



AMERICAN
SPEECH-LANGUAGE-
HEARING
ASSOCIATION

Service Provision to Children Who Are Deaf and Hard of Hearing, Birth to 36 Months

*Joint Committee of the American Speech-Language-Hearing Association and the
Council on Education of the Deaf*

Reference this material as: American Speech-Language-Hearing Association. (2008). *Service Provision to Children Who Are Deaf and Hard of Hearing, Birth to 36 Months* [Technical report]. Available from www.asha.org/policy.

Index terms: early intervention, newborns, infants and toddlers, children, deafness, hearing loss
doi:10.1044/policy.TR2008-00301

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About This Document

This technical report was developed by the Joint Committee of the American Speech-Language-Hearing Association and the Council on Education of the Deaf (ASHA-CED). It was approved by the ASHA Board of Directors and the Executive Board of CED in 2008. Members of the Joint Committee include Roberta Aungst (past vice president for professional practices in audiology, 2004–2006), Linda Charlebois, Larry Fleischer, Robin Gashler, Ginger Jones, Marilyn Sass-Lehrer (past member), Pam Mason (past ex officio), George Mencher (past member), Kym Meyer (chair), Gwendolyn Wilson (vice president for professional practices in audiology, 2007–2009), Rachel Friedman Narr, and Anne Oyler (ex officio).

Background

This document supersedes the 1994 technical report of the Joint Committee of the American Speech-Language-Hearing Association and the Council on the Education of the Deaf (ASHA-CED) entitled *Service Provision Under IDEA, Part H, to Children Who Are Deaf and Hard of Hearing, Ages Birth to 36 Months*, which was rescinded in 2005. Since that time, there have been significant advances in the identification, assessment, and service provision for children with hearing loss. The Individuals with Disabilities Education Improvement Act of 2004 (IDEA, 2004) and the Newborn and Infant Hearing Screening and Intervention Act of 1999 have led to improved services for infants, toddlers, and their families.

Research and advances in technology since the mid-1990s have resulted in the development and implementation of universal newborn hearing screening programs, a better understanding of the importance of the early years of development, and greater access to information about hearing, hearing loss, hearing disorders, and deafness. Further, new trends in education of deaf and hard-of-hearing children; advances in the fields of audiology, genetics (Arnos, 2008), and neurobiology (Dorman, Sharma, Gilley, Martin, & Roland, 2007); and heightened awareness and involvement of the medical community have also had a positive impact on services. Advances in linguistic studies have revealed the importance of early language acquisition and the striking parallel of language milestones between spoken and signed languages (Calderon, 2000; Newport & Meier, 1985; Schlesinger & Meadow, 1972; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998).

The vast majority of children who are deaf and hard of hearing are born to families who have limited or no experience with hearing loss (Mitchell & Karchmer, 2004). The characteristics of children with hearing loss being served through early intervention have changed significantly in the past decade. Because of newborn hearing screening, these children are younger, may have mild or unilateral hearing losses, may have auditory neuropathy/dys-synchrony, or may be from culturally and linguistically diverse families. Also, a significant number of these children are born with developmental, visual, or other physical disabilities (Gallaudet Research Institute, 2006; see Guardino, 2008).

Unfortunately, the availability of qualified providers to work with children who are deaf and hard of hearing is insufficient (Johnson, 2004; LaSasso & Wilson, 2000). Parents, caregivers, professionals, and members of the Deaf community recognize the need for a greater number of qualified professionals and improved

Early Hearing Detection, Intervention, and Follow-Up

service provision (*The national agenda*, 2005). These and other factors have combined to encourage medical, health care, and education agencies and programs to collaborate as a way of providing a more cohesive, cooperative, and organized program of services.

Children who are deaf and hard of hearing and their families constitute a unique group whose communication needs differ from those of hearing children. Children with hearing loss, unlike their hearing peers, lack full access to communication through the auditory channel. Complete and clear language input is essential for the child's cognitive, linguistic, and social-emotional development. Even with advances in technology, these children often need access to visual communication, which should be facilitated by the adults in their environment. The manner and degree of visual support provided will depend on the unique needs of the child. Children who receive early comprehensive services may reach or exceed age-appropriate developmental milestones by the time they begin school (Calderon, 2000; Moeller, 2000; Yoshinaga-Itano, 2003).

Newborn hearing screening programs were established to identify infants with hearing loss and subsequently provide earlier opportunities for professional and family involvement. Newborn hearing screening has become part of the standard of care in the United States, and more than 90% of all newborns are now being screened for hearing prior to hospital discharge. Families whose newborns do not pass the hearing screening are referred for further hearing evaluation upon discharge from the hospital. Screening, however, is only the first step of an often complex journey for families and must be followed by additional hearing and medical evaluations and then, if recommended, early intervention services. The Joint Committee on Infant Hearing (JCIH, 2007) recommends that hearing and medical evaluations be completed by 3 months of age and that infants with confirmed hearing loss receive early intervention services by 6 months of age. Since the initiation of newborn hearing screening, the average age of the confirmation of hearing loss has decreased from 24–30 months to 2–3 months of age (Harrison, Roush, & Wallace, 2003).

Despite these advancements, almost half of newborns who are referred from hearing screening do not have appropriate follow-up to determine the presence of a hearing loss and to initiate appropriate early intervention services, when needed (Centers for Disease Control and Prevention, 2008; Early Hearing Detection and Intervention Act of 2007 [EHDI 2007]; JCIH, 2007). Contributing factors include (a) ineffective procedures and strategies that would otherwise help ensure that families return for further evaluations and (b) a lack of qualified professionals available to work with infants and families (Folsum et al., 2000; White, 2007). Families who lack the necessary economic resources, who have poor health care services, or who face barriers accessing comprehensive information because of language, literacy, or cultural differences are especially at risk (Christensen, 2000; Lynch & Hanson, 1998; Sass-Lehrer, 2004; Young & Andrews, 2001).

The potential benefits of early hearing screening are lost without effective follow-up and early professional and family involvement. IDEA 2004 provides the legal foundation for the provision of services to young children who are deaf and hard of hearing and their families. This legislation endorses early intervention services that are family centered, interdisciplinary, and collaborative among agencies and

Family Involvement

providers. This legislation also recommends that services be provided by highly qualified professionals with expertise in working with young children and families. Additionally, EHDI 2007 endorses early confirmation of hearing loss followed by comprehensive early intervention.

The report from the National Consensus Conference on Effective Educational and Health Care Interventions for Young Children with Hearing Loss (Marge & Marge, 2005) provided recommendations regarding education, health care, and coordination of services. Derived from scientific evidence, conventional wisdom and agreement, and perceived best practices, this report recommended that early identification, assessment, and management should be conducted by qualified professionals who understand the needs of deaf and hard-of-hearing children and their families. Programs should be designed to meet the unique needs of the child and family and should enable families to play an active, collaborative role in the planning and provision of early intervention services for their child. In addition, ongoing monitoring of these children's progress must be done to ensure that they develop language at a rate commensurate with their age and cognitive abilities.

The best outcomes for children who are deaf and hard of hearing can only be achieved with increased availability of resources and professionals from a variety of disciplines working together with families to ensure delivery of appropriate services. Calderon and Greenberg (1997) examined the efficacy of early intervention and noted that specific program variables that are similar across successful intervention programs may help describe what works and for whom. These variables included the quality of the relationship between professionals and parents, the parents' sense of efficacy in relating to their child, and their hopefulness and realistic—but positive—expectations. Professionals need to facilitate appropriate services soon after confirmation of a hearing loss. It is also critical that they establish a foundation for families to become engaged in the process and realize their ability to shape their child's future. From first contacts with the hearing screening program through enrollment in early intervention, a family-centered approach can enhance the likelihood that families are both willing and able to take an active role in their child's early development.

Effective and meaningful parent–child communication commensurate with the age and developmental needs of the child must be the focus of early intervention services and continue into the formative learning years. Moeller (2000) suggested that a high level of family involvement helps ensure successful outcomes by 5 years of age. Children in Moeller's study who were enrolled in early intervention programs before their first birthday and who had strong family support demonstrated a higher level of vocabulary development and verbal reasoning skills. Calderon (2000) found that family involvement was a strong predictor of academic and social outcomes. In the same study, parent–child communication was an even stronger predictor of early reading skills and social–emotional development.

Professionals play a critical role in working with families. Parents face challenges soon after the confirmation of their child's hearing loss, including decisions regarding medical procedures, selection of hearing technology, communication methodologies, language choices, and early intervention services and approaches. Formal and informal support from a variety of sources, including other families

The Interdisciplinary Model

with deaf and hard-of-hearing children, promotes parental well-being, positively affects parent–child interaction, and helps guide decision making (Luckner & Velaski, 2004). Professionals should provide families with information regarding the availability of parent-to-parent support and other community resources. Many families identify deaf and hard-of-hearing adults as valuable sources of support (Meadow-Orlans, Mertens, & Sass-Lehrer, 2003). Therefore, Deaf community organizations and deaf and hard-of-hearing adults should be an important part of the EHDI system (Marge & Marge, 2005).

In working with families, professionals may face ethical dilemmas as a result of the issues that have arisen from early identification and advances in technology (Arnos, 2008; Chute & Nevins, 1997; Hintermair & Albertini, 2005). Professionals can have a powerful influence over the families they serve. Families have the right to receive comprehensive information about all available options for their child. This understanding is enhanced when professionals are well informed and when the family's cultural and linguistic backgrounds are respected.

Service delivery models can vary significantly, depending on the needs of the child and family and what is available within the community (ASHA, 2008b). Family-centered services can take place in a variety of different settings such as the home, school, community center, day care center, hospital, or clinic (ASHA, 2006).

Early intervention professionals work in collaboration with families to identify priorities, resources, and concerns in the development and implementation of the Individual Family Service Plan (IFSP; ASHA, 2008b). The knowledge, skills, and experiences required by the early intervention team address the ongoing assessment, implementation, and evaluation of services that support families and promote child development (ASHA, 2008a). IDEA 2004 Part C requires a team approach and a strong family focus in the development and implementation of the IFSP as the core of an early intervention program. Regardless of philosophy, agencies and programs should work collaboratively.

The purpose of the interdisciplinary team is to ethically and confidentially support the family in maximizing the child's overall developmental potential (ASHA, 2008d). This support may be achieved through the provision of early intervention services by qualified professionals who understand child development, understand how to work with families, and have a rich knowledge of community resources. Presently, there is shortage of personnel uniquely qualified to provide services to deaf and hard-of-hearing infants and their families (Johnson, 2004; LaSasso & Wilson, 2000). Therefore, it is strongly recommended that these services be provided on a regional basis to pool resources and expertise as well as to provide a critical mass of children.

In addition to the family, the core members of the early intervention team are professionals with expertise in early intervention with deaf and hard-of-hearing children, including the pediatric audiologist, teacher of the deaf and hard-of-hearing, speech-language pathologist, and service coordinator (ASHA, 2004, 2008c; ASHA-CED, 2004). Depending on the needs of the child, other professionals who may be involved include but are not limited to

- early childhood special educator;

- sign language specialist;
- listening and spoken language specialist;
- cued speech specialist;
- deaf-blind specialist;
- occupational therapist;
- physical therapist;
- psychologist;
- counselor;
- social worker;
- physician (e.g., family practitioner, pediatrician, otologist);
- geneticist.

The interdisciplinary team serving deaf and hard-of-hearing children requires collective expertise in the following areas:

- child development
- hearing loss and auditory system disorders
- spoken language development
- sign language development
- auditory skill development
- hearing technologies
- visual technologies
- developmental or other disabilities
- blindness and visual impairment
- cognitive development
- emergent literacy
- social–emotional development
- counseling and family support
- Deaf culture and communities
- cultural and linguistic diversity
- advocacy and empowerment
- transition planning
- current research

Conclusion

Comprehensive planning and implementation of services must integrate assessment information from all disciplines. Communication throughout the process will be most effective when the family's primary/preferred language is used through direct communication, when possible. All educational services and options for the child and family must be considered—not only during early intervention but also into the preschool and primary years. The interdisciplinary team should also access resources available at the local, state, and national levels to facilitate these goals. By receiving family-centered early intervention services that use current evidenced-based practices, deaf and hard-of-hearing children will be able to achieve their maximum potential.

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