## ACHIEVING THE PROMISE OF A BRIGHT FUTURE

# DEVELOPMENTAL SCREENING OF INFANTS AND TODDLERS

hen an infant is born and we look into his or her eyes, we can see the promise of a bright future for that child and for all of us. For some infants and toddlers, healthy development may not be a clear path, and intervention is needed to achieve that promise of a bright future. Occasionally, there are obstacles that compromise an infant's growth—a medical condition, prenatal or birth trauma, or factors in their environment. Many months may elapse between the time a problem or concern first emerges and when a child is enrolled in appropriate services, which can make a difference in the child's developmental outcome.1 Developmental screening programs identify children whose development may deserve closer observation or assessment and children who may be at risk of later developmental problems. Early identification of developmental issues, partnered with a system of supports to intervene, can prevent early challenges from compromising the child's development. Building ongoing developmental screening into services that routinely have contact with infants, toddlers, and their families allows professionals to monitor and support children's development. If screening raises concerns, children can be referred for in-depth evaluation and appropriate intervention to improve developmental outcomes. Policymakers can offer a bright future for infants and toddlers by ensuring that all children have access to developmental screening and that followup services are available for those children who need more detailed evaluation and treatment.



### Finding a Needle in a Haystack

**¬** ometimes, finding what you're looking for is like trying to find a needle in a haystack. A systematic strategy is much more effective than a random search. When it comes to identifying children who face developmental challenges, we need to do much better than a random search in a haystack. With ongoing developmental monitoring, guidance to parents on typical development, a well-planned referral system, and coordinated developmental screening services, we can identify children with developmental problems much more readily and comprehensively. For the more than one in four children eligible for Medicaid, Early and Periodic Screening, Diagnosis, and Treatment (EPSDT), screening requirements can make it easier to find that needle. We can turn a random search into an



effective plan for low-income children if we ensure that every eligible child is enrolled in Medicaid and receives the comprehensive screening, diagnosis, and treatment mandated by EPSDT.

# **FAST FACTS**

- Approximately one of every seven children in the United States faces a developmental disability or a disabling behavioral problem before age 18. Yet fewer than 50% of these children are identified before they start school.<sup>2</sup>
- Poverty is a strong predictor of poor developmental outcomes in children. Low-income children are more likely than children from other income groups to have poor health and special health care needs that place them at risk of developmental delays.<sup>3</sup> Yet these children are less likely to receive developmental screening.<sup>4</sup>
- Uninsured children are less likely to receive developmental screenings and preventive health care than children enrolled in public insurance programs such as Medicaid or the Children's Health Insurance Program (CHIP).<sup>5</sup>
- Only 5 states meet the standard for frequency of well-child checkups in the first year of life as recommended by the American Academy of Pediatrics for monitoring the infant's health and development.<sup>6</sup>



## **Policy Recommendations**



Ensure that all infants and toddlers who are eligible for Medicaid and the Medicaidexpansion Children's Health Insurance Program (CHIP) are enrolled and receive periodic developmental screening under the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program, which includes physical, mental, and dental health. Low-income infants and toddlers are more likely to have poor birth outcomes or experience physical and social-emotional challenges that can lead to developmental delays and disabilities.<sup>7</sup> More than 25% of U.S. infants and toddlers live in poverty and are eligible for health services under public health programs such as Medicaid or CHIP.<sup>8</sup> Medicaid mandates health and developmental screening through the EPSDT requirements. However, not every eligible child is enrolled, and even many enrolled children do not receive the full services to which they are entitled. In 2008, 40 states met the federal benchmark that at least 80% of the infants enrolled in Medicaid receive at least one developmental screening during their first year of life, and 44 states met the benchmark of two screenings for toddlers. Only five states have implemented the American Academy of Pediatrics (AAP) recommendation that infants receive seven well-child visits, where ongoing screening and monitoring can take place. Ongoing monitoring is important because **one in five** children with a disability will not be identified through a single developmental screening. Disabilities are more likely to be detected if monitoring and screening are continued in all well-child medical care visits.<sup>10</sup> State Medicaid managed care agreements, and publicly funded children's health plans should clearly outline required EPSDT services, screening frequency, and other screening mandates, and ensure that these important services are delivered to all eligible children. Children eligible for CHIP services should also receive EPSDT-like screening, diagnosis, and treatment services regardless of whether the state uses CHIP funds for Medicaid expansion or for a separate children's health insurance program.

## **Key Definitions**

Surveillance or monitoring refers to the ongoing process of observing a child's development and tracking parents' concerns. Developmental screening is the process of identifying children who may have a developmental problem or a delay in one or more domains of development, or who are at risk of developmental problems in the future. Comprehensive developmental screening should include consideration of the child's physical, cognitive, language, and social-emotional development and risk factors in the child's background. Standardized screening tools are measures that gather evidence indicating the probability of or potential for a developmental problem, delay, or risk. Assessment is a more intensive process that evaluates the child's development in depth in order to identify a specific developmental problem and to determine whether the child could benefit from intervention.

Early and Periodic Screening, Diagnosis, and Treatment (EPSDT): Under Medicaid, every eligible child is entitled to periodic developmental screening and treatment for diagnosed conditions to ensure that physical and mental conditions that could affect development are identified and corrected. The screening component includes keeping a health history and conducting a physical exam; laboratory tests; developmental and mental health screening; and dental, vision, and hearing screening.

**Child Find:** The Individuals with Disabilities Education Act (IDEA) requires that states create a system to "find" children from birth to 3 years of age who may be eligible for services provided under Part C of IDEA, and children ages 3–18 years for Part B services. Child Find systems must coordinate with other state agencies and systems in efforts to identify children in need of services.



Require the use of standardized developmental screening tools through regulation, including tools that screen for issues in social-emotional development.

Some developmental issues may pass unnoticed during the early years, <sup>12</sup> and some issues, especially relating to social-emotional development and behavioral health, are not identified early or easily without the help of standardized screening tools. The AAP recommends that surveillance be conducted at all well-child checkups (at 3–5 days of age, at 2, 4, 6, 9, 12, 15, 18, 24, and 30 months, and at the 3rd birthday). Developmental screening using a standardized screening tool should be conducted at 9, 18, and 30 months. <sup>13</sup> Surveillance should consider parents' concerns as well as risk and protective factors. These include family conditions, such as parental depression or alcohol or substance abuse, that impact the child's development and security. Policymakers should make funding available to provide training and technical assistance to support professionals (pediatricians, home visitors, early care and education professionals, and others) to incorporate standardized screening tools into their contacts with infants, toddlers, and families. In addition, state Medicaid and CHIP regulations and private health care plans should spell out covered screening, diagnosis, and treatment services and identify appropriate screening tools.

**Ensure that physicians and mental health professionals are reimbursed adequately for conducting screenings**. Physician reimbursements under private insurance or Medicaid/CHIP for well-child visits may be low, and pediatric care providers may have limited time to devote to surveillance and screening activities during well-child visits. Policymakers should ensure that reimbursement for well-child visits covers the time required to complete surveillance and screening along with other visit activities. Payment should also reimburse for screening as a separate activity whenever a concern is suspected between checkups. More favorable reimbursement rates for preventive care activities have been provided through 2014 under the Affordable Care Act (ACA), but funds will be needed to maintain this increase in the long term and to support state cost-sharing under ACA.



Policymakers should assure that reimbursement for well-child visits covers the time required to complete screening and other visit activities.

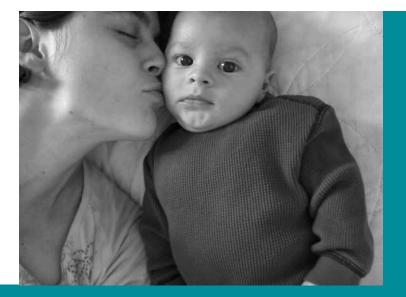


4.

Promote linkages between early identification services and a network of treatment services so that children's developmental concerns are addressed. Identifying a possible developmental concern is the first step to successful prevention or intervention. If health providers and others are linked in a network providing early identification, preventive and treatment services, and family supports, they can recognize developmental concerns early and respond to children's needs. Some valuable linkages include coordinating care through a medical home; building relationships between pediatricians and local IDEA Child Find and intake services; strengthening information and referral networks; providing health and mental health consultation to child care providers and home visitors; and building collaboration between public health, child welfare, and early intervention services to ensure that children in the child welfare system are screened and referred. Funding should be provided to support increased service coordination, to increase community screening and referral networks through collaborative efforts such as Early Head Start, for 17 and to develop data systems that support tracking of children across service sectors.

**5.** 

**Support outreach to inform parents about developmental screening and followup services**. Many parents seek assurance that their children are developing on a typical path, yet they may not understand the purpose of developmental screening. If they have a concern, they often do not know where to go for help. <sup>19</sup> Community helpers who enter the lives of infants and toddlers (for example, child care providers, parent educators, home visitors, and health clinic staff) should understand that services are available for developmental screening, assessment, and treatment and should be able to provide information about these services. Funds should be provided to raise awareness and conduct outreach campaigns to educate community providers and increase family participation in screening activities.



Low-income children are more vulnerable to health and development problems, which requires a more concerted effort to ensure that low-income infants and toddlers receive the screening and services they need.



## Research

#### Early investments have significant benefit to children and to society at large. 20, 21

An example of this long-term benefit is found in the test to detect congenital hearing problems in newborns. This simple test allows children to be identified beginning in the first months of life. Early treatment may prevent severe disabilities in communication and language development. Although the incidence of congenital hearing problems is low, its personal and economic cost is great. The Centers for Disease Control and Prevention estimates that the cost of providing special education services to a child with significant hearing loss is \$11,006 per year. Early detection and treatment could greatly reduce this expense. Children whose hearing loss is detected in infancy and who receive treatment services have better language outcomes at 8 years of age.<sup>22</sup> This in turn is linked to better educational outcomes and enhanced lifelong productivity. The newborn hearing screening test has been mandated in 43 states,<sup>23</sup> and it is one of the 30 newborn screening tests recommended by the March of Dimes.<sup>24</sup>

#### Low-income children are at greater risk of developmental delays and problems.

Low-income children are more likely to face a number of risks that make them more vulnerable to health and development problems. These risks include parental depression, poor housing conditions (contributing to problems like lead poisoning or asthma), and nutrition deficiencies. In addition, the greater risk of exposure to substance abuse in the family, child abuse or neglect, or family disruption among low-income families puts children at greater risk of long-term problems in health and behavior. These risks could be detected and addressed through comprehensive screening and followup programs. While the number of low-income children covered by Medicaid or CHIP grew steadily in the early 2000's through CHIP expansion programs, low-income children still continue to face barriers to care such as frequent eligibility redetermination; lowered eligibility ceilings; shortages of participating pediatricians, dentists, and specialists; language barriers; and challenges due to immigration status. Their mothers are less likely to receive adequate prenatal care and screening for perinatal depression. In the current fiscal climate, states are shrinking eligibility for health services and early intervention programs or increasing families' out-of-pocket expenses, making preventive care, screening, and treatment programs even less available for vulnerable families.

#### Training and support for pediatricians can improve screening rates and

**practices**. The Assuring Better Child Health and Development (ABCD) project, designed to incorporate developmental monitoring and screening into pediatric practices and link pediatricians to referral networks, has significantly increased the occurrence of developmental screening and adoption of validated screening tools across the 27 participating states. The project has also demonstrated strategies for taking these best practices to scale and made policy recommendations to improve practice statewide, such as revising Medicaid payment policies and training health providers on billing procedures so that reimbursement for screening activities was adequately covered. New voluntary benchmarks for use by Medicaid and CHIP programs to track health care quality will support states' efforts to improve screening practices. Programs to track health care quality will support states.

#### ACHIEVING THE PROMISE OF A BRIGHT FUTURE



Author: Florence Nelson, Consultant February 2009; Updated September 2012

## **About Us**

The ZERO TO THREE Policy Center is a nonpartisan, research-based resource for federal and state policymakers and advocates on the unique developmental needs of infants and toddlers. To learn more about this topic or about the ZERO TO THREE Policy Center, please visit our website at www.zerotothree.org/public-policy.



- I Center on the Developing Child, The Science of Early Childhood Development: Closing the Gap Between What We Know and What We Do. Center on the Developing Child, Harvard University, 2007, www.developingchild.harvard.edu.
- 2 Centers for Disease Control and Prevention, Developmental Monitoring and Screening, 2011, www.cdc.gov.
- 3 Data Resource Center for Child and Adolescent Health, "Nationwide Profile from the 2009/10 National Survey of Children with Special Health Care Needs." NS-CSHCN 2009/10. Child and Adolescent Health Measurement Initiative, www.childhealthdata.org.
- 4 B. Strickland, P. van Dyck, M. Kogan, et al., "Assessing and Ensuring a Comprehensive System of Services for Children with Special Health Care Needs: A Public Health Approach." *American Journal of Public Health* 101 (2011): 224–231.
- 5 Kaiser Commission on Medicaid and the Uninsured, *The Impact of Medicaid and SCHIP on Low-Income Children's Health*. February 2009, www.kff.org/medicaid/7645.cfm.
- 6 W. Schneider, S. Smith, D. Walters, et al., *Promoting Young Children's Health and Development:Taking Stock of State Policies*. New York: National Center for Children in Poverty, 2010, www.nccp.org.
- 7 Center on the Developing Child, The Science of Early Childhood Development: Closing the Gap Between What We Know and What We Do.
- 8 National Center for Children in Poverty, Young Child Risk Calculator, National Center for Children in Poverty, www.nccp.org.
- 9 Schneider, Smith, Walters, et al., Promoting Young Children's Health and Development: Taking Stock of State Policies.
- 10 American Academy of Pediatrics, "Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening." *Pediatrics*, 118 (2006), 405–420.
- II D. Bergman, Screening for Behavioral Developmental Problems: Issues, Obstacles, and Opportunities for Change. National Academy for State Health Policy, 2004, www.nashp.org.

- 12 American Academy of Pediatrics, "Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening."

  13 American Academy of Pediatrics, "Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening."
- 14 K. Johnson and N. Kaye, Using Medicaid to Support Young Children's Healthy Mental Development. Commonwealth Fund, 2003, www.commonwealthfund.org.
- 15 K. Johnson, Maximizing the Use of EPSDT to Improve the Health and Development of Young Children. Short Take No. 2. National Center for Children in Poverty, 2006, www.nccp.org.
- 16 Early Head Start National Resource Center, Developmental Screening, Assessment, and Evaluation: Key Elements for Individualizing Curricula in Early Head Start Programs, Early Head Start National Resource Center, 2000, www.ehsnrc.org/101/ menu/pdfs/TechAssistPapers-English/ta4.pdf.
- 17 S. Rosenbaum, S. Wilensky, and K. Allen, EPSDT at 40: Modernizing a Pediatric Health Policy to Reflect a Changing Health Care System. Center for Health Care Strategies, 2008, www.chcs.org.
- 18 J. Kavanagh, M. Gerdes, K. Sell, et al., An Integrated Approach to Supporting Child Development. Policy Lab Evidence to Action Brief, Children's Hospital of Philadelphia, Summer 2012, http://policylab.us/images/pdf/policylab\_e2a\_ summer2012\_series.pdf.
- 19 U.S. General Accounting Office, Medicaid: Stronger Efforts Needed to Ensure Children's Access to Health Screening Services. U.S. General Accounting Office, 2001, www.gao.gov.
- 20 B. Guyer and S. Ma, "Investing in Children's Health." Paper presented at West Coast Economic Forum on Early Childhood Investment, Santa Monica, CA, February 28, 2008.
- 21 L. Sices, Developmental Screening in Primary Care: The Effectiveness of Current Practice and Recommendations for Improvement. Commonwealth Fund, 2007, www.commonwealthfund.org.

- 22 H. Nelson, C. Bougatsos, and P. Nygren, Universal Newborn Hearing Screening: Systematic Review to Update the 2001 U.S. Preventive Services Task Force Recommendation. Rockville, MD: Agency for Healthcare Research and Quality, Evidence Syntheses, No. 62, Report No. 08-05117-EF-1, 2008, www.ncbi.nlm.nih.gov/books/NBK33992/. 23 National Institutes of Health, NIH Fact Sheet, http://report.nih.gov/nihfactsheets/Pdfs/NewbornHearingScreening(NIDCD).pdf.
- 24 March of Dimes, Newborn Screening Overview. March of Dimes, www.marchofdimes.com. Recommended newborn screening test (Updated June 2010).
- 25 Center on the Developing Child, *The Science of Early Childhood Development*. National Scientific Council on the Developing Child, 2007, www.developingchild.harvard.edu.
- 26 Kaiser Commission on Medicaid and the Uninsured, The Impact of Medicaid and SCHIP on Low-Income Children's Health.
- 27 Schneider, Smith, Walters, et al., Promoting Young Children's Health and Development: Taking Stock of State Policies.
- 28 N. Kaye and J. May, Findings from the ABCD Screening Academy: State Strategies to Support Practice Changes that Improve Identification of Children at Risk for or with Developmental Delays, National Academy for State Health Policy, March 2009, www.nashp.org.
- 29 U.S. Department of Health and Human Services, Children's Health Insurance Program Reauthorization Act: CHIPRA Children's Health Care Quality Measurement and Improvement Activities. Agency for Healthcare Research and Quality, July 2012, www.ahrq.gov.

Design: Metze Publication Design

Photo credits: Page 1 – Debbie Rappaport; iStockphoto; Page 3 – Marilyn Nolt; Page 4 – Marilyn Nolt. Models in images are for illustrative purposes only.