Implementing an Early Childhood Developmental Screening and Surveillance Program in Primary Care Settings: Lessons Learned From a Project in Illinois

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Enhancing Developmentally Oriented Primary Care (EDOPC) is a project with a goal to increase the financing and delivery of preventive developmental services for children birth to age 3 years in the state of Illinois. Primary care providers have more opportunities to screen and observe infants and toddlers than any other professional, because they see them up to 13 times in the first 3 years of life for well-child visits. The project focused on using a 1-hour, on-site training for primary care providers and their entire office staff as the method of increasing knowledge, focusing on intent to change practice and implementation of routine early childhood developmental screening. Although many primary care providers routinely use only developmental surveillance in their practices, clinical practice guidelines recommend routine use of standardized developmental screening, using validated developmental screening tools. This article includes lessons learned and recommendations based on clinical practice guidelines and experiences of the team members during implementation of the EDOPC project. Primary care providers are critical to this process because children with developmental disorders have the best long-term outcomes and opportunities for improved family functioning with early detection, diagnosis, and treatment. J Pediatr Health Care. (2014) *28*, 516-525.

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Developmental screening, developmental surveillance

It is estimated that 12% to 16% of American children meet diagnostic criteria for either a developmental or behavioral disorder (Garzon, Thrasher, & Tiernan, 2010; Mackrides & Ryherd, 2011). Children with developmental disorders have the best long-term outcomes when they receive tailored early intervention designed to maximize their individual potential. Significant research confirms the effectiveness of early intervention before age 3 years for these children and their families (Mackrides & Ryherd, 2011; Sand et al., 2005). One program in Minnesota demonstrated an $8 return for every dollar invested in early intervention, with benefits to society including more efficient use of school services and less use of criminal justice and other public systems (Adams, Tapia, & The Council on Children with Disabilities, 2013). However, up to 50% of children with developmental or behavioral problems remain unidentified before entering kindergarten (Mackrides & Ryherd, 2011; Rydz, Shevell, Majnemer, & Oskoui, 2005). The Centers for Disease Control and Prevention reports that the median age at diagnosis for autism is 48 months and that the median age at diagnosis for autism spectrum disorder/pervasive developmental disorder is 53 months (Daniels, Halladay, Shih, Elder, & Dawson, 2014). This article aims to provide busy primary care providers with insight into the formation of a developmental screening and surveillance program and to share the lessons learned during the 11-year implementation of this project. This information is based on published evidence, clinical practice guidelines, and the experiences of the team members of the Enhancing Developmentally Oriented Primary Care (EDOPC) project.

Primary care providers are critical to the detection of developmental issues because of their regular contact with children and parents of young children from birth to age 3 years. This contact includes up to 13 well-child visits. Parents look to the health care home as a source of guidance for their child's well-being. Nearly all pediatric primary care providers practice developmental surveillance at well-child visits. Nonetheless, sensitivity of surveillance alone in detecting developmental or behavioral problems in children is quite low—in most cases lower than 54% (Sheldrick, Merchant, & Perrin, 2011). However, developmental screening with a validated screening tool has been found to increase accurate identification of these children (Rydz et al., 2005; King et al., 2010).

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In 2001 the American Academy of Pediatrics (AAP) issued a statement recommending the use of standardized, validated tools to screen for developmental delays and concerns during well-child visits to increase the early identification of children at risk for delays (AAP, 2001). At approximately the same time, the Illinois Unmet Needs Project, a research and policy initiative led by Ann Cutler, MD, and Linda Gilkerson, PhD, assessed the developmental screening protocols of approximately 1000 pediatricians and family physicians in Illinois. They found that 87% (92% of pediatricians) reported providing developmental monitoring or surveillance but that 64% reported they did not use standardized screening tools (Cutler & Gilkerson, 2002). Screening with a standardized, validated tool is more accurate than surveillance alone. Further, of the 36% of providers who used validated screening tools, the majority used the Denver or the Denver II tool, which is criticized for lower sensitivity and specificity and is no longer commonly used in practice (Glascoe et al., 1992).

The EDOPC project partnership was formed in Illinois in 2005 to improve developmentally oriented primary care for young children. The project used a variety of strategies and included goals to improve developmental screening and early intervention referrals by primary care providers for children from birth to age 3 years. This article includes recommendations regarding implementation of clinical practice guidelines and experiences from the interdisciplinary EDOPC project to help pediatric primary care providers develop and implement routine early child developmental screening in their practices.

DEVELOPMENTAL SCREENING AND SURVEILLANCE

The main objective of developmental screening and surveillance is to assess a child's risk of developmental delay (Radecki, Sand-Loud, O'Connor, Sharp, & Olson, 2011). Ideally, this process includes evaluation of a child's physical, social/emotional, and cognitive abilities. Early identification of children with developmental disorders allows for early intervention for treatments with proven optimizing outcomes (King et al., 2010; Radecki et al., 2011). The health care home is the most likely place where children younger than 5 years receive health care, so it is the ideal setting for developmental and behavioral screening, especially because of the critical role that primary care plays in the health care home (AAP Committee on Children with Disabilities, 2001; AAP Council on Children with Disabilities, 2006).

Developmental surveillance is based on the observation and subjective impressions made by the primary care provider (Radecki et al., 2011). During this

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