004)
McKay, 2006; Bogin, 2006,[47,48] Connecticut	141 Community pediatric practices; 507 staff; 918 children	Pre–post, comparison	Primary care practices	State-wide primary care provider training in early detection of DD, study length unspecified	SPRC: 9% vs. 18%; Other: 47% practices received training intervention; 90% charts evidence of developmental surveillance (no difference in intervention vs. control); Increase calls to info line; Referral age: 23 mo (intervention) vs. 21 (comparison)
Shannon and Anderson, 2008,[49] New Hampshire	3,343 Children, <36 mo	Pre–post	Pediatric practices; Community health centers	DD screening by developmental specialists, the Baby Steps Program, over 43 mo	SPR: 28%: RR: 100% (among screen positive): Other: 16% referrals to EI; 185 referrals completed; 146 eligible for EI
Silow-Caroll, 2008,[53] Iowa	41,000 Children; 39 primary care practices	Post only	Primary care practices	Statewide collaborative of in-site training, DD screening, care coordination, the 1st Five Initiative, length of study period not specified	486 Referrals to care coordinators; 22% referrals related to child development concerns; 1,575 referrals to services; 3–4 needs identified per child

TABLE 1 Continued

Study, Location	Participants	Design	Setting	Intervention	Outcomes
Solomon *et al.*, 1994,[50] Pennsylvania	3 Sites; 109 physicians; 313 children	Post only	Community-based develop-mental assessment sites	Designated service coordinator sites to support DD screening and referrals, train pediatric residents and provide community outreach, over 17 mo	SPR: 30%; RR: 100% (to multidisciplinary evaluation); Other: 95% EI eligible; Reduced costs; High parental and provider satisfaction
Warren, Stone, and Humberd, 2009,[51] Tennessee	5 Pediatricians; children, 24-36 mo	Post only	Community-based pediatric practices	ASD screening and diagnosis training program for pediatricians, study length unspecified	25 Children referred; 21 completed evaluation; Age 22-37 mo at time of evaluation; High provider-diagnostic agreement; Over identification a concern
Webb, 2011,[52] Missouri	29 Children, 9–30 mo	Post only	Federally Qualified Health Center	Quality improvement and routine DD and ASD screening at well-child visits, over 4 mo	SPR: 7%; SR: 35%; RR: 7% (all children), 100% (screen positive); Other: 50% eligible for EI

Note: DD = developmental delay; EI = early intervention; RR = referral rate; RRD = referral rate difference (intervention vs. control); RRC = referral rate change (pre–post); SPR = screen positive rate; SR = screening rate; SRC = screening rate change (pre–post); SRC = screen positive rate change (pre–post); SRD = screening rate difference (intervention vs. control); SPRD = screen positive rate difference (intervention vs. control).

Routine Screening

Twenty-one routine screening approaches were described in 25 studies.[13,19-42] In this review, screening is defined as the systematic interview or other evaluation, by professionals, for signs and symptoms autism and/or developmental delay with the use of standardized (primarily but not exclusively parent-completed) instruments. The majority of approaches described (n = 15) reported findings on the implementation of routine screening in health care settings. Among them, 5 focused on urban settings,[23,24,26,27,38] and all but 3 implemented screening during well-child visits only.[23,27,35] A few focused on the delivery of routine screening expressly to at-risk populations or underserved communities; for instance, 1 study screened children in foster care,[31] and others described approaches specifically targeting the Medicaid population.[13,20,21] Several studies described screening in non–health care settings including schools,[22,28] a city-wide call line,[39] and child care centers,[40] many of which focused on at-risk or difficult-to-reach populations such as rural communities[28] or children in foster care.[19,36]

Of all routine screening approaches described, 11 focused on DD, 6 focused on ASD, and 4 included both DD and ASD. The mode of screening varied considerably across approaches. Among those reporting the use of standardized instruments (n = 18), the Ages and Stages Questionnaire (n = 8)[19,20,23,24,29,31,32,42] and the Modified Checklist for Autism in Toddlers (n = 7)[24,26,27,34,35,38,39] were the mostly commonly used for DD and ASD screening, respectively. Other instruments included the Parents' Evaluation of Developmental Status (n = 4)[32,34,39]; the Denver Developmental Screening Test–II (n = 3)[19,36,40]; the Autism Syndrome Screening Questionnaire (n = 1)[28]; the Communication and Symbolic Behavior Scales Developmental Profile Infant-Toddler (n = 1)[37]; the Infant-Toddler Checklist (n = 1)[35]; and the Michigan Scales of Child Development (n = 1).[41] Only 1 study reported using standardized instruments in a language other than English (Spanish) to participants.[35]

The most commonly reported outcome was screening rate, which ranged from 54%[29,30] to 96%.[31] The screen positive rate ranged from 14%[32] to 58%[31] for DD and from 3%[27] to 24%[35] for ASD. A number of studies also reported referral rates, which generally ranged from 3%[34] to 32%[22] among all children screened (1 study reported

referring 92% of all screened children to services[39]), and from 26%[35,37] to 98%[19] among screen-positive children. Outcome measures used less frequently included differences in the screen-positive rates pre–post, percentages screened and referred pre–post, and comparisons of these outcomes between intervention and control groups. Two studies documented significant increases in screen-positive rates post-intervention.[31,41] With respect to changes in screening rates, 1 study documented an almost doubling in screening rate pre–post,[20,31] and another reported a 3-fold increase in screening for DD post-intervention.[33] A third study documented an 18% increase in average screening rates across 17 practices over the course of the study period.[32] With respect to referral rates, 1 study found a 224% increase post-intervention,[29] and another documented a significant increase among 3-year old children only.[41] One study cited a difference in referral rates comparing the intervention group to state-level data on early intervention (EI) referrals,[20] and the only study with a comparison sample found referral rates among the 2 routine screening groups to be 18% and 20% as compared to 10% in the surveillance-only group.[24] Even fewer studies reported on more distal outcomes (see Table 1 for full range of outcomes).

Practice Improvement to Enhance Screening

Eleven studies described 10 approaches that incorporated at least 1 additional practice improvement component into a routine screening program.[43-53] The approaches described in these studies included comprehensive state-wide programs to enhance early detection, provider training, community outreach, service coordination, and implementation of continuous quality improvement strategies into routine practice. Three state-wide programs described in 4 studies supplemented screening with the following components: disseminating resources, in-practice provider training, and ongoing technical assistance (Illinois's Enhancing Developmental Oriented Primary Care)[43]; provider training and referral of at-risk families to a child development info line (Connecticut's Help Me Grow programs)[47,48]; and provider training and support through specialty-trained care coordinators to identify needs (Iowa's 1st Five Initiative).[53] In addition to the state initiatives described, 3 studies tested approaches to train providers in developmental surveillance, screening, and diagnosis.[44,45,51] One study in particular tested the use of academic detailing on providers' use of formal screening tools per the AAP recommendations and billing codes for reimbursement.[45] The use of community outreach to raise awareness,[46,51] and care coordination across primary care and referral sites[46,49,50] were described in a number of studies. Finally, 1 study evaluated the use of a quality improvement intervention to enhance routine screening for DD and ASD.[52]

Of all approaches described, 6 focused on DD, 1 focused on ASD, and 3 included both DD and ASD. Among studies reporting the use of standardized screening instruments (n = 5), the ASQ for DD and M-CHAT for ASD were the most common. The types of outcome measures varied considerably and ranged from input and process-related measures, such as numbers of providers trained, to more distal measures, such as percentage of children eligible for EI. Despite the focus on screening, few studies reported screening and referral rates to the extent reported in the routine screening studies. Among those that reported comparable outcomes, screening and referral rates ranged from 35%[52] to 100%[44] and from 7%[52] to 100%,[49,50] respectively.

DISCUSSION

This systematic literature review identified 40 studies describing 35 approaches implemented in community-based settings to enhance the early detection of autism and developmental delay. The majority of studies evaluated the feasibility or effectiveness of implementing routine screening only, and most approaches incorporated at least 1 standardized screening instrument into routine practice. In addition, a majority of the recent studies evaluating routine screening in primary care delivered screening for DD and ASD at the AAP-recommended 9-, 18-, and 30-month visits and 18- and 24-month visits, respectively. For the most part, studies implementing routine screening found high (>80%) or significantly increased screening[20,25,26,29,31,35,39] and referral rates.[29,41] Although not explicitly examined, variation in particular drivers of practice or provider change across studies could have explained the wide ranges of screening and referral rates observed. Other possible explanations include variations in screening methods and referral ascertainment, which ranged from record or claims review, to clinician-report.

Of particular note is that not all screening was performed during well-child care visits in

pediatric/primary care settings. Some studies examined different opportunities to screen during physician visits (i.e., during sick visits),[23,27,35] and others took advantage of opportunities to screen outside of the health care system.[28,39] In both cases, screening was feasible and improved identification of children at risk for ASD. For instance, Miller *et al.* found that 32% of children screened during all primary care visits over a 6-month period did not attend a well-child visit.[35] Findings from these studies suggest that taking multiple opportunities to screen would result in fewer children at risk for or with developmental delays remaining unidentified.

Irrespective of the study setting, a number of common challenges to implementing routine screening emerged. These included effecting practice change in the context of time and resource constraints,[26,32] identifying the optimal mode and context of screening,[29] and failing to follow-up post–positive screen.[24,32] Beyond those highlighted in the included studies, other barriers to implementing screening in community settings commonly cited in the literature include lack of provider knowledge about screening tools[54] and reimbursement issues.[55]

Several studies used provider training applying didactic teaching methods as a strategy to increase knowledge around early detection. However, studies that trained professionals (most often primary care providers) to increase their confidence and/or ability to screen and diagnose autism had mixed findings.[16,44,51] For instance, the McKay study found that training did not result in an increase in developmental surveillance,[47] and Bauer *et al.* found that training was not associated with greater self-rated confidence to screen.[44] These findings are consistent with behavior change research that has shown that didactic training alone is unlikely to result in significant behavior/practice changes.[56,57] In an effort to increase human resource capacity, 1 study assessed the feasibility of training how to screen over the Internet; however, although training resulted in knowledge gains, the extent to which it affected provider practice was not evaluated.[17] This underscores the need for a multipronged approach to enhance early detection. These approaches include training of pediatricians, other clinicians, and office staff on autism/developmental delays, reimbursement policies and practice, the administration of evidence-based screening tools and referral practice,[45,46] and establishing partnerships with early-intervention providers.[33,50]

Recommendations for Future Research and Practice in the Context of Limited Resources

Although there is no lack of potential research and practice directions to follow to enhance the early detection of autism and developmental delay in the United States, limited resources necessitate establishing a clear set of priorities. Findings from this review suggest that a focus on improving the scientific rigor of early detection approaches and on enhancing the reach of such approaches to underserved populations, particularly linguistic, racial, and ethnic minority communities, should be prioritized.

Among the 40 studies included in this review, only 2 were randomized controlled trials, and more than half reported post-intervention data only. Furthermore, most studies did not track child outcomes beyond the number screened and rates of screening and referral. Ultimately, the extent to which screening for developmental delay and autism resulted in early identification and access to early intervention services was only rigorously tested in 1 study.[24] Future studies should use metrics that capture child outcomes from first concern through service receipt; the Screening, Early identification, Referral, Intake, Evaluation, and Services (SERIES) paradigm, as described in a policy brief included in this review, may be a useful model to adopt in an effort to standardize outcomes across studies and programs to enhance early detection efforts.[25] Establishing benchmarks for early identification at the state and federal levels may also serve as an impetus for tracking child outcomes in the health and education systems; for example, increasing the proportion of all children identified by 36 months, as assessed in the most recent CDC prevalence study, may serve as 1 such benchmark.[6]

In addition to tracking outcomes, there is a need for greater research on strategies to enhance the proportion of children who screen positive and who go on to receive evaluations or services. Among the few studies that followed up children beyond screening, fewer examined the reasons for failing to refer or follow-up post-referral. Inability to reconnect with caregivers,[39] parent lack of understanding of referral,[32] and lack of clinician adherence to referral guidelines[24] were a few reasons cited. Collectively, findings from these studies suggest that much greater emphasis on the post-positive screening period is essential for enhancing early detection. One possible strategy is the use of electronic medical records and

Web-based technologies that connect multiple systems, such as health, early intervention, and education, to track children as they move from screening to evaluation to service enrollment.[58,59] Another may be the use of human resources such as community health workers or patient navigators to personally assist families as they move from 1 step in the process to the next.

In addition, there is a need for additional research on the comparative effectiveness of using different modes/contexts of screening administration, such as home versus office based, Web versus mail, parent-report versus clinician-administered, and the extent to which these modalities may contribute to the timely diagnosis of autism. Finally, most studies included in this review did not use more than 1 approach at a time. Although it would appear from the research that routine screening alone has the potential to enhance the early detection of developmental delays in children, the use of screening combined with practice improvement approaches requires further exploration.

Albeit not the focus of this review, a considerable body of research outside the United States has evaluated early identification approaches,[60,61] and a review of this literature would contribute immensely to the field. For the purposes of this study, restricting studies to those from the United States allowed for greater comparability of approaches and outcomes across studies. Furthermore, as there are a number of state and federal efforts underway to enhance early detection in the United States, this review may service as a baseline for assessing the extent to which these efforts have succeeded over time. Nonetheless, future research and practice in this area would benefit from a review of international approaches and associated outcome metrics.

Despite a relatively large body of research citing significant disparities in age at autism diagnosis in underserved communities,[7] a minority of studies included in this review focused on such populations, particularly on linguistic, racial, and ethnic minority communities. As such groups are often underidentified[6] or diagnoses are made later,[7] it is particularly crucial that future research and practice focus on these populations. In an effort to study and extend the reach of such approaches, the field may benefit from examining research in other disease areas that have tested detection strategies in underserved populations. In the field of cancer screening, for example, programs have been developed and evaluated for specific populations such as the Latino and African American communities.[62,63] Such studies have also explored the feasibility and effectiveness of conducting awareness and screening campaigns in nontraditional settings, such as community centers, churches,[63] and Young Men's Christian Associations (YMCAs).[64] The use of lay or paraprofessionals, such as community health workers or promatoras, and patient navigators have also been widely studied as a means of raising health awareness, promoting screening, and reducing time from first concern to diagnosis among underserved communities.[65,66]

Fortunately, there are a number of opportunities to leverage existing resources and knowledge gained by state and national efforts toward enhancing early detection. As this review demonstrates, in recent years a number of state initiatives have developed comprehensive approaches for improving early detection, many of which have a particular focus on underserved communities. Existing state programs such as the Assuring Better Child Health and Development project,[20] among others, inform the development of systematic approaches to early detection. On a national level, advocacy organizations (i.e., Autism Speaks), government agencies (i.e., CDC), and professional societies (i.e., AAP) are encouraged to coordinate resources and activities to ensure minimal overlap and maximal coverage. &

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