Meeting Needs of Young Children at Risk for or Having a Disability

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Abstract Poverty-related factors place children at higher risk for disabilities and also serve as barriers to families accessing services for their children and themselves. Early childhood practitioners can play a critical role in supporting families by providing services to overcome these obstacles and by working in partnership with specialized early intervention programs to assure the families and children receive those services. Families (N = 3,001)enrolled in the Early Head Start (EHS) Research and Evaluation Project were randomly assigned to the program group (who received EHS services) or the control group in a rigorous, experimental design study in order to evaluate program impacts. All participating families were living in poverty, included a pregnant woman or a child below age 1, and were eligible for EHS. The majority of children enrolled in the EHS Research and Evaluation Project was identified as having at least one of a great variety of disability indicators (e.g., family received Part C services, child has been diagnosed as having asthma). There was a very small number of families, however, actually enrolled in Part C services. Enrollment in EHS was associated with children being less likely to have cognitive or language delays and their families being more likely to receive early intervention (Part C) services and have Individualized Family Service Plans (IFSPs) when they needed them.

Keywords Early Head Start · Disability indicators · Recommendations to early intervention providers

Families who have children with disabilities and live in poverty are truly in a double-bind. The same povertyrelated factors that place their children at higher risk for disabilities also serve as barriers to accessing services for their children and themselves. Early childhood practitioners can play a critical role in supporting families by providing services to overcome these obstacles and by working in partnership with specialized early intervention programs to assure that families and children receive needed services. The purposes of this article are, first, to describe the role of early childhood programs to meet the needs of children and families facing multiple risks associated with both poverty and disability. Second, we provide recommendations for practitioners illustrated by examples of the types of issues and opportunities early childhood practitioners experience. Throughout the article, we will provide support for these recommendations and illustrate issues highlighted by using the results from a large-scale study of disability-related factors that was part of a large national Early Head Start (EHS) Research and Evaluation Project in the United States.

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Childhood Poverty and the Role of Early Intervention Services

Overall, 12% of US residents live in poverty (Annie E. Casey Foundation 2009); however, 21% of preschool-aged children are poor (Annie E. Casey Foundation 2009; Douglas-Hall and Koball 2006; US Census Bureau 2010). Young children are the age group most likely to be poor in



the US (Douglas-Hall and Koball 2006) and are more likely to be poor than young children in other developed countries (Lewit et al. 1997). Children living in poverty are at great risk for poor development in many areas including: cognitive skills (Korenman et al. 1995), language skills (Walker et al. 1994) and social skills (McLeod and Shanahan 1993; Peisner-Feinberg et al. 2001). Poverty is associated with poorer physical health (Miller and Korenman 1994), learning disabilities, and developmental delays (Brooks-Gunn and Duncan 1997) as well. Unfortunately, these early risks are associated with poor adult outcomes (Kokko and Pulkkinen 2000). The associations between poverty and developmental risks are not news. However, there is still much to learn about the specific risks that young children face when they are living in poverty, how these risks work, and which resources are available to address these risks.

Children with disabilities in the US are entitled to specialized services as mandated by the Individuals with Disabilities Individualized Education Improvement Act (IDEA; 2004). Part C of the IDEA mandates that, beginning at birth, children and their families are entitled to a variety of early intervention services individualized to meet their specific needs; Part C services are guided by an Individualized Family Service Plan (IFSP). Further, Part C mandates active child find procedures to identify children in need of specialized services. Many countries, as in the US, have social policies that shape the provision of specialized early intervention services (Kamerman 2000), and they utilize similar general principles to guide design and delivery of these services (Guralnick 2008). For example, calls for monitoring of children's development, individualization of services, partnering with families, coordination among service providers, and maximization of inclusion in community programs for typically developing children are increasingly accepted universally (Guralnick 2008). There is also an international focus on the development of crosscultural disability classification systems to allow for a more global understanding of disability and the services that children are receiving (Florian et al. 2006; McLaughlin et al. 2006).

Increased attention to the importance of early development has, more recently, prompted global initiation of a variety of programs often targeted to vulnerable young children and their families. In the US, EHS, begun in 1996, serves families of infants and toddlers living in poverty through a two-generation approach designed to strengthen the family's capacity to promote their child's development (Office of Head Start 2010). Healthy Families America (HFA) was launched in 1992 to promote positive parenting, enhance child health and development, and prevent child abuse (PCA America 2010). Parents as Teachers (PAT) is designed to enhance parents' understanding of child

development and improve parenting practices during their children's early years (Parents as Teachers National Center 2010). Programs such as these often collaborate with Part C early intervention programs to serve children who have a disability but they are, unfortunately, not available in every community.

What Does This Mean for Families and Professionals? Recommendations and Implications of the Research with EHS

Four important messages are highlighted below. First, young children living in poverty are very vulnerable; it is essential that all service providers interacting with these children and families be vigilant about identifying disability indicators. Second, some children from low-income backgrounds are facing multiple challenges that make it difficult for them and their families to participate in disability-related services; therefore, it is important to develop clear procedures to help program staff members know when and how to refer families for disability-related services. Third, collaboration among community partners (e.g., Early Head Start programs, health care providers) is having a positive impact on many of these very vulnerable children and families. Finally, practitioners should work to ensure that all families, but especially those whose children have identified risks or a disability, have the supports they need to help their children grow healthy and strong. Recommendations for practitioners working with vulnerable families are presented on Table 1 and discussed below. These recommendations are based on our work with the EHS Research and Evaluation Project which provided a unique opportunity to examine the prevalence of disabilities among young children living in poverty. While these recommendations are based on research conducted in the US, they are applicable to practitioners in international contexts as well. For each of the primary recommendations, we present a vignette illustrating the issue and the strategies used, followed by a discussion of the research support for the practice.

Table 1 Recommendations for professionals

Monitor children closely when their families face multiple risks Develop clear procedures to determine when and how to refer families to disability-related services

Collaborate closely with community partners, including Part C programs

Collaborate with the health care community to address health issues and identify potential disabilities

Focus on early intervention strategies to prevent problems from becoming delays

Provide services and supports to families of children with disabilities



The EHS Research and Evaluation Project enrolled 3,001 families into a rigorous, experimental design study. Half of these families were randomly assigned to participate in program services, and the other families did not receive EHS services (they served as a control group). An experimental design study was undertaken to examine the impact of EHS services which were previously unproven to be beneficial. Receipt of EHS services was the only difference between families in the program and control groups; families in the control group could access any community services, other than EHS, for which they were eligible and they wished to have. All participating families were living in poverty and included either a pregnant woman or a child below age 1. All the participating children were vulnerable to a wide variety of risks. For example, some children had diagnosed health conditions, while others had depressed mothers or lived in families or neighborhoods with high levels of violence. Sadly, many of the children faced several risks simultaneously. We will introduce readers to several families who were served by EHS programs (names have been changed to protect anonymity) to illustrate how early childhood practitioners can implement recommendations regarding disability-related services based on findings from the EHS Research and Evaluation Project.

Monitor Children Closely When Their Families Face Multiple Risks

An EHS program's work with Robert and Rita illustrates the challenges professionals face in implementing this recommendation.

Rita did not have any concerns about Robert's development when they enrolled in EHS. Rita was living in a crowded apartment with her son, mother, and brother. She had dropped out of high school at age 16 when Robert was born. Both Rita and her mother had received special education services. Robert was diagnosed with severe allergies and asthma, needed frequent nebulizer treatments, made frequent visits to the emergency room, and had frequent ear infections.

The EHS home visitor became increasingly concerned about Robert's development and validated her concerns through routine developmental screenings. Rita was willing to listen to the home visitor's concerns but was very resistant to following up with early intervention. Rita's main goals were to complete a general educational diploma (GED) and to manage Robert's asthma and allergies; her life circumstances were overwhelming her. She was not interested in adding appointments to her schedule and

seemed to view early intervention as a burden. Though the EHS home visitor respected Rita's decision, she continued to monitor Robert's development closely and share her concerns with Rita. The home visitor also talked with her supervisor regularly to get advice on how to keep sharing her concerns with Rita.

After completing her GED, Rita began working for the EHS program where she learned more about child development and interacted with children who were developing typically. She began to realize how Robert differed from some of the other children and began to be much more interested in talking with the home visitor about his development. She watched a speech and language pathologist provide early intervention services to a child and asked questions about communication development. She realized that speech and language therapy was not scary, and she became willing to have Robert evaluated.

Robert began to attend a family child care home when Rita started working, and the child care provider worked closely with EHS staff and Rita to ensure that Robert's needs were met. The child care provider became a partner in monitoring Robert's development; she reported concerns about Robert's behavior and communication skills. Robert could not verbally communicate his wants and needs clearly, and when he became frustrated, particularly with other children, he began to be aggressive. The child care provider was committed to caring for Robert but was concerned about how his behavior was affecting the other children in her care. With the support of the EHS home visitor, Rita referred Robert to the early intervention program. An IFSP was written, after evaluation, and Robert was provided with speech and language therapy services. As Robert's language skills improved, his aggressive behaviors decreased.

Robert's situation is not unique, and it is important to consider that risks and disability, while related, are not synonymous. In the EHS Research and Evaluation Project, we used parent and EHS staff reports, as well as child assessments, to identify children who were already experiencing developmental problems as well as those who were at especially high risk for disability indicators (Peterson et al. 2004). For example, parents answered questions regarding their children's needs for special services (e.g., Does your family receive Part C early intervention services? Has a professional ever diagnosed your child as having a vision problem? Does your child have asthma or experience wheezing?). Parents reported on their children's verbal language development and described their children's social development and behavior concerns.



Table 2 Categories of disability indicators

Receives Part C services	Eligible for Part C services	Children with risks for developmental delay	Children with biological risks
Parent report of service receipt	Parent report of child eligibility, but services had not been received	Child had ever scored below 77 on the Bayley MDI	Dr. has said child has recurrent ear infections
EHS program staff member report of child eligibility	Professional diagnosed child with a vision problem	Child had behavior problems at 36 months	Child has been diagnosed with high level of lead
	Dr. had ever said child had mental retardation	Child has trouble using (or cannot use) hands or feet	Child has an anemia problem

We gathered these data for both the control group and program group families in the study, and also assessed the children's cognitive and receptive language development directly. For families in the program group, we also asked EHS staff members whether the family had ever been found eligible for Part C services.

Next, we considered several practical and conceptual issues related to risk factors in order to identify variables drawn from all these data sources that are known to be associated with disabilities or developmental delays. We grouped appropriate variables to develop four categories of disability indicators that reflect conceptualizations of disability and developmental risk outlined in the IDEA (2004) and then used these categories to identify children who had a disability indicator. Table 2 presents examples of variables in each category of disability indicators. (See Peterson et al. 2004 for further information). The first category included children whose families actually received Part C services; the remaining three categories represent a continuum of likelihood that the child would be considered eligible for Part C services. Children with diagnosed conditions included children who were evaluated and deemed eligible for Part C services, as well as children who had established medical conditions that likely would have made them eligible had they been referred. Children with suspected delays included children with a developmental or behavioral problem suspected by a parent or identified via direct assessment. These types of conditions are moderately associated with developmental delay (Besag 2002; Parkinson 2002), and these were children who might have been eligible for Part C services or who might become eligible for early childhood special education if they fall further behind their peers as they grow older. Children with biological risks included children who had a chronic health condition involving a body system other than the brain or central nervous system. Children with these health conditions may develop disabilities. For example, it is possible that their illnesses might deprive them of stimulating learning experiences or perhaps these chronic illnesses could lead to neurological damage. These children are similar to Robert who was described above. Practitioners who monitor children's development on a regular basis are poised to provide the services children and their families need without delays. We do not know all the mechanisms, but we do know the statistics. For instance, children with asthma are 1.7 times more likely to have learning disabilities than healthy children, and children with "fair" or "poor" health are twice as likely to have learning disabilities as those reported to have "good" health (Fowler et al. 1992).

Almost all the children (87%) enrolled in the EHS Research and Evaluation Project had a disability indicator in at least one of the categories described above, even though a very small number of families (140; 7.4%) actually had received Part C services. Another 146 children (7.0%) had a diagnosed condition that likely would have made them eligible for Part C services. Very large numbers of children had suspected delays (1,173; 64.42%) based on direct child assessment and/or parent report or faced biological risks (1,421; 61.38%) based on parent report of health-related conditions. Note that many children were included in more than one of the categories identified above, and the percentages are based on the numbers of children for whom that specific kind of data was available. This finding provides a stark confirmation of what the literature has been saying all along: children in poverty are at especially high risk for disabilities (Peterson et al. 2004). Early childhood practitioners are at a critically important vantage point to identify these factors early and seek help for the child and family where needed.

Develop and Follow Clear Referral Procedures

The Head Start Performance Standards (Administration on Children and Families [ACF] 2006) outline policies for EHS staff to follow when they identify a concern about a child. Other early intervention programs serving infants and toddlers, such as PAT, also have established procedures for identifying "red flags" indicating a need to refer to Part C or other specialized service providers. The clearer these procedures, the more likely staff will be able to follow through and help families to access services they need. Programs and agencies may want to have collaborative discussions with community partners (including Part C



providers) to ensure referral procedures are clear to everyone involved in implementation or oversight activities. Marco's story illustrates the importance of having clear procedures to guide staff members' work with families, as well as the importance of persisting with implementation of the procedures.

Marco and his mother, Sandra, who had emigrated from Central America legally, enrolled in EHS services when he was 10 months of age. Sandra wanted help managing living issues: she was about to be evicted and had accumulated significant debt which was largely related to relying on the emergency room for medical care for Marco's frequent ear infections. The home visitor was concerned immediately about Marco's development as he was not making sounds. When she mentioned her concerns over a few weeks. Sandra brushed them off. Sandra felt that Marco was doing OK, that everyone in her family talked late, and that the primary focus should be on their financial situation. Marco passed the first and second developmental screenings, but the home visitor still had concerns about Marco's speech and language development, and she followed established program procedures for working with families when a delay was suspected. First, the home visitor helped Sandra learn new activities she could do to promote Marco's development. Second, she documented his development monthly, and indicated both progress that he was making and her continuing concerns. Third, she regularly reported Marco's status in meetings with her supervisor ensuring that her concerns were known to the program managers.

At age two, Marco was not babbling or using any words. He was screened again as per the program policy for regular assessment, and the results indicated a clear need for more comprehensive assessment. Sandra agreed to pursue additional evaluation, but the evaluation was delayed when the early intervention program had difficulty scheduling a bilingual speech therapist. The pediatrician then recommended ear tubes for Marco, and evaluation was delayed to determine if the tubes would make a difference. The home visitor continued to follow program policies for documentation and follow-up to ensure that the need for a referral was not forgotten. When the evaluation was completed, Marco was found eligible for Part C services, and the home visitor supported Sandra and Marco through initial receipt of specialized services.

Few families in the EHS Research and Evaluation Project actually received Part C services though many more families would likely have qualified for and benefited from

those services had they been enrolled. Families least likely to receive Part C services were those of Hispanic background, those with parents who were teens or less welleducated, and those with parents who had specific demographic characteristics (e.g., especially low income, being a member of an ethnic minority group). For those children with suspected delays, not speaking English was also associated with a decreased likelihood that their family would receive Part C services. The sad conclusion is that children who are more likely to face one or more risks for disabilities are also less likely to be receiving disabilityrelated services (Peterson et al. 2004). This may be due to family and child service providers not knowing procedures to make referrals for disability services. When agency guidelines are established and communicated clearly to staff, those staff members may be able to support families through the process as Sandra's and Marco's home visitor did.

Collaborate Closely With Community Partners

Early intervention partners such as EHS, Parents as Teachers, Part C, and others could evaluate together how the needs of children with early delays are addressed in their communities. Working together, programs might take specific steps to partner with parents to monitor children's development closely and identify potential delays in cognitive, language, and/or social-emotional motor development or sensory impairments as early as possible. Jessica's story illustrates how Part C and EHS programs collaborated to provide services to her family.

Jessica, age 2, experienced delays in gross motor, fine motor, cognitive, and speech and language development related to her Cerebral Palsy. She also needed to use a feeding tube. She was receiving occupational, physical, and speech and language therapies as part of her early intervention services. Jessica's father was employed full time, but her mother was not working outside their home in order to care for Jessica and her other children. Jessica's family had accepted her diagnosis of Cerebral Palsy, but they were having difficulty coping with the day to day ramifications of living with a child with a severe disability. They felt that they were not able to give each of their other children individual attention due to Jessica's care needs. They seemed to be torn between their commitment to wanting the best for Jessica and feeling overburdened by the responsibilities involved with her care. They also expressed numerous concerns for Jessica's future. They knew that it was likely that she would need some level of care throughout her life and were concerned about her future opportunities.



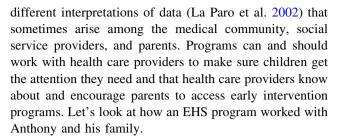
Jessica's Part C service coordinator, who knew that the family was interested in having Jessica in an inclusive child care setting that would give her opportunities to interact with typically developing children, referred the family to EHS. The Part C coordinator believed the EHS program would be a good fit because she knew the supervisors and staff from various community care coordination meetings they had attended together. Jessica was included into an EHS toddler room where she was assigned a primary caregiver who worked closely with Jessica's mother to ensure that she was providing Jessica with appropriate care. The service coordinator also felt that child care would be beneficial for Jessica's mother, who was feeling significant stress and anxiety over Jessica's care needs. Jessica's early intervention service providers began to see her at the EHS center, rather than at home as they had been, so that they could interact with Jessica in the child care setting and work directly with her primary caregiver. Jessica's EHS case manager, her family, and the Part C service coordinator talked frequently to make sure that Jessica was doing well in the child care setting. The therapists regularly left documentation of their visits in the EHS file and for the family to ensure accurate communication, and Jessica's EHS case manager participated in IFSP reviews.

A profound moment came several months after Jessica had been enrolled in the EHS classroom. After getting Jessica settled in the classroom, her mother had moved away to talk with the caregiver. Observing Jessica from across the room, she noticed that another toddler approached Jessica and offered her a toy. Jessica's mother began to cry saying that she had hoped for the day she would see another child approach Jessica and want to play with her, but she had been deeply afraid she never would see that happen.

In the EHS Research and Evaluation Project, many families who received Part C services were highly engaged with their EHS programs (Roggman et al. 2008). Early childhood program staff may be able to build on this strength by working with families and the broader service community to identify and further develop the supports that programs can provide to help families who have children with a disability, either individually or collectively.

Collaborate With the Health Care Community

Continued attention to increasing communication between all community partners is vital (American Academy of Pediatrics 2001; Liptak 1995) and should help alleviate



Anthony and his mother, Margaret, enrolled in the EHS program when he was 2 months old. Margaret's main goals were to have EHS staff members help her budget resources, find child care, and find a medical home. Margaret and her husband, Paul, had married shortly after learning that Margaret was pregnant and had relocated for Paul to find work. They felt very isolated, had not made any friends in the area, and were having significant financial and marital difficulties.

The EHS home visitor initially focused extensively on helping Margaret meet her basic needs. The home visitor, however, also noted concerns about Anthony's development as he was not yet rolling over or imitating speech sounds and could not grasp a rattle when he was 3 months of age. She felt that continued observation would be needed, as well as teaching Margaret about child development and parent-child interaction. Anthony's developmental screening at age 12 months revealed that he was "typical" in all areas, but the home visitor was still concerned about his personal-social and language skills: he was not yet imitating activities or drinking from a cup, and he had a lot of difficulty calming himself when upset or when transitioning from one activity to another.

The home visitor was concerned about the lack of continuity of Anthony's medical care and helped to find a pediatrician for him. When Margaret took Anthony for a routine check-up, she asked the pediatrician about his development. Margaret was told that Anthony's development was a little slow but he would likely catch up. The home visitor was not satisfied with this answer and suggested that Margaret schedule another appointment with the pediatrician; this time, the home visitor accompanied Margaret and Anthony. During that follow-up appointment, they had a frank discussion about Anthony's development, and the pediatrician expressed support for referring Anthony to the Part C program.

Relations among a variety of disability indicators, demographic characteristics, and service participation highlight the extreme vulnerability of some children and families. In the EHS Research and Evaluation Project, for



example, children whose parents were in the group facing the highest number of risks or had specific demographic characteristics (e.g., Hispanic background) were among those most likely to have delayed cognitive or language development, but these families were among those least likely to receive Part C services.

The medical community has taken steps to impress upon pediatricians the importance of screening for developmental delays, helping their colleagues learn about tools to assist with this process and about the early intervention service system, as well as helping families understand their children's development (Glascoe and Shapiro 2006). Still, parents' reports of physicians' diagnoses or suspicions, or lack thereof, frequently did not match other evidence of disability indicators (e.g., low scores on developmental measures; Peterson et al. 2004). Not surprisingly, those families most at risk may need additional assistance to navigate the complex array of available services and communicate effectively with health care providers. Understanding the notion that a variety of disability indicators exist along a continuum may help practitioners consider whether or not to refer a family for Part C services. For example, professionals need to consider when to urge parents to get an evaluation for their child, when to monitor closely for signs of delay, and when to work hard to make sure the child has plenty of opportunities that might prevent a delay from developing in spite of risks. The EHS worker accompanying Anthony and his mother to an appointment with the pediatrician is one way that practitioners can collaborate with the health care community. Other possible collaborations that would meet the needs of particular families or communities could be explored through discussions among community partners.

Focus on Early Intervention Strategies to Prevent Problems from Becoming Delays

Current theory and research in early brain development emphasizes that adequate nutrition, appropriate stimulation, stress reduction, relationship support, and screenings for general health and sensory/motor problems all can help maximize every child's developmental potential (Shonkoff and Phillips 2000). In a sense, this is a central mission of early intervention programs—to make sure that the biological and environmental risks experienced by children living in poverty do not result in actual developmental delays and disabilities.

One critical question is whether early childhood program staff can help to turn around the gloomy statistics that associate developmental delays, living in poverty, and gaps in services. The answer is, yes! Families enrolled in EHS were more likely to receive Part C services and have IFSPs when they needed them than were families in the control

group (5.7 vs. 3.7%; ACF 2002). We attribute these higher rates of identification to EHS program services: child screening and support of parents through referral, eligibility, and IFSP development, as well as to coordination with Part C service providers. All these things represent specific program components mandated by the Head Start Program Performance Standards (ACF 2006).

Equally important, children enrolled in EHS were less likely to have cognitive or language delays (ACF 2002). At age 3, children in the EHS program group were less likely to score one standard deviation or more below the mean on a test of cognitive development (27 vs. 32%) or score low on a test of receptive language development (51 vs. 57%). These results suggest that EHS program activities may be effective in preventing children who face one or more risk factor from falling farther behind in their development.

Discussion

Cautions and Limitations

We need to share a few limitations of this research that practitioners should consider. The proportion of children identified as having some indicator of disability in this study is shockingly high, but a very small number of families received Part C services. Some of the specific disability indicators we identified (e.g., some in the suspected delays and biological risks categories) have relatively low rates of association with actual developmental delay and should be viewed as risks or indicators of a potential disability. Still, it is noteworthy that such a large percentage of these children had identified concerns regarding health or development. Similarly, low scores on developmental assessments may not always be synonymous with eligibility for Part C services. Cognitive and language delays are important criteria for eligibility for Part C services, but performance on a single measure is usually considered in combination with other available data.

Parent report of disability indicators did not always agree with other evidence of disability indicators (e.g., report of professionals, developmental delays identified via assessment). As well, discrepancies were found between reports of eligibility for Part C services from parents and EHS staff members. It is possible that some parents may have been unaware of their children's eligibility; it may even be that some of these families were dually enrolled but failed to distinguish between Part C and EHS services. Staff reports corresponded to levels of Part C service receipt reported by the Hilton Foundation study of EHS programs (Sonoma State University 2002). Also, the gap between eligibility and service receipt may have been due to time lags in getting families into services, the possibility



that parents did not understand that they were enrolled in Part C services, or that parents declined Part C services because they did not feel the additional services were important for their children or themselves (Summers et al. 2001).

Summary

Early intervention programs in the US, and other social service programs abroad, are important resources for families parenting infants and toddlers with a disability. The alarming vulnerability of young children living in poverty and the challenges faced by their families highlight the need to facilitate collaborations among Part C programs and a variety of community-based programs, such as EHS, Parents as Teachers, and child care programs that serve young children and their families. All the vignettes presented illustrate how the multiple challenges faced by families living in poverty can be addressed when early childhood programs work with families to understand their circumstances while concurrently helping families learn about child development and a variety of services; find resources; and navigate the education, health, and social service systems.

The good news is that early childhood programs in the US and in other countries can make a difference, both in helping children with disabilities be identified and served, and in preventing risk factors from pushing children into those disability categories in the first place. The bad news is that we still have a great deal of work to do to enhance services for children with a disability and to prevent more children from developing a disability.

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