The Role of primary care in Early Childhood Developmental Screening

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Abstract:

Most children experience routine well child visits to health care practitioners, primarily pediatricians, family practitioners, and advanced nurse practitioners. There is a relatively standardized agenda for well child visits. In addition to immunizations and screening for disease, these visits have a stated purpose of monitoring growth and development. It would seem that following a child’s development would be a priority. Any delays or issues related to abnormal development should be identified early. Parents need to either be reassured that all is proceeding normally, or efficiently directed towards resources devoted to diagnosis and treatment. Nevertheless, most children with developmental problems are not identified until school entry. Monitoring development is not as straightforward as monitoring height, weight, BMI and head circumference as a person matures. Many pediatricians use an informal process of observation and parental reporting to follow development. Although pediatricians may feel that their current processes of early identification are sufficient, more formal screening is needed at defined ages. A number of reliable and valid screening instruments, each with their own strengths and weaknesses, are available. Research has determined that screening tools, as used in clinical practice, are sufficiently sensitive to be useful when applied to populations. A variety of pilot efforts have shown that population screening is feasible, and that increases above baseline screening rates are possible. Early intervention has been shown to reduce the negative and expensive outcomes related to pregnancy, occupational success and incarceration. Although obstacles and objections to screening exist, the prevalence, ability to screen, and need for early intervention make a strong argument for developmental screening to be among a health system’s priorities. Even in an era of limited resources, a program of improving the health care system’s ability to screen, diagnose and treat developmental problems represents a use of resources that is a good value for society.

Epidemiology:

The U.S. Census Bureau estimates that 6.9% of the population in the United States, or 21 million people was under the age of 5 in 2008. Studies have shown that 15 to 18% of the children in the United States have a behavioral disability, with certain at-risk populations (such
as Medicaid recipients) having a prevalence of up to 39%.\textsuperscript{2} Speech and language problems have been found in kindergarteners at rates of 11-20%.\textsuperscript{3} 1 out of 3 children have either disabilities or substantial school difficulties. These difficulties contribute to 18% dropping out of high school.\textsuperscript{4} A conservative estimate of the affected population would be upwards of three million children.

Although over 95% of children see a health care provider within the first three years of life, traditional topics of immunizations, nutrition and sleeping habits are discussed far more consistently than topics related to developmental needs.\textsuperscript{5} A survey of 41 board certified pediatricians showed that only about 20% routinely performed developmental screening in their practice.\textsuperscript{6} It should then come as no surprise that data from the National Survey of Children’s Health show that nationally, only 19.5% of children receive a standardized screening for developmental problems. Rates vary by state. Pennsylvania reported the lowest rate of 10.7%; North Carolina the highest of 47\%\textsuperscript{7}. Although socioeconomic and educational factors clearly contribute to the variation seen, the impact of coordinated statewide efforts to improve screening rates is also evident (Figure 1).
The rates of low screening become even more meaningful when one realizes that only 20-30% of children that need services related to developmental or behavioral issues are identified prior to school entry. 

Developmental problems are common, yet it is uncommon for the medical community to conduct formal screening.

**Pathophysiology**

The basic architecture of the brain is constructed as part of a process starting before birth and persisting into adulthood. It begins with foundational processes of predictable sequence, and incorporates features related to individuality over time. The concept of a hierarchy is
important. The most basic of circuits is wired in early childhood. Higher level circuits are built upon lower level circuits. If the lower levels are improperly wired, the higher levels will show increasing difficulty in adaptation.\(^9\)

Brain architecture is built over periods of time that include a succession of “sensitive periods” associated with forming specific neurologic circuits related to specific abilities.\(^10\) During these periods of time, the brain is exquisitely sensitive to certain external environmental stimuli. These represent windows of opportunity for an individual to acquire and develop specific skills. Sensitivity periods for the development of binocular vision, emotional control and peer social skills occur periodically in the first three years of life (Figure 2).\(^11\)
For example, speech and language problems are among the most common handicapping issues of childhood. Children with speech and language problems are more likely to be retained at grade level, or participants in special education classrooms. Intervention prior to the first grade may prevent the development of secondary handicaps, particularly disabilities in spoken language, listening or reading comprehension.\(^\text{12}\)

If interventions are to be effective, delays need to be first identified early. Waiting until higher order circuits have become mis-wired, or missing natural periods of sensitivity to stimulation is likely to decrease the impact of any therapy, as well as render it more complex and costly. Early detection followed by early intervention has been determined to have more impact than interventions taken later in a child’s life. Early intervention increases the chances of high school graduation, holding a job, living independently, and avoiding teen pregnancy.\(^\text{13}\)

**Diagnosis**

It can be difficult to diagnose developmental and behavioral problems early. Practitioner concern may be heightened by parental concerns, or known risk factors. In the absence of risk factors or concerns, subtle delays are likely to be under-detected. The subtle and emerging nature of children’s difficulties also contributes to low rates of identification. Most disabled children learn to walk, talk, and eventually read, but not to the degree that allows them success in school or with their peers.\(^\text{14}\)
The American Academy of Pediatrics (AAP) considers developmental surveillance and screening as integral parts of necessary well-child care. They are critical functions of the medical home concept.\textsuperscript{15}

There are inconsistencies in the usage of terminology used to describe processes of identification of risk, screening and diagnosis. Even in the literature, one can find examples of the interchangeable usage of terms like surveillance, screening, evaluation, and assessment. This can lead to confusion as to the desirable attributes and outcomes of these processes. The AAP uses the specific terms \textit{surveillance}, \textit{screening} and \textit{evaluation}; each has a definition.

\textbf{Surveillance} is the process of identifying children at risk. It is, at best, a flexible and continuous process. It requires a knowledgeable professional making skilled observations during a health care visit.\textsuperscript{16} It should include key components:

1. Obtaining a relevant Developmental history
2. Eliciting and responding to parental concerns
3. Making observations of children that are accurate and informative
4. Sharing opinions and concerns as needed

\textbf{Screening} is defined as the use of a standardized tool to identify and refine risk. Standardized screening tests offer advantages over informal assessments in that they have explicit norms, efficiently and effectively record observations, and can even be part of a system to remind practitioners to assess developmental status. They are helpful in identifying more children with delays than informal assessment or surveillance alone.\textsuperscript{17}
**Evaluation** is the identification of specific developmental disorders. It may be the appropriate first step in a child who is clearly delayed, or it may be a process that results in a diagnosis of a child who has been identified through surveillance and/or screening.\(^\text{18}\)

The AAP currently recommends surveillance at all visits, with formal screening using an accepted screening tool to be performed at ages 9, 18 and 30 months, or when a child has been identified due to surveillance activities.\(^\text{19}\) (Figure 3)
A variety of developmental screening tools are available ranging in brevity, complexity and time commitment. Information may be gathered by parent questionnaires, history/interview, direct elicitation and observation. Effective instruments have been shown to be valid and tested for reliability. Since 47% of the population under 5 years old in the U.S. are members of a minority, a good test must be standardized across diverse populations.

Sensitivity is the ability of the test to identify true positives, or those children in need of evaluation. Specificity is a measure of the test’s ability to identify true negatives, which are developing without problems. The complexities of measuring the processes of child development is illustrated by the fact that good screening tests may only have sensitivities and specificities of 70-80%, and may even be considered the “gold standard”.

From a parent’s perspective, a test with a high negative predictive value (NPV) means that if their child has “passed” the screening process, they are unlikely to have a hidden problem. From an insurer’s perspective, a test with a high positive predictive value (PPV) means that patients that “fail” the test are likely to have a real condition, and not represent an unnecessary referral (and expense). A failure to understand, or to even publish the salient analytics contributes to the confusion regarding the proper roles of screening and assessment.

Practical considerations include the tool’s cost, and the time and resource use in administering the screen, and seeking consultation for identified issues. Any materials for parent use should be available in a variety of languages (25% of the under five population is Hispanic). Literacy levels also are a consideration, as they can represent a barrier to the use of written materials in any language.
The earliest developmental screening tool to gain widespread acceptance was the Denver Developmental Screening Test I (DDST I). The DDST I is still in use today in many practice settings. It was originally published in 1967, with norms established on a very specific and limited population. The DDST II is the successor test, with 20 added items. In 2006, new norms were established on a more diverse population.

The DDST has issues with sensitivity and specificity. It has structural issues, in that certain test items may be untestable (due to physical or sensory limitations) or return a questionable response that may be variably characterized by an observer as a “pass” or a “fail”. With standard scoring (such items counted as failures) the Denver shows 83% sensitivity, but only 43% specificity – more than half the children with normal development would be referred for evaluation. If the questionable/untestable results are regarded as “passes”, specificity rises to 80%, but sensitivity then drops to 56%, missing nearly half the children with problems.\(^{23}\) The standard scoring may be reassuring to parents; it has a negative predictive value of 92.5%. However, with a positive predictive value of only 23%, this would represent vast amounts of over-referral, and attendant unforeseen consequences for both the misidentified individual, as well as the economics of the health system.

The Ages and Stages Questionnaire (ASQ-3) is a 30 question parent completed questionnaire that assesses five areas of development:

1. Communication
2. Gross Motor Skills
3. Fine Motor Skills
4. Problem Solving

5. Personal Social Development

The ASQ was developed in 1981, with norms derived from a population of over 2000 children. It has been revised twice; in 1991, and again in 1994. It is available in English, Spanish, French and Korean. It has been validated against a variety of “gold standard” tests, such as the Gesell, Bailey, Stanford-Binet, McCarthy, and the Batelle Developmental Inventory (BDI). It has an overall agreement with such tests of 83%.^{24}

In a sample of 574 children, the ASQ-3 was compared to a professionally administered BDI. Sensitivity was 86.1% and specificity was 85.6%. Positive predictive value was 82%; negative predictive value was 88.9%.^{25}

The ASQ-SE is a supplement to the ASQ, designed to specifically examine the social and emotional components of child development. It is a 21-30 question parent completed survey. It covers seven areas:

1. Self-Regulation
2. Compliance
3. Communication
4. Adaptive
5. Autonomy
6. Affective functioning
7. Interaction with people
The ASQ-SE has been validated on over 3000 diverse children. Sensitivity is 78%, with specificity of 94%. Parents complete the surveys in an average of 10-15 minutes.\textsuperscript{26}

Estimates of the costs involved in materials and administration for the ASQ-3 alone is $\sim$4.60 per screen; the costs double to $\sim$9.20 if the ASQ-SE is added.\textsuperscript{27}

The Parents Evaluation of Developmental Status (PEDS) tool was developed in 2002. It is a very simple 10 item parent questionnaire. Decision pathways are included to guide the practitioner as to when to refer, screen further, counsel, reassure, temporize or monitor development. It has been standardized on 2823 families from diverse backgrounds, across the U.S. It has been validated on a sample of children, displaying a sensitivity of 74-79%, and a specificity of 70-80% across age groups.\textsuperscript{28} At about $1.19 a test for materials and administration, it is one of the most economical.

The PEDS is available in English Spanish and Vietnamese. The test is in process of being translated into a number of other languages. (Table 1)

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<th>PEDS Language Versions in Process</th>
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Both the ASQ-3 and the PEDS rely on information reported by parents. Despite concerns about the reliability of parental reporting, studies have demonstrated that parents are able to provide highly accurate and reliable data that may be very predictive of developmental delays. Parental concern as a screening tool alone has a very high sensitivity, with a low specificity and positive predictive value. This reflects high levels of parental worry about their child’s development. However, the elicitation of parental concern has the added advantage of engaging the parents in a conversation where they can relate any concerns or unmet needs.

There are a number of other screening tests, including the Bayley Infant Neurodevelopmental Screener (BINS), and the Brigance Screens II. Disadvantages of these tests include the need for a specialized kit, a quiet environment, limited availability in languages other than English, and the need for administration by a trained professional.

Salient characteristics of the most commonly used tests are summarized in Appendix I.

**Barriers to Appropriate Screening**

Major barriers related to appropriate screening in primary care include those related to the use of appropriate screening tests, misconceptions regarding the need for referral, inadequate training to deal with developmental issues, and reimbursement issues manifested by the need for resources, notably time and money.

Practitioners vary widely in their use of methods to assess developmental and behavioral status. The definitions and algorithms for surveillance, screening and assessment, as well as the use of the standardized tools mentioned above, unfortunately do not represent the usual standard of care in the community. Methods in use include clinical judgment based on the
child’s history and physical exam, unstructured observation in the office, utilizing questions about milestones or age appropriate tasks taken from informal lists, or performing a partial screening test\textsuperscript{30} (with the clinician’s bias influencing the items selected, and no information about the sensitivity or specificity of such a partial screen).

Practitioner misconceptions regarding their ability to detect developmental and behavioral problems without the standardized use of a screening tool are a major barrier to the implementation of screening programs in primary care. Even experienced clinicians relying on subjective impressions will miss almost half of the children with developmental disabilities, and many children with emotional and behavioral problems.\textsuperscript{31} Even when clinical suspicion is high due to the presence of risk factors, waiting for a developmental milestone to be missed leads to later identification, and intervention. If the issue is, for example, a hearing delay, we know exactly how critical the sensitive periods for hearing intervention are for future language development.

Using checklists derived from items based on the original DDST may miss up to 50% of global delay (mental retardation) and up to 70% of children with language impairment.\textsuperscript{32}

Practitioners also commonly use screening tests on a subset of selected patients, whose problems have become evident through observation or parental reporting. Screening tests were never designed to be assessment tools on children already identified as having problems. Even the continued use of the DDST, a tool that cannot be scored to allow BOTH sensitivity and specificity to be much more reliable than a coin flip, is a problem.
Waiting until a problem becomes obvious to clinical observation is insufficient. A child may achieve a certain milestone such as walking or talking. Achieving a milestone is different than being proficient at an activity.

Without a validated screening tool, it is not possible to accurately discriminate between what is adequate, and what is problematic. “We would never select tools for blood lead or other medical screens with questionable or unknown levels of accuracy. Why do we do this with development?”

Concerns about over referral and parental anxiety may also mitigate against appropriate screening. Even a properly administered test does a child no good, if the practitioner takes an unwarranted “wait and see” attitude. Tests are designed to identify parental concerns that are not predictive of problems, so that clinicians can educate instead of refer. Even when children are over-referred, and do not have an actual delay; they tend to have characteristics that may be amenable to intervention. Over identified children tend to have numerous psychosocial risk factors, and may benefit from referral to Head Start, quality preschool, parental training and other programs.

Clinicians are often concerned about downstream resources for children identified by screening tests and referred for services. They may be unaware of mandates and services available through local agencies and school systems. (Since 1997, The Individuals with Disabilities Education Act (IDEA) has mandated early identification and intervention for developmental disabilities. All states are required to provide services; including community based early intervention programs and systems.)
About 65% of pediatricians do not feel adequately trained to assess the developmental status of children. These practitioners may well feel ill equipped to perform screening, interpret results, refer for further treatment, and counsel parents.

Cost is always cited as a barrier to the screening, diagnosis and treatment of any medical condition. Developmental screening is no exception. Costs to a general pediatric practice that may be associated with screening include those related to the administration of a test, and those associated with counseling to parents regarding both the positive and negative results.

When studying the costs of any screening test, certain assumptions need to be made. The amount of time spent by professionals administering a screen, their level of training and compensation, the amount of time counseling parents with a normal screen, the amount spent counseling and referring a parent with a child who has had an abnormal result, and the percentage of parents that will need additional language or reading assistance must all be factored into cost models. Tools utilizing parental time for data discovery are less costly than those relying on dedicated professional time. Tools with a low positive predictive value will cost more practitioner time dealing with false positives; a lack of sensitivity will cause missed diagnoses, necessitation re-screening, and potentially more problematic and complex counseling and referral issues.

One study, comparing the various standardized tests, found a wide variation in cost, depending on the choice of test or a combination of tests, and the frequency of screening. The DDST II ranged in total cost from $55.12-$59.57. The ASQ-3 costs $12.41-$16.86. The Parental Evaluation of Developmental Status (PEDS) test had a total cost to the practice of $11.43 -
Calculating the total cost of screening, with a variety of schedules and tests for the ASQ-3 at each screening visit, with a annual psychosocial screening of the family, totaled out at $167.20.\(^\text{37}\)

Against this backdrop of cost, one must consider the cost avoidance involved in successful screening. There is a strong relationship between early childhood problems, delinquency, and later criminal behavior. The associated costs of late intervention related to incarceration and rehabilitation alone have been cited as a compelling reason to routine screen for developmental and behavioral problems.\(^\text{38}\)

Children who participate in early intervention programs are more likely to graduate from high school, hold jobs, and live independently. They are less likely to succumb to teen pregnancy, delinquency and violent crime. The net positive outcome to society has been estimated between $30,000 and $100,000 per child, representing a significant return on investment of $13.00 for every $1 invested in screening.\(^\text{39}\)

The savings realized are so substantial that countries such as Great Britain fund early intervention programs from their national treasury, to assure access to quality programs for all, without regard to ability to pay.\(^\text{40}\)

**Initiatives to Promote Screening**

A number of initiatives, at both the National and State level have sought to improve the quality and rates of developmental screening, increase the identification of developmental problems,
and improve referral rates for services. Notable ventures include **Bright Futures**, the **Child Find Demonstration Project** and the **ABCD Initiative**.

Bright Futures is a federally funded program funded by the Maternal Child Health Bureau of the Health Resources and Services administration (HRSA). It is a public/private partnership working together with HMO’s, academic centers and other stakeholders. In 2002, Bright Futures began a partnership with AAP to prevent disease, addressing children’s health care needs with a developmentally based approach, taking into account the context of family and community.\(^{41}\)

The Bright Futures Education Center includes enhancing knowledge among professionals and the public about health promotion, prevention, guidelines and tools. Bright Future Guidelines (3rd edition) highlight key issues, discussion points and guidance on issues that emerge across developmental stages.

The Bright Futures Intervention Project involved 15 primary care practices in 9 states over a 9-month period. Identified barriers included non-standard screening tools, lack of follow up, and weak linkages to community resources. Offices were supported with toolkits that outlined QI methods and data analysis. 21 possible office system components that contributed to good care were identified. These included reminder/recall systems, checklists of community resources, and systematic questioning about unmet or special healthcare needs. After nine months, the median number of implemented office systems was 15, an increase from the baseline measure of 10.\(^{42}\)

The Child Find Demonstration Projects work to increase public awareness of the need for screening and evaluation of all children. The mission is to locate, identify, and refer as early as
possible all young children with disabilities and their families who are in need of Early Intervention Program (Part C) or Preschool Special Education (Part B/619) services of the Individuals with Disabilities Education Act (IDEA). There are six participating states. The usage of standardized reliable measure is highly recommended. A number of states have improved provider knowledge, increased referral rates and the numbers of children served.

Between 2000 and 2006, the National Academy for State Health Policy (NASHP) and the Commonwealth Fund collaborated on two state learning consortia called Assuring Better Child Health and Development Program (ABCD). The ABCD program initially worked with four state Medicaid programs (North Carolina Utah, Vermont and Washington) to improve the delivery of developmental services for young children. The effort was expanded to eight states in 2003, with the addition of Illinois, Minnesota, Iowa and Utah. The NASHP published a road map and best practices for implementing policies to prototype the use of standard screening tools, to improve the identification of children with delays, and to improve access to services and follow up.

The policy strategies consisted of three major categories: improving program coverage, performance improvement, and changes in reimbursement. Participating states made changes to covered benefits and eligibility policies and procedures. Minnesota created an entirely new benefit, the Children’s Therapeutic Services and Supports (CTSS), to provide mental and social service to children diagnosed with emotional disorders.

A number of states specified requirements for providers to use an objective screening tool as part of the delivery of Early Periodic Screening Diagnosis and Treatment (EPSDT) programs.
North Carolina required the use of a formal validated tool at all EPSDT visits. It changed its policy, and replaced The DDST with the ASQ, PEDS or Brigance Screens II at 6, 12, 24, 36, 48 and 60 months. Illinois and Minnesota required the 96110 CPT code from providers billing for developmental screening. Other states unbundled CPT codes so that the 96110 code could be used to bill for developmental screening tests. Some efforts employed incentives to promote the use of standard screening tools. Increased coding not only improved reimbursement, but also led to better data collection, down to the individual physician level.

Other state initiatives included Performance Improvement Projects directed at well child care for children under 3, improvements to access to follow up care and using an EQRO to look at coordination of care.

North Carolina made several changes at the state level as part of the ABCD initiative. In addition to the requirement for a standardized tool, the state enhanced its Primary Care Case Management networks to provide additional resources for screening. Pilot projects used the Plan-Do-Check-Act model of continuous improvement to select a screening tool, design workflow systems, develop training, and identifying feedback, metrics and system supports.

Lessons learned from the North Carolina ABCD experience include the need for physician champions to provide leadership and communication with stakeholders. The group elected to use the ASQ-3, and leveraged office resources by relying on parental reporting using that tool. Offices that succeeded in improving screening practices featured workflows that were changed to allow orientation, training and the incorporation of screening into a busy day without
disruption. Constant measurement and feedback to providers helped raise screening rates to 70% of designated well child visits.\textsuperscript{50}

**International Experience**

The need to detect problems in development and to intervene at an early stage is universal. The resources, focus, and methods vary across countries and societies. Variables include the level of economic development, cultural influences, the availability of valid instruments in other languages, and the method of health care delivery, particularly in the area of developmental screening. Although the availability of resources is an overriding factor, countries as diverse as India\textsuperscript{51} and Singapore\textsuperscript{52} have noted the importance of routine screening tests by pediatricians, and the need for parental involvement.

In contrast to the United States, many countries do not place the responsibility for all well child components with a single primary care provider. In particular, behavioral/developmental problems may be provided by different clinicians and within different service systems.\textsuperscript{53}

Sweden, the U.K., and certain Australian states such as Victoria, use interdisciplinary child health teams to provide components of health care in geographically dispersed centers. The Netherlands uses both maternal child health nurses and physicians, each with distinct responsibilities. In contrast, general practitioners deliver well child care in Canada.\textsuperscript{54}

Even with universal access, cost sharing may present another variable. While the U.K. and Sweden have no cost sharing, parents in Canada and Australia may have a variety of cost sharing responsibilities.\textsuperscript{55}
Sweden routinely is cited as an example of a “child friendly” society. It recently ranked as number 1 of 100 countries in preparing children to succeed in school. Sweden utilizes a system of Child Health Centres (CHC) managed by nurses and pediatricians to provide routine health surveillance activities, including developmental screening. The staff at these centers includes public health nurses, primary care pediatricians, social workers and speech therapists. Nurses perform a variety of preventive and health promotion activities between 0 - 7 years of age. They assess psychomotor development at all contacts, auditory screening at 0 - 1 years, speech exam at 2.5 - 3 years, and a vision, auditory, and speech exam at 4 years. Physicians perform health exams and developmental screening at 6 weeks, 6 months and 10 - 12 months. In practice, the system covers essentially 100% of children.

Research is focused on developing screening tools in Swedish. Although a variety of methods may be used to assess developmental status, a survey published in 2007 demonstrated that all but four districts in Sweden were using a standardized tool, the Deficit in Attention Motor Control Perception (DAMP) at 5.5-6 years to screen for deficits in attention, motor development and perception. Tools have been studied to detect language delay at 18 months of age, and to screen for autism at age 8 months.

The Netherlands utilizes “Child Health Doctors”, medical school graduates without a pediatric residency who are given specialized training in administering the Von Wiechen, the Dutch nationalized developmental screening tool. They also use the DDST II, translated into Dutch, and a formal Dutch language screening test, The Dutch Taal Screening test (TST). The DDST in Dutch has been found to have a 72% sensitivity and a 79% specificity. This gives the tool a
positive predictive value of 40%, and a Negative Predictive value of 93%. This is not too
dissimilar from the experience in the United States with traditional scoring; many children are identified by the tool that do not have a delay.

An examination of English speaking countries reveals a number of familiar issues related to funding, awareness, training and the use of standardized instruments.

In the U.K, Routine Child Health Surveillance is an important screening tool at the 2 and 3.5 year checkups. It includes testing and history taking in areas of vision, hearing, motor and speech development and behavior. One survey showed that 57.9% of children with speech and language problems had documented issues at the 2 year surveillance check, while behavior problems appeared somewhat later, with 47.1% detected at the 3.5 year check. Recently, concerns have been raised over decreased funding, with resultant changed guidelines for screening. Many Community Child Health Departments have ceased to carry out the routine 2 and 3.5 year old surveillance checks, instead utilizing targeted or selective screening.

A survey of pediatricians in Australia and New Zealand shows attitudes towards developmental screening that are similar to those seen in the U.S. 88% indicated that they felt they needed more training in developmental pediatrics. 83% thought that they should be taught a formal developmental assessment tool.

Although the system of health insurance in Canada results in different coverage and access issues, Canadian society is similar in almost every other way to American society. Canadian efforts in early childhood screening and development have included studying risk factors of affected populations, and the selection, usage and timing of formal screening instruments.
Implications for Health Care Policy

The idea behind the need for early identification and intervention is that the lack of a child’s ability to master early developmental skills leaves children less equipped to master later developmental challenges. This can lead to behavioral problems, such as aggressive, violent or antisocial behaviors.\textsuperscript{69} Similarly, undetected developmental delays can lead to poor school performance, which can lead to further school failure, and the development of secondary maladaptive behavior.\textsuperscript{70} Children as young as age two who are at risk of developmental delay may already be showing signs of increased behavioral problems.\textsuperscript{71}

The lack of routine developmental screening during primary care encounters represents innumerable missed opportunities for earlier identification of delays and disorders. Delays in identification mean less opportunity to provide treatments earlier, or at critical sensitive periods. Providing resources devoted to improving routine developmental screening at the primary care practice allows children to improve their functioning, and ultimately reduce costs to society.

Most disease prevention efforts cost more than they save. The priority is not necessarily save money, but to get value for the money spent. Efforts in cholesterol reduction, diabetes control, immunizations, cancer screening and high blood pressure control all meet the criteria for prevention at the population level.\textsuperscript{72} By any comparable measure, early childhood screening meets these criteria equally as well, if not more convincingly so.
Yet, in 2006, when the U.S. Public Health Task Force reviewed the issue of screening for speech and language delay in preschool children, they issued an ‘I’ recommendation --they concluded that the evidence was “Insufficient to recommend for or against the routine use of brief formal screening instruments in primary care to detect speech and language delay in children up to 5 years of age.” The group acknowledged that there was fair evidence from short term studies, but cited the lack of outcomes assessments after intervention, as part of long term studies as a reason for not recommending routine screening. They also noted that no studies have been conducted to assess the possible negative effects of screening, including parental anxiety and labeling of a child. They were unable assess possible harm against benefit. They did acknowledge the primary care doctors responsibility to address speech and language concerns, and to identify and intervene early for children with delays.73

Acknowledging the need for long term outcomes data measuring the effectiveness of intervention, and the burden of misidentification, the lack of a concerted Public Health effort to promote early childhood screening represents society’s priorities. In 1965, 37% of all social welfare expenditures were directed at children. By 1986, only 25% were aimed at children. In contrast, the proportion of social welfare spending directed at the elderly rose from 21% to 33%.74 Spending on social welfare programs has been directed by political concerns, without regards to social equity across generations, or the macroeconomic future considerations.

**Recommendations**

We need to advocate for adequate resources to be allocated to fund research, screening programs and treatment services. Larger studies, with outcomes after early intervention, are
needed. Better data are needed on the relative prevalence of various delays, as quantified by standardized measurements. Much of the data collected to date relates to speech and language delays, autism and mental retardation. Much less is known about milder delays across other developmental domains. The impact of lower cost interventions, perhaps those that can be performed by parents, has not been studied in these children. There needs to be a more solid scientific foundation on the benefit of early identification and treatment.

Pediatric residents and Pediatric Nurse Practitioner students should receive adequate training on developmental issues. This should include knowledge of acceptable screening tools, pitfalls of screening, and preparation to interpret results and provide guidance to parents.

The experience shows that a quality improvement model can be effectively used to promote the incorporation of brief and easy to administer tools as an integral part of medical practice. Requirements for screening as part of EPSDT services using a standard tool, with appropriate reimbursement and coding, has improved both screening rates and data capture in pilot projects, and should be implemented nationwide. If Pay for Performance programs, or payments for “Medical Home” services become operational, measurements should be directed at early childhood screening. Practices not meeting standards should not receive “quality bonuses”.

We need to ensure that Medicaid and SCHIP programs require the use of standard screening tools as part of routine screening at specific intervals for all children as part of comprehensive preventive health services. Provisions should be made for separate reimbursement for these
screening services to incentivize practitioners, and to facilitate data collection for performance measurement and improvement efforts.

We need to strongly advocate, with mandates as appropriate, for the general use of appropriate, valid and reliable screening tests with sufficient sensitivity and specificity, at appropriate intervals during early childhood. Consideration in choosing a screening tool needs to be given to the issues of ease of administration and interpretation, practitioner and staff time, cost, and periodicity. We need practitioners to abandon the use of unreliable tests in favor of those that have demonstrated validity and reliability. We need practitioners to move toward the use of low cost screening tests such as ASQ and PEDS that have demonstrated good sensitivity and specificity and that have demonstrated general acceptance among practitioners who utilize these tools. The use of simple standard screening tools and the implementation of routine developmental screening at selected visits should constitute a standard of care. This would address at least some of the challenges in providing these services in a busy primary care practice.

The AAP recommendations that rely heavily on conducting appropriate surveillance activities at each preventive health visit along with routine use of an accepted screening tool at 9, 18 and 30 months (or at 24 months as an alternative to the 30 month visit) and screening when a (concern arises) need to be implemented across all practices and populations.

International experience can provide direction in U.S. public policy, but the United States is a different society, open, urban and multicultural, that is in sharp contrast to static small town societies with homogenous ethnic populations. The use of cross disciplinary teams
would seem to be an efficient and effective use of resources, no matter the social setting. Perhaps the nascent medical home concept needs to be better refined for pediatrics. The pediatrician should be the team leader, ensuring excellent care for the whole child, but administration of screening tools and parent interviews can be conducted by other well trained professionals. The use of laypersons with experience and credibility in the community, especially when significant language or social barriers exist, needs to be seriously explored in the United States.

Barriers to implementation at the practice level include ineffective and inefficient work flows, lack of integration with other preventive health activities, lack of parent involvement and education need to be addressed. More information needs to be made available to practitioners on referral options for diagnostic testing and treatment. These processes need to be more made more transparent for both practitioners and parents. We need to move towards a coordinated system of care that allows for surveillance, screening, evaluation and provision of services. Practitioners, governmental agencies, community based organizations, and school systems should collaborate. The unmet need is to identify developmental issues and provide services and support to families in a seamless fashion.

Finally, we need to realize that we will never be able to use a double blind, prospective study to make decisions that affect a generation, and last for one. We must be “awake at the switch”, safeguarding the human capital that is our future. We need to be sure that our country can deliver not only screening services, but also assessment services, and interventions, that are effective, and with payment mechanisms we can sustain. How will our nation handle the
manpower needs in primary care across all age bands? We need to not merely extend life when it is nearly over, but give everyone a chance for a quality life from the very start.
## Appendix I: Commonly Used Screening Tools

<table>
<thead>
<tr>
<th>TEST</th>
<th>TYPE</th>
<th>SENSITIVITY</th>
<th>SPECIFICITY</th>
<th>TIME</th>
<th>COST (Materials and Admin)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ASQ Parental Report</strong></td>
<td>Parental Report</td>
<td>70-90%</td>
<td>76-91%</td>
<td>10-15 minutes</td>
<td>$4.60</td>
</tr>
<tr>
<td>0-60 months</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>ASQ -SE (Social Emotional)</strong></td>
<td>Parental Report</td>
<td>74-79%</td>
<td>70-80%</td>
<td>2 minutes</td>
<td>$1.19</td>
</tr>
<tr>
<td>Birth - 8 years</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>PEDS Parental Report</strong></td>
<td>Parental Report</td>
<td>70-93%</td>
<td>70-90%</td>
<td>3-5 minutes to answer 1 minute to score</td>
<td>$1.15</td>
</tr>
<tr>
<td>Birth-8 years</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>DDST II</strong></td>
<td>Direct Elicitation</td>
<td>56%</td>
<td>80%</td>
<td>20 minutes</td>
<td>$55.12</td>
</tr>
<tr>
<td><strong>Brigance Screens II</strong></td>
<td>Direct Elicitation</td>
<td>70-82%</td>
<td>70-82%</td>
<td>10 minutes</td>
<td>$11.68</td>
</tr>
<tr>
<td>0-90 months</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>BINS</strong></td>
<td>Direct Elicitation</td>
<td>75-86%</td>
<td>75-86%</td>
<td>10-15 minutes</td>
<td>$10.45</td>
</tr>
<tr>
<td>3-24 months</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix II: Logic Model for Developmental Screening

Resources:
- Screening Tools/Materials
- Time:
  - Parental
  - Admin
  - Provider
- Training and educational classes and resources
- Research funding
- Public/Private Payor dollars

Intervention Activities:
- Coding and reimbursement changes
- Training of staff
- Screening material selection, ordering and supply
- CME on early childhood development
- Involvement of Parents
- Awareness efforts regarding community resources and intervention programs
- Research into effectiveness of early interventions

Outputs:
- Financial incentives for early screening
- Screening goals prior to school entry of 100% of children who visit a healthcare provider (5% population)
- Identify 90% children with issues prior to school entry
- Effective referral for diagnostic testing and intervention
- Normative and observational data to guide future screening and effective intervention.

Changes in Determinants:
Individual Level Changes
- Increased confidence of parents regarding child's development
- Increased confidence of health care providers in meeting parental needs regarding development and behavior

Interpersonal Level Changes
- Increased support for early childhood intervention programs
- Decrease burden on educational system in providing special education and individualized educational planning

Community Level Changes
- Increase social capital by increasing the habilitation and adjustment of individuals more effectively

Fundamental Level Changes
- Increase Generational Equity in social spending

Behavior Changes:
- Increase in early screening, diagnosis and effective intervention for behavioral and developmental issues
- Decrease in school problems and resource consumption, with better educational achievement

Morbidity/Mortality Changes:
- Decreased Teen pregnancy
- Decreased crime/incarceration
- Decreased unemployment and poverty
- Decreased Mental health and Substance Abuse problems
- Economic and social prosperity
Appendix III: Glossary of Terms

AAP - American Academy of Pediatrics is a professional organization of pediatricians committed to the attainment of optimal physical, mental, and social health and well being for all infants, children, adolescents, and young adults.

ABCD - The Assuring Better Child Health and Development Program is funded by the commonwealth fund, administered by NASHP, and designed to assist states in improving the delivery of early child development services for low-income children and their families.

ASQ - The Ages and Stages Questionnaire is a screening tool relying on parental report over four domains including language, personal social, motor and cognition for each age range.

BINS - The Bayley Infant Neurodevelopmental Screener is a screening tool that relies on a small number of directly elicited items per 3-6 month age range to assess neurological processes, neurodevelopmental skills and developmental accomplishments.

Brigance II - This is a developmental screening tool that utilizes direct elicitation to screen for speech language, motor readiness and general knowledge.

CTSS - The Children’s Therapeutic Services and Supports is one of the rehabilitative mental health packages covered by Minnesota Health Care Plans (MHCP). CTSS establishes policies and practices for certification and coverage of mental health services for children who require varying therapeutic and rehabilitative levels of intervention. Services available under CTSS allow providers to address the conditions of emotional disturbance that impair and interfere with children’s abilities to function. These rehabilitative services offer a broad range of medical and remedial services and skills to restore a child’s functional abilities as much as possible.

DDST II – This is one of the oldest and most widely used screening tests. It relies on direct elicitation to rate development over four domains including: Personal-Social, Fine Motor - Adaptive, Language, and Gross Motor

Evaluation - Defined as the use of a standardized tool to identify and refine risk

HRSA - The Health Resources and Services Administration (HRSA), an agency of the U.S. Department of Health and Human Services which is the primary Federal agency for improving access to health care services for people who are uninsured, isolated or medically vulnerable.
 IDEA - The Individuals with Disabilities Education Act Amendments of 1997 were signed into law on June 4, 1997. This Act strengthens academic expectations and accountability for the nation's 5.8 million children with disabilities and bridges the gap that has too often existed between what children with disabilities learn and what is required in regular curriculum.

 MCB - Maternal Child Branch is the Children's Bureau of the HRSA, which was established in 1912. In 1935, the U.S. Congress enacted Title V of the Social Security Act, which authorized the Maternal and Child Health Services programs and provided a foundation and structure for assuring the health of American mothers and children.

 NAHSP - The National Academy for State Health Policy is an independent academy of state health policymakers working together to identify emerging issues, develop policy solutions, and improve state health policy and practice. NASHP provides a forum for constructive, nonpartisan work across branches and agencies of state government on critical health issues facing states. They are a non-profit, non-partisan organization dedicated to helping states achieve excellence in health policy and practice.

 PEDS- Parent’s Evaluation of Developmental Status is a screening tool utilizing parental report to detect a variety of developmental issues including mental health and behavioral problems.

 Predictive Value

 - **Positive Predictive Value** - The probability that a person with a positive test is a true positive

 - **Negative Predictive Value** – The probability that a person with a negative test does not have the disease

 Reliability - The degree of stability exhibited when a measurement is repeated under identical circumstances. It refers to the degree to which results obtained by measurement can be replicated

 USPHTF - The U.S. Preventive Services Task Force first convened by the U.S. Public Health Service in 1984, is the leading independent panel of private-sector experts in prevention and primary care. The USPSTF conducts rigorous, impartial assessments of the scientific evidence for the effectiveness of a broad range of clinical preventive services, including screening, counseling, and preventive medications. Its recommendations are considered the "gold standard" for clinical preventive services. The mission of the USPSTF is to evaluate the benefits of individual services based on age, gender, and risk factors for disease; make
recommendations about which preventive services should be incorporated routinely into primary medical care and for which populations; and identify a research agenda for clinical preventive care.

**Screening** - Defined as the use of a standardized tool to identify and refine risk

**Sensitivity** - The proportion of truly diseased persons in the screened population who are identified by the screening test

**Specificity** - The proportion of truly non-diseased persons who are identified as such by the screening test

**Surveillance** - The process of identifying children at risk.

**Validity** - An expression of the degree to which a measurement actually measures what it purports to measure
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