

# Identifying Developmental Disabilities and Delays in Young Children

#### THE ROLE OF CHILD WELFARE PROFESSIONALS AND PARTNERS

Child welfare professionals and partners often work with highly vulnerable children and youth—those who have, or are at risk of, developmental disabilities or delays. Early identification of developmental disabilities or delays is critical for a child's health and well-being. When disabilities and delays are caught early, steps can be taken to improve the child's short- and long-term outcomes. Early identification and intervention also can reduce family stress and ensure that parents have the help they need to support their children effectively. Child welfare professionals and partners play an important role in this effort.

This brief provides information on the importance of early identification of developmental disabilities and delays and how the Centers for Disease Control and Prevention's (CDC's) "Learn the Signs. Act Early." resources and tools can support child welfare professionals, parents, and caregivers in early identification and intervention. Additional resources around early childhood development, screening, and support for parents are also included.

#### Developmental delays and disabilities are common.

In the United States, 1 in 6 children aged 3–17 years have developmental disabilities,<sup>1</sup> and 1 in 4 children ages 0–5 are at moderate or high risk for developmental, behavioral, or social delay.<sup>2</sup> Children who have experienced abuse or neglect often have high rates of physical, cognitive, social-emotional, relational, and psychological problems.<sup>3</sup> About one-third of children in foster care in the United States have a disability.

#### Developmental delays and disabilities are stressful.

When disabilities are not identified and not supported, parents may be overwhelmed by their child's needs, or may neglect their child unintentionally by not providing the care and support needed to address the disability. Parents also may have unrealistic expectations of their child and experience frustration and anger. Children with disabilities are at least three times more likely to be abused or neglected than their peers without disabilities, and they are more likely to be seriously harmed by maltreatment.<sup>4</sup>



#### Early identi ication is critical.

Neural circuits in the young child's brain are most adaptable in the first 3 years of life, and they are the foundation for learning, behavior, and health. Over time, these connections become more difficult to change.<sup>5</sup> Many children with a developmental disability are not identified until after starting school,<sup>6</sup> so they miss out on early intervention services and supports that could improve outcomes. High-quality early intervention services to children who have or are at risk for developmental disabilities have been shown to positively impact outcomes across developmental domains, including health, language, and communication; cognitive development; and social-emotional development.



#### Early identification has other benefits.

In addition to positive developmental outcomes for children, participating in early intervention can be beneficial to families in other ways. Families benefit by learning how to navigate a complicated system of medical and social services, which reduces stress and confusion. Early intervention also helps build skills so that parents are better able to meet their children's special needs from an early age and throughout their lives.

#### The Role for Those at the Front End of Child Welfare

Everyone working to promote the well-being of children and families can contribute to maltreatment prevention and the early identification of developmental disabilities or delays in children. Staff in home visiting programs, family support programs, and other child and family-serving organizations can help in these ways:

- Educate parents and the general public about the effects of childhood adversity and promote strategies that can prevent adversity, such as livable wages, family-friendly work, a strong safety net, high quality early care and education, enhanced primary health care, and parenting programs.
- Help parents and caregivers understand the importance of identifying developmental disabilities or special needs early.
- Support and encourage all parents and caregivers to monitor their child's development and have recommended screenings.
- Help parents and caregivers to act early if they have a concern and to access early intervention if needed.

Child welfare professionals have legal obligations around referral to early intervention services (see sidebar). Additional steps to take include:

- Integrating validated developmental screening tools into assessments.
- Working with both parents and resource families to ensure that:
  - » Parents have tools and resources about typical developmental milestones and check in with parents about any concerns they may have about their child's developmental progress.
  - » Parents talk with their child's health care provider about their child's development and any concerns they may have.
  - » Families are connected to programs such as Help Me Grow that intentionally monitor and support families around developmental progress.

2

- » Monitor children's development and refer families as soon as possible to early intervention systems if developmental delays are suspected.
- Recruiting resource parents with experience in supporting children with disabilities.

#### "Learn the Signs. Act Early." Offers Tools to Help Identify Developmental Concerns and Support Families

A number of excellent resources are available to support parents, caregivers, and service providers in early identification and intervention (see "Resources" section). An especially useful program is "Learn the Signs. Act Early.", which offers free, family-friendly materials and tools in a variety of formats that encourage families to monitor development and act early on developmental concerns. Developed by the Centers for Disease Control and Prevention (CDC), information and tools are available online at <a href="www.cdc.gov/ActEarly">www.cdc.gov/ActEarly</a>.

"Learn the Signs. Act Early." resources are customizable to accommodate local needs. They are available in English and Spanish. Many are available in simplified Korean, Vietnamese, Haitian, and Creole, and some are available in other languages.

The "Learn the Signs. Act Early." materials complement and support the Protective Factors Framework by doing the following:

### LEGAL OBLIGATIONS OF CHILD WELFARE PROFESSIONALS IN EARLY IDENTIFICATION OF DEVELOPMENTAL DISABILITIES

In recognition that children who are abused or neglected often experience physical, cognitive, emotional, behavioral, and social problems, including attachment disorders, cognitive delays, and altered brain development, as well as the benefits of early intervention, the Keeping Children and Families Safe Act of 2003 (P.L. 108-36), requires States to develop "provisions and procedures for referral of a child under age 3 who is involved in a substantiated case of child abuse or neglect to early intervention services funded under Part C of the Individuals with Disabilities Education Improvement Act" (IDEA) (§ 106(b)(2) (A)(xxi)). The 2004 reauthorization of IDEA contains language parallel to this.

IDEA 2004 also details specific requirements for State early intervention programs (EIPs), which are administered by lead agencies in each State (including departments of health, developmental disability, social services, children and families, or education).

Child welfare workers can help ensure that the developmental needs of children who are abused and neglected are addressed by attending training on child development, referring children to the EIP, and working closely with EIP staff. An EIP service coordinator can then help families (and child welfare professionals) navigate the eligibility process, design an IFSP, and ensure needed services are provided.

Steps in the early intervention process begin with referral. These first steps are outlined in Part C of IDEA: A child under the age of 3 is referred to Part C because of a possible developmental delay or disability. When a child is identified as being potentially eligible for Part C, a formal referral must be made as soon as possible but in no case more than 7 days after the child has been identified as potentially eligible. All children under age 3 who (a) are the subject of a substantiated case of abuse or neglect or (b) are identified as being directly affected by substance use or withdrawal symptoms resulting from prenatal drug exposure must be referred to the EIP. Child welfare professionals are also able to refer other children they believe may be eligible for services.

For more information, see https://www.childwelfare.gov/pubPDFs/partc.pdf.

- Providing parent-friendly developmental milestone information that educates families about child development across all domains (language/ communication, cognitive, social-emotional, and physical/movement)
- Helping families adopt appropriate developmental expectations and offering positive parenting tips and strategies to enhance parent-child interaction and promote social-emotional development in children
- Supporting parents' role as their child's best advocate and decision maker
- Building confidence in parents to accurately observe their children's developmental milestones
- Offering supportive messages, guidance, and practical tips for how to act early on developmental concerns

CDC's "Learn the Signs. Act Early." program also supports more than 50 <u>Act Early Ambassadors</u> who expand the reach of the program and work as community champions in their respective state's

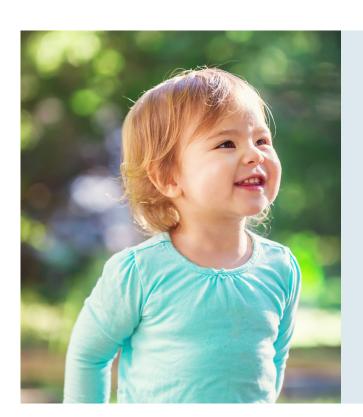
or territory's efforts to improve early identification. More information on the Act Early Ambassadors and other state-based resources is available online at <a href="https://www.cdc.gov/ActEarly/Ambassadors">www.cdc.gov/ActEarly/Ambassadors</a>.

## CDC's Act Early Ambassadors Working in Child Welfare Programs

The following are some examples of how the 2018 Act Early Ambassadors partnered with local child welfare programs around early identification and intervention.

#### **South Carolina**

The Act Early Ambassador to South Carolina is the developmental screening coordinator at Help Me Grow South Carolina. She is also a Strengthening Families Alliance Certified Trainer. She is collaborating with the South Carolina Department of Social Services Early Care and Education Division to provide "Learn the Signs. Act Early." materials within the child welfare system in three South Carolina counties. Help Me Grow South Carolina and Maternal, Infant, and Early Childhood Home Visiting (MIECHV) programs have also developed a model for using "Learn the Signs. Act Early." materials with families.



"Before we had early childhood intervention (ECI) services, we couldn't communicate with her at all. She couldn't walk, and her only form of communication was screaming and throwing a fit.

"ECI helped develop skills so she can learn how to communicate and we can see triggers of her behavior and calm her down.

"They also helped me with management tools for when I get frustrated with her. It wasn't her fault, and they taught me how to manage my stress level—which has dropped, and so has hers."

-A mother of a child with developmental delays

The model includes the following elements:

- An engaging training on developmental milestones for families
- Discussions with families at each visit about their child's development, using materials like a South Carolina version of the *Milestone Moments* booklet
- A process to refer children to appropriate providers for further evaluation if parental concerns arise during visits

#### Wisconsin

The Act Early Ambassador to Wisconsin is the training director of the Wisconsin Leadership Education in Neurodevelopmental and Related Disabilities program at the Waisman Center at the University of Wisconsin–Madison. She has worked with the Milwaukee Child Welfare Partnership at the University of Wisconsin–Milwaukee to integrate the use of "Learn the Signs. Act Early." into a developmental screening training curriculum. The Milwaukee Child Welfare Partnership does a significant portion of the state's developmental screening training for in-home family services professionals, including home visitors, Early Head Start educators, Birth to Three (Part C of the IDEA) staff, Child Protective Services, and public health departments.

Through this initiative, resource tote bags of "Learn the Signs. Act Early." materials are shared with providers. The Milwaukee Child Welfare Partnership developed a developmental monitoring online training module and wrote guidelines to support home visitors and early childhood professionals in the use of "Learn the Signs. Act Early." They also provide training on how "Learn the Signs. Act Early." resources can be used by court-appointed special advocates to support developmental monitoring and positive parenting among the children and caregivers they serve.

For more information about these examples or how to find your Act Early Ambassador, please visit <a href="www.cdc.gov/ActEarly/Ambassadors">www.cdc.gov/ActEarly/Ambassadors</a> or email <a href="mailto:ActEarly@cdc.gov">ActEarly@cdc.gov</a>.



Milestone Tracker App—Educate and encourage parents to learn about, support, and track their child's development from age 2 months through 5 years with a free app offered by "Learn the Signs. Act Early." Learn more at www.cdc.gov/MilestoneTracker.

#### **Additional Resources**

Birth to Five: Watch Me Thrive!

https://www2.ed.gov/about/inits/list/watch-me-thrive/index.html

Birth to 5: Watch Me Thrive! encourages healthy child development, universal developmental and behavioral screening for young children, and support for the families and providers who care for them.

The Compendium of Screening Measures for Young Children is a collection of research-based screening tools for children under the age of 5. <a href="https://www2.ed.gov/about/inits/list/watch-me-thrive/guides.html#compendium">https://www2.ed.gov/about/inits/list/watch-me-thrive/guides.html#compendium</a>

#### **Center for Parent Information and Resources**

https://www.parentcenterhub.org/

Find your state's parent center that supports families of infants, toddlers, children, and youth with disabilities.

Early Childhood Technical Assistance Center <a href="http://ectacenter.org/topics/earlyid/capta.asp">http://ectacenter.org/topics/earlyid/capta.asp</a>

ECTA is a national technical assistance center focused on building state and local system capacity to improve outcomes for children with disabilities and their families.

## Essentials for Childhood Framework: Creating Safe, Stable, Nurturing Relationships and Environments for All Children

https://www.cdc.gov/violenceprevention/childabuseandneglect/essentials.html

The Essentials for Childhood Framework proposes strategies communities can consider to promote relationships and environments that help children grow up to be healthy and productive citizens so that they, in turn, can build stronger and safer families and communities for their children.

## Essentials for Parenting Toddlers and Preschoolers <a href="https://www.cdc.gov/parents/essentials/index.html">https://www.cdc.gov/parents/essentials/index.html</a>

Designed for parents of 2- to 4-year-olds, Essentials for Parenting addresses common parenting challenges, like tantrums and whining. The purpose of the resource is to provide as much information as possible on things you can do to build a positive, healthy relationship.

#### Help Me Grow

https://helpmegrownational.org/

Help Me Grow is a system model that works to promote cross-sector collaboration in order to build efficient and effective early childhood systems that mitigate the impact of adversity and support protective factors among families, so that all children can grow, develop, and thrive to their full potential.

#### **Protective Factors Framework**

https://www.childwelfare.gov/topics/preventing/promoting/protectfactors/protective-factors/

Visit this page to view resources with examples of a protective factors framework around child welfare systems.

#### References

- 1. Boyle, C.A., Boulet, S., Schieve, L., Cohen, R.A., Blumberg, S.J., Yeargin-Allsopp, M., Visser, S., & Kogan, M.D. (2011). Trends in the prevalence of developmental disabilities in U.S. children, 1997–2008. *Pediatrics*, *27*, 1034–1042.
- National Survey of Children's Health, 2011–12. With funding and direction from the Maternal and Child Health Bureau, Health Resources and Services Administration, these surveys were conducted by the Centers for Disease Control and Prevention's National Center for Health Statistics.
- 3. Wiggins, C., Fenichel, E., & Mann, T. (2007). *Literature review:*Developmental problems of maltreated children and early intervention options for maltreated children. Retrieved from <a href="http://aspe.hhs.gov/hsp/07/Children-CPS/litrev/index.htm">http://aspe.hhs.gov/hsp/07/Children-CPS/litrev/index.htm</a>
- Jones, L., Bellis, M. A., Wood, S., Hughes, K., McCoy, E., Eckley, L., . . . Officer, A. (2012). Prevalence and risk of violence against children with disabilities: A systematic review and meta-analysis of observational studies. *Lancet*, 380, 899–907.
- Center on the Developing Child (2007). The Science of Early Childhood Development (InBrief). Retrieved from <a href="http://www.developingchild.harvard.edu">http://www.developingchild.harvard.edu</a>.
- Macrides, P. & Ryherd, S. (2011). Screening for developmental delay. *American Family Physician*, 84(5), 544-549

