

Promoting Early Identification and Intervention for Children Who Are Deaf or Hard of Hearing, Children with Vision Impairment, and Children with DeafBlind Conditions

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Abstract

Children who are deaf or hard of hearing (DHH) with Vision Impairment (VI) have unique needs requiring adaptations to intervention strategies, compared to those strategies used for DHH or VI alone. Based on the National Center on DeafBlindness Census data, 6% of the total number of reported children who are DeafBlind are in the birth through two age range (Part C eligible), and 12% are in the three through five years age range (Part B eligible), suggesting that there may be a gap in identification of children who are DeafBlind within Part C programming.

This work is intended to allow for improved identification of children of hearing loss, vision impairment, and children with both hearing and vision needs (DeafBlind). The authors provide principles to guide evidence-based best practice for Early Intervention providers. Resources for expanding supports for young children who are DeafBlind are also included.

Acronyms: ASHA = American Speech-Language Hearing Association; ASQ = Ages and Stages Questionnaire®; CMV = cytomegalovirus; DeafBlind = children with both hearing and vision needs; DHH = deaf or hard of hearing; DHH Plus = deaf or hard of hearing plus developmental disabilities; EI = Early Intervention; EHDI = Early Hearing Detection and Intervention; IDEA = Individuals with Disabilities Education Act; IEP = Individualized Education Plan; IFSP = Individualized Family Service Plan; INSITE = IN-home Sensory Impaired Training and Education; JCIH = Joint Commission on Infant Hearing; NCDB = National Center on DeafBlindness; O&M = orientation and mobility; VI = vision impairment

Introduction

Children who are deaf or hard of hearing with vision impairment (DeafBlind) have unique needs and require adaptations to intervention strategies, compared to those strategies used for children who are deaf or hard of hearing (DHH) or who have vision impairment (VI) alone. Compared to the general population, there are higher rates of developmental delays in children who are DHH (approximately 40%; Gallaudet Research Institute, 2011; Nikolopoulos, Lioumi, Stamatakis, & O'Donoghue, 2006; Szymanski, Brice, Lam, & Hotto, 2012) and in children with VI (up to 66%; Hatton, Bailey, Burchinal, & Ferrell, 1997; Rahi, Cable, & the British Childhood Visual Impairment Study Group, 2003; Mervis, Boyle, & Yeargin-Allsopp, 2002; Mervis, Yeargin-Allsopp, & Boyle, 2000).

Children who are DHH with developmental disabilities have been described as being "Deaf/HH Plus" to indicate their needs while still keeping a positive developmental perspective for the future (Wiley, St. John, & Lindow-Davies, 2015). The Joint Committee on Infant Hearing (JCIH) published a supplement to their 2007 position statement (JCIH, 2013) focusing on the needs of children who are DHH related to intervention services, and included a tenet on serving children who are DHH Plus.

By the very nature of having a developmental concern, children enrolled within Part C programs (often referred to as Early Intervention [EI] services) are more likely to also have a hearing loss or vision loss. Causes of developmental delay (such as prematurity, congenital infections, and certain genetic syndromes) can confer risk for hearing loss and/or vision loss. Therefore it is important to recognize a co-existing hearing loss or vision impairment, as the combination of hearing loss and vision impairment can impact various domains of development. Hearing loss is commonly attributed to impacting language development while vision impairment is attributed to impacting motor development. EI providers can play a critical role in the identification of hearing and vision difficulties in young children, thus allowing access to needed services and improving child and family outcomes.

Children with both hearing loss and vision impairment (DeafBlind) have needs which further complicate intervention strategies. Children who are DeafBlind benefit from early specialized intervention services. With the term DeafBlind, it is important to recognize that it does not imply full deafness and full blindness, but rather includes children with any degree of hearing loss and any degree of vision impairment impacting educational needs. The Individuals with Disabilities Education Act (IDEA, 2004) specifically defines DeafBlindness as "concomitant hearing and visual

impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness” (U.S. Department of Education, IDEA Part 300/A/300.8D). Unfortunately, the diagnosis of vision or hearing loss, or the recognition that both are occurring, can be delayed due to a number of barriers (Liu, Farrell, MacNeil, Stone, & Barfield, 2008; Chapman, et al., 2011; Mark & Mark, 1999; Williams et al., 2013).

Census data collected by the National Center on DeafBlindness (NCDB, 2014) provides information about this population, and system gaps that may exist. DeafBlindness is a low incidence disability with great variability. In the U.S., there are about 10,000 children (ages birth to 21) with DeafBlindness (NCDB, 2014). For a sub-set of the data ($N = 9,384$) 89% of the children had one or more additional conditions. Among the children with data on age ($N = 9,384$), 6% were in the birth through two age range (Part C eligible), and 12% were within the three through five year age range (Part B eligible). This two-fold increase suggests improved recognition at older ages. There are also conditions which occur in early childhood (such as traumatic brain injury, post-natal infections) that can contribute to new cases of children who are DeafBlind entering the census at older ages. For a sub-set of children ($n = 8,822$) that had data regarding their IDEA Part B Reported Category, only 17% had an educational category of DeafBlind, while 35% were categorized as having multiple disabilities. It may be difficult, however, to interpret this information as processes vary in determination of educational category.

The data from the NCDB (2014) survey is concerning in that all children in the census in fact meet the educational definition of DeafBlind, but are not identified as such in educational settings. This may suggest that educational teams note that other issues are more prominent in guiding the educational planning. It is also concerning that the primary needs related to the dual sensory impairment may be under-recognized using U.S. Department of Education data. Although the census is limited by those who are reported and may have reporting biases (potentially more complex children reported), there is a high rate of issues noted in this population beyond merely hearing and vision.

The field of special education has specific training for educators related to DHH and VI, however, there are not specific training programs for children who are DeafBlind. The IN-home Sensory Impaired Training and Education (INSITE; Ski-Hi Institute) curriculum addresses many tenets helpful in serving children who are DeafBlind. State DeafBlind Projects are agencies that can provide this unique perspective for families and educators (see NCDB State Project List, n.d. for a list of the agencies in each state). Because there are best practices within the field of deaf education and the field of vision impairment, it can be helpful to understand best practices for each educational category separately and then bring the two fields together.

Children who are DeafBlind cannot be simply served by each area of expertise without integration of the learning needs and based on the specific skills and needs of the individual child. In this paper we will review the needs of those with DHH and VI separately and then review the needs when hearing loss and vision impairment co-occur. The goal of this paper is to discuss strategies to decrease the age of identification of hearing and vision impairments of children enrolled in Early Intervention, thus improving access to appropriate interventions to help children meet their potential.

This document includes sections on best practices as well as tools to consider in meaningfully supporting children who are DHH, children with VI, and children who are DeafBlind. We have also included decision trees to improve the identification of children who are DeafBlind to ensure EI providers consider these potential needs for children within Early Intervention services.

Principles Guiding Best Practice

- Recognition is the first step toward accessing specialized services.
- Integration of expertise within the context of services is essential for optimal outcomes for children.
- When transitioning children who are DHH, children with VI, and children who are DeafBlind to Part B programming, it is essential for the EI team to describe the impact of specialized services for the child’s needs which impact the educational setting.
- A strengths-based approach is essential.
- Family-to-Family Support is an important component of family-centered intervention.

There can be state-by-state variability in eligibility services for children who are DHH, children with VI, and for children who are DeafBlind. For the purpose of this document, we will include definitions from the United States Department of Education IDEA Regulations Part 300/A/300.8 (U.S. Department of Education IDEA, n.d) with the recognition that Part C providers should refer to state-specific guidelines.

Deaf or Hard of Hearing Best Practices

Definition

“Deafness” means a hearing impairment that is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification that adversely affects a child’s educational performance and “Hearing Impairment” means an impairment in hearing, whether permanent or fluctuating, that adversely affects a child’s educational performance but that is not included under the definition of deafness in this rule (IDEA, 2004).

Early Identification of Hearing Loss

- Early identification and intervention is associated with

improved language, social-emotional, and academic outcomes (Meinzen-Derr, Wiley, & Choo, 2011; Moeller, 2000; Kennedy et al. 2006; Vehaert, Willems, Van Kerschaver, & Desloovere, 2008; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998).

- Universal Newborn Hearing Screening programs do not identify all children with hearing loss (due to screening equipment thresholds and the possibility of late-onset or progressive hearing loss). Therefore, a high level of suspicion is important to identify hearing loss in all children (JCIH, 2007). Resources for accessing audiology services include:
 - o State services directories: many state Early Hearing Detection and Intervention (EHDI) programs have state-based pediatric audiology services directories that can be provided by the state EHDI coordinator (<http://infanthearing.org/status/cnhs.php>).
 - o National resource: Early Hearing Detection & Intervention - Pediatric Audiology Links to Services (EHDI-PALS; <http://www.ehdipals.org/>).
- Infants and children of any age or developmental abilities can have their hearing evaluated by audiologists knowledgeable in pediatric hearing.
- A functional listening evaluation is important and can guide intervention services (American Speech-Language Hearing Association [ASHA] Practice Policy, 2006).
- Children with an identified hearing loss should be reported to the state EHDI program at any time during their enrollment in Early Intervention (JCIH, 2007).
- Children who are identified with any type or degree of hearing loss should have their vision evaluated by an ophthalmologist knowledgeable in pediatrics (JCIH, 2007; Figure 3).

Early Intervention for Hearing Loss

Permanent hearing loss of any degree or type should be considered an established condition which automatically implies eligibility for Part C programming (JCIH, 2013), however there is state-to-state variability in eligibility determination. States should provide specialized services and should be included on the Individualized Family Service Plan (IFSP) of all children who are DHH (JCIH, 2013). Best practices for intervention for children who are DHH have been established by the Joint Committee on Infant Hearing (2013).

Vision Impairment Best Practices

Definition

“Visual impairment” including blindness means an impairment in vision that, even with correction, adversely affects a child’s educational performance. The term includes both partial sight and blindness (IDEA, 2004).

Early Identification of Vision Impairment

- Recognizing risk factors and visual behaviors in young

children can improve early identification of vision impairment (Taking a Look, n.d.; Figures 1 and 2).

- A child’s ophthalmological report will provide the foundation for understanding the child’s underlying vision concerns (Figure 3). Children with cortical vision impairment have a brain-based reason for their vision difficulties (with a normal eye exam). This sometimes requires a neurologist or ophthalmologist with specific expertise in this type of vision impairment to recognize the vision loss.
- A functional vision assessment is essential and can guide interventions to account for the child’s visual skills (Figure 3).
- Children with vision impairment should have an evaluation of hearing as a hearing loss would impact access to information and alter intervention strategies (Figure 3).

Early Intervention for Visual Impairment

- Vision loss should be considered an established condition that automatically implies eligibility for Part C programming, however there is state-to-state variability in eligibility determination.
- Specialized services are important to guide a child’s programming (U.S. Department of Education, n.d.).
- Although vision services (vision specialists, orientation, and mobility) can be limited in many areas, it is important to link children with service providers closest to the family’s home. School districts may also be aware of services for the family’s geographic location.

DeafBlind Best Practices

Definition

“DeafBlindness” means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness. A child does not have to be totally deaf and totally blind to receive this educational category (IDEA, 2004).

Early Identification of DeafBlindness

- Early identification of children who are DeafBlind can allow families and intervention specialists to develop appropriate team support for needs and access therapeutic specialists to address both developmental and educational needs (Figures 1 and 2).
- Reporting children who are DeafBlind to the State DeafBlind Centers for Education census (National Center on DeafBlindness, 2014) allows continued national and state support and assistance for children with this low incidence condition as well as provides a mechanism to initiate technical assistance and supports for the families and Early Intervention providers (Figure 3).

Figure 1. Risk Factors and Behaviors Suggesting A Possible Vision and/or Concerns in Young and School-Aged Children.

Child with Risk Factors for Vision Impairment:

Low birth weight (<3 pounds)
 Cerebral palsy
 Head Trauma
Hearing Loss
 Hydrocephalus/Shunt
 Meningitis/Encephalitis
 Congenital infections (such as CMV)
 Retinopathy of Prematurity
 Seizures
 Syndrome associated with vision concerns
 Delayed motor milestones

Child with Risk Factors for Hearing Loss Speech/Language Delay

Parental concern about hearing
 Family History of Hearing Loss
 Prematurity/NICU > 5 days
 Congenital Infection (such as CMV)
 Bacterial meningitis
 Craniofacial abnormalities
 Syndromes associated with hearing loss
 Ototoxic medications (gentamycin, lasix, chemotherapy)
 Head Trauma

Child has concerning vision behaviors:

Any time:

Does not look at faces, give eye contact
 Rubs eyes
 Squints/closes eyes/cries, turns away from bright lights
 Tilts/turns head to look

If not occurring by 3 months of age

Does not notice objects above or below the head
 Notices objects only on one side

If not occurring by 5-6 months of age

Doesn't visually follow moving objects
 Doesn't reach for objects
 Over or under-reaches for objects
 Seems unaware of self in mirror
 Seems unaware of distant objects

Older Ages

Covers or closes one eye when looking
 Does not look at pictures in books
 Holds books or objects close to eyes
 Stops and steps/crawls over changes in floor texture or color
 Trips over/bumps into things in path

Child has notable eye concerns:

Child has a known hearing loss
 Far-away look in eyes
 Cloudy or milky appearance of eyes
 Droopy eye lid(s) (ptosis)
 Jerky or wiggling eyes (nystagmus)
 Random eye movements
 Squinting, excessive blinking
 Unequal pupil size
 Watery, red, irritated eyes or eyelids

Child has concerning listening/speaking:

Does not look or attend to voices, sounds (all children with autism spectrum disorder should have a definitive hearing evaluation)

Asks "what" or "huh" a lot
 Asking for people to repeat what they have said

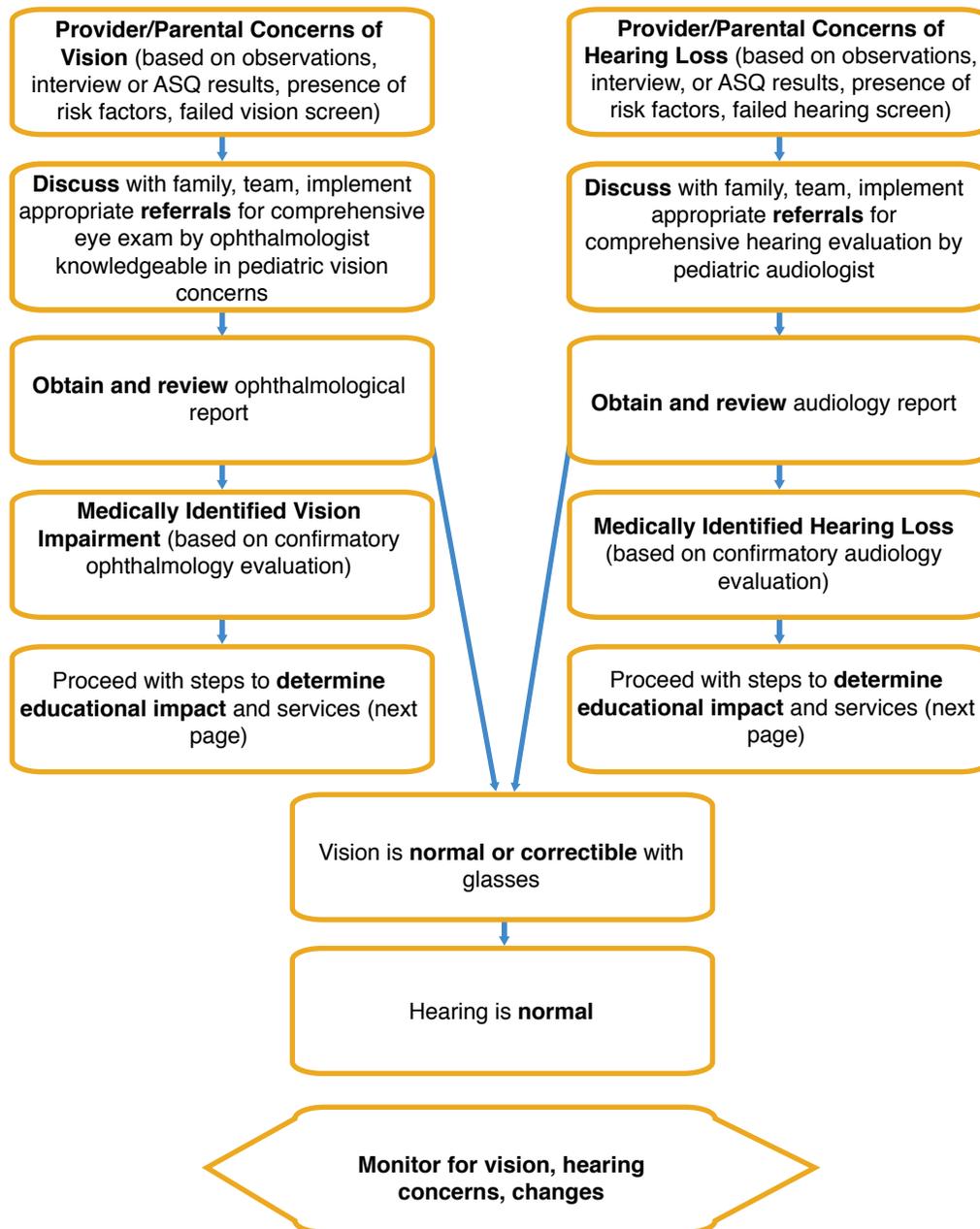
Talking too softly or too loudly
 Favoring one ear/turning one ear to a speaker or the TV
 Difficulty localizing sounds (i.e. calling the child from another room and the child not knowing where to look)
 Having to face the person talking to understand what is being said
 Speech delay
 Language delay
 Articulation problems which are not improving
 Concerns about behavioral compliance
 Distractibility

Child has notable physical concerns:

Child has a known vision impairment
 Frequent ear infections
 Child has a cleft lip/palate
 Child has skin tags or pits in the front of the ear
 Shape of ear is abnormal
 White patches of skin or white patches of hair
 Kidney problems
 Heart problems

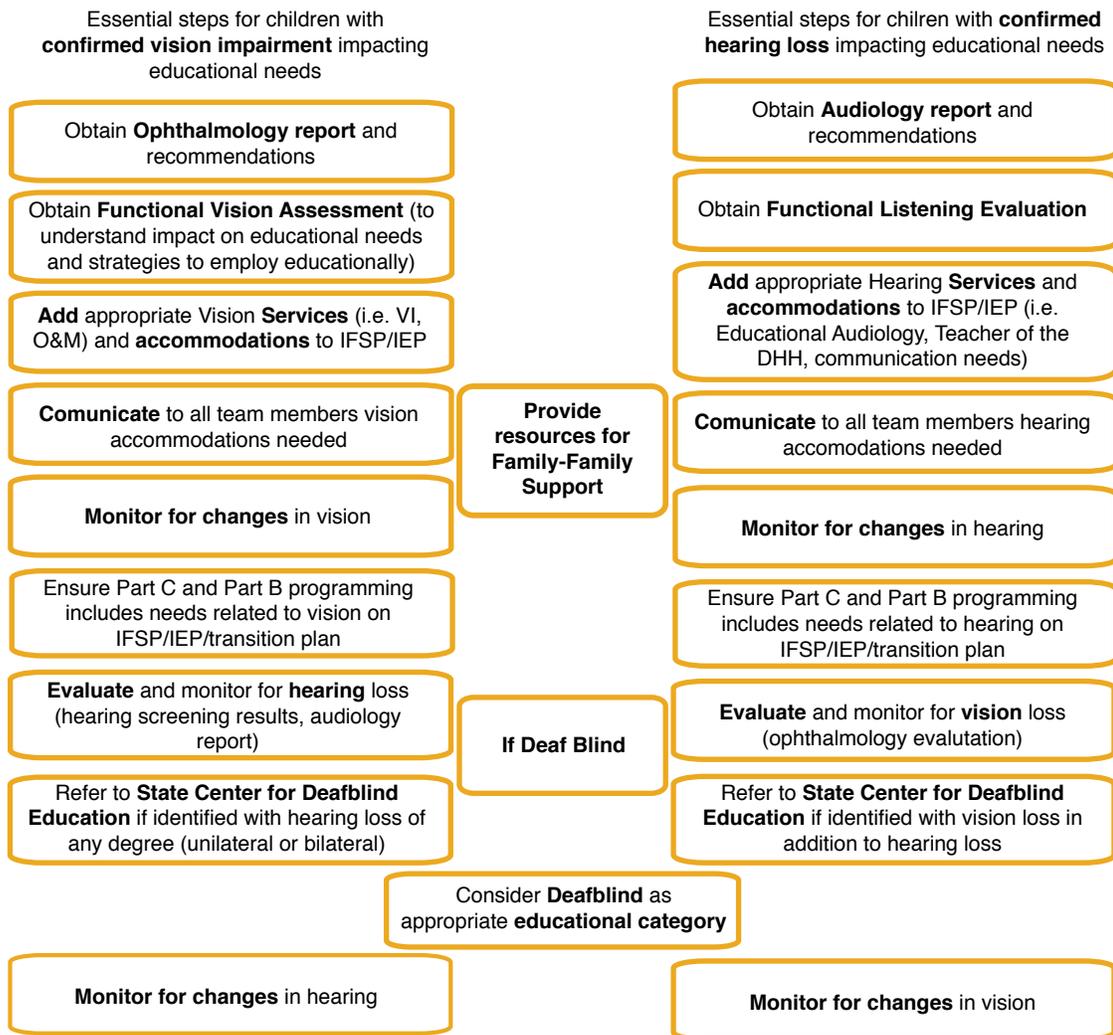
Note. CMV = cytomegalovirus; NICU = neonatal intensive care unit

Figure 2. Next Steps If A Child Has Concerns About Vision or Hearing



Note. ASQ = Ages and Stages Questionnaire©

Figure 3. What To Do For Children with Known Vision Impairment and/or Hearing Loss



Note. IEP = Individualized Education Plan; IFSP = Individualized Family Service Plan; O&M = orientation and mobility; VI = vision impairment

Table 1. Online Resources Relevant to Children who are DeafBlind

Resource	Description	URL
National Center on Deaf-Blindness	National technical assistance center funded by the federal Department of Education. NCDB includes several national initiatives, as well as a diverse library of resources and information for families and professionals. Resources also available in Spanish.	https://nationaldb.org
National Family Association for Deaf-Blind	National association with large network of families focusing on Deaf-Blind issues. Provides opportunities to connect with other families, and well as online learning, resources, and shared stories.	http://nfadb.org/
Center for Parent Information and Resources, Deaf-Blindness	Basic information, and a collection of resources including state specific for deaf-blind children	http://www.parentcenterhub.org/repository/deafblindness/
iCanConnect	Campaign by the National Deaf-Blind Equipment Distribution Program. Provides technology, training, and resources to individuals who qualify.	http://www.icanconnect.org/
Ski-HI Institute IN-home Sensory Impaired Training and Education	Program offering in-home support, as well as a resource manual for families with infants, toddlers and pre-schoolers, age birth to five, with sensory impairments and additional disabilities.	http://skihi.org/INSITE.html
Perkins School for the Blind	School for the blind with expertise in serving children who are DeafBlind, library of webinars and resources.	http://www.perkins.org/
American Foundation for the Blind	Foundation committed to ensuring individuals with vision impairments have equal access and opportunities. Website includes resources, e-learning courses, an online parent community, and advocacy efforts.	http://www.afb.org
Hands and Voices	Parent-driven support organization for families of children with hearing loss, providing unbiased support and information regarding all methods of communication.	www.handsandvoices.org/
Early Hearing Detection & Intervention - Pediatric Audiology Links to Services (EHDI-PALS)	Information, resources, and services directory for finding audiology services for children with hearing loss.	http://ehdipals.org/
Taking a Look Checklist: A First Step in Vision Assessment for Ohio's Infants and Toddlers	A checklist for parents and professionals to help identify children who need referral for possible vision problems.	http://www.helpmegrow.ohio.gov/~media/HelpMeGrow/ASSETS/Files/Professionals%20Gallery/HMG%20Home%20Visiting/HV%20Screening%20Tools/Taking%20a%20look.pdf

Early Intervention for DeafBlindness

- DeafBlindness should be considered an established condition which automatically implies eligibility for Part C programming.
- The integration of specialized hearing and vision services are important to guide a child's programming.
- Accessing technical assistance from the state Deafblind Centers for Education (NCDB state project list, n.d.) can help facilitate a team approach to a child's needs.
- When transitioning to Part B programming children who are DHH, children with VI, and children who are DeafBlind, it is essential for the EI team to describe the impact of specialized services for the child's needs which impact the educational setting (U.S. Department of Education, n.d.).

Resources

Figures 1–3 provide a structure by which EI providers can ensure that children entering Part C services systematically address vision and hearing needs. They provide easy-to-use tools to improve the identification and intervention services for children with hearing and vision needs. By systematically using these tools for children entering Part C systems, EI providers may be more inclined to consider the vision and hearing needs of children served.

Table 1 provides online resources for further information guiding practices for identified children.

Conclusion

Children enrolled in Early Intervention Services benefit from early identification of hearing and vision needs. Hearing and vision impacts child development and identified hearing loss and/or vision impairment requires alterations in how intervention is approached. Building strategies to systematically identify needs and access broader team members to meet a child's specific needs will improve our intervention for children who are DHH, children with VI, and children with DeafBlindness.

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