

Demographic Considerations in Serving Children Who are Hard of Hearing or Deaf

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Abstract: People involved with Early Hearing Detection and Intervention (EHDI) programs should understand that fewer than 15% the babies identified by EHDI programs have bilateral profound hearing loss and more than 50% have mild bilateral or unilateral hearing loss. Further, less than 5% of newborns with congenital hearing loss have two parents who are hard of hearing or deaf. It is important that EHDI program managers and staff ensure that educational, audiological, and medical care are tailored to the needs and circumstances of the child and family. Achieving this goal requires that participants in the EHDI system recognize and respect the heterogeneity of this population and the many options that families have for educating and communicating with their child who is hard of hearing or deaf.

Acronyms: ASL = American Sign Language; CDC = Centers for Disease Control and Prevention; HH/D = hard of hearing or deaf; EHDI = Early Hearing Detection and Intervention; HRSA = Health Resources and Services Administration; NCHAM = National Center for Hearing Assessment and Management; SEE = Signed Exact English; UHL = unilateral hearing loss

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Introduction

Every U.S. state now has an Early Hearing Detection and Intervention (EHDI) program that is responsible for ensuring that all newborns are screened for hearing loss, that those who do not pass the screen receive timely audiologic diagnosis, and those diagnosed with permanent hearing loss are enrolled in appropriate early intervention programs (White, 2014). The success of the screening portion of EHDI programs is demonstrated by the fact that the Centers for Disease Control and Prevention (CDC, 2018) reported that 98.0% of newborns are now screened for hearing loss. However, there is still much work to be done informing and supporting families as they (a) make decisions about how they will communicate with their child who is hard of hearing or deaf (HH/D), and (b) learn how to effectively engage in new skills important for language learning.

Most EHDI stakeholders agree that to be effective, early intervention services need to be tailored to the child's characteristics and the needs of their families (Joint Committee on Infant Hearing, 2013). It is clear that one size does not fit all and interventions are more effective when they reflect the needs of individuals (Zolnierek & DiMatteo, 2009). Even though it may seem intuitive that services for children who are HH/D should be designed and delivered in a way that accounts for differences in parent/family factors (e.g., ethnicity, education, religious

and cultural beliefs), other child variables can be overlooked and can powerfully affect service delivery decisions.

What is the Child's Hearing Status?

Congenital hearing loss for any given child ranges from mild unilateral to profound bilateral. Even though the implications for a child's development are significantly different depending on the degree of hearing loss, all childhood hearing loss has important developmental consequences as noted by the Department of Health and Human Services in their landmark 1990 document establishing National Health Promotion and Disease Promotion Objectives:

It is difficult, if not impossible, for many [children with congenital hearing loss] to acquire the fundamental language, social, and cognitive skills that provide the foundation for later schooling and success in society. When early identification and intervention occur, [children who are HH/D] make dramatic progress, are more successful in school, and become more productive members of society. The earlier intervention and habilitation begin, the more dramatic the benefits. (p. 460)

Many people do not realize that infants with unilateral hearing loss are by far the largest group of children identified in newborn hearing screening programs. –As shown in Figure 1, based on data reported by state-based EHDI programs to CDC (2018) for the years 2012–2014, almost 40% of all babies who were reported by EHDI programs to the CDC during this time period had unilateral hearing loss (UHL). According to Lieu (2018),

School-aged children with UHL score lower on standardized tests of language and cognition and need increased assistance in school for educational and behavioral issues than siblings with normal hearing, and report lower hearing-related quality of life, similar to children with bilateral hearing loss. (p. 74)

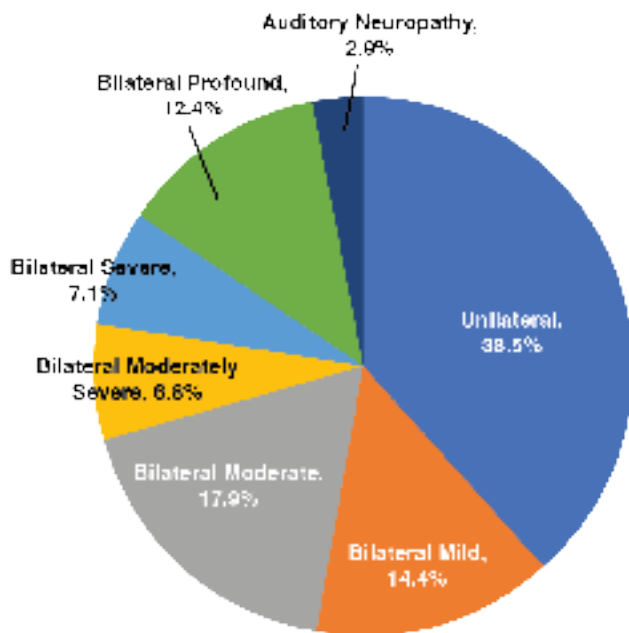


Figure 1. Centers for Hearing status of newborns reported to Centers of Disease Control and Prevention by Early Hearing Detection and Intervention programs during 2012 through 2014.

Even though the needs of a child with unilateral hearing loss are much different than a child with bilateral moderate or profound hearing loss, all children who are HH/D, and their families, need assistance if they are to reach their full potential.

Hearing Status of Parents

For children who are HH/D to learn language, they need consistent access to fluent language models as early as possible. We have known for decades that which specific language is used is not nearly as important as consistently exposing children to a rich language environment from the time they are born (Hart and Risley, 1995). According to Gallaudet University’s 2011–2012 *Annual Survey of Deaf and Hard of Hearing Children and Youth* (Gallaudet

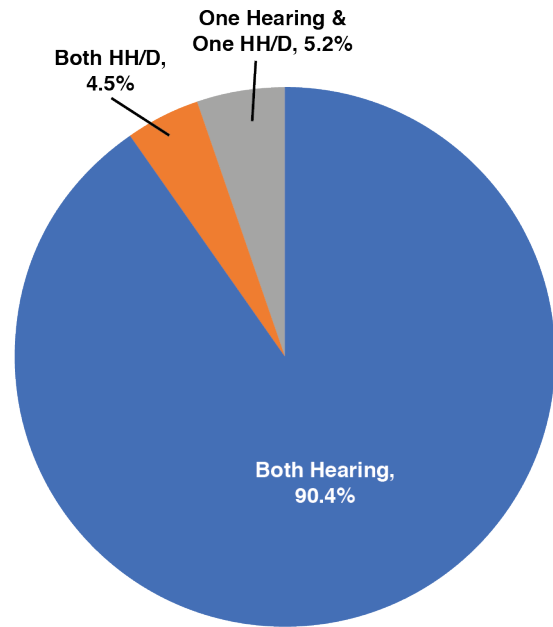


Figure 2. Hearing status of parents in the Gallaudet 2011-2012 Annual Survey of Deaf or Hard of Hearing Children and Youth. HH/D = hard of hearing or deaf.

Research Institute [GRI], 2013), less than 5% of children and youth sampled had parents who were HH/D (see Figure 2).

Thus, for the vast majority of children who are HH/D, their earliest language environment is one of spoken language (usually English, but not always). For families who choose to use a visual language such as American Sign Language (ASL) or Signed Exact English (SEE), or a visual support system such as cued speech, it is important that as many family members as possible become fluent in that choice so that the child has consistent language models during this important developmental period. Although research is sparse, there is evidence that most children who are deaf and are raised with fluent ASL do just as well as children who are deaf and are raised with a spoken language such as English or Spanish (Giezen, Baker, & Escudero, 2014; Marschark, Sarchet, Rhoten & Fabich, 2010).

Communication Modalities Used by Families of Children Who Are HH/D

One of the most frequently discussed issues among people involved in EHDI programs is how families and others will communicate with the child who is HH/D. Will the child communicate using Listening and Spoken Language, ASL, Cued Speech, SEE, or some combination (Gardiner-Walsh & Lenihan, 2017)? Questions about communication modality can be confusing for parents to navigate, particularly as they encounter conflicting information and controversy on this topic, and this can interfere with their ability to make informed decisions about the educational and audiological services they want to have for their child. Discussions about the pros and cons

of various communication modalities (Fitzpatrick et al., 2016; Humphries et al., 2017) can consume considerable time and energy on the part of people managing EHDI programs.

Based on currently available data, there is no “best way” for a child who is HH/D to communicate. Families choose to communicate with their children who are HH/D in a variety of ways, based on an array of factors that are important to their family. EHDI programs, early intervention staff, and health care providers have an important role in assisting families in learning about and considering options, and in helping them access the best possible services and support for their communication choice. According to a recent national survey by the National Center for Hearing Assessment and Management (NCHAM, 2018), a significant number of families explore multiple options during the child’s early years, and many change their approach or combine options from time to time. Table 1 shows the percentage of families using various communication options based on that national survey. These findings are consistent with Gallaudet’s 2011–2012 *Annual Survey of Deaf and Hard of Hearing Children and Youth* (GRI, 2013) which reported that 51.8% of the respondents were taught using only spoken language, 15.5% were taught using spoken language with cues, 15.2% were taught using sign language only, 13.2% were taught with sign language and spoken language, and 4.2% were taught with “other.”

Table 1
Family Report of Child’s Primary Communication Modality

Communication Modality	Percentage of Families
Listening and Spoken Language only	48%
Sign Language only	3%
Mostly Listening and Spoken Language (supplemented by sign language, cued speech, or other)	17%
Mostly Sign Language (supplemented by listening and spoken language, cued speech, or other)	3%
Mostly Cued Speech (supplemented by listening and spoken language, or other)	12%
Equal Parts Sign Language and Listening and Spoken Language (including total communication)	11%
Other	1%

Hearing Status Demographics for Serving Children Who Are HH/D

The vast majority of families who have an infant or young child diagnosed as HH/D have no experience and often have never met a person who has been HH/D since childhood. Thus, those responsible for managing EHDI systems have responsibilities far beyond just making families aware of the various communication options. Instead, EHDI program managers and staff need to ensure that families have opportunities to interact with people who have used various communication options, including those who have used multiple options.

Current federal funding guidelines have begun to address this issue, but are not as broad as they need to be. For example, Health Resources and Services Administration (HRSA) Funding Opportunity Announcement 17-061 (HRSA, 2017, p. 3) encouraged

... the establishment of Deaf Mentor programs for families with deaf or hard of hearing infants and children in all states/territories. Deaf Mentor programs should provide families regular opportunities with a Deaf Mentor, a qualified deaf or hard of hearing adult, to interact with their child using American Sign Language (ASL) and effective visual communication strategies, and to guide understanding of deafness and Deaf Culture.

Ensuring that families of newly identified children who are HH/D have opportunities to interact with ASL-using adults is important, but it is not enough given that only 6–15% of children who are HH/D being identified in EHDI programs are using ASL as their primary mode of communication (GRI, 2013; NCHAM, 2018). The EHDI system also needs to provide families with opportunities to interact with adults who are HH/D and use Listening and Spoken Language, cued speech, SEE, and other communication modalities.

It is important to remember that many adults who are HH/D were children learning language before EHDI existed. Thus, the experiences that most adults who are HH/D had as children are often radically different than what is currently happening. It is equally important for families of children who are HH/D to have opportunities to interact with families using various communication modalities. Additionally, parents of newly identified children benefit from interacting with other parents of children who are HH/D (Henderson, Johnson, & Moodie, 2016).

An oft-repeated slogan among adults who are profoundly deaf and use ASL, is, “Nothing about us, without us.” It is a good guideline, but it is important to be thoughtful about who “us” is. Including people in EHDI programs who are profoundly deaf and use ASL is important. But it is equally important to include people with varying degrees of hearing loss who use Listening and Spoken Language, cued speech, SEE, and other communication options. It must be remembered that decisions that families make are influenced by multiple factors. Respect and support for their family-specific context should be paramount. Families have the best opportunity to thrive when intervention and support are aligned with their values and needs, and this ultimately helps children who are HH/D reach their full potential.

Conclusion

Identifying children who are HH/D is only the first step in helping these children reach their full potential. Providing appropriate educational, audiological, and medical care requires that services are tailored to the needs and circumstances of the child and family. Achieving this goal

requires that participants in the EHDI system recognize and respect the heterogeneity of this population and the many options that families have for educating and communicating with their child who is HH/D.

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