



DEVELOPMENTAL SCREENING IN PRIMARY CARE: THE EFFECTIVENESS OF CURRENT PRACTICE AND RECOMMENDATIONS FOR IMPROVEMENT

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ABSTRACT: Developmental delays and conditions are common in early childhood, and are predictive of later learning and behavioral difficulties. Early treatment improves outcomes. For this report, a literature review was conducted to determine the effectiveness of current efforts by primary care providers to detect developmental delays in early childhood. Although data are limited, there appears to be significant under-detection of developmental delays in early childhood. While the prevalence of developmental delays is at least 10 percent, early intervention programs aimed at addressing these concerns serve only 2.3 percent of children under age 3. Use of validated developmental screening tools is supported by American Academy of Pediatrics guidelines, but these instruments are neither widely nor systematically used in pediatric practice. The report makes several recommendations to strengthen developmental surveillance and screening, and thereby improve outcomes for young children and families.

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EXECUTIVE SUMMARY

Developmental delays and conditions are common in early childhood, affecting at least 10 percent of children. Early developmental delays are markers for later developmental conditions such as autism, intellectual disability, hearing or vision impairment, cerebral palsy, speech and language disorders, and learning disabilities. Risk factors such as family poverty, parents' mental illness, and child neglect and abuse increase the likelihood of developmental delays.

Recent studies emphasize the importance of the interaction of brain development and environment on children's developmental and behavioral outcomes. The tremendous adaptability of the brain in the first three years of life means that early treatment of delays leads to improved outcomes, whereas later intervention is less effective. In order to provide treatment to improve children's outcomes, early identification of delays and sensory impairments (i.e., vision and hearing problems) is critical.

Pediatricians and other primary care medical providers who see children for regularly scheduled preventive care visits during their first three years of life, and who are trained in child development, could play a key role in the early identification of developmental delays. For this report, a literature review was conducted to determine the effectiveness of current efforts by primary care providers to detect developmental delays in early childhood and to consider ways to improve.

Key Findings

According to the literature review, early developmental delays are often not identified in a timely way. Many children are not identified until kindergarten entry or later—well beyond the period in which early intervention is most effective. Therefore, in many cases, opportunities to intervene early to improve children's developmental outcomes are missed.

To monitor children's development, pediatricians and other primary care medical providers rely mainly on informal developmental milestones and their clinical impressions. Validated developmental screening tools that could increase identification of developmental delays exist, but most physicians do not use them systematically to screen all patients. Recently revised guidelines from the American Academy of Pediatrics recommend routine screening at three specific ages in early childhood, and may lead to the increased use of screening tools.

Given the prevalence and impact of developmental conditions in childhood, the number of scientific studies in this area is surprisingly limited.

Recommendations

The following steps could promote early identification of developmental delays in young children:

- Research is needed to: 1) elucidate the reasons for the gap between the prevalence of developmental conditions and their identification in early childhood; 2) document the effectiveness of physicians' developmental monitoring and screening efforts over time, as policies to encourage developmental screening are implemented; and 3) understand and address any negative consequences of developmental screening, such as increasing parental anxiety.
- Financial, educational, and other barriers to the use of developmental screening tools need to be addressed to increase physicians' use of these tools.
- Residents in pediatrics and family medicine need to be trained to use developmental screening tools as part of the routine care of pediatric patients, to ensure that the next generation of providers is ready to use developmental screening tools.
- Resources are needed to develop high-quality screening tools that are available in the public domain and are compatible with electronic medical records.
- Communication models need to be developed to assist physicians in discussing with families the implications of developmental screening test results.
- Adding a 30-month preventive care visit to the well-child visit schedule, as recommended by organizations such as Bright Futures, would increase the number of opportunities to provide developmental screening and identify developmental delays at a critical time in young children's development.
- Successful models to promote developmental screening, such as the Assuring Better
 Child Health and Development (ABCD) program in North Carolina, need to be
 spread to other states. This is already occurring through the ABCD Screening
 Academy, jointly sponsored by National Academy for State Health Policy and
 The Commonwealth Fund.

Systematic developmental screening will mean that greater numbers of children with developmental delays are identified. Planning and resource allocation at the state and federal levels are needed to ensure sufficient resources for their evaluation and treatment.

DEVELOPMENTAL SCREENING IN PRIMARY CARE: THE EFFECTIVENESS OF CURRENT PRACTICE AND RECOMMENDATIONS FOR IMPROVEMENT

INTRODUCTION

Developmental delays and conditions affect at least 10 percent of children in the United States. Delays in the development of speech and language as well as fine motor, gross motor, social, and problem-solving skills in early childhood are markers for specific developmental conditions, including speech and language disorders, learning disabilities, cognitive disability (mental retardation), autism spectrum disorders, cerebral palsy, and vision or hearing impairment. Language delays affect at least 5 percent to 10 percent of young children. An estimated 8 percent of children have a learning disability and 1 percent to 1.5 percent of children have a cognitive disability (Table 1). Any children have delays in more than one developmental domain. Factors that place young children at increased risk for developmental delays include low maternal educational attainment, poverty, maternal depression or mental health issues, 11,12 lead poisoning, 13,14 premature birth, 15 suboptimal nutrition (including failure to thrive 16 and anemia 17), and male gender.

Developmental delays and disabilities have important impacts on society in terms of the costs of providing health care, educational support, and ongoing services. In addition, they have indirect costs, such as lost income potential for affected individuals over their lifespan. Substantial resources are expended for the educational, medical, and community support of individuals with developmental delays and conditions. Affected children have significantly increased rates of health care use compared with children without such conditions. The economic costs to society associated with developmental conditions, including expenditures for additional medical care and indirect costs related to lost productivity, were estimated to be an average of \$1,014,000 over the lifetime for an individual with mental retardation, \$921,000 for an individual with cerebral palsy, and \$417,000 for an individual with hearing impairment in 2003 dollars.

Early treatment of developmental delays leads to improved outcomes for children, and therefore reduced costs to society. Early intervention has been shown to be particularly effective at improving outcomes for children who are at increased risk for developmental delays, or later academic underachievement, based on socioeconomic, medical, or other risk factors. A systematic review of early childhood development programs aimed at narrowing the achievement gap for children at risk because of poverty found that participation in such programs resulted in a mean 14 percent reduction in

special education placement later in childhood, 13 percent reduction in not passing a grade in school, and an increase in IQ test scores of about 6.5 points. ²⁶ In addition, participation had significant long-terms benefits in terms of reducing rates of teen pregnancy, increasing rates of high school graduation, and increasing rates of employment in early adulthood. ²⁶ The Infant Health and Development Program, a randomized, multi-site trial of a comprehensive early intervention effort aimed at premature children, from birth to 36 months, demonstrated sustained benefits, particularly for heavier infants in the cohort. ^{23,27}

Early identification is supported by federal legislation under Part C of the Individuals with Disabilities Act (IDEA), which provides program support to promote community-based efforts to identify young children with or at risk for developmental conditions, as well as treatment for affected children under age 3. In 2005, federal funds allocated under IDEA Part C totaled \$440.8 million. Federal appropriations of \$11.6 billion—26 times what is spent on early intervention—were made under IDEA Part B, which supports special education for children and youth ages 3 to 21. Head Start programs received \$6.84 billion in federal funding in 2005 to serve children 3 to 6 years of age at increased risk of poor educational outcomes due to poverty. ²⁹

In order to benefit from early intervention, children with developmental delays and conditions must be identified and referred at a young age. ^{24,30} Primary care physicians have the opportunity to monitor young children's development during 14 recommended health supervision visits between birth and age 5, ^{31,32} are trained in child development and behavior, ³³ and are therefore ideally suited to identify developmental delays.

The findings in this report are based on a review of the literature. The objectives of the review were to:

- assess the effectiveness of current primary care practices in the identification of developmental delays in young children;
- describe current practices related to the identification of developmental delays; and
- identify factors that affect current practice.

This report summarizes the existing research on the content and effectiveness of current practice and provides recommendations for future research and policy development. Such a review is timely, given that the American Academy of Pediatrics (AAP) published in 2006 revised practice guidelines on developmental surveillance and screening in the primary care setting.³⁴

METHODS

This review builds on prior reviews on the topic of developmental screening and the identification of developmental delays. These include: clinically oriented studies that provide an overview of the approach to identifying developmental delays^{35,36} or criteria for selecting a developmental screening test from among available tools;^{37–39} reviews that focus on the role of parents in identifying developmental delays;⁴⁰ reviews of general research findings⁴¹ (which occurred prior to the most recent two revisions of AAP practice parameters on developmental surveillance and screening);^{34,42} and a review of primary care services that promote healthy development for children under age 3.⁴³

For this report, a literature search was conducted using the PubMed and PsychInfo databases to identify peer-reviewed studies related to the identification of children with developmental delays in the primary care setting. Studies included in the review were published between 1986 and 2006, with a focus on U.S. and Canadian studies. Search terms included developmental delay, developmental screening, developmental surveillance, and primary care. The definitions of developmental surveillance, screening, and assessment used are summarized in <u>Table 2</u>. Validation studies of developmental screening measures were not included, nor were studies of screening in settings other than primary care (e.g., high-risk follow-up clinics or community-based screening programs).

The review identified several types of studies: 1) practice guidelines on developmental surveillance and screening from professional organizations; ^{34,42,44–48} 2) studies of the use of developmental screening tools in primary care settings; ^{49–52} 3) surveys of physicians on their developmental surveillance and screening practices; ^{53–57} 4) surveys of parents that included information about experiences related to screening or identification in primary care; ^{58–63} 5) retrospective chart reviews or other studies of identification patterns from referral clinics; ^{64–66} and 6) economic analyses of developmental screening. ^{67,68} No randomized controlled trials or case control studies of developmental screening in the primary care setting were identified. A single prospective cohort study in the primary care setting was identified. ⁵²

RESULTS

Evidence for the Effectiveness of Current Practices

Prevalence of Delays Versus Rates of Participation in Treatment Services

One way to determine the effectiveness of current efforts in primary care to identify developmental delays is to compare rates of identification, as measured by participation in early intervention services, to the known prevalence of these conditions. While the prevalence of delays in young children is at least 10 percent, only 2.3 percent of children

between birth and age 3 participated in IDEA Part C Early Intervention (EI) programs in 2005.⁶⁹ This means that nearly four of five potentially eligible children did not participate.

Participation rates in EI programs vary widely by state: from 1.28 percent of all children under age 3 in Alabama to 7.09 percent in Hawaii in 2004.⁶⁹ The variation is due, in part, to differences among the states in terms of whether children deemed to be at risk for delays are eligible for the programs. Across all U.S. states, preschool special education programs under IDEA Part B for children ages 3 to 5 served 5.87 percent of children on average in 2004,⁷⁰ or 2 1/2 times as many children as are served by Part C. The differences in rates of participation between states mean that a child's developmental outcome may be determined in part by his or her state of residence.

Age of Child at Initial Parental Concern Versus Age at Diagnosis

Another way to determine the effectiveness of current detection efforts is to examine the experiences of children diagnosed with developmental conditions. Two studies reported on age at presentation for developmental concerns to specialty diagnostic clinics. ^{64,65} The first reported on age at referral compared with the type of developmental diagnosis among a group of patients evaluated in the early 1980s. ⁶⁴ Whereas the median age of presentation for a child diagnosed with cerebral palsy was 11 months, children were referred for evaluation of mental retardation/global developmental delays at a median age of 27 months and for communication disorders at 32 months. ⁶⁴ The severity of the condition did not affect the age at referral. Yet, it is likely that children referred for such evaluations represented the most severe cases, and that milder cases, which are the most amenable to treatment, were not seen for referral.

The second study evaluated referral patterns in Canada in the late 1990s. On average, parents reported that they had concerns when their child was 23 months and had an assessment 15 months later, at 38 months. For children diagnosed with global developmental delays, mean age at initial parental concern was 19 months, with assessment on average 16 months later, at 35 months. For children with speech and language delays, parents had concerns at a mean age of 27 months, with assessment on average 16 months later, at 43 months. Overall, most parents had concerns about their child's development during the second year of life, but diagnostic assessments by specialists were often not conducted until age 3 1/2 or 4. The authors noted that the wait to be seen in the specialty clinic for assessment accounted for only a small part of the lag, and speculated that a large part was related to a "watch and wait" approach taken by referring physicians.

A study that interviewed mothers of boys with Fragile X syndrome, a genetic condition associated with developmental delays, reported that, on average, parents had concerns at nine months, with recognition by the primary care medical provider of the child's developmental delay at 24 months and diagnosis of Fragile X at 35 months. Many families reported that physicians discounted their concerns at first, or were told that it was too early to tell if there was a problem. ⁶⁶

A population-based study of the prevalence of speech and language impairment among a large group of children tested in kindergarten in the 1990s found that, among those with speech and language impairment, 71 percent had not been diagnosed before the study. There was no difference in severity between children identified before school entry or during kindergarten. According to this study, the majority of children with significant speech and language problems are not receiving the benefit of early identification and treatment.

Referral Patterns for Children Receiving Treatment Services

A third way to examine the effectiveness of current detection practices is by studying referral patterns for children enrolled in treatment services. A recent national study reported on the experiences of families of children participating in IDEA Part C Early Intervention services who had a signed service plan before their children were 31 months old. 61,62 On average, families reported a concern about their child at 7.4 months, received a diagnosis 1.4 months later, were referred to Early Intervention programs 5.2 months after the diagnosis, and had a service plan developed 1.7 months later, at 15.7 months of age. 61 About one-quarter of children entered the program early, by seven months old, and about one-quarter started the program later, between 23 and 30 months. Children starting EI programs sooner tended to have a diagnosed condition or risk factor (e.g., prematurity), whereas those with later entry tended to have developmental delays. Families with children entering EI programs later were less likely to have discussed their concerns with a medical professional, and less likely to report that the professional had been helpful. The waiting times to diagnosis for children actually receiving EI services therefore appears to be significantly shorter than the waiting time for diagnosis among all children with developmental conditions. Unfortunately, as discussed above, children participating in EI services represent only a small proportion of children with developmental conditions.

A multi-site, community-based study conducted in the 1980s of children in kindergarten through sixth grade who were receiving special education services provides the most comprehensive information available on the timing of identification for children with developmental delays. ⁶⁰ Rare but severe conditions such as Down syndrome and

cerebral palsy were likely to be identified early, often by physicians. In contrast, milder, more common conditions such as speech and language disorders were unlikely to be identified by physicians (only 19%; most were identified by other professionals, such as educators) and were identified later, usually at school entry.

Children who are not served through EI or special education programs may participate in other therapy services, such as those available through their family's health insurance. Still, these findings imply that the majority of children with developmental delays may not be identified until school entry, at kindergarten or later. In general, children with milder conditions—those most likely to have a significant response to treatment—are less likely than those with more serious conditions to be identified early.

Current Primary Care Practices to Identify Children with Developmental Delays

Given the evidence of under-detection of developmental delays and conditions in early childhood, what do the practice guidelines recommend and how do primary care physicians' actual practices compare with these guidelines?

Practice Guidelines

The American Academy of Pediatrics (AAP) has issued a number of policy statements related to the identification of developmental delays from primary care. A 2001 statement, "Developmental Surveillance and Screening of Infants and Young Children," a revision of an earlier version, 44 emphasized the important role of pediatricians in early identification. The committee recommended that "all infants and young children should be screened for developmental delays." Pediatricians were encouraged to incorporate use of a developmental screening tool appropriate for their population, with the recommendation to "perform periodic screenings of all infants and young children during preventive care visits." Guidelines on the frequency or timing of screening were not provided.

The AAP statement was revised recently, incorporating more specific recommendations for the timing of formal screening (<u>Table 3</u>).³⁴ The AAP now recommends that all health supervision visits before age 5 include developmental surveillance, with use of a standardized screening tool whenever a concern is raised by a parent or identified by a physician. General developmental screening of all children using a standardized tool is recommended at three specific ages (9, 18, and 30 or 24 months), with additional screening for autism at 18 months. There has been some difference of opinion in the field between the need for developmental surveillance or ongoing monitoring ^{35,71} versus systematic screening of all children using a validated tool. ⁴² The current practice guidelines address this issue by recommending screening of all children at specific ages, and monitoring of development at all other visits during the first 5 years of life.

Use of General Versus Condition- or Domain-Specific Screening Tools

Two types of developmental screening tools exist: general tools that address multiple developmental domains and tools that are either condition-specific, aimed at identifying a specific developmental condition (e.g., autism), or domain-specific, aimed at screening a particular area (e.g., speech and language). Recommendations have focused on general tools, although the most recent AAP statement endorses the use of an autism-specific screen at the 18-month visit, even in the absence of a suspicion of autism. This recommendation differs from practice guidelines from the American Academy of Neurology and the Child Neurology Society on the screening and diagnosis of autism, which recommend routine use of a general developmental screening tool, with secondary screening with an autism-specific tool if a child fails the general screen or if specific delays or deficits are noted. 45,47

Condition- or domain-specific tools are not typically recommended for general screening in primary care. In the area of speech and language development, the U.S. Preventive Services Task Force recently concluded that there is insufficient evidence to recommend the use of specific screening to detect speech and language delays in young children at the current time. 46,48

Physician Practice

Although practice guidelines from the American Academy of Pediatrics recommend the use of developmental screening tools in primary care, most physicians do not appear to use these tools systematically, if at all. In surveys, most physicians report using developmental milestone lists or informal checklists as part of an overall strategy of developmental surveillance. About half of physicians report using a validated developmental screening instrument, though most use the tools selectively, rather than systematically with all patients. Among physicians who use a screening tool, the Denver-II instrument is most commonly used, despite concerns that this tool lacks the sensitivity needed to effectively identify children with delays.

In a national survey, parents of children between the ages of 10 to 35 months were asked whether their child had ever received a "developmental assessment," defined as a formal or informal assessment or screening done by a health care provider, with or without the use of a validated screening tool.⁵⁸ More than 40 percent of parents reported that their child had never received such an assessment. Parents who reported that their children had received a developmental assessment were more likely to be satisfied with their child's medical care; these visits were also associated with higher quality ratings. These results suggest that providers and practices who take a structured approach to

developmental assessment are providing a higher level of care overall, thereby potentially contributing to improved child health outcomes.

The Role of Structured Developmental Screening in Primary Care

Review of the literature identified few studies of developmental screening delivered by pediatricians as part of preventive care in actual primary care settings. As part of the North Carolina Assuring Better Child Health and Development (ABCD) program, use of a parent-completed developmental screening tool, the Ages & Stages Questionnaire (ASQ), was implemented among a network of primary care practices. Screening rates increased from 15 percent of visits at baseline to more than 70 percent of designated health supervision visits after implementation. Increased rates of screening translated into increases in referral to EI programs, from 2.6 percent of children at baseline to 7 percent to 8 percent. The study did not report on the accuracy of the screening results or the characteristics of the children and providers.

A recent study of developmental screening with the ASQ at the 12- and 24-month visits among primary care practices in Oregon found that 54 percent of forms were returned by parents. Use of the ASQ led to a 224 percent increase in referral rates for developmental concerns, compared with baseline practice.⁵²

Most studies of developmental screening in practice have reported positive results in terms of increased rates of detection/referral and/or parental satisfaction. Yet, one study in a community practice in Canada had mixed results. It examined the accuracy of two screening tools, the ASQ⁷³ and the Child Development Inventory (CDI), ⁷⁴ at the 18month health supervision visit. 49 While the authors concluded that use of these parentcompleted questionnaires was feasible, the sensitivity of both measures in terms of correctly identifying those children who have an actual developmental delay, and the specificity of the ASQ in terms of avoiding false positive results, were found to be significantly lower than expected. Incorporating physicians' opinion about a child's developmental status did not increase the accuracy of either screening tool. Although the study raised concerns about the accuracy of single-point screening at the 18-month visit in community practice settings, a number of serious limitations and concerns about the study exist and have been commented on in letters to the editor. 75,76 In particular, 40 percent of children in this sample of middle-class families failed the ASQ screener (i.e., the screening result suggested a concern about the child's development), an unusually high rate. Most other studies of the use of this tool among comparable populations have found failure rates closer to 10 percent.

In summary, few published studies of the use of developmental screening tools in primary care settings exist. Studies examining the effect of standardized screening on rates of referral to Early Intervention services have generally demonstrated a significant increase in identification of developmental delays and referrals to Early Intervention services.

Factors Influencing Developmental Surveillance and Screening in Primary Care

Studies have identified a number of factors that affect the delivery of developmental surveillance and screening in primary care, and physicians' ability to identify developmental delays in a timely way. First, structural barriers related to the timing of health supervision visits and access to care can reduce the likelihood of early detection. Between birth and age 2, children are scheduled for 10 health supervision visits. Beginning at age 2, the recommended schedule of health supervision visits is only yearly. 31,32 Opportunities to monitor children's development therefore decrease significantly after age 2, although increasingly complex language, social interactions, and understanding begin to emerge. In addition, although according to AAP recommendations a child should have 14 health supervision visits before school entry, ideally by a provider who is familiar with the child and family, this may not occur in practice. 77-79 A study of 81 health plans found that only 31 percent of Medicaid enrollees had more than six health supervision visits by age 15 months, compared with 53 percent of children with private insurance. Fifty percent of Medicaid enrollees had yearly check-ups between ages 3 and 6, compared with 55 percent of those enrolled in private insurance.⁷⁷ Even with private health insurance, only slightly more than half of children received the recommended number of preventive care visits. The rates of adherence were even lower among children covered by Medicaid, who are actually at greater risk for developmental problems due to family poverty.

Beyond these systems issues (concerns that the current preventive care visit schedule is not optimal for the goal of monitoring children's health after age 2, and limited adherence to the existing schedule of visits by families) which affect the delivery of preventive health care services in general, physicians identify a number of barriers to the use of developmental screening tools. These include: a lack of time to administer screens during health visits; inadequate compensation; lack of training in the use of specific tools; and lack of, or perceived lack of, assessment and treatment resources. ^{54,55,57}

Cost as a Barrier to Developmental Screening

Cost is one of the most frequently cited barriers to the use of formal screening tools cited by physicians. Two studies gauged the costs of different methods of developmental screening in primary care. One analysis compared the use of a parent-completed survey with two screening tests administered by a professional.⁶⁷ In terms of short-term costs to

physicians, the study found significant differences, with parent concern questionnaires entailing lower costs to the provider to administer and interpret. When long-term costs and benefits to society were considered there was no significant difference between the two approaches. The authors concluded that much of the cost of the screening was borne by clinicians, who were not adequately compensated for their time and efforts.

A second study estimated the cost of developmental and behavioral screening of children from birth to age 3 using a variety of approaches, with screening occurring at least every six months and as frequently as every health supervision visit. From the perspective of providers, the primary driver of cost was the time and staffing required to administer, score, and interpret the screen. Parent-completed questionnaires entailed the lowest costs and physician-administered tools entailed the highest costs.

Based on this evidence, use of parent-completed screening tools seems to be a cost-effective alternative to traditional provider-administered tools.

Physician and Child Characteristics

Both physician and patient characteristics affect physicians' assessment and management decisions. In response to case vignettes describing children with likely developmental delays, female physicians were more likely than male physicians to report that they would provide a referral. Pediatricians were more likely than family physicians to say they would provide referrals.⁵⁵ In response to a vignette describing an 18-month-old child with probable language delay, only 41 percent of physicians said they were likely to refer the child to Early Intervention services.⁵⁵ These findings highlight opportunities to provide training to primary care physicians on when referrals for developmental services might be appropriate, and to enhance training of family physicians as well as pediatricians.

Limited Sensitivity and Specificity of Available Screening Tools

There are a number of developmental screening tools that are suitable for use in primary care.³⁴ The choice of tool depends on physicians' preferences and the characteristics of the population served. The sensitivity and specificity of these tools are limited, however, with general screening tools achieving moderate levels of sensitivity and specificity (mid-80s, i.e., the screens accurately identify around 80% of children with an actual developmental problem; and correctly classify 80% of children who do not have a developmental delay, as not having a problem) at best (<u>Table 4</u>).³⁴ This is because developmental skills are innately difficult to measure, characterized by broad normal variation, and are constantly changing. Limitations in the screening tools' sensitivity and specificity can lead to misclassification of children's developmental status (i.e., false positives and false negatives). There is evidence, however, that children with a false positive screen (those who fail screening but are not

found to have a clinically significant delay on further assessment) are at greater risk than those who pass initial screening for suboptimal scores when their development is formally assessed, and may therefore benefit from closer monitoring.⁸⁰

Sharing the Results of Surveillance or Screening with Families

A recent survey found that 64 percent of physicians believed an established diagnosis (as opposed to a less specific concern about a "delay") is important for referral to EI services, and this perception was associated with a decreased likelihood of referral for child with speech delay.⁵³ Such beliefs, together with physicians' discomfort in discussing the implication of a positive result on a developmental screening test, mean that even when children are identified as being at increased risk, they might not be referred in a timely way. The literature on "breaking the news" of a developmental condition to parents for diagnoses such as Down syndrome, autism, cognitive disability, cerebral palsy, or neurological disability is well developed.^{81–83} These studies and the resulting recommendations focus on care in the inpatient hospital setting. No parallel literature exists to guide physicians on effective strategies to discuss the results of developmental screening with families in primary care settings, when the ultimate diagnosis may be much less clear.

CONCLUSIONS

This review found convincing evidence of suboptimal rates of detection of developmental delays in early childhood. Although current scientific data are somewhat limited, there is evidence of a significant gap between the known prevalence of developmental delays and conditions and the much lower rates of participation in educational and therapy programs that are the mainstay of treatment. Data suggest a significant delay, often of a year or more, between the time at which parents first have a concern about their child's development and the child's eventual assessment and treatment. The majority of children with cognitive disabilities or speech/language disorders not associated with a medical risk factor do not appear to be initially identified by physicians. Among Many affected children may not be identified before school entry. Opportunities to identify problems and provide treatments during the early developmental period, when they are most likely to lead to improved outcomes, are therefore missed.

Although practice guidelines from professional organizations recommend the use of formal developmental screening tools as part of preventive care visits with young children, a significant gap exists between recommended and actual practice. Most physicians do not use structured developmental screening tools, which could improve early detection, in a systematic way. ^{54,56} Physicians instead appear to rely mainly on surveillance strategies.

Limited adherence to the schedule of health supervision visits reduces opportunities for developmental surveillance and provides an argument for a more structured approach to this area of practice. Increasing the use of validated developmental screening tools during health supervision visits is one obvious way to improve rates of early identification of developmental delays and conditions. Implementation of screening guidelines is likely to be complex, however, and will require further research as well as public policy initiatives to overcome significant barriers to the use of these tools in practice.

RECOMMENDATIONS

1. There is a need for ongoing studies to:

- better understand the reasons for the gap between the known prevalence of developmental conditions and their actual identification in early childhood;
- document the effectiveness of physicians' developmental monitoring and screening efforts over time, as policies to promote developmental screening are implemented;
- determine the cost and cost-effectiveness of different screening strategies in light of the new AAP guidelines for developmental screening; and
- understand and address any negative consequences of developmental screening.

There have been few systematic, population-based studies, and no recent studies, of the timing of the identification of children's developmental conditions from birth to school entry. There is a need for research to elucidate reasons for the gap between the known prevalence of developmental conditions and the percentage of children receiving treatment services at different ages.

Available data suggest that many, if not most, opportunities to identify young children with developmental delays are missed. Studies are needed to determine ways to improve use of screening tools in practice. In addition, research is needed to examine the fidelity of implementation—to ensure that tools are used in appropriate, validated ways.

Stakeholder input is needed to better define the effectiveness of physicians' developmental monitoring and screening efforts. Effectiveness will likely be defined on multiple levels: at a population level, in terms of narrowing the gap between the number of children expected to have a condition and the number receiving treatment; and at the level of individual children and families, as a decrease in the time lag between initial parent or provider concerns and referral to evaluation and treatment services.

Setting benchmarks for the timing of identification of different types of developmental delays or conditions would provide useful guides for providers and Early Intervention programs. Data collection on the timing of initial identification, referral to evaluation and treatment services, and clarification of a child's diagnosis is needed to monitor performance and progress in this area.

In addition, analyses of the costs of screening using different tools following the schedule of the revised AAP practice guideline are needed.³⁴ Such analyses should consider the cost of dealing with false positive screening results produced by different screening methods. Analyses are also needed to examine the effectiveness and cost-effectiveness of use of general tools, condition-specific tools, or both. Given the limited adoption of developmental screening tools in primary care, it may not be effective to recommend the systematic use of condition- or domain-specific tools until there is broader uptake of general screening tools.

The limited sensitivity and specificity of screening instruments can lead to mislabeling of a child's developmental status. A false positive result can cause anxiety among parents of children whose development is found to be within the normal range on further assessment.⁸⁴ There is a need for research on the potential negative consequences to families who receive false positive screening results. In addition, qualitative studies are needed to increase providers' comfort in sharing positive screening results, and determine effective and efficient ways for caregivers to provide counseling and information to families.

2. Financial, educational, and other barriers to the use of developmental screening tools need to be addressed to promote physicians' use of these tools.

Inadequate compensation to providers for administering and interpreting developmental screening tools is a major barrier to their use. ⁶⁷ Parent-completed screening questionnaires, which reduce the time required of providers, could help, but they are not in common use. In addition, all states need to develop policies—already in place in some states—to adequately compensate providers for developmental screening. ^{50,85} Enhanced compensation could "bundle" developmental screening into the health supervision visit as part of the overall care package ⁸⁵ or designate developmental screening as a separate billable component, with its own procedural code. ³⁴ Research is needed to measure the impact of such payment policies on identification of developmental problems and outcomes for affected children and their families.

There is an existing procedure code (CPT code 96110) for enhanced reimbursement to providers for using a validated tool to perform developmental screening. Yet, insurance

plans may not provide reimbursement for this code. For this reason, physicians may hesitate to use the billing code, even if it is reimbursed by Medicaid plans in their state, if they think privately insured families will be expected to pay out-of-pocket for this service. To encourage developmental screening, both publicly and privately insured patients must be billed for this service in a similar manner. Consumers and/or providers should advocate for all private insurers to recognize and reimburse this developmental screening procedure code.

3. Training residents in pediatrics and family medicine to use developmental screening tools as part of the routine care of pediatric patients will ensure that the next generation of providers is ready to use developmental screening tools in practice.

The content of training for medical residents, as well as pediatric nurse practitioners, significantly affects their future practice. It is therefore imperative that regular use of developmental screening tools in the care of pediatric patients be incorporated into such training.

4. Resources are needed to develop high-quality screening tools that are available in the public domain and compatible with electronic medical record systems.

Because of concerns about the limited sensitivity and specificity of available screening tools, support is needed to develop and refine cost-effective tools that perform well in clinical settings. The tools need to take into account the increasingly diverse cultures of children and families in the United States. Development and validation of tools with an adequate sample of children who are representative of the geographic, socioeconomic, and racial/ethnic diversity of the United States will require adequate funding. In addition, screening tools should be compatible with electronic medical record systems.

5. Communication models need to be developed to assist physicians in discussing the implications of developmental screening test results with families.

A rich literature exists on "breaking the news" to families of a specific developmental diagnosis. Yet, there is no parallel literature on effective ways to discuss the results of developmental screening tests, which suggest a potential problem requiring further evaluation rather than a specific diagnosis. Communication models could alleviate providers' discomfort and reduce parental anxiety and distress.

6. Adding a 30-month preventive care visit to the visit schedule, as recommended by organizations such as Bright Futures, will create more opportunities to provide developmental screening and identify developmental delays.

A 30-month preventive care visit is not currently part of the schedule of routine visits for children, but it is recommended in the most recent AAP guidelines on developmental surveillance and screening.³⁴ An additional visit between ages 2 and 3 would enable providers to screen for developmental problems during a critical time in the child's development, and at an age when children are still eligible for birth-to-3 Early Intervention services.

7. Successful models of developmental screening, such as the ABCD program in North Carolina, need to be spread to other states. This is already occurring through the ABCD Screening Academy, sponsored by NASHP and The Commonwealth Fund.

Approaches such as the office systems model—in which responsibility for different aspects of preventive care services is shared among trained office staff, thereby reducing the burden on physicians ⁸⁶—could promote developmental screening in primary care. In a demonstration project to implement Bright Futures guidelines, the office systems approach increased the provision of structured developmental screening from 29 percent to 75 percent of visits. ⁸⁷

In addition, public health approaches have been shown to be effective at increasing rates of early detection. For example, the advent of newborn hearing screening has had a major impact on the early detection of hearing impairment. Connecticut has adopted a statewide, coordinated system of identification, triage, and referral for children at risk for developmental and behavioral problems. The system, called *Help Me Grow*, gives providers a single point of access to all developmental programs and services for children birth to age 5 through a toll-free referral line. In North Carolina, the success of the ABCD program, which promotes use of developmental screening in primary care, has led to statewide implementation of the program. The state Medicaid program has adopted requirements for structured developmental screening using tools as part of a bundled set of preventive health services for children. Research on the effect of such public policy initiatives on detection rates and outcomes, as well as funding to promote successful programs in other communities, is needed.

8. Planning and resource allocation at the state and federal levels are needed to ensure sufficient resources for evaluation and treatment of the increased number of young children who will be identified through systematic developmental screening.

The widely varying rates of participation in Early Intervention services among the states mean that where a child lives may greatly affect his or her developmental outcomes. Significantly more resources are now devoted to later, mainly remedial special education services (through IDEA Part B) than to earlier, often preventive services (through IDEA Part C). This means that many opportunities to address children's delays during a time of maximum brain adaptability, the first three years of life, are missed.

Increased use of developmental screening tools by primary care providers will inevitably lead to increased identification of developmental delays in young children. Planning and resource allocation are needed to ensure that sufficient services will be available to meet the needs of children and families. Investment in development and continued support of public health programs that improve communication and collaboration between primary care providers, Early Intervention and educational programs, and providers of assessment and treatment services are needed. Such models will address the concerns reported by primary care providers about the lack of, or perceived lack of, outlets for children with developmental delays.

Table 1. Prevalence of Developmental Conditions

Condition	Prevalence		
Attention Deficit Hyperactivity Disorder			
— Brown, 2001 ⁸³	4% to 12% (median 5.8%)		
Autism/Autism Spectrum Disorders			
— Bertrand, 2001 ⁸⁴	All autism spectrum: 6.7 cases per 1,000		
	— Autistic disorder: 4.0 per 1,000		
	— PDD-NOS* and Asperger disorder:2.7 per 1,000		
Cerebral Palsy			
— Boyle, 1994 ¹	2.3 per 1,000		
— Murphy, 1993 ⁸⁵			
Cognitive Disability/Mental Retardation			
— Murphy, 1995 ⁷	Overall: 12.0 per 1,000 children		
	Mild: 8.4 per 1,000 children		
	Severe: 3.6 per 1,000 children		
Hearing Impairment			
— Bhasin, 2006 ⁸⁶	1.2 per 1,000		
Learning Disability			
— Boyle, 1994 ¹	6.5%		
Speech & Language Delay/Disorder			
— Horwitz, 2003 ⁴	Expressive language delays:		
	13.5% delay at 18–23 months		
	17.5% delay at 30–36 months		
— Tomblin, 1997 ²	Language impairment: 7.4% at kindergarten		

^{*} PDD-NOS is a pervasive developmental disorder, not otherwise specified.

Table 2. Definition of Terms: Identification of Developmental Delays

Term	Definition
Developmental surveillance (monitoring)	Use of information from multiple sources (parent concerns or questions, asking about developmental milestones, informal observation of the child, and physical examination) to monitor a child's development over time.
Developmental screening	Systematic use of a validated screening tool to identify children likely to have a developmental delay, with all children in a practice or population, regardless of risk.
Secondary/selective developmental screening	Use of a validated screening tool with a subset of children identified as having an increased risk for developmental delays. These children might be identified through developmental surveillance.
Developmental assessment/evaluation	Formal testing of a child's developmental skills using a standardized assessment tool, and/or evaluation by a specialist in the area of child development, to determine the specific nature of a child's developmental difficulties and diagnosis.

Table 3. Summary of AAP Recommendations on Developmental Surveillance and Screening at Health Supervision Visits (2006)²⁸

A. At each visit:

- Developmental surveillance
- If concern during surveillance: do developmental screening

B. At 9- and 30-month* visits:

— General developmental screening (all children)

C. At 18-month visit:

- General developmental screening (all children)
- Autism-specific screening (all children)

D. If positive screen result (A, B, or C):

- Refer child for developmental and medical evaluation
- Refer child to Early Intervention services (< 3 years old)
- Refer child to Early Childhood services (≥ 3 years old)

^{★ 30-}month visit not currently part of routine health supervision schedule. If no 30-month visit planned, screen at 24-month visit.

Table 4. Definition of Terms Related to the Properties of Screening Tools

Term	Definition	
Sensitivity	The ability of a test to correctly identify those who have a condition or disease	
	or	
	The proportion of children with a condition (developmental delay) who are correctly identified as having the condition by the test	
Specificity	The ability of a test to correctly identify those who do not have a condition or disease	
	or	
	The proportion of children without a condition (developmental delay) who are correctly called negative by the test	
Positive predictive value	The proportion of patients with a positive screening result who actually have the condition	
	The predictive value depends on the prevalence of the condition; higher prevalence, such as developmental conditions, leads to a better predictive value of a screening test result	
Negative predictive value	The proportion of patients with a negative screening result who do not have the condition	

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