

Appendix 4

Areas to Address with All Families

Whose Infants/Toddlers are Identified with Sensory Disabilities (Hearing Loss and/or Visual Impairment)

A Checklist and Guide for Family Resources Coordinators and Early Intervention Teams

This document serves as a checklist to be used by the FRC and IFSP team when a child diagnosed with sensory disability is referred for early intervention (EI) services. Our goal is to help guide your team as you work together with the family to develop the first IFSP, and beyond. Washington ESIT strives to follow best practices and stay current with the latest research in the field. Each family should have an early childhood specialist in deaf/hard of hearing or deaf-blindness, or a consulting Teacher of the Visually Impaired (TVI), to help guide them through information they receive from the audiologist and/or ophthalmologist. Parents need to receive timely and accurate information—*as well as time to get to know their child*—so they can make healthy and informed decisions regarding early supports.

Below is an overview of steps to follow with all families when a child with visual impairment and/or hearing loss is referred for early intervention supports. Each is elaborated on the pages that follow.

Deaf/Hard of Hearing		Blind/Visually Impaired	
Area	Comments/Contact Info	Area	Comments/Contact Info
1. AUDIOLOGY RECORDS (and relevant medical records)		1. OPHTHALMOLOGY RECORDS (and relevant medical records)	
Gather the child’s audiology reports, as well as relevant medical records.	Contact: Audiologist, hospital	Gather the child’s medical reports, including any eye or neurology reports.	Contact: Hospital, ophthalmologist, neurologist (if appropriate)
<p>The audiology reports and medical records contain important information needed for developing an appropriate IFSP. Reports may include: audiogram, tympanogram, and audiologist’s summary report, diagnostic testing results, family history, and documentation pertaining to additional medical conditions and/or syndromes.</p> <p><i>TIP: Find out who the child’s pediatric audiologist is and his/her hospital or clinic affiliation. The audiologist will provide information to parents about appropriate amplification to match the needs of the child’s hearing levels.</i></p>		<p>Medical reports contain important information needed for developing an appropriate IFSP. Reports may include medical reports from the pre-, peri-, and post-natal period, as well as an ophthalmologist’s summary report, family history, and information pertaining to additional medical conditions and/or syndromes.</p> <p><i>TIP: Find out who the child’s pediatric ophthalmologist and/or optometrist are and his/her hospital or clinic affiliation. The ophthalmologist and optometrist will provide information to parents about child’s needs for glasses, medical treatments, etc.</i></p>	

2. REFERRALS TO RESOURCES: Deaf/Hard of Hearing (DHH)	2. REFERRALS TO RESOURCES: Blind/Visually Impaired (BVI)
Kris Rydecki Ching 360-418-4292 kris.ching@cdhl.wa.gov	DeEte Snyder 360-947-3305 deette.snyder@wssb.wa.gov
<i>Early support for infants/toddlers with sensory disabilities must begin as soon as possible following identification.</i>	
<i>Supports for children who are deaf/hard of hearing and blind/visually impaired are included among those listed under IDEA, Part C services, and could include the following. Also see Appendix 3. Self-Evaluation Tool, for a more complete listing of possible services.</i>	
For infants/toddlers who are deaf/hard of hearing:	For infants/toddlers who are blind/visually impaired:
<ul style="list-style-type: none"> • Specialized services from a Teacher of the Deaf (TOD); • Supports for families wishing to gain skills in a specific communication approach, e.g., Listening and Spoken Language (LSL), ASL-English Bilingual Education, or simultaneous use of the family's spoken home language and visual communication/Signing Exact English (SEE); • Supports for families wishing to connect with other families locally, regionally, and statewide; • Connections with adults who are DHH or deaf-blind. 	<ul style="list-style-type: none"> • Specialized services from a Teacher of the Visually Impaired (TVI) or Certified Orientation & Mobility Specialist (COMS); • Supports for families wishing to connect with other families locally, regionally, and statewide; • Connections with adults who are BVI or deaf-blind.
<i>Families decide on their priorities. We help locate specialty services as needed, whether they are provided in person or via distance technology.</i>	
Here's how CDHL can help:	Here's how WSSB can help:
<ul style="list-style-type: none"> • Ensure <u>all avenues of services are explored</u> to support the development of the child who is deaf/hard of hearing. • Identify <u>appropriate assessment tools</u> for young children who are DHH or DB to determine current levels and monitor progress. • <u>Explain technologies</u> (e.g., hearing aids, cochlear implants, and other listening and visual technologies) in understandable language. • Guide family's learning of strategies to <u>promote communication</u> in children who are deaf/hard of hearing. • <u>Locate local, regional, and state resources</u> to support ongoing services to the family and the entire EI team. 	<ul style="list-style-type: none"> • Ensure <u>all avenues of services are explored</u> to support the development of the child who is BVI, e.g., access to TVI, COMS. • Identify <u>appropriate assessment tools</u> for young children who are BVI or DB to determine current levels and monitor progress. • <u>Explain, in understandable language</u>, vision conditions and recommended treatment options (e.g., patching, glasses). • Guide family's learning of strategies to <u>promote concept development</u> in children with blindness or visual impairment. • <u>Locate local, regional, and state resources</u> to support ongoing services to the family and the entire EI team.
Other Resources for Infants/Toddlers who are Deaf/Hard of Hearing:	Other Resources for Infants/Toddlers who are Blind/Visually Impaired:

<p>Regional Service Centers of the Deaf and Hard of Hearing located around the state offer education and training, among other services. To learn more: http://www.dshs.wa.gov/alt%20sa/odhh/regional-service-centers</p>	<p>Department of Services for the Blind/Child and Family Program. Their counselors offer education and parent advocacy training to families in the home. To learn more: http://www.dsb.wa.gov/services/childrenandfamilies.shtm</p>
<p><i>REMEMBER: As with all children, early supports for infants/toddlers with sensory disabilities are most effective when delivered in the child’s natural environment—wherever the child spends time, including the home, childcare center, recreational settings, homes of relatives.</i></p>	

<p>2.b Are there concerns about <u>child’s vision</u>, in addition to hearing loss?</p>	<p>2.b Are there concerns about <u>child’s hearing</u>, in addition to visual impairment?</p>
<p>Contact Katie Humes WSDS/Deaf-Blind Project: 800-572-7000 (or) khumes@psed.org (or) wds@psed.org www.wsdsonline.org</p> <p>Washington Sensory Disabilities Services is a statewide project that provides information, training, technical assistance and resources to families and educators regarding individuals who are deaf/hard of hearing, blind/visually impaired, or have a combined hearing and vision loss (deaf-blind). Special supports, including a lending library, are available for families and service providers of infants/toddlers diagnosed with, or at risk for, a combined hearing loss and visual impairment. These infants/toddlers, their families, and service providers are eligible for on-site and distance consultation and training.</p> <p>Any birth-to-three year old who is diagnosed as deaf/hard of hearing should be considered “at risk” for visual impairment, including cortical visual impairment. Likewise, infants and toddlers diagnosed as blind/visually impaired are “at risk” for hearing loss, including auditory processing problems. This is especially true for babies who:</p> <ul style="list-style-type: none"> • Were born prematurely and had a low birth weight • Had complications at birth, including elevated bilirubin, seizures, or were on oxygen for an extended period • Have a diagnosis of cerebral palsy • Are diagnosed with a syndrome such as CHARGE, Cornelia de Lange, Dandy Walker, Down, Marshall, or Usher syndrome <p>Please contact WSDS/Deaf-Blind Project for more information.</p>	

<p>2.c Parent-to-Parent Support (DHH/DB)</p>	<p>2.c Parent-to-Parent Support (BVI/DB)</p>
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<p><i>Parent-to-Parent Support:</i> Contact Guide-By-Your-Side (GBYS) to request a visit or phone conversation with an experienced parent.</p>	<p>Christine Griffin 425-268-7087 gbys@wahandsandvoices.org www.wahandsandvoices.org</p>	<p><i>Parent-to-Parent Support:</i></p> <ul style="list-style-type: none"> <p>National Association for Parents of the Visually Impaired (NAPVI): www.napvi.org</p> <p>“We believe that if parents obtain the support and information they need they will become the best advocates for their children. When parents join together with common concerns, they have a powerful voice that can make significant changes and improvements for the services and education of ALL children with visual impairments.”</p> <p>Lighthouse Guild also offers a National Tele-Support Network that can connect you with parents of children with the same eye condition as your child. You can share resources, experiences, strength and hope. To register call 800-562-6265 or email parentgroups@lighthouseguild.org</p> <p>American Foundation for the Blind (AFB): Family Connect http://www.familyconnect.org/parentsitewhome.aspx</p> <p>“On Family Connect you'll find videos, personal stories, events, news, and an online community that can offer tips and support from other parents of children who are blind or visually impaired.”</p> <p>National Federation of the Blind (NFB): www.nfb.org</p> <p>“The National Federation of the Blind knows that blindness is not the characteristic that defines you or your future. Every day we raise the expectations of blind people, because low expectations create obstacles between blind people and our dreams. You can live the life you want; blindness is not what holds you back.”</p>
<p>Trained Parent Guides provide unbiased emotional support and information to families with deaf/hard of hearing children. GBYS is a program of “Hands and Voices,” a national parent organization with a Washington State chapter.</p> <p>Here’s how Guide By Your Side can help:</p> <ul style="list-style-type: none"> Family members can get support and learn from experienced parents. Learn about all communication options and resources. Link up with other families and family events. Get tools to navigate challenging systems. <p>Hands & Voices National Organization http://www.handsandvoices.org/index.htm</p> <p>Hands & Voices Washington State Chapter http://www.wahandsandvoices.org/</p>		

3. AREAS OF UNDERSTANDING FOR ALL FAMILIES	
Deaf/Hard of Hearing	Blind/Visually Impaired
<p><i>Parent Notebook for Families of Children Who are Deaf or Hard of Hearing</i></p> <p>At the time their child’s hearing loss is diagnosed, families should receive a copy of: <i>Parent Notebook for Families of Children Who are Deaf or Hard of Hearing</i>¹. This publication was developed by the Washington State Department of Health’s Early Hearing-loss Detection, Diagnosis, and Intervention (EHDDI) Program, with sections adapted from publications of other state EHDI programs.</p> <p>This comprehensive guide for families contains sections titled: Getting Started, Your Child’s Hearing, Your Child’s Team, Tests, Communication Options, Advocacy, Resources, Staying Organized. These sections will be referenced as each “Area” is described below.</p>	<p>AREA 1. The family/caregivers will be able to describe their child’s vision diagnosis and their child’s level of functional vision, become comfortable with appropriate low vision devices/visual aids, and understand the basic impact of vision loss on all areas of development.</p> <ul style="list-style-type: none"> • Ophthalmology and other medical records, as well as the TVI’s Functional Vision Assessment (FVA) report, will provide information about the child’s visual condition and use of functional vision. • The TVI and O&M specialist can provide support and further information regarding vision, impact of vision loss on all areas of development, especially concept development, pre-literacy, socialization, and independent and safe movement through environment. • The family will become familiar with the roles and responsibilities of the various vision professionals in the child’s life such as medical professionals (ophthalmologists and optometrists) and educational professionals (TVI, O&M specialist, and brailist). The educational vision professional will assist families with implementation of the recommendations from medical professionals such as use of refractive correction, magnification devices, and patching protocols.
<p>AREA 1. The family/caregivers will be able to describe their child’s hearing levels and understand the potential impact on child development and family communication.</p> <p>See <i>Parent Notebook</i> sections: Your Child’s Hearing; Tests.</p> <ul style="list-style-type: none"> • Audiology reports and observations of how a child uses his hearing or listening skills will provide information about the child’s hearing levels with and without amplification. • An early childhood D/HH specialist can provide support and information regarding hearing and impacts on language, cognitive, and social development, as well as family communication. 	

¹ To order a copy of the *Parent Notebook*, contact the EHDDI program at: 1-888-923-4334. To request this guide in other formats, please call: 1-800-525-0127. Or, go to: http://www.doh.wa.gov/Portals/1/Documents/Pubs/344-017_EHDDIResourceGuideEng.pdf and download a copy.

Deaf/Hard of Hearing	Blind/Visually Impaired
<p>AREA 2. The family/caregivers will gain information about early infant/caregiver communication, bonding and attachment, and how language development is supported with joint attention, following the child’s lead and interest, and creating an optimal communicating environment.</p> <p><i>Parent Notebook</i> sections: Getting Started; Communication Options.</p> <ul style="list-style-type: none"> • An early childhood Teacher of the Deaf (TOD) and other D/HH specialists will coach the caregivers on effective parent-child interaction strategies that promote early language and communication development. • The child and family’s IFSP will include outcomes to encourage early language acquisition and communication skills during daily routines and activities. • Members of the IFSP team who are not trained in early childhood deaf/hard of hearing education will collaborate with TOD to learn about early language development for children with hearing loss and become knowledgeable about potential impacts of sensory deprivation. 	<p>AREA 2. The family/caregivers understand early infant/care-giver communication (verbal and non-verbal), bonding, and attachment, and how social/emotional skills can be visually dependent through observation, responses, and reciprocity in order to establish a meaningful relationship with their child.</p> <ul style="list-style-type: none"> • A TVI will coach the caregivers on effective parent-child interaction strategies when child lacks the visual ability to read necessary non-verbal cues and may not respond as expected. • Information regarding social and communication (verbal and non-verbal) will be provided over time and according to developmental stages of the child during daily routines and play activities. • Information will be shared with family through an informed infant mental health approach, with focus of visual dependency on social emotional skills.
<p>AREA 3. The family/caregivers will understand and feel comfortable with their child’s amplification system (e.g., hearing aids, ear molds, batteries) and possible future amplification options (e.g., cochlear implant/s, FM systems), as appropriate.</p> <p><i>Parent Notebook</i> sections: Communication Options.</p> <ul style="list-style-type: none"> • Many deaf and hard of hearing children are fitted with hearing aids (HAs) through an audiologist at a clinic or hospital shortly after being identified as deaf or hard of hearing. <p style="text-align: right;">(continued)</p>	<p>AREA 3. The family will be introduced to information regarding their child’s unique learning through the use of alternative senses and appreciation of multiple sensory capabilities, including the child’s use of touch, hearing, smell, and taste to gain access to the environment.</p> <ul style="list-style-type: none"> • TVI and other team members will create accessible learning environments for the child through adaptations to environment, toys, and other learning materials according to child’s use of all his/her senses. <p style="text-align: right;">(continued)</p>

Deaf/Hard of Hearing	Blind/Visually Impaired
<ul style="list-style-type: none"> Parents often need time to process new information and vocabulary from the audiologist, as well as how to care for and check their child’s amplification system. Young children also need support in using HAs, as the auditory stimulation will be a new experience for their brain. Also, HAs are very small and may be pulled out of ears to mouth and play with. A team of medical professionals will determine if a child is a good candidate for a cochlear implant (CI). Parents will need to work closely with the CI team and IFSP team to support development of auditory pathways and language. <p><i>Tip: Communication modality is not chosen based on the hearing technology a child uses.</i></p>	<ul style="list-style-type: none"> The child and family’s IFSP will include outcomes to encourage compensatory skills to accommodate for the visual impairment and use of other senses during daily activities. Members of IFSP team who are not trained in visual impairment will collaborate with TVI to learn about the sensory modalities of the child and become knowledgeable about the potential differences in concept development of individual children.
<p>AREA 4. The family/caregivers will increase their knowledge of different communication modalities and strategies to provide their child with access to communication and language.</p> <p><i>Parent Notebook</i> sections: Communication Options.</p> <ul style="list-style-type: none"> Families need accessible, balanced, and up-to-date information to support their understanding of what it means to be a parent of a child who is deaf or hard of hearing. The better the parents’ understanding the more positively they will respond, accept, and effectively advocate for their child. As families get to know their child and explore communication options, the most important consideration is that their child is able to access communication and language—whether through a visual modality (i.e., gestures and sign language), an auditory modality (i.e., via hearing aids or cochlear implants), or both. <p><i>Tip: Parents who choose to use amplification may also use sign language along with spoken language. Sign language stimulates early brain development, especially for language acquisition. It can also be used as a bridge to spoken language.</i></p>	<p>AREA 4. The family will gain knowledge about the pre-literacy needs of children with vision loss with attention to tactile learning for braille readiness, interactive shared reading experiences and hands on participation in learning activities for enhanced concept development.</p> <ul style="list-style-type: none"> Parents and caregivers will become familiar and comfortable with alternative reading mediums such as braille and tactile representations of pictures. Parents will demonstrate shared reading experiences with their child with vision loss, as these activities are critical for language and literacy development. Parents will learn non-visual (tactile and interactive) methods to engage child in activity such as through the use of book boxes, experience, or child-routine based stories. TVI and EI program staff will share resources with parents for the purposes of obtaining braille books and other toys/materials to enhance concept development through interaction and play with family members.

Deaf/Hard of Hearing	Blind/Visually Impaired
<p>AREA 5. The family/caregivers will learn to observe and report their child’s responses, and partner with their IFSP team in monitoring their child’s growth of communication skills, both receptive and expressive.</p> <p><i>Parent Notebook</i> sections: Your Child’s Team; Advocacy; Staying Organized.</p> <ul style="list-style-type: none"> • Provide specific information to the parents describing the elements of the communication development monitoring process at each IFSP review. • The family will learn how to observe their child’s communication behaviors in various settings, and become familiar with the communication monitoring checklists. • The ultimate purpose of monitoring the child’s communication development is to determine if the expected 6 months progress in communication development has been demonstrated. If not, the need for adjustments and new strategies can be discussed. <p><i>TIP: The Statewide Center on Childhood Deafness & Hearing Loss (CDHL) can provide evaluation services or support with assessments.</i></p>	<p>AREA 5. The family will gain understanding and recognize their child’s individual motor patterns, both gross and fine motor skills, and be able to encourage their child’s self-directed, safe and independent mobility.</p> <ul style="list-style-type: none"> • Parents will become familiar and confident with independent and safe traveling skills of their child with the help of the OMS coaching the family on mobility skills. • OMS and EI program staff will share resources with the family on materials and/or equipment needed for independent and safe mobility skills. • The IFSP team will assist family to understand and encourage their child’s functional use of hands skills for daily living skills as well as pre-literacy activities. <p>AREA 6. The family will receive support from the EI program and IFSP team focused on experience and routine-based opportunities for children to practice daily living skills and concept development through hands-on learning.</p> <ul style="list-style-type: none"> • The EI team will employ specific techniques to support the development of daily living skills, such as hygiene, toileting, eating, dressing, organizational skills, and sleeping patterns/habits, in order to increase their child’s independence and reduce the risk of learned helplessness due to lack of vision related to incidental learning. • The family will be encouraged to participate in family recreational activities that support creativity and enjoyment of both their child with BVI and their family as a unit.

Deaf/Hard of Hearing	Blind/Visually Impaired
<p><i>The family will be able to access family supports that include both emotional and informational support, including local, state, and national resources for parenting a child who is deaf/hard of hearing, blind/visually impaired, or deaf-blind.</i></p>	
<p>We strongly support the philosophy that families need time—</p> <ul style="list-style-type: none"> • to process feelings and information about their child’s hearing loss (and possibly other diagnoses); • to talk with other families, as well as with adults who are Deaf or Hard of Hearing; • to bond and get to know their child. <p>That doesn’t mean they can’t start communicating with their child immediately! The early childhood TOD, and other DHH specialists will work with the family and EI team to ensure that all areas above are addressed, while reinforcing parent-child communication and modeling new strategies.</p> <ul style="list-style-type: none"> • The family will be introduced to state agencies that provide services for individuals who are DHH across the lifespan including, but not limited to, Washington School for the Deaf (WSD), Washington Sensory Disabilities Services (WSDS), and Office of the Deaf and Hard of Hearing Services (ODHH). • The family will have access to information available through the internet, e.g., websites, online parent support groups and blogs. • The family will gain resources on national parent groups such as Hands & Voices and its Washington chapter, and the National Family Association for Deaf-Blind (NFADB), where families can meet and connect with other families or individuals who are deaf/hard of hearing or deaf-blind. 	<p>We strongly support the philosophy that families need time—</p> <ul style="list-style-type: none"> • to process feelings and information about their child’s visual impairment (and possibly other diagnoses); • to talk with other families, as well as with adults who are Blind or Visually Impaired; • to bond and get to know their child. <p>That doesn’t mean they can’t start interacting with their child immediately in ways to promote development! The early childhood TVI will work with the family and EI team to ensure that all areas above are addressed, while at the same time reinforcing parent-child communication and modeling new strategies.</p> <ul style="list-style-type: none"> • The family will be introduced to state agencies that provide services for individuals with BVI across the lifespan including, but not limited to, Washington State School for the Blind (WSSB), Washington Sensory Disabilities Services (WSDS), Department of Services for the Blind (DSB), and Washington Talking Book & Braille Library (WTBBL). • The family will have access to information available through the internet, e.g., websites, online parent support groups and blogs. • The family will gain resources on national parent groups such as the National Association for Parents of the Visually Impaired (NAPVI) and also consumer groups such as the National Federation of the Blind (NFB) and the American Foundation for the Blind (AFB). Each of these groups may also have state and local chapters where families can meet and connect with other families or individuals with BVI.