We need to strengthen early detection and intervention system for children

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*AAP News* 2014;35;30

DOI: 10.1542/aapnews.2014358-30
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by Kevin P. Marks, M.D., FAAP

Early intervention (EI) depends heavily on early detection. Early detection relies heavily on medical homes. Medical homes must wield evidence-based screening tools in combination with developmental-behavioral promotion to prevent future problems. The Academy already has connected these dots.

However, two commonly overlooked barriers to preventing and treating developmental-behavioral problems more effectively are the absence of 1) a centralized/system-wide care coordination and accountability entity in every state and 2) a federal-level, evidence-based definition for which U.S. children, 0 to 3 years of age, possess a developmental-behavioral delay or “at-risk” condition deserving of EI services under the Individuals with Disabilities Education Act Part C.

To optimize the long-term physical, mental and social well-being of children, the ideal time to intervene is before a child’s third birthday.

In addition, an appropriate screening tool should be administered whenever a child is deemed to be “at-risk.”

After a psychometrically sound screening tool or clinician’s less structured surveillance detects a problem, studies indicate that about 50% of children who are referred will be promptly linked to a Part C agency. If the child/family happens to live in a community with a system-wide referral and care coordination program (e.g., Help Me Grow www.helpmegrownational.org.), then about 80% of these children will be linked to the Part C agency or an alternative resource like Early Head Start, pediatric psychologist, evidence-based parenting or home visitation program.

Clearly, linking at-risk children to alternative community resources is important. However, children with a positive/concerning result on a nationally standardized, psychometrically sound developmental-behavioral screening tool should be receiving Part C services more consistently. An under-appreciated but pervasive problem is that there are no less than 22 state-specific, numerical definitions for Part C eligibility (http://pediatrics.aappublications.org/content/131/1/38.abstract), and the majority of states have inappropriately strict eligibility criteria. Definitions for EI eligibility (http://pedsinreview.aappublications.org/content/35/1/e1.full) range from possessing any delay (Hawaii, Nebraska and Vermont) to a 50% delay in one domain (Alaska, Arizona and Missouri).

Twenty-four states use percent delay (1 – mental age/chronological age × 100 = percent delay) alone to define developmental delay; 12 use percent delay and standard deviation (SD) information in their eligibility criteria; 11 use SD alone; and one uses a combination of SD and percentile delay. The remaining states use any delay. As a result, the proportion of children enrolled in Part C ranges from 1.5% (Georgia) to 7% (Massachusetts), even though about 17% of children possess a developmental disability and 20% have a mental health disorder. Many states serve children with “high-risk” biological...
and/or environmental conditions, but only six states (Hawaii, Illinois, Massachusetts, New Hampshire, New Mexico and West Virginia) serve moderately “at-risk” in addition to delayed children under Part C.

If a child happens to live in Massachusetts, she might easily qualify for EI while another child with the exact same developmental-behavioral issues would not qualify if she lives in Missouri. Wild variability in eligibility criteria across states typically is the result of short-sighted state budget decisions. Strict eligibility standards reduce short-term EI costs to states and schools but increase long-term costs to society, especially because EI has been proven more effective for children with mild delays.

Therefore, an AAP policy priority should be the creation of a centralized/system-wide care coordination and accountability entity in every state so that, with parents’ permission, data can be shared seamlessly across the silos of the medical, educational and social service sectors.

Another priority should be to create a research- and/or expert-driven “baseline” definition for Part C eligibility. Once created, the benefits of such a definition would need to be communicated to the general public and policymakers. Real-world, compelling stories should be told about infants and toddlers who were appropriately red-flagged and referred by their pediatrician, subsequently deemed “ineligible” for EI services and later diagnosed with a developmental-behavioral disorder — but only after a critical window of opportunity was lost forever.

To prevent or ameliorate developmental-behavioral problems (e.g., academic failure or remediation, criminal/anti-social behavior, alcohol/tobacco/substance abuse, suicidal ideations or attempts), we need to strengthen our early detection and intervention system. To accomplish this, a superhero team effort will be required on behalf of the Academy and organizations representing policymakers, early intervention specialists, early childhood educators, mental health providers, social service professionals and very importantly, Part C funding stream stakeholders.

Early interventioners assemble!

Dr. Marks is a member of the AAP Council on Children with Disabilities.

To view a slide presentation from Dr. Marks on the importance of early intervention, visit http://www.youtube.com/watch?v=p6zlLFaBr9U.
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