

## Early Intervention: A Critical Support for Infants, Toddlers, and Families

Infants and toddlers with developmental delays or disabilities should be identified and receive early intervention services in a timely manner. Infants and toddlers learn a lot in the first three years of life: how to roll over, sit up independently, crawl, stand, walk, and use language to communicate with caregivers and peers. However, sometimes children's developmental progress does not go as expected. Infants and toddlers with developmental delays and disabilities likely need extra help in the form of early intervention to meet their developmental milestones. "Early intervention" refers to a system of services—including assistive technologies; speech and language, occupational, or physical therapy; nursing or other medical services; and resources for parents to better understand and promote their child's development—that supports infants and toddlers with developmental delays or disabilities and their families.<sup>2</sup>

Early identification and intervention are critical for infants and toddlers who have or are at risk for delays and disabilities. When problems are identified early, timely intervention can mitigate or even eliminate the long-term effects on children's language, cognitive, motor, and social-emotional development,<sup>3</sup> while possibly reducing the need for intensive special education services later. One national study of children who participated in early intervention found that roughly one-third of infants and toddlers who received services did not have a disability at entry into kindergarten.<sup>4</sup> In an evaluation of Early Head Start, researchers found that low-income infants and toddlers who received early intervention services were more likely to catch up to their peers without delays or disabilities compared to children who were suspected of delay but did not receive services.<sup>5</sup> Early intervention services benefit parents as well by equipping them with the skills necessary to support their children's special needs.<sup>6</sup>

Part C of the federal Individuals with Disabilities Education Act (IDEA) provides grant funding to states to support early intervention systems.<sup>7</sup> States are required to operate a Child Find program as part of this system to identify children with developmental delays and disabilities and refer them to services. States must serve all eligible children younger than age 3 who meet the state-established criteria for developmental delay, or whose diagnosed condition is associated with a high probability of developmental delay. Providers develop an Individualized Family Service Plan (IFSP), which identifies the child's needs, developmental goals, and the services he or she will receive. By law, these services must be provided in children's "natural environments"—their homes, child care programs, or communities—to the maximum extent possible. States can impose fees on families but cannot deny services to families due to an inability to pay.

Despite the importance of early identification and intervention, many infants and toddlers with disabilities or developmental delays are not being identified and receiving early intervention. In federal fiscal year 2016, roughly 3 percent of children under age 3 received services through Part C,<sup>8</sup> yet experts estimate that as many as 13 percent of infants and toddlers could benefit from early intervention.<sup>9</sup> A significant proportion of children with unmet needs are probably in low-income families, as low-income children are more likely to be at risk of developmental delay or disability but less likely to receive services.<sup>10</sup> Some evidence also indicates that children of color with developmental delays are less likely to receive services compared to their White peers.<sup>11</sup> Accessing early intervention services is a multi-step process, and, unfortunately, families have many opportunities to fall through the cracks.

Overall, the rate of developmental screenings in the United States is low—just 31 percent of parents reported that their child aged 10 months to 5 years received a standardized developmental screening in the last 12 months.<sup>12</sup> Proper screening is an important first step in ensuring that problems with development are identified and further evaluated, and that children are referred for services.<sup>13</sup>

Even if all infants and toddlers were being screened, evaluated, and referred for services, early intervention systems would likely struggle to adequately serve all eligible infants and toddlers due to significant funding challenges. Federal appropriations for Part C have been mostly flat over the last decade and have declined in real dollars since 2003. A Notably, federal funding for Part C of IDEA is intended to support states in planning, developing, and implementing their early intervention systems, rather than to fully fund the provision of services. Services are supported by a combination of state and other federal funds, and some states have local funding as well. Medicaid is the largest federal funding source for early intervention services, comprising at least 20 percent of total funding. Conversely, federal Part C funds comprise just 13 percent of total funding. At present funding levels, federal support for Part C cannot even function as the "glue" for state early intervention systems as it was intended.

While federal regulations require that states serve infants and toddlers with developmental delays, states have the flexibility to define Part C eligibility criteria and can choose whether or not to serve those who are at high risk for delay. At present, just five states serve children at risk for delay: Illinois, Massachusetts, New Hampshire, New Mexico, and West Virginia. States' methods for determining eligibility vary widely, and even those who serve children at risk define "risk" differently. Consequently, the proportion of infants and toddlers served varies widely, from 1.72 percent in Mississippi to 9.05 percent in Massachusetts. In the last decade, 20 percent of states narrowed their eligibility criteria in response to budgetary pressures, which has resulted in lower enrollment rates.

States also have the flexibility to determine how they will administer services. Year after year, states make adjustments to their programs to meet increasing demand with limited funding. Some states implement or increase fees for families; reduce reimbursement rates for providers; or require families to use private insurance.<sup>24</sup> States are also increasingly relying on Medicaid to provide early intervention to Medicaid-eligible infants and toddlers through the program's Early and Periodic Screening, Diagnostic, and Treatment benefit.<sup>25</sup> While these approaches are intended to help states better serve all eligible children, they may reduce the availability, frequency, or intensity of services available to families, particularly those who are uninsured or under-insured.<sup>26</sup>

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Changes in funding levels and in how states administer programs also affect providers, who face decreasing reimbursement rates, increasing caseloads, and high staff turnover in some states.<sup>27</sup>

The first three years of children's lives set the stage for their developmental trajectories. Early intervention equips parents with the skills to support their children's special needs and enhances children's developmental progress, reducing the need for more intensive and costly services later. At present, too many infants and toddlers with delays and disabilities are going unidentified and are not accessing early intervention due to budget shortfalls. Significant federal and state investments in Part C are necessary to bolster states' Child Find efforts; improve service coordination and provision; and address provider availability, training, and oversight. Early intervention provides infants and toddlers with disabilities and delays the support they need to learn and grow, but will continue to fall short of serving all families in need until policymakers invest substantial resources.

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- 1 Centers for Disease Control and Prevention, *Developmental Milestones*, 2016, <a href="www.cdc.gov/ncbddd/actearly/milestones/">www.cdc.gov/ncbddd/actearly/milestones/</a>.
- 2 Center for Parent Information and Resources, What is Early Intervention? 2014, www.parentcenterhub.org/repository/ei-overview/.
- 3 Kathleen Hebbeler, Donna Spiker, Don Bailey, et al., *Early Intervention for Infants and Toddlers with Disabilities and their Families:*Participants, Services, and Outcomes, SRI International, 2007, <a href="https://www.sri.com/sites/default/files/publications/neils\_finalreport\_200702.pdf">www.sri.com/sites/default/files/publications/neils\_finalreport\_200702.pdf</a>.
- 4 Hebbeler et al., Early Intervention.
- 5 Hyun-Joo Jeon, Carla A. Peterson, Shavaun Wall, et al., "Predicting School Readiness for Low-Income Children with Disability Risks Identified Early", Exceptional Children 77 (2011).
- 6 Hebbeler et al., Early Intervention.
- 7 Congressional Research Service, *The Individuals with Disabilities Education Act (IDEA), Part C: Early Intervention for Infants and Toddlers with Disabilities*, 2016, www.everycrsreport.com/files/20160516\_R43631\_2ee3a55e20941c19b719c6eed81e7a49b031bfa2.pdf.
- 8 This represents a point-in-time count: the proportion of infants and toddlers receiving early intervention on a given day. Starting in 2016, states must also report the cumulative number of infants and toddlers who participate in Part C, broken down by race and ethnicity. For historical data on Part C participation, see The Early Childhood Technical Assistance Center, *Part C Infant and Toddler Program*, 2017, <a href="http://ectacenter.org/partc/partcdata.asp">http://ectacenter.org/partc/partcdata.asp</a>.
- 9 Steven A. Rosenburg, Duan Zhang, and Cordelia C. Robinson, "Prevalence of Developmental Delays and Participation in Early Intervention Services for Young Children," *Pediatrics* 121 (2008).
- 10 Beth McManus, Marie C. McCormick, Dolores Acevedo-Garcia, et al., "The Effect of State Early Intervention Eligibility Policy on Participation Among a Cohort of Young CSHCN," *Pediatrics* 124 (2009); Child Trends, *Screening and Risk for Developmental Delay*, 2013, <a href="www.childtrends.org/wp-content/uploads/2013/07/111\_Developmental-Risk-and-Screening.pdf">www.childtrends.org/wp-content/uploads/2013/07/111\_Developmental-Risk-and-Screening.pdf</a>; Coleen A. Boyle, Sheree Boulet, Laura A. Schieve, et al., "Trends in the Prevalence of Developmental Disabilities in US Children, 1997-2008," *Pediatrics* 127 (2011); National Academy of Sciences, "Poverty and Childhood Disability," *Mental Disorders and Disabilities Among Low-Income Children*, 2015; Beth M. McManus, A.C. Carle, and M.J. Rapport, "Classifying Infants and Toddlers with Developmental Vulnerability: Who is Most Likely to Receive Early Intervention?" *Child: Care, Health, and Development* 40 (2012); Carla A. Peterson, Shavaun Wall, Helen Raikes, et al., "Early Head Start: Identifying and Serving Children with Disabilities," *Topics in Early Childhood Special Education* 24 (2004).
- 11 Emily Feinberg, Michael Silverstein, Sara Donahue, et al., "The Impact of Race on Participation in Part C Early Intervention Services," *Journal of Developmental and Behavioral Pediatrics* 32 (2011).

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- 12 "National Survey of Children's Health," 2016 data query, Data Resource Center for Child and Adolescent Health, http://childhealthdata.org.
- 13 Christina Bethell, Colleen Reuland, Edward Schor, et al., "Rates of Parent-Centered Developmental Screening: Disparities and Links to Service Access," *Pediatrics* 128 (2011).
- 14 Congressional Research Service, The IDEA Part C.
- 15 Congressional Research Service, The IDEA Part C.
- 16 IDEA Infant & Toddler Coordinators Association, 2016 ITCA Finance Survey, 2017, <a href="http://ideainfanttoddler.org/pdf/2016-ITCA-Finance-Survey.pdf">http://ideainfanttoddler.org/pdf/2016-ITCA-Finance-Survey.pdf</a>; IDEA Infant & Toddler Coordinators Association, 2016 ITCA Tipping Points: Part C Implementation: State Challenges and Responses, 2017, <a href="https://www.ideainfanttoddler.org/pdf/2016-ITCA-State-Challenges-Report.pdf">www.ideainfanttoddler.org/pdf/2016-ITCA-State-Challenges-Report.pdf</a>.
- 17 Only 13 states are able to accurately report the actual revenue generate by each funding source the remaining 36 of 49 responding states report incomplete revenue. The IDEA Infant & Toddler Coordinators Association estimates that the total revenues at all levels are under-reported, with the exception of federal Part C funding. The Association estimates that Medicaid's significance would only grow if all Medicaid revenue was reported. For more information, see 2016 ITCA Finance Survey.
- 18 IDEA Infant & Toddler Coordinators Association, 2016 ITCA Finance Survey.
- 19 The Early Childhood Technical Assistance Center, *Minimum Components Required under Part C of IDEA*, Frank Porter Graham Child Development Institute, University of North Carolina at Chapel Hill, 2017, <a href="https://ectacenter.org/partc/componen.asp">https://ectacenter.org/partc/componen.asp</a>.
- 20 Steven Rosenberg and Duan Zhang, "A Rigorous Definition of Developmental Delay," presentation, NECTAC Webinar Series on Early Identification and Part C Eligibility, March 10, 2010; The Early Childhood Technical Assistance Center, 2015 Child Count Data Charts, 2015, <a href="http://ectacenter.org/~pdfs/topics/earlyid/partc\_elig\_table.pdf">http://ectacenter.org/~pdfs/topics/earlyid/partc\_elig\_table.pdf</a>; http://www.ideainfanttoddler.org/pdf/2015-Child-Count-Data-Charts.pdf.
- 21 Office of Special Education Programs, *Part C Child Count and Settings*, U.S. Department of Education, 2017, <a href="https://ed.gov/programs/osepidea/618-data/static-tables/index.html">https://ed.gov/programs/osepidea/618-data/static-tables/index.html</a>.
- 22 Council for Exceptional Children, Federal Outlook for Exceptional Children Fiscal Year 2016, 2015, https://www.cec.sped.org/~/media/Files/Policy/Current%20Sped%20Issues%20Home/Federal%20Outlook%202016%20FINAL.pdf.
- 23 Batya Elbaum, Seniz Celimli-Aksoy, Jennifer Marshall, et al., "How Does the Narrowing of Eligibility Criteria Affect Enrollment in Part C Early Intervention?" *Infants & Young Children* 30 (2017); Beth H. McManus, Dawn Magnusson, and Steven Rosenberg, "Restricting State Part C Eligibility Policy is Associated with Lower Early Intervention Utilization," *Maternal and Child Health Journal* 18 (2014).
- 24 See IDEA Infant and Toddler Coordinators Association, "Board Approved Surveys," <a href="https://www.ideainfanttoddler.org/board-approved-surveys.php">www.ideainfanttoddler.org/board-approved-surveys.php</a>.
- 25 Centers for Medicare and Medicaid Services, "Early and Periodic Screening, Diagnostic, and Treatment Benefit," <a href="www.medicaid.gov/medicaid/benefits/epsdt/index.html">www.medicaid.gov/medicaid/benefits/epsdt/index.html</a>.
- 26 Rena A. Hallam, Beth Rous, Jaime Grove, et al., "Level and Intensity of Early Intervention Services for Infants and Toddlers with Disabilities," *Journal of Early Intervention* 31 (2009); Beth M. McManus, Laura A. Prosser, and Mary E. Gannotti, "Which Children Are Not Getting Their Needs for Therapy or Mobility Aids Met? Data from the 2009-2010 National Survey of Children with Special Health Care Needs," *Physical Therapy* 96 (2016).
- 27 See for example, Stephanie Rubin, Rebecca Hornbach, Jay Moreno, et al., *Left Out: The Impact of State Cuts to Early Childhood Intervention (ECI) For Young Texas Kids with Disabilities*, Texans Care for Children and Methodist Healthcare Ministries, 2016, <a href="https://ccf.georgetown.edu/2016/11/30/new-report-from-texas-thousands-of-young-kids-with-disabilities-excluded-from-early-intervention-amid-state-cuts/">https://ccf.georgetown.edu/2016/11/30/new-report-from-texas-thousands-of-young-kids-with-disabilities-excluded-from-early-intervention-amid-state-cuts/</a>; Annie McGowan, *Failing to Keep Pace: An Analysis of the Declining Value of Illinois Human Services Reimbursement Rates*, Illinois Partners for Human Service, 2016, <a href="https://www.everthriveil.org/sites/default/files/docs/pr/ILPHS\_Report.pdf">https://www.everthriveil.org/sites/default/files/docs/pr/ILPHS\_Report.pdf</a>.