



Executive Summary: EI SNAPSHOT

Early Intervention for
Children who are Deaf or
Hard of Hearing: Systematic
Nationwide Analysis of
Program Strengths, Hurdles,
Opportunities, and Trends



Executive Summary

Early Intervention Systematic Nationwide Analysis of Program Strengths, Hurdles, Opportunities and Trends (EI SNAPSHOT)

The National Center for Hearing Assessment and Management (NCHAM) received funding from the Maternal and Child Health Bureau and the Oberkötter Foundation to assess the early intervention system in the United States for families of children who are deaf or hard of hearing (DHH). The goals of the Early Intervention: **S**ystematic **N**ationwide **A**nalysis of **P**rograms' **S**trengths, **H**urdles, **O**pportunities, and **T**rends (EI SNAPSHOT) project were to assess:

- I. **Family Perceptions, Needs, and Choices** via surveys with families of children ages 2-6 years who are deaf or hard of hearing (DHH).
- II. **EI and Audiology Direct Service Provider Perceptions** via surveys with EI providers and audiologists about their training, experience, and practices in regard to service provision and coordination.
- III. **Systems-level Coordination Among Part C, EHDI and Other Relevant Programs** via telephone interviews with state-level EHDI and Part C coordinators.
- IV. **Family Access to Information via Family-to-Family Support Organizations and Part C Websites** through phone surveys with federally-funded Parent Training and Information Centers and Family-to-Family Health Information Centers along with critiques of all Part C websites.
- V. **Characteristics of Current Personnel Preparation Programs for Teachers of the Deaf** via interviews with university program directors and surveys with recent graduates.



Findings: Cross-cutting Trends

Trends - consistent themes identified across methodologies and participants – reveal insights about the state of early intervention for families of children who are DHH, both in terms of what appears to be working well (strengths) and areas that warrant attention (hurdles):

Strengths

Part C EI programs are accessible and are viewed as positively supporting families.

- Almost 90% of families reported that it was easy to get connected to early intervention services and that it improved their child's quality of life.
- About two thirds of babies identified as DHH before 3 months of age were connected to EI before 6 months of age.
- EI providers generally have a positive attitude about their work and the role of EI in serving families of children who are DHH.
- Good working relationships and formal referral processes between EHDI and Part C EI to support families are in place in most states.
- Family-to-family support organizations funded to educate and support families of children with disabilities (not specific to hearing loss) report that they consistently refer families to EI when they call with concerns about their child's hearing and thus are an important conduit to the EI system.



Hurdles

A significant number of families believe that publicly funded EI programs are not providing enough services.

- Almost one third of families reported arranging for supplemental private EI services.
- Some families experience frustration in finding providers to address the family's desired communication option.
- Almost two thirds of audiologists received requests from parents seeking supplemental EI services.
- Very few programs for teachers of the deaf provide coursework or practical experience focused on EI/early childhood education in spite of the fact that children who are DHH are increasingly being identified during their first six

months of life as a result of newborn hearing screening programs.

- The number of students graduating from deaf education programs is small, thus few are entering the workforce at any one time.

Families have difficulty connecting with family-to-family support systems.

- The majority of families reported that they received little or no opportunities to meet with other parents of children who are DHH.
- About two-thirds of families reported little to no information provided about general disability-focused family-to-family support organizations, and 44% received little to no information about DHH-specific groups like Hands & Voices.
- One-third to one-half of EI providers reported inadequate knowledge about family-to-family organizations.
- Fewer than half of Part C websites – an initial source of information for families – have information about family-to-family support organizations.

Family-level service coordination needs strengthening, particularly to address financial and social supports.

- Almost half of families reported that their child's hearing-related needs posed a moderate to unbearable financial burden, reflecting the need for the EI system to help families access financial resources.
- The minority - about 35% of families - reported that their service coordinator had helped them get non-therapeutic services such as child care or food stamps.
- Inclusion of the medical home to support coordination of EI services is a need, given that 40% of families reported that their medical home did not receive information about their EI services.
- Although the majority of EI service coordinators reported that they coordinate with other providers, about one quarter of respondents reported that coordination with relevant partners "needs more work." Although the large majority of audiologists refer families to EI, only about 32% received copies of their clients' IFSP's and only 13% reported that they participated in an IFSP meeting within the past year.

Opportunities for Systems Improvement

Opportunities – potential policies and practices for improving the EI service system – reveal ways that EHDI, Part C, family organizations, and other stakeholders can work together to address hurdles:

- State EHDI and Part C programs should consider building formal partnerships with family-to-family support organizations, both DHH-specific and non-disability-specific. The expansion of such efforts would be a great enhancement of family support opportunities.
- Although referrals from EHDI to EI seem to happen easily, no babies should “fall through the cracks.”
- Developing more efficient shared data systems would allow for more timely tracking of families who are not receiving appropriate services. States with “live” integrated data systems that adhere to privacy and security regulations allow for more effective monitoring, and they can serve as models for other states.
- Further investigation into EI service coordination models would provide insights into how to ensure the broad needs of families are being met, such as connections to financial resources and social supports. Some states have identified service coordinators who specialize in serving families of children who are DHH, ensuring these service coordinators know about DHH-specific resources. Methods to increase inclusion of audiologists in the IFSP process is also important along with greater inclusion of family organizations.
- Expanding personnel preparation options would provide an opportunity to create a workforce of more providers with expertise to serve infants and toddlers who are DHH. Also, EHDI programs can support EI providers via training and technical assistance, e.g., increasing their knowledge about the importance of ensuring families are connected to EI and the contribution of audiologists in promoting optimal learning environments.
- Part C, EHDI, and family organizations’ websites need to be improved to ensure families can find information more easily. Improvements would include ensuring diverse families are represented in website material, using simpler language, providing videos to help families with low literacy levels, offering linkages to family organizations, and inclusion of hearing-related resources.
- Inter-agency collaboration and family engagement should be emphasized. EHDI HRSA grant requirements to partner with family organizations and to form learning communities with key stakeholders are two relevant activities that can address the challenges found in this study.



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