

Systemwide Solutions to Improve Early Intervention for Developmental–Behavioral Concerns

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“Birth to Five: Watch Me Thrive!” (<http://www.acf.hhs.gov/programs/ecd/child-health-development/watch-me-thrive>) seeks to systematically increase early detection of developmental–behavioral problems among at-risk children, from birth through 5 years. This initiative represents a coordinated effort to increase early screening and detection rates across the health, education, and social service sectors. Although the earliest detection of children who need extra developmental–behavioral support is a laudable goal, these efforts will be for naught without appropriate supports to document follow-up and enrollment into services. To meet the challenge of what happens next, our nation must address its capacity crisis. The leadership issue across sectors is to build the capacity to increase and improve access to evidence-based services that are tailored to child and family needs.

This initiative is the stated promise of early intervention (EI) for ages 0 to 3 years, early childhood special education (ECSE) for ages 3 to 5 years, and other high-quality early learning programs. In 2011 and 2012, 2% to 3% of US children received EI under the Individual with Disabilities Education Act (IDEA; <https://ideadata.org/>) Part C, and 5% to 6% of children received ECSE under IDEA Part B, Section 619.¹ Twelve percent of children are diagnosed with any developmental disability between 3 and 10 years and 16% between 11 and 17 years.² Mental health disorders emerge in 21% of children between 9 and 17 years.³ Although it can be challenging to reliably identify infants, toddlers, and preschoolers with the more prevalent mild disabilities and disorders, red flags (eg, positive or concerning screens) may be identifiable. Alas, the chasm between percentage identified and served is unacceptable given the assortment of interventions or supports proven to improve outcomes (<http://www.ectacenter.org/topics/effective/effective.asp>).⁴

This discrepancy exists in the face of a wide array of uncoordinated health, education, and social service supports. Leaders across these sectors need to coordinate efforts to connect at-risk children and families to the most effective and appropriate community services that focus on the child’s needs. Addressing the capacity crisis will require integrated

systems such as the Early Childhood Comprehensive Systems approach outlined by the Maternal Child Health Bureau. Ensuring that the many programs that do exist to support children and families actually work in a timely, unified, and effective way will require 4 bold actions.

CHILD- AND FAMILY-FOCUSED EARLY DETECTION AND CARE COORDINATION ENTITY IN EVERY STATE

States without system-wide early detection and care coordination overlook at-risk and disadvantaged children. Among states with narrow EI eligibility criteria, poor children are 18% less likely to receive EI services.¹ Some children live in communities where early detection systems struggle to address parental language or literacy barriers. Black children with developmental delays are 5 times less likely (adjusted OR 0.19; 95% CI 0.09, 0.39) than white children to receive EI services.¹ Individual pediatricians can help alleviate disparities by advocating for EI eligibility reform, universally adhering to the academy's recommendations for developmental-behavioral surveillance and screening, and implementing referral interventions to support culturally and linguistically different populations.¹

System-wide programs can improve screening, referral, and care coordination efforts. Access to a range of early developmental supports is facilitated by Connecticut's "Help Me Grow" (<http://www.helpmegrownational.org/>) and Los Angeles county's 211 LA program (<https://www.211la.org>), but sadly, most states and communities lack a system-wide approach. Studies suggest that ~50% of children referred by their primary care provider are promptly linked to EI services.¹ For a variety of reasons, many parents do not follow up, or medical offices do not share referral

information with Part C agencies.¹ However, for families who live in communities with patient navigator or care coordination programs, 83%⁵ of referred children are linked to Part C services. If they are deemed ineligible for EI services, care coordinators should link at-risk children and families to a continuum of resources such as evidence-based home visitation programs, parenting programs, and Early Head Start or Head Start.

COMPREHENSIVE, EQUITABLE, TIERED APPROACH TO ASSESSING DEVELOPMENTAL-BEHAVIORAL NEEDS AND CORRESPONDING SUPPORTS

Bewilderingly, there are 22 state-specific, numerical definitions for EI eligibility,⁶ and the majority of states have inappropriately strict eligibility criteria. Only 6 states serve at-risk, in addition to developmentally delayed, children.⁶ To make matters worse, EI services are not always delivered to families free of charge, service availability varies geographically, eligibility criteria have steadily become more stringent, and services have become less intensive because of budget constraints over the past decade. Strict criteria decrease the predicted probability of EI participation.⁷ The infant with a low-income, single mother who is suffering from depression typically is not EI-eligible, even though problems often evolve by the time the child reaches kindergarten age. Other programs intended to foster the positive development of young children in poverty are sometimes not used at capacity.

One solution is to apply a response to intervention approach to assessment and intervention from birth through 5 years of age that includes the array of early comprehensive developmental supports from nutrition, housing, and child care to more specialized, targeted, and intensive intervention. IDEA Part B specifies a tiered

approach starting with high-quality education for all, more specialized supports, and then the most specialized supports based on the child's response to each tier of support and need. For the youngest children, assessing developmental-behavioral need based on risk factors and developmental-behavioral status would correspond to a tiered approach to include the array of child and family supports available in the community in a way that is more understandable and accessible.

Just as IDEA Part B services are mandated by law, Part C services should be required by the federal IDEA statute and not treated as discretionary. The creation of a federal-level research- or expert-driven baseline definition for early comprehensive developmental support eligibility would provide a clear, national definition for what constitutes an at-risk condition or developmental-behavioral delay. EI services should be appropriately intensive for children who qualify for developmental-behavioral interventions or supports based on the continuum of need. Such a proposal would require a substantial investment and leadership support from federal and state governments.

UNIVERSAL ACCESS TO HIGH-QUALITY EARLY LEARNING PROGRAMS AND PRESCHOOL

Universal preschool would result in far fewer children, particularly those with biological or environmental risk factors, being missed before kindergarten entrance. Mildly delayed or at-risk children who were not identified, not referred, not linked, or not EI or ECSE-eligible could still be enrolled in high-quality programs. After all, for every dollar spent on high-quality early learning, there is a 7% to 10% annual return rate in cost savings; the younger the child

served, the higher the rate of return (<http://www.heckmanequation.org/>).

CONTINUOUS ACCOUNTABILITY FOR EARLY DETECTION, INTERVENTION, AND DEVELOPMENTAL-BEHAVIORAL STATUS

If we are to help reduce the impact of delays and disabilities, we must begin to provide universal screening, high-quality supports, and intervention as early as possible, monitor progress, and evaluate developmental-behavioral status at key time points. Ongoing, individualized assessment of the specific child is important to inform high-quality intervention. At the same time, we need to evaluate what is happening with whole population cohorts. States must begin to create or strengthen their existing infrastructure to properly measure the proportion of children in 4 processes: children screened with a psychometrically sound developmental-behavioral screening tool in the 12 months preceding the child's first, second, and third birthday; children identified at developmental-behavioral risk who are appropriately referred to a Part C agency or other evidence-based community services; referred children who are appropriately receiving evidence-based community services; and children screened for developmental-behavioral status at kindergarten entry.

Measuring these 4 processes will require every state to have a system-wide accountability and care coordination program. Solutions for integrated data sharing will be needed to evaluate whether populations are being universally screened and whether children with

suspected developmental-behavioral concerns are identified accurately, appropriately referred, and then connected swiftly to the most effective interventions. Some states have already begun measuring the early detection process and have implemented quality incentives.⁸ This approach must become universal.

CONCLUSIONS

To make early detection and intervention processes more effective, the next step is for leaders in health, education, and social service sectors to boldly address our nation's capacity crisis in a system-wide manner. US early learning (especially IDEA Part C) services must become more equitable, efficient, and effective so that the focus is on the developmental-behavioral needs of the child.

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ABBREVIATIONS

ECSE: early childhood special education
EI: early intervention
IDEA: Individuals With Disabilities Education Act

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