

RESEARCH TO PRACTICE

Children with Disabilities in Early Head Start

EARLY HEAD START RESEARCH AND EVALUATION PROJECT

from the Early Head Start Research and Evaluation Project the Early Head Start Research and Evaluation Project the pertain to children with disabilities. Information for this t is drawn from the 36-month Early Head Start report or pacts (Administration for Children and Families [ACF], 2002b), a report on health and disabilities in Early Head Start (ACF, 2004), and selected other studies conducted by Early Head Start local researchers and others. Data were collected from 1996 to 2001.

Background. Early Head Start is a comprehensive twogeneration program with services beginning as early as pregnancy and continuing until children are age 3. Early Head Start programs must make 10% of their funded enrollment opportunities available for children with disabilities¹ (U.S. Department of Health and Human Services [DHHS], 1998). Children with previously diagnosed disabilities may be referred to Early Head Start or disabilities may be identified after enrollment in Early Head Start. The process of identification includes a referral to a local Part C service provider, an assessment, and, if the child qualifies, development of an Individualized Family Service Plan (IFSP), as defined by Part C of the Individuals with Disabilities Education Act (IDEA).²

The Challenge for Early Head Start. There are a number of challenges for Early Head Start programs working with children with disabilities. These include (1) parent needs for support during identification of child's special needs; (2) staff needs for training to guide and support parents through the identification process; (3) community needs for infrastructure to collaborate across health, Part C, and Early Head Start sectors; and (4) need for awareness about early development and the potential of Part C Early Intervention services among parents, Early Head Start staff, and community members. Because of the opportunities of the early years, Early Head Start programs should be aware of progress in the area of Early Intervention and gaps in service provisions identified by the research.

Findings about children with disabilities from the experimental-design study

The Early Head Start report of final impacts showed that on average Early Head Start children benefited over control group children in cognitive, language, and social development and in services received (ACF, 2002b). Two impact findings had particular relevance to children with disabilities.

Early Head Start children were less likely to have delays in cognitive and language functioning (ACF, 2002b). When children were 36 months old, 27% of Early Head Start children had Bayley Mental Development Index (Bayley, 1993) scores below 85 (the national average is 100), compared to 32% of the control group. Similar effects were found for language delays. These differences are attributed to usual Early Head Start program services in child development, nutrition, health, and mental health and to program impacts on parental child language/cognitive stimulation (ACF, 2002b).

Early Head Start children were significantly more likely to receive Part C services than control group children (ACF, 2002b). Higher rates of identification are attributed to program screening and referral services and coordination with Part C partners.

- Approximately 5.4% of families in Early Head Start reported receiving Part C services and having IFSPs. This contrasts to 3.8% in the control group. The most common reasons for identification were speech problems; disabilities related to mobility, vision, and hearing; and other serious conditions such as spina bifida.
- In parent interviews, 7% of Early Head Start and 6% of control families reported that they were *eligible* for Part C services.

Early Head Start children were significantly more likely to receive Part C services than control group children.

EARLY HEAD START

Research Findings: Children with Disabilities

The Early Head Start Research and Evaluation Project enrolled 3,001 children into a rigorous experimental design study to evaluate program impacts. Children, including those with disabilities or suspected disabilities, had an equal chance of being assigned to the program or control groups. Therefore, it is possible to learn about the effects of Early Head Start for children with disabilities by comparing program to control group children. This report also includes information about service variation within the Early Head Start program group.

- The gap between eligibility and actual receipt of Part C services may have been due to (1) time lags in getting families into Part C services, (2) the possibility that parents were not clear about Part C services, and (3) parents declining to enroll their children in Part C because they did not feel that the additional services were important for their children or themselves.
- According to reports by Early Head Start program staff, 13% of children in the research sample had been identified as eligible to receive Part C services by the time families left the Early Head Start program. Staff reports may have been higher than parent reports because parents may have been unaware of their children's eligibility or may not have distinguished between Part C and Early Head Start services. Staff reports corresponded to levels of Part C service reported by the Hilton Foundation study of Early Head Start programs (California Institute on Human Services, 2002) and Program Information Reports in 2001, 2002, and 2003 (ACF, 2002a, 2003a, and 2003b).

Health services are a central focus of Early Head Start because good health is important to children's development.

Early Head Start services to children with disabilities and their families

Families of children with disabilities were highly involved in Early Head Start services. Early Head Start staff rated families of children with disabilities as "highly involved" in the program (50% compared to 35% of other families). Families with children identified as eligible for Part C compared to other families also remained in the Early Head Start program longer (average of 27 months compared to 22 months for other families) and had greater participation in Early Head Start parentchild socializations, parenting education, and parent support groups.

Early Head Start programs and Part C providers engaged in proactive community collaborations to identify children with disabilities and provide needed services. Examples of these activities included the following:

- Early Head Start staff members at a number of the research sites completed SpecialQuest training,³ which resulted in enhanced integration and collaboration between Early Head Start and Part C programs at the community level (ACF, 2002c; Summers et al., 2001; California Institute on Human Services, 2002).
- Early Head Start programs had established policies for staff to follow if they identified a concern about a child, leading to a referral to Part C.

- Staff helped parents interpret the required regulations and access the services, and they provided emotional/ logistical support for the Part C evaluation and individualized family service planning process.
- Early Head Start program staff also worked directly with Part C professionals to help them establish rapport with the families and to coordinate their home visits.

Gaps between need for and receipt of Part C services

While Early Head Start programs took many steps to identify children for Part C services, a number of gaps were found in the receipt of Part C Early Intervention services. In addition to some gaps between eligibility and

> identification, other gaps were found among families with specific demographic characteristics, children with cognitive and language delays, and those with behavior disorders.

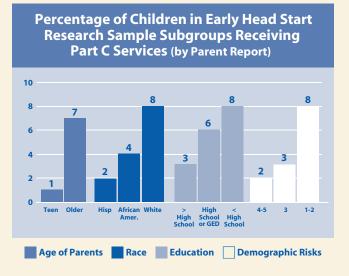
Children with specific demographic characteristics were less likely to receive Part C services⁴ (see page 3). Children in Hispanic families, of teen and less-educated parents, and of parents with moderate or high levels of cumulative demographic risks⁵ were the least likely to receive Part C services.

There were also gaps between need and service receipt among children with cognitive delays. Cognitive delays as assessed in the evaluation using the Bayley MDI were fairly common (about 18% of the sample, when delay was defined as having received an MDI score below 70 by age 3)⁶ (ACF, 2002b).

• Only approximately one-third of Early Head Start children with cognitive delays below 70 on the MDI were identified as eligible for Part C services.

- Cognitive delays were highest among children whose parents had the highest number of demographic risk factors (26% of children of parents at highest risk had cognitive delays) (ACF, 2004). Children in this group were among those least likely to receive Part C services.
- Many parents appeared to be unaware of children's cognitive delays. However, nearly all the children had received well-baby examinations. Across the entire sample, less than one-third of parents (and very few Hispanic or teen parents) of children who ever scored below 70 on the MDI also reported that a doctor had told them that their child had a developmental delay.⁷

Many children with delays in receptive language development did not receive Early Intervention Part C services. Analysis of child assessments showed that over 26% of the children had delayed receptive language



(received a score lower than 1.5 SD below the mean on the Peabody Picture Vocabulary Test-III) (Dunn & Dunn, 1997; ACF, 2002b). About a fifth had been identified as eligible for Part C services.⁸ Parents were somewhat more aware of language delays than was true for cognitive delays (reported earlier). About half of the parents of children with delays in receptive language were aware of a communication difficulty:

- Parents with *fewer* demographic risk factors were more aware of children's communication difficulties than were parents with more risks, and their children were more likely to receive Early Intervention services.⁹
- However, children of parents with more demographic risk factors were more likely to have receptive language delays, as determined from the 36-month research assessment.

Parents were unlikely to report that any behavior problems had been identified in their children (about 1%, as noted to them by a physician). The study assessed parent report of child behaviors using the *Childhood Behavior Check List* (Achenbach, Edelbrock, & Howell, 1987). Nine percent of all children's scores were in the clinical range, indicating behavior problems, and about a quarter of these children were identified as eligible for Part C.

Implications for Program Practice

While Early Head Start programs working in partnership with local Part C agencies have made significant progress in identifying children with disabilities, some service gaps exist, suggesting that community partners should examine whether there are time delays that could be reduced along the pathway from referral to service provision.

Many families who receive Early Intervention services appear to be highly engaged with their Early Head Start programs. The programs may be able to build on this strength by asking: What are the needed supports that programs can provide to help families with children identified by the Part C system?

Early Head Start programs and community Part C partners should jointly evaluate how the needs of children with early delays are addressed.¹⁰ What steps can programs and Part C partners take to promptly identify potential cognitive and language delays and social-emotional disorders during the infant/toddler years? How can programs and Part C work together to provide appropriately intensive intervention, whether through Early Head Start, Part C, or both?

The research indicates a surprising lack of awareness about children's cognitive delays, though nearly all children had well-baby exams and delays, as defined here, were relatively large.¹¹ Most parents whose children had significant delays did not report they had been apprised of delays by their physicians during these exams. How can programs support parents in medical discussions and work directly with the medical community to better facilitate early identification of children with serious cognitive developmental delays? How can such support be provided across a range of health service delivery systems, including

those in which different physicians may attend to a child over time?

Programs and community partners can support families at greatest risk by helping them to understand child development, the referral and identification processes, and the importance of Early Intervention in the prevention of later difficulties. Children of parents with



many demographic risk factors, in Hispanic families, of parents at lowest levels of education, and of teen mothers were least likely to receive Part C services. Children in several of these groups were also most likely to be very low functioning in cognitive and language development. Programs can address: How can Early Head Start and Part C partners jointly examine barriers to enrolling families at greatest risk, Hispanic, teen, and less-educated parents into the Part C system?

The Study

The Early Head Start Research and Evaluation Project included studies of the implementation and impacts of Early Head Start. The research was conducted in 17 sites representing diverse program models, racial/ethnic makeup, auspice, and region. In 1996, 3,001 children and families in these sites were randomly assigned to receive Early Head Start services or to be in a control group who could utilize any community services except Early Head Start. Children, families, and children's child care arrangements were assessed when children were 14, 24, and 36 months old, and families were interviewed about services at 7, 16, and 28 months after random assignment. Child assessments included a wide array of child cognitive, language, and social-emotional measures using direct assessment and parent report. Parent assessments included observation (videotaped and by interviewers) and self-report. Families in the program and control groups were demographically comparable at baseline and assessment points. Several research briefs have been published based on findings from this study. A prekindergarten followup was completed and a 5th grade followup is currently underway. Information for this research brief was drawn from the 36-month Early Head Start impacts report (ACF, 2004), from a report on health and disabilities in Early Head Start (ACF, 2004), and from selected other research studies conducted by Early Head Start local researchers and others.

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Notes

¹ Eligibility for Part C is determined by states. There is great variability across states regarding who is defined as an infant or toddler with a disability. When Early Head Start programs were beginning, changes were being implemented in both IDEA and the Head Start Program Performance Standards (DHHS, 1996), affecting services as Part C and Early Head Start providers sought interpretation of the regulations. See http://www.nectac. org/%7Epdfs/pubs/nnotes20.pdf

² See www.ideapractices.org/law/regulations/indexPartC.php

³ SpecialQuest, also known as the Hilton/EHS Training Program, is a new initiative sponsored by the Conrad Hilton Foundation in partnership with the Office of Head Start to help communities refine coordination between Early Head Start and Part C. SpecialQuest trains community teams to develop systems that are sensitive to the community context to identify, refer, and serve children with special needs.

⁴ The findings are consistent with a recent report from the NEILS study, which speaks to the problems of Early Intervention outreach to underserved populations: http://sri.com/neils/FE_ ReportExecSummary.pdf

⁵ Demographic risk factors that were added to create a cumulative risk index were whether the mother was a teen at the time of the child's birth, lacked a high school education, was unmarried, was receiving cash assistance, and was not in school or working.

⁶ This level of delay is consistent with Part C eligibility criteria outlined by every state: http://www.nectac.org/%7Epdfs/pubs/ nnotes20.pdf

⁷ While families in the Early Head Start program were highly likely to have a regular health care provider (94%-98% at different measurement periods), there was considerable variation in the kinds of contacts children may have had with physicians. For example, Hispanic children were less likely than other children to receive regular health care in a private doctor's office (24% vs. 41% and 48% of African American and White children, respectively). Hispanic children were also less likely to receive screening tests (including hearing tests and lead screenings) than other children (59% vs. 77% and 63% of African American and White children, respectively) (ACF 2003a).

⁸ The measure of receptive language is not universally used to assess children's language development for Part C programs, and, if it is, a score -1.5 SD might not qualify a child for Part C in all states. Therefore, it cannot be assumed that all children with delays at this level would qualify for Part C. In making comparisons between the measure of receptive language and parent report of communication difficulties, it is also possible that different areas of language development are being considered.

⁹ As all children enrolled in the research began program services before age 1, it is not likely that recognized needs for speech and language intervention motivated parents with fewer risks to enroll in the program. However, it is possible that parents with fewer demographic risks enrolled in the program if their children had multiple disabilities that could have affected language capacity.

¹⁰ It may be possible to affect some early cognitive and language delays. Current theory and research in early brain development would suggest that nutrition, appropriate stimulation, stress reduction, relationship support, and health screenings are helpful agents.

¹¹ Pediatrics organizations are aware of concerns. See http:// www.aap.org/healthtopics/discond.cfm and www.dbpeds. org/articles/detail.cfm?id=5

Administration for Children and Families U.S. Department of Health and Human Services