# **Early Support for Infants & Toddlers**





Kids' Potential, Our Purpose

# Practice Guide: Infants and Toddlers with Sensory Disabilities (Deaf/Hard of Hearing, Blind/Visually Impaired, or Deaf-Blind)

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# **Early Support for Infants & Toddlers**





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# **Background**

With the advent of universal newborn hearing screening, with 96% of all newborns screened, numbers of infants in Washington State identified with hearing loss have skyrocketed. Early Support for Infants & Toddlers (ESIT), in collaboration with the Washington State Center for Childhood Deafness and Hearing Loss (CDHL), the Department of Health (Screening and Genetics) Early Hearing-loss Detection, Diagnosis, and Intervention program (EHDDI), the Office of Deaf & Hard of Hearing Services (ODHH), and Washington Sensory Disabilities Services (WSDS), has worked to develop new systems and services to support families of birth-to-three year olds who are identified as **deaf or hard of hearing**, regardless of where they might live in the state. Our charge is to ensure that Washington meets the national EHDDI goal: *infants are enrolled in early intervention services by six months of age when a hearing loss is found*.

Concurrently, ESIT collaborated with representatives of Washington State School for the Blind (WSSB), Department of Services for the Blind (DSB), the Office of Superintendent of Public Instruction (OSPI), WSDS, and Washington Talking Book and Braille Library (WTBBL) to develop new systems and services to support families of birth-to-three year olds who are identified as **blind or visually impaired (BVI).** The goal is to ensure that infants who are BVI are identified and enrolled in early intervention services within four months following diagnosis of a visual condition that may be associated with visual impairment. In particular, this work group aims to improve access to appropriate specialty services, i.e., early supports provided and guided by Teachers of the Visually Impaired (TVIs) and Certified Orientation and Mobility Specialists (COMS), who function as integral partners on the early intervention team.

Via representation of the WSDS Deaf-Blind Project in the above work, we also have addressed the needs of infants and toddlers with **combined hearing loss and visual impairment (DB)**, who present special challenges in our early identification efforts. *The goal is to ensure that infants and toddlers with dual sensory loss are identified during the early intervention years, prior to transition to preschool.* 

As of 2016, this work has resulted in new processes for data sharing among agencies to increase speed of referrals to early intervention, collecting demographic data on infants and toddlers with sensory disabilities, and increasing services available to local communities to better

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support these families. In particular, this group has focused on increasing supports to rural and remote communities that often have less access to the specialized services these young children need in order to develop at a rate commensurate with their peers.

# **Eligibility Criteria for Early Intervention Services**

Before introducing the parts of this Practice Guide, a review of eligibility criteria for infants and toddlers highlights an important fact: any child with a diagnosed visual impairment and/or hearing loss as described below is eligible for early intervention services in Washington State. See the ESIT Developing WAC: Washington Administrative Code (January 2014 draft), WAC 179-300-01010 (pp. 9-11). Eligibility criteria are presented in Figure 1 as written in the 2014 WAC.

# Figure 1.

# **Eligibility Criteria for Sensory Disabilities**

(2) In the case of hearing and vision, the criteria listed within hearing impairment and vision impairment in subsections (i) and (j) of this section apply.

# **Eligibility Criteria for Visual Impairment**

Visual Impairment-infants and toddlers with visual impairment/blindness are:

- i) Those children who have a visual impairment that adversely affects the child's development, even with correction. Eligibility shall be dependent on the documentation of a visual impairment, including one or more of the following conditions:
- ii) Legal blindness or visual handicap, as they are customarily defined, either in terms of qualifying reduction in visual acuity and/or a qualified reduction in visual fields.
- iii) A visual impairment that is progressive in nature and can be expected to lead to blindness within a reasonable period of time.
- iv) If a visual acuity or field cannot be determined:
- A) The qualified personnel must identify a diagnosis or medical history that indicates a high probability of visual loss that may adversely affect the child's development
- B) A functional vision evaluation by a qualified professional is necessary to determine eligibility.

# **Eligibility Criteria for Deafness/Hearing Loss**

Deafness/hearing loss that adversely affects a child's development is:

- (i) Unilateral sensorineural hearing loss and/or permanent conductive hearing loss of forty-five dB or greater.
- (ii) Bilateral sensorineural hearing loss and/or permanent conductive hearing loss that includes:
- (A) Hearing loss of twenty dB or greater, better ear average of the frequencies five hundred, one thousand, and two thousand Hz;
- (B) High frequency loss greater than twenty-five dB at two or more consecutive frequencies or average of three frequencies between two thousand and six thousand Hz, in the better ear;
- (C) Low frequency hearing loss greater than twenty-five dB at two hundred and fifty and five hundred Hz, in the better ear;
- (D) Thresholds greater than twenty-five dB on auditory brainstem response threshold testing in the better ear; or
  - (iii) A six-month history of fluctuating conductive hearing loss or chronic middle ear effusion/infection of three months, unresolved past initial evaluation; or [sic]

# Eligibility Criteria for Deaf-Blindness

Infants and toddlers who meet the above eligibility criteria for <u>both</u> hearing loss and visual impairment will also qualify for supports from the WSDS Deaf-Blind Project. *It is important to note, however, that children who are eligible under the following criteria also are at high risk for dual sensory loss. Special attention should be paid to ensure that both hearing and vision have been appropriately screened.* 

- (4) A child is eligible if he or she has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay. Such conditions include, but are not limited to:
  - (a) Chromosomal abnormalities;
  - (b) Genetic or congenital disorders;
  - (c) Sensory Impairments [sic];
  - (d) Inborn errors of metabolism;
  - (e) Disorders reflecting disturbance of the development of the nervous system;
  - (f) Congenital infections. . .
  - (h) Disorders secondary to exposure to toxic substances, including fetal alcohol syndrome.

A child who meets one or more of the eligibility criteria above for hearing loss and/or visual impairment needs no additional evaluation to determine eligibility for early intervention services. The sensory loss alone creates the eligibility. Refer to the ESIT publication titled *Practice Guide: Evaluation, Assessment, Eligibility and the Initial IFSP* (October 2013). Children with sensory disabilities would be considered eligible under Path 1: Medical Diagnosis.

This Practice Guide will introduce the following:

- 1. Pathway to Services Flowcharts (for BVI and DHH) (Appendix 1)
- Registry Form for B-3 BVI and DHH (Appendix 2)
   (and) American Printing House (APH) Federal Quota (BVI) (Appendix 2.b)
- 3. Self-Evaluation Tool for Early Intervention Programs on Services to Birth-to-Three Year Olds with Sensory Disabilities (Appendix 3)
- 4. Areas to Address with All Families Whose Infants/Toddlers are Identified as Blind or Visually Impaired, Deaf or Hard of Hearing, or Deaf-Blind (Appendix 4)

Following are brief descriptions of each section of this Practice Guide.

# 1. Pathway to Services Flowcharts (for BVI and DHH)

Because of (a) differences in how vision and hearing concerns are identified in the first months of life, and (b) federal legislation mandating newborn hearing screening, the pathway to early intervention services is different for infants with blindness/visual impairment and those who are deaf/hard of hearing.

A. Infants who are Deaf/Hard of Hearing

The Department of Health EHDDI program created a surveillance tracking and monitoring system and trained hospital birthing center staff and midwives to conduct universal newborn hearing screening. Refer to **Appendix 1.a. Pathway to Services: DHH**, which depicts steps between newborn hearing screening and entry into early intervention, as you follow the description below.

When a child is diagnosed with a hearing loss, the audiologist refers the family directly to the Local Lead Agency (LLA) via an EHDDI data-sharing link with the ESIT database. The Family Resources Coordinator (FRC) obtains parental permission to complete a **Registry Form** (see p. 5). If needed, a conversation between the CDHL birth-to-preschool Outreach Director and the FRC determines local/regional supports for the family, and also ensures that a certified or licensed professional in early childhood deaf education assists in developing the family's Individualized Family Services Plan (IFSP).

# B. Infants who are Blind/Visually Impaired

Refer to **Appendix 1.b. Pathway to Services: BVI**, which depicts steps between birth and entry into early intervention, as you follow the description below.

When a child is diagnosed with a visual impairment and the family referred to its Local Lead Agency, the FRC obtains parental permission to complete a **Registry Form** (see p. 5). If needed, a conversation between WSSB's State Birth-to-Three Coordinator and the FRC can determine local resources for supports for the family, and also ensures that a person with expertise in early childhood visual impairment assists in developing the family's Individualized Family Services Plan (IFSP).

# C. Infants who are Deaf-blind (Combined Vision and Hearing Loss)

Infants and toddlers with diagnosed visual impairment *and* hearing loss, or with a medical diagnosis that puts them at risk for both (e.g., prematurity, cerebral palsy, CHARGE syndrome), are eligible for consultative services from the WSDS Deaf-Blind Project. WSDS staff will help determine next steps for in-person and distance services. These are usually delivered in coordination with the Early Intervention team. Calls/emails are welcomed from both service providers and family members.

The FRC (or other IFSP team member) ensures that a Registry Form (p. 5) is completed and submitted for each child diagnosed with a hearing loss, visual impairment, or combined hearing loss and visual impairment (deaf-blindness).

Because optimal outcomes are best achieved with appropriate specialized services for families, families must have access to well-qualified staff who have certification, specialized training and experience in supporting infants/toddlers who are DHH, BVI, or DB. If the LLA and/or early intervention (EI) agency has a well-developed plan for providing such supports to these unique populations, the team proceeds with developing the IFSP. (See **Self-Evaluation Tools for Early Intervention Agencies** on p. 6.)

<u>DHH.</u> If the LLA/EI agency does not have a certified teacher of the deaf (TOD) within the community to support families of young children with hearing loss, then the FRC, in cooperation with CDHL, will identify potential early intervention partners both within and outside of the local community. In addition to local birth-to-three programs, these partners might include individuals working in a specialty program for infants/toddlers who are DHH, a nearby regional service center for the deaf and hard of hearing, or Guide By Your Side<sup>™</sup> (a parent-to-parent networking program).

**BVI.** If the LLA/EI agency does not have a certified teacher of the visually impaired (TVI) within the community to support families of young children with blindness/visual impairment, then the FRC, in cooperation with WSSB, will identify potential early intervention partners. These partners might include Department of Services for the Blind's Child and Family Program.

Consultative specialty services for DHH, BVI, and DB populations may be delivered via "tele-therapy" or "tele-intervention" through the use of technology, in addition to in-person services.

As with any IFSP, services will be driven by the family's identified priorities and needs. To help guide families and FRCs in focusing on critical content areas, however, FRCs can refer to **Areas to Address with All Families** (see p. 6). This document identifies several areas as the most essential for families of infants and toddlers with sensory disabilities to address, with support from partners with expertise in early childhood deafness, visual impairment, and deaf-blindness.

# 2. Registry Form for B-3 Children with Sensory Disabilities (http://www.wssb.wa.gov/B3)

WSSB and CDHL are state agencies required by law (RCW 72:40.070) to collect data on the population of children with sensory disabilities in the State of Washington. This information is confidential and is used to justify funding requests and to develop appropriate programs to support children who are deaf/hard of hearing, blind/visually impaired, and deaf-blind.

The Registry Form is the document used to register all children between the ages of birth and three years who have been diagnosed with a sensory disability:

- (a) deaf or hard of hearing—including children with any type or degree of hearing loss; or
- (b) blindness or visual impairment—including children with any type or degree of visual impairment, including cortical visual impairment (CVI); or
- c) deaf-blindness. If the child is suspected or known to have *both* hearing loss and visual impairment, the "Registry Type" drop-down menu allows that to be selected as well.

The Registry Form is online and has four parts: 1) Identifying Information, 2) Hearing Information, 3) Vision Information, and 4) Early Intervention Services.

Once completed, the Registry Form is submitted electronically to a secure database. This process gathers demographic data on children across the state, is aggregated to protect confidentiality, and documents needs to funding agencies and others. It is not a referral to a particular program, nor a request for technical assistance or consultation, and families will not be contacted without a formal request for technical assistance or consultation by the FRC.

# 2.b American Printing House (APH) Federal Quota (BVI)

The APH is the official supplier of educational materials to all students in the U.S. who meet, or function at, the definition of blindness or visual impairment. *This includes children under the age of 3.* In Washington, WSSB's Ogden Resource Center (ORC) is the state-appointed Instructional Resource Center (IRC) designated to distribute materials to children and families.

Early Intervention agencies register as an account holder (one time) with the ORC and then register individual infants/toddlers who qualify (yearly). The agency can then order and receive products and materials created especially for children with visual impairments to use in the home or other natural environments such as child care centers.

Materials include books with braille and textured pictures, games and toys, materials specific for children with CVI, and resources for both service providers and families. Materials are free to the agency and families, as they are provided by the federal quota funds. Most of the items are considered "consumable" and do not need to be returned. The TVI on the family's IFSP team will assist the agency in the registration process and the determination of appropriate materials, as well as instruction in their use within the routine of the child and family.

For instructions for completing APH registration, see Appendix 2.b.

# 3. Self-Evaluation Tool for Early Intervention Programs on Services to Birth-to-Three Year Olds who are Blind or Visually Impaired or Deaf or Hard of Hearing

The purpose of this tool is to help LLAs and EI agencies evaluate their readiness to support families with newly identified birth-to-three year olds with sensory disabilities. Some programs and counties have well-developed services to support families; others have few specialized resources and little previous experience in serving families of young children who have hearing loss and/or visual impairment. Partnering with CDHL, WSSB, and WSDS/Deaf-Blind Project will help LLAs determine strengths and needs, and can ensure that appropriate services are located or developed. LLAs that complete this self-evaluation will be better prepared to collaborate with CDHL, WSSB, and the WSDS/Deaf-Blind Project.

See Appendix 3 of this Practice Guide for the self-evaluation tool.

# 4. Areas to Address with All Families Whose Infants/Toddlers are Identified with Sensory Disabilities: BVI, DHH, and DB

This document is intended to guide the FRC through "first steps" following referral of a child with sensory disability to the LLA, including developing the first IFSP, and contains three sections: Medical Records, Referrals to Resources, and Areas of Understanding for All Families.

See Appendix 4 of this Practice Guide.

Key references and state and national resources on sensory disabilities may be found below. This is not intended to be a comprehensive list.

# References

- Hatton, D., Anthony, T., Bishop, V., Gleason, D., Greeley, J.C., Miller, T., Moore, S., Riggio, M., Robinson, L., Teplin, S., & Tompkins, C. (2003). *Family-centered practices for infants and young children with visual impairments*. Position paper of the Division on Visual Impairments, Council for Exceptional Children. Arlington, VA: Council for Exceptional Children.
- Joint Committee on Infant Hearing (2013). Supplement to the JCIH 2007 position statement: *Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. Pediatrics, 131*, e1324-e1349.
- Moeller, M.P., Carr, G., Seaver, L., Stredler-Brown, A. & Holzinger, D. (2013). Best practices in family-centered early intervention for children who are deaf or hard of hearing: An international consensus statement. *Journal of Deaf Studies and Deaf Education (18:4)*, 429-445.
- Spungin, S.J., & Ferrell, K.A. (2007). *The role and function of the teacher of students with visual impairments*. Position paper of the Division on Visual Impairments, Council for Exceptional Children. Arlington, VA: Council for Exceptional Children.

# Sample Resources for Infants and Toddlers with Sensory Disabilities

# **Washington State Resources:**

- Department of Services for the Blind http://www.dsb.wa.gov/services/childrenandfamilies.shtml
- Early Hearing-loss Detection, Diagnosis and Intervention (EHDDI) http://www.doh.wa.gov/earlyhearingloss

Link to Parent Notebook:

http://www.doh.wa.gov/Portals/1/Documents/Pubs/344-017 EHDDIResourceGuideEng.pdf

Link to Resources by County Guide:

http://here.doh.wa.gov/materials/EHDDI-resources/13 EHDDIres E15L.pdf

- Guide By Your Side (GBYS)
   http://www.wahandsandvoices.org/gbys/
- Washington Sensory Disabilities Services (WSDS) Infant/Toddler and Deaf-Blind pages <a href="http://www.wsdsonline.org/infant-toddler/">http://www.wsdsonline.org/infant-toddler/</a>

http://www.wsdsonline.org/video-library/blind-visually-impaired-videos/http://www.wsdsonline.org/deaf-blind/

- Washington State Center for Childhood Deafness & Hearing Loss (CDHL) <a href="http://www.wsdsonline.org/deaf-hard-of-hearing/">http://www.wsdsonline.org/deaf-hard-of-hearing/</a>
- Washington State Hands & Voices

# http://www.wahandsandvoices.org/

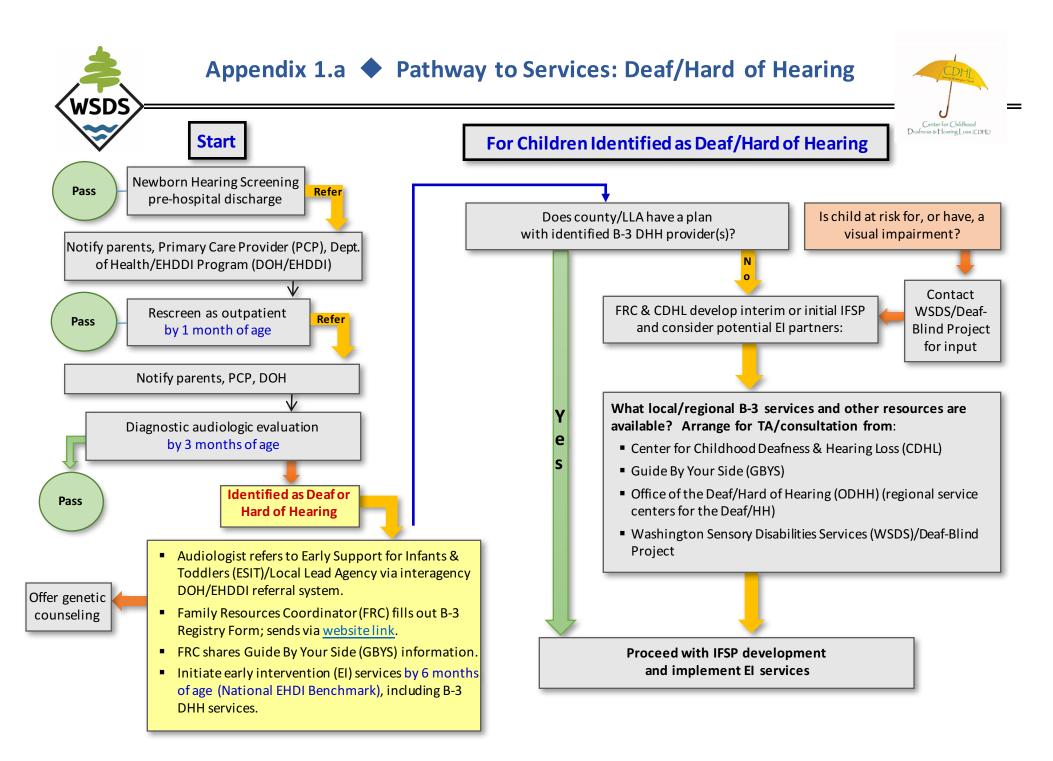
 Washington State School for the Blind (WSSB) – Birth to Three <a href="http://www.wssb.wa.gov/Content/oncampus/b3.asp">http://www.wssb.wa.gov/Content/oncampus/b3.asp</a>

# National Resources (find more on the above Washington State websites):

- Centers for Disease Control and Prevention: Hearing Loss in Children http://www.cdc.gov/ncbddd/hearingloss/index.html
- Family Connect
   http://www.familyconnect.org/parentsitehome.aspx
- My Baby's Hearing www.babyhearing.org
- National Center for Hearing Assessment and Management www.infanthearing.org
- National Center on Deaf-Blindness
   <u>www.nationaldb.org</u>

   <a href="https://nationaldb.org/library/list/35">https://nationaldb.org/library/list/35</a> (early intervention resources in library)
- Perkins School for the Blind <u>www.perkins.org</u> <u>www.perkinselearning.org</u>
- Wonder Baby www.wonderbaby.org

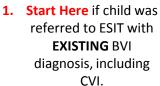
Prepared by Nancy Hatfield, Kris Rydecki Ching, DeEtte Snyder, and Kerianne Christie. Edited by ESIT Staff (April 2016).





# **Appendix 1.b** • Pathway to Services: Blind/Visually Impaired (BVI)







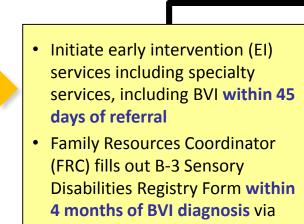
2. Start Here if child does not have BVI at initial enrollment in EI services, but concerns about vision are present.



2a. Babies seen at Well-Child Check Up and concern identified.

2b. Babies has CVI high-risk factors and team administered the CVI screening tool.

2c. EI and family/team has vision concerns after completion of 3-Prong Vision Screen.

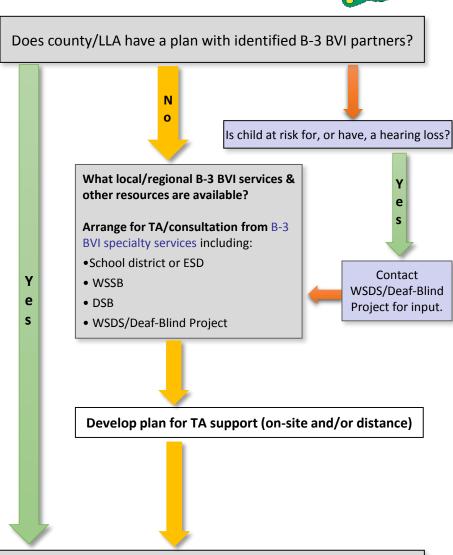


 Develop IFSP with input from BVI specialty service providers including B-3 BVI Partner

http://www.wssb.wa.gov/b3

Refer to pediatric ophthalmologist for diagnostic eye examination

Child Diagnosed with BVI Medical Condition



Proceed with IFSP development and EI services with B-3 BVI partner on team.

# Appendix 1.c

# **Pathway to Services Key to Acronyms**

Washington State Agencies Involved in Developing the ESIT Practice Guide			
Deaf/Hard of Hearing	Blind/Visually Impaired		
Center for Childhood Deafness & Hearing Loss (CDHL)  www.wsdsonline.org/deaf-hard-of-hearing CDHL Outreach (Birth-5): 360-418-4292  Department of Health/Genetic Services  www.doh.wa.gov EHDDI Program: 206-418-5613 Genetics: 253-395-6742	Department of Services for the Blind (DSB)  http://www.dsb.wa.gov/services/ 800-552-7103  Washington State School for the Blind (WSSB)  www.wssb.org 360-947-3305		
Office of the Deaf & Hard of Hearing www.dshs.wa.gov/hrsa/odhh/ 800-422-7930			

# **Early Support for Infants & Toddlers**

www.del.wa.gov/esit/

Family Health Hotline: 800-322-2588

# Washington Sensory Disabilities Services (WSDS)/Deaf-Blind Project

www.wsdsonline.org 800-572-7000

Key to Abbreviations: DHH	Key to Abbreviations: BVI
B-3 = Birth to three years of age	B-3 = Birth to three years of age
<b>CDHL</b> = Center for Childhood Deafness and	BVI = Blind/Visually Impaired
Hearing Loss	<b>CSHCN</b> = Children w/Special Health Care Needs
<b>CSHCN</b> = Children w/Special Health Care Needs	<b>DSB</b> = Department of Services for the Blind
<b>DHH</b> = Deaf and Hard of Hearing	EI = Early Intervention
<b>DOH</b> = Department of Health	FRC = Family Resources Coordinator
<b>EHDDI</b> = Early Hearing-loss Detection	IFSP = Individualized Family Service Plan
Diagnosis & Intervention	PCP = Primary Care Provider
EI = Early Intervention	WSDS = WA Sensory Disabilities Services
<b>ESIT</b> = Early Support for Infants & Toddlers	<b>WSSB</b> = Washington State School for the Blind
FRC = Family Resources Coordinator	WTBBL = Washington Talking Book & Braille
<b>GBYS</b> = Guide By Your Side <sup>TM</sup>	Library
IFSP = Individualized Family Service Plan	
<b>LLA =</b> Local Lead Agency for County or Multi-	
County (ESIT)	
ODHH = Office of Deaf/Hard of Hearing	
PCP = Primary Care Provider	

# Appendix 2.a

# Instructions for Completing the Sensory Disabilities Child Registry Form Registry is located online at http://www.wssb.wa.gov/b3

Per RCW 72.40.070 WSSB and CDHL are state agencies required to collect data on children with sensory disabilities in the state of Washington. The regulation is located here: http://app.leg.wa.gov/RCW/default.aspx?cite=72.40.070

The Registry helps the agencies identify where families are in each county and work together with local Family Resources Coordinators (FRCs) and Early Intervention (EI) professionals to provide information and resources to families.

# **Basic Instructions:**

- Form is submitted electronically.
- Release of Information is required to be on file with early intervention service agency and does not need to be submitted with registry.
- FRCs who have children referred to their LLA with qualifying sensory disabilities are required to assure completion of registry for each child. Each Local Lead Agency (LLA) contract with Early Support for Infants & Toddlers (ESIT) aligns with this requirement.
- Complete all required fields (indicated with an \*), and provide other information if available.
- Registry is only required for children aged birth-to-3. When a child turns 3, the school
  district will follow their reporting requirements through OSPI for children eligible for
  special education services.
- Complete both hearing and vision impairment sections if child has BOTH sensory disabilities.
- The registry <u>does not request or refer for services</u> from the Washington State Center for Childhood Deafness & Hearing Loss (CDHL), Washington State School for the Blind (WSSB), or Washington Sensory Disabilities Services/Deaf-Blind Project (WSDS/DB Project). Please contact the appropriate agency to request help regarding a child.

# Washington State School for the Blind (WSSB) Center for Deafness and Hearing Loss (CDHL)

Children Aged Birth to 3 with Sensory Disabilities REGISTRY FORM

The purpose of this form is to gather demographic information on the children aged birth to 3 who are blind/visually impaired, deat/hard of hearing, or both deat/blind in the state of Washington. It is not a referral to a particular program nor a request for technical assistance or consultation.

If you have any questions completing this form, please contact DeEtte Snyder (BVI) DeEtte.Snyder@wssb.wa.gov or Kris Ching (DHH) Kris.Ching@cdhl.wa.gov

NEED HELP? (WORD DOC)

# Appendix 2.b

# Instructions for APH Federal Quota Registration for Infants and Toddlers with Blindness/Visual Impairment

The American Printing House for the Blind (APH) received a federal mandate in 1879 when the Congress of the United States passed the Act to Promote the Education of the Blind. This act designates APH as the official supplier of educational materials to all students in the U.S. who meet, or function at, the definition of blindness or visual impairment. This includes children under the age of 3. *In Washington, WSSB's Ogden Resource Center (ORC) is the state appointed Instructional Resource Center (IRC) to distribute materials to children and families*.

Early Intervention agencies can register as account holders with the ORC and then register their individual children who qualify. The agency can receive products and materials created especially for children with visual impairments to use in the home or other natural environments such as childcare.

Materials include books with braille and textured pictures, games and toys, materials specific for children with cortical visual impairment (CVI), and resources for both service providers and families. Everything is **FREE** to agencies and families as they are provided by the federal quota funds. Most of the items are considered "consumable" and do not need to be returned (one exception is the Light Box).

# **Steps to Register and Order Materials:**

- **1.** Go to <a href="www.wssb.wa.gov">www.wssb.wa.gov</a> to obtain all forms and more information. A link to the ORC is on the left side of the homepage.
- **2.** The agency must assign an individual to act as an authorized representative. Typically this is the administrator and/or the teacher of the visually impaired (TVI).
- **3.** The authorized individual completes an "Account Holder Registration Form" through the ORC at WSSB. (We recommend that the TVI also is included on the account to offer assistance in ordering materials and provide instruction to team and family on appropriate use of materials.)
- **4.** The authorized account holder will then receive a welcome letter with a username and password for login on the ORC ON-LINE web page. <a href="http://www.wssb.wa.gov/IRC/welcome.aspx">http://www.wssb.wa.gov/IRC/welcome.aspx</a>.
- **5.** Register each child individually, following the instructions given in the welcome letter. A video tutorial on how to register individual children is included on the ORC web page.
- **6.** Order fun stuff! Go to <a href="www.shop.aph.org">www.shop.aph.org</a> and look at all the early childhood materials available...then order materials from ORC Online on the WSSB webpage. You can also order a catalog to keep. See the following page for some examples.

Need more help?

Contact DeEtte Snyder at (360) 947-3305 or DeEtte.Snyder@wssb.wa.gov

# **Instruction per Section:**

1. Identifying Information (\* indicates a required field) (See screen shot below.)

Required fields marked with **				
*Registry Type: Blind/Visually Impaired 🧿				
*Child's Last Name:	*Child's First N	lame:	*Date	of Birth:
Parent(s)/Guardian(s) Name:		*Phone Nu	umber:	
Address:	*City:	State:	*Zipcode:	*County:
*School District:	MENSELLA PROPERTY AND PROPERTY	Language(s) Used in Ho	me:	

\*Registry Type: From the drop-down menu, select "Blind/Visually Impaired," "Deaf/Hard of Hearing" or "Deaf-blind."

Child Data: Type in \*Child's Last Name, \*Child's First Name and \*Date of Birth.

**Family Data:** Type **in \*Parent(s)/Guardian(s) Name** and **\*Phone Number.** If phone number is unknown, type "NA" in that field.

\*Address: Include street address or PO Box, \*City, \*Zipcode, and \*County.

\*School District: Type in the name of the school district where the family lives, regardless of whether the school district is providing early intervention services.

**Language(s) Used in Home:** If known, please type in this field.

- 2. **Hearing Loss Information (\*Indicates a required field)** (See screen shot, next page.)

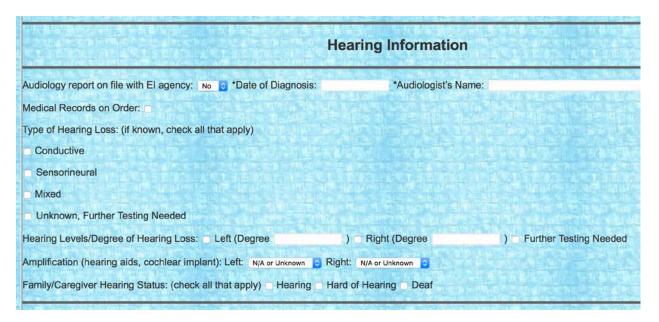
  Complete this section only if this is a deaf/hard of hearing registry OR a deaf-blind registry.
  - \* Audiology report on file with EI agency:

If the agency has a copy of report on file, select "YES" from the drop-down menu, then type in the \*Date of Diagnosis (from the first report to include diagnosis) and \*Audiologist's Name.

**OR:** If the agency does <u>not</u> have a copy of report on file, select "NO" from the dropdown menu and click the box to indicate "Medical Records on Order." If the \*Date of Diagnosis and/or \*Audiologist's Name are known, please type in that information.

The \*Date of Diagnosis and \*Audiologist's Name are required fields. If additional information is available (i.e., Type of Hearing Loss, Hearing Levels/Degree of Hearing Loss, Amplification, and Family/Caregiver Hearing Status), please include that as well.

(continued)



The type of hearing loss will be documented in the audiology report and will be identified as conductive, sensorineural, or a mixed loss (both).

- Conductive. This refers to a decrease in sound caused by a barrier or issue to the outer or middle ear. Such an etiology suggests normal inner ear status. Possible causes of a conductive loss may be: wax in the ear canal, a perforation in the eardrum, fluid in the middle ear, or microtia/atresia. Conductive hearing loss is usually treatable with either, bone conduction hearing aids (BAHA), and/or medical or surgical intervention.
- **Sensorineural.** This refers to an issue along the nerve pathway between the inner ear and the brain. This type of hearing loss may be caused by aging, infection, ototoxic drugs, noise exposure, or it may be related to a genetic disorder. It is usually permanent and not treatable by medical or surgical intervention (unless cochlear implant candidate).
- Mixed Loss. This refers to a conductive loss and a sensorineural etiologies occurring at
  the same time. While the conductive component may be medically treatable, the
  sensorineural component is permanent.
- Unilateral (One Ear) means the hearing loss affects only one ear.
- Bilateral (Both Ears) means the hearing loss is in both ears.

# **Hearing Levels/Degree of Hearing Loss:**

Read the summary paragraph of the audiological report and choose the level below that matches that information most closely for each ear.

Minimal hearing loss – For infants and toddlers who are in the process of acquiring spoken language, there is cause for concern if a hearing loss is 15 decibels (dB) HL.
 While this level of hearing loss will not cause major problems for adults who have mastered a spoken language, it can affect a child's development of speech and medical treatment and/or hearing aids may be recommended.

- **Mild hearing loss** With mild hearing loss, children cannot hear sounds softer than 25-40 decibels (dB). An example of sound they cannot hear is whispering, which is around 40 dB loudness. They also cannot hear some soft speech sounds even when spoken at a typical speaking level.
- **Moderate hearing loss** Sounds softer than 40-55 dB will not be heard by children with moderate hearing loss, including many English speech sounds.
- Moderate to severe hearing loss Children with this hearing level cannot hear sounds softer than 55-70 dB. An example of a sound at this level is a dishwasher (60 dB).
- Severe hearing loss With severe hearing levels, children cannot hear sounds softer than 70-90 dB. Examples of sounds they may not hear are a vacuum (70 dB), or a blender or hairdryer (90 dB).
- **Profound hearing loss** Children with profound hearing levels cannot hear sounds softer than 91 dB. Examples of this are MP3 players with the volume turned up all the way (100 dB) and car horns (110 dB).

**Amplification**: From the drop-down menu, select Hearing Aid, Cochlear Implant, or NA/Unknown for left ear and right ear.

**Family/Caregiver Hearing Status:** List the hearing status (if known) of family members or caregivers. Examples: (1) If one parent is Hearing and one Deaf, you would check those two boxes. (2) If both parents are hearing and an older sister is hard of hearing, you would check those two boxes.

- **3. Visual Impairment Information (\*Indicates a required field)** (See screen shot, next page.) *Complete this section only if this is a blind/visually impaired registry OR a deaf-blind registry.* 
  - \* Eye report on file with EI agency:

If the agency has a copy of report on file, select "YES" from the drop-down menu, then type in the \*Date of Eye Exam (from the first report to include diagnosis) and the \*Ophthalmologist's (or Optometrist's) Name.

### OR

If the agency does <u>not</u> have a copy of report on file, select "NO" from the drop-down menu and click the box to indicate "Medical Records on Order." If the \*Date of Eye Exam and/or \*Ophthalmologist's Name are known, please type in that information.

The \*Date of Eye Exam and \*Ophthalmologist's Name are required fields, but if the additional information is available (e.g., Visual Condition), please include that as well.

Visual In	Visual Impairment Information			
Eye report on file with EI agency: No 3 *Date of Eye Exam: *Ophthalmologist's Name:				
Medical Records on Order:				
/ision Condition(s):(if known, check all that apply)				
Cortical Visual Impairment (CVI) or Delayed Visual Maturation (DVM)	Optic Nerve Hypoplasia (ONH)			
Retinopathy of Prematurity (ROP)	Anophthalmia/microphthalmia			
Albinism	☐ Cataract			
Aniridia	Corneal defects			
Coloboma	Retinoblastoma			
Leber's Congenital Amaurosis (LCA)	Glaucoma			
Retinal Disorder	Strabismus			
Nystagmus				
Other:				
Unknown, further testing needed				
Vears: Glasses Contacts Prosthetics				

**Vision Conditions.** A list of common vision conditions that can cause a visual impairment is provided (see screenshot above). Based on the eye exam and/or family report, check one or more boxes to describe the vision condition. If the child's vision condition is not listed, type it in the field available or check the "Unknown, further testing needed" box.

**Wears:** Also check the appropriate box if the child wears corrective lens such as glasses or contacts, or has a prosthetic ("fake eye").

# 4. Early Intervention Services (\* indicates a required field)

(See screen shot, next page.)

- \* Current IFSP Date: If current date is unknown or not yet completed, write "NA" in field.
- \* Name of Agency Providing El Services: Indicate the name of the agency providing ongoing or primary services, not the LLA. However if the LLA is also the service agency, then write the LLA name.
- \* Lead FRC or Assigned FRC: Type in the name of the FRC, as well as contact information (\*Email and \*Phone). If an FRC has not yet been assigned, then type in the name of the lead FRC for the LLA.

Early Intervention Services						
*Current IFSP Date (if completed):  *Name of Agency Providing El Services:						
*Lead FRC or Assigned FRC:	*Email:	*Phone:				
Primary El Provider (if known):	Email:	Phone:				
TVI (if known):	Email:	Phone:				
TOD (if known):	Email:	Phone:				
Agency providing TVI/TOD Service:(if known)						
Submit (If form does not submit, scroll up and check to see if all required fields have been filled in)						

Only the \*Current IFSP Date, \*Name of Agency, and \*Lead FRC or Assigned FRC (along with that person's contact information) are required. However, if a Teacher of the Visually Impaired (TVI) and/or Teacher of the Deaf (TOD) are included on the IFSP team, please type in their name, Email, and Phone number if known. Also type in the Agency providing TVI/TOD Service (if known).

# Then, click "SUBMIT"! ©

If all required fields have been completed, your registry form will be automatically submitted and you will be directed to this screen:

Washington State School for the Blind  Thank you for your submitting Registry Information						
						If further technical or consultative assistance is needed, please contact Kris Ching from CDHL ( <a href="mailto:Kris.ching@cdhl.wa.gov">Kris.ching@cdhl.wa.gov</a> ), DeEtte Snyder from WSSB ( <a href="mailto:DeEtte.snyder@wssb.wa.gov">DeEtte.snyder@wssb.wa.gov</a> ), or Katie Humes from WSDS/Deaf-Blind Project ( <a href="mailto:khumes@psesd.org">khumes@psesd.org</a> ).
And the second s						
one, de la presenta en ser reguns de la presenta en ser reguns de la presenta de la presenta de la presenta de La presenta de la pr La presenta de la pr						

The registry <u>does not request or refer for services</u> from CDHL, WSSB, or WSDS/Deaf-Blind Project. Please contact the appropriate agency if you wish to request technical assistance and/or consultation.

CDHL: Kris.Ching@cdhl.wa.gov

WSSB: DeEtte.Snyder@wssb.wa.gov

WSDS/Deaf-Blind Project: Khumes@psesd.org

# Appendix 3

# Self-Evaluation Tool for EI Programs: Services for Infants/Toddlers with Sensory Disabilities (Blind/Visually Impaired, Deaf/Hard of Hearing, or Deaf-Blind)

The purpose of this tool is to help LLAs and EI agencies evaluate their readiness to support families with newly identified birth-to-three year olds with sensory disabilities. Some programs and counties have well-developed services to support families; others have few specialized resources and may not have had previous experience in serving families of young children who have hearing loss or visual impairment, or a combined vision and hearing loss. Partnering with CDHL, WSSB, and WSDS/Deaf-Blind Project will help LLAs and EI programs determine strengths and needs, and can ensure that appropriate services are located or developed. Programs that complete this self-evaluation will be better prepared to collaborate with CDHL, WSSB, and WSDS.

Services for Infants/Toddlers	who are Deaf/Hard of Hearing	Services for Infants/Toddlers who are Blind/Visually Impaired	
KEY:  CDHL = WA Statewide Center for Ch D/HH = Deaf/Hard of Hearing EI = Early Intervention  ODHH = Office of Deaf & Hard of He WSDS — Washington Sensory Disabi	earing	KEY:  BVI = Blind or Visually Impaired  TVI = Teacher of the Visually Impaired, certification from OSPI  O&M = Orientation & Mobility Specialist, certification through ACVREP  WSSB = Washington State School for the Blind  WSDS = Washington Sensory Disabilities Services	
Elements	Examples/Comments	Elements	Examples/Comments
WELL-QUALIFI	ED STAFF: DHH	WELL QUALIFIED STAFF: BVI	
<ul> <li>WELL-QUALIFIED STAFF: DHH</li> <li>1. El program has a collaborative working relationship with a TOD with necessary certification and additional experience and training with infants, toddlers, &amp; families.</li> <li>2. Program staff includes individuals who have completed specialized training in birth-to-three DHH.         <ul> <li>Additional training in B-3 DHH does not supersede the services of a certified early childhood teacher of the deaf.</li> <li>Program has staff person with certification as a TOD.</li> <li>Educational audiologist, speech/language therapist, ASL specialist, or others with additional D/HH training.</li> <li>Contract with CDHL, local ESD or school district to provide TOD services.</li> <li>Use of distance technology for joint home visit with EI provider.</li> </ul> </li> </ul>		<ol> <li>El program has a collaborative working relationship with a TVI with the necessary certification and additional experience/ training with children aged B-3.</li> <li>El staff includes individuals who have completed specialized training in BVI.</li> <li>Additional training in B-3 BVI does not supersede the services of a TVI or O&amp;M specialist.</li> </ol>	<ul> <li>Program has a staff person with certification as a TVI and/or O&amp;M.</li> <li>Contract with WSSB, local ESD, or school district to provide TVI or O&amp;M services.</li> <li>Use of distance technology for joint home visit with EI provider.</li> </ul>

Elements	Examples/Comments	Elements	Examples/Comments	
WELL-QUALIFIED STAFF: DHH (continued)		WELL QUALIFIED STAFF: BVI (continued)		
<ul><li>3. Program staff includes people who are Deaf/Hard of Hearing.</li><li>4. Staff knows adults, or can access</li></ul>	Individuals are staff members, or available on a contractual basis.	3. El program staff is knowledgeable about using "3-Prong Screening Tool" to identify concerns regarding vision.	EI staff has completed in-service training and participated in professional development opportunities in B-3 BVI.	
adults, who are D/HH, who communicate via a variety of methods, and who are sensitive		EI program staff is knowledgeable about identifying cortical visual	Agency tracks hours of training/in-service for all staff members on BVI topics.	
<ul><li>to families' needs and concerns.</li><li>5. Staff has training in developing cultural competency.</li></ul>		impairment (CVI).  5. EI program staff knows resources to	EI staff completes training on use of "3-Prong Vision Screening Tool" during intake/initial eligibility procedures.	
		access adults with varying degrees of BVI who are sensitive to family needs and concerns to act as positive mentors.	EI staff is able to use "3-Prong Vision Screening Tool" when family has concerns regarding child's use of vision.	
		Staff has training in developing cultural competency.	Staff is knowledgeable about risk factors for CVI, including the completion of the CVI screening procedures consisting of "2 questions and 3 observations."	
			EI program includes TVI on IFSP team for children with identified CVI when presented with multiple disabilities.	
			Adults who are BVI:	
			<ul> <li>Participate on panel during family support group.</li> <li>Provide individual support during joint home visit with EI provider.</li> </ul>	
			Consult with team on issues surrounding vision loss.	

Elements	Examples/Comments	Elements	Examples/Comments
ACCESS TO PEDIATRIC	AUDIOLOGY SERVICES	ACCESS TO PEDIATRIC OPHTHALMOLOGY AND OPTOMETRY	
5. Program services include pediatric audiology to monitor children's hearing levels (aided and unaided). Services may include fitting and maintaining hearing aids, and determining or referring for cochlear implant eligibility as appropriate.  (or)  Program has a referring relationship with pediatric audiology services.	<ul> <li>Program has pediatric audiologist/s within agency or on staff.</li> <li>El staff partner with pediatric audiologist/s to conduct hearing assessments.</li> <li>Program has a close working relationship with a nearby pediatric audiologist, to facilitate access to services and to communicate about child's and family's needs.</li> </ul>	6. El program has referring relationship with pediatric ophthalmology and optometry services for diagnostic and monitoring of children's medical and visual diagnosis.	<ul> <li>Staff has knowledge of local and state medical resources in order to refer families if needed for vision concerns.</li> <li>Staff requests appropriate medical records for information and eligibility requirements.</li> <li>Staff is able to consult and counsel families in the implementation of doctor's recommendations such as patching programs and use of corrective lenses.</li> </ul>
DEVELOPMI	ENT OF IFSP	DEVELOPMENT OF IFSP	
<ul> <li>6. EI/IFSP team includes an early childhood TOD who meets the "Staff Qualifications" of #1.</li> <li>7. Prior to development of IFSP, FRC completes Child Registry form: www.wssb.wa.gov/B3 and contacts Kris Ching as needed: kris.ching@cdhl.wa.gov</li> <li>Phone: 1-360-418-4292</li> </ul>	<ul> <li>A certified TOD is on the EI team in some capacity when a child has a diagnosed hearing loss.</li> <li>A certified TOD might participate in initial IFSP development and subsequent review via distance technology.</li> <li>If a TOD is not providing ongoing services, but consultation, he/she participates in each IFSP meeting (initial and review) to ensure high quality of service to D/HH child and family.</li> </ul>	7. EI/IFSP team includes a TVI/O&M who meets the "Staff Qualifications" of #1.  Prior to development of IFSP, FRC completes Child Registry form: www.wssb.wa.gov/B3 and contacts DeEtte Snyder as needed: deette.snyder@wssb.wa.go V  Phone: 1-360-947-3305	<ul> <li>A certified TVI/O&amp;M is on the EI team in some capacity when child has a diagnosis of BVI.</li> <li>A certified TVI might participate in initial IFSP development and subsequent review via distance technology.</li> <li>If TVI is not providing ongoing services, but consultation, he/she participates in each IFSP meeting (initial and review) to ensure high quality of service to child with BVI and family.</li> </ul>

Elements	Examples/Comments	Elements	Examples/Comments
SERVICES IN THE FAMILY'S	NATURAL ENVIRONMENT(S)	SERVICES IN THE FAMILY'S NATURAL ENVIRONMENT(S)	
<ul> <li>8. The majority of family-centered learning takes place in the family's natural environments.</li> <li>9. Children's play groups, audiology services, and access to sign language instruction, if desired by the family, are offered in other settings.</li> </ul>	<ul> <li>Natural environments might include: home, childcare setting, home of other family member, church, favorite community places.</li> <li>As needed, services include delivery via distance technology within the family's home.</li> <li>El program staff shares information with family regarding playgroups or family events for D/HH children being offered community or statewide.</li> </ul>	<ul> <li>8. The majority of family-centered learning takes place in the family's natural environment so that caregivers can learn how to modify daily routines to achieve functional outcomes.</li> <li>9. El staff is knowledgeable about children's playgroups and parent support groups offered in other settings such as community childcare programs and centerbased programs.</li> <li>Center-based programs are considered complementary to home-based natural environments.</li> </ul>	<ul> <li>Natural environments might include: the home, childcare setting, church, home of other family members, or favorite community place.</li> <li>As needed, services include delivery via distance technology within the family's home.</li> <li>El program staff shares information with family regarding playgroups or family events for children with BVI being offered in local community or statewide.</li> </ul>
COMPREHENSIVE RANGE	OF FAMILY SERVICES (DHH)	COMPREHENSIVE RANGE	OF FAMILY SERVICES (BVI)
10. El program Family Resource Coordinators (FRCs) are trained and knowledgeable about the completion of the "Registry Form" to be submitted to the online data base: www.wssb.wa.gov/b3	<ul> <li>A Registry Form is completed for EACH child with a diagnosis of hearing loss in the program, regardless if the child is receiving services from a TOD.</li> <li>This includes B-3 with a dual hearing loss and visual impairment.</li> </ul>	10. El program Family Resource Coordinators (FRCs) are trained and knowledgeable about the completion of the "Registry Form" to be submitted to the online data base: www.wssb.wa.gov/b3	<ul> <li>A Registry Form is completed for EACH child with a BVI condition or diagnosis in the program, regardless if the child is receiving vision services from TVI or O&amp;M.</li> <li>This includes B-3 with a dual hearing loss and visual impairment.</li> </ul>

Elements	Examples/Comments	Elements	Examples/Comments	
COMPREHENSIVE RANGE OF F	AMILY SERVICES (DHH) (cont.)	COMPREHENSIVE RANGE OF FAMILY SERVICES (BVI) (cont.)		
11. Program offers a menu of early intervention services designed to support the unique needs of families with infants and toddlers who are D/HH.  Some services might be delivered via distance technology (e.g., phone, email, Skype, other webbased methods) as needed.  Frequency of support is contingent on needs of child, as well as concerns/priorities of family.	A B-3 D/HH specialty program would typically offer many or most of these components:  • Home visits with an early childhood TOD; joint visits with TOD and team member  • Parent support & networking (e.g., "Guide by Your Side")  • Instruction in communication method of family's choice, including Deaf Culture  • Audiology services or partnership with audiologist  • Infant-toddler play groups  • Opportunities to learn from a variety of adults who are D/HH (e.g., staff, panels, Deaf mentors)  • Sibling supports  • Partnership with pediatric audiology services	11. Program offers a menu of early intervention services designed to support the unique needs of families with infants/toddlers who are BVI.  Some services might be delivered via distance technology (e.g., phone, email, Skype, other webbased methods) as needed.  Frequency of support is contingent on needs of child, as well as concerns/priorities of family.	<ul> <li>Specialty services for B-3 who are BVI would typically offer many or most of these components (not exhaustive):</li> <li>Home visits with a TVI; joint visits with TVI and a team member</li> <li>Parent support and networking, including with parents of children with similar etiologies and diagnoses</li> <li>Supports to learn strategies for development of basic concepts</li> <li>Supports to enhance social and emotional relationships between child w/ BVI, their families, peers</li> <li>Supports to learn strategies for development of pre-literacy skills in large print or braille</li> <li>Supports to learn orientation and mobility skills; independent movement at home, community</li> <li>Supports to address adaptive or self-help skills such as feeding or sleeping issues</li> <li>Appropriate toddler play groups</li> <li>Opportunities to learn from adults who are BVI</li> <li>Sibling supports</li> <li>Partnerships with eye care and medical professionals (ophthalmologists, optometrists)</li> </ul>	

Elements	Examples/Comments	Elements	Examples/Comments
FLEXIBLE POSITIVE SUPPORT FOR COMMUNICATION DEVELOPMENT		COMPREHENSIVE RANGE OF FAMILY SERVICES (BVI) (cont.)	
<ul> <li>12.a. Families have opportunities to learn to communicate with child in ways that best match child's needs as well as family's goals and priorities; are encouraged to discover what works best for their child and adapt as indicated.</li> <li>12.b. Families have opportunities to learn about communication approaches throughout EI period. Where there is only one program available, it offers supports for various communication approaches via staff skills or by partnering with other agencies.</li> </ul>	<ul> <li>Families have a choice among programs specializing in a communication approach, e.g., ASL-English Bilingual Education, Listening and Spoken Language (LSL), or Signing Exact English (SEE) combined with spoken home language.</li> <li>A program with staff skilled in only one communication system arranges for others with complementary skills to participate in El services (e.g., a regional service center for the D/HH provides ASL instruction; a LSL program offers consultative support).</li> </ul>	12. EI program staff is knowledgeable about accessing services from the Ogden Resource Center (ORC) at WSSB to obtain materials from the American Printing House (APH) for the Blind.	<ul> <li>Program holds account with ORC at WSSB.</li> <li>All children who are eligible are registered with ORC at WSSB to access materials from APH through program account administrator.</li> </ul>
ASSESSMENT & MONITORING OF CHILD PROGRESS AND OUTCOMES		ASSESSMENT & MONITORING OF CHILD PROGRESS AND OUTCOMES	
13. El program includes a TOD on the evaluation team for a D/HH child as the program conducts initial child assessment and following ESIT requirements/timelines.	<ul> <li>Early childhood TOD is notified of initial assessment and is included on evaluation team.</li> <li>If child is identified as D/HH after initial intake and assessment, the TOD assists as soon as possible with interpretation of results and IFSP development.</li> <li>Staff uses appropriate tools (e.g., curriculum-based assessments such as the AEPS, Carolina, or Hawaii) and/or adapts items on standardized tools to yield functional information rather than invalid standardized scores.</li> </ul>	13. El program includes TVI on the evaluation team for a child with BVI (including those at risk for CVI) as the program conducts initial child assessment and following ESIT requirements/timelines.	<ul> <li>If diagnosis of BVI is known at intake, TVI is notified of initial assessment procedures and included on evaluation team.</li> <li>If diagnosis of BVI is identified after initial intake and assessment, the TVI assists as soon as possible with interpretation of results and IFSP development.</li> <li>(continued)</li> </ul>

Elements	Examples/Comments	Elements	Examples/Comments
ASSESSMENT & MONITORING OF CHILD PROGRESS AND OUTCOMES		ASSESSMENT & MONITORING OF CHILD PROGRESS AND OUTCOMES	
<ul> <li>14. Program monitors child's progress on communication skills three to four times yearly, with the goal of performance at a level commensurate with child's age or cognition, including one month progress for each month in El.</li> <li>15. Based on results of ongoing assessment, staff is open to changing focus of intervention strategies to optimize child's communication/language development.</li> </ul>	<ul> <li>Staff uses appropriate tools (e.g., SKI-HI Language Development Scale, MacArthur Communicative Development Inventory, Visual Communication and Sign Language Checklist, Cottage Acquisition Scales of Listening, Language, and Speech) that assess receptive and/or expressive communication and yield age-level equivalents.</li> <li>Based on child's progress, the El team suggests strategies to enhance and support the family's skills in the area of communication/language.</li> </ul>	<ul> <li>14. El program conducts initial child assessment using tools appropriate for a child with BVI following ESIT requirements/ timelines, understanding that BVI may invalidate results of some standardized tools.</li> <li>15. El program staff monitors child's progress on an ongoing basis with input from TVI.  Frequency of support is contingent on needs of child, as well as concerns/priorities of family.</li> </ul>	<ul> <li>TVI conducts functional vision assessment as part of initial evaluation, or when BVI is detected, to assist team/family with understanding functional use of vision in all areas of development/routines and appropriate development of IFSP with family.</li> <li>TVI uses CVI Range assessment procedures for children with a diagnosis of CVI or those at risk for CVI.</li> <li>With input from the TVI, staff uses appropriate assessment tools (e.g. CVI Screen &amp; Range, Oregon Project, INSITE, etc.) and/or adapts items on standardized tools to yield functional information rather than a standardized score.</li> <li>TVI assists and supports EI staff in regularly monitoring of child's progress in all areas with recommendations of strategies/ adaptations for the child's VI to achieve optimal outcomes.</li> <li>TVI completes review of functional vision regularly; shares information with program staff.</li> </ul>

Elements	Examples/Comments	Elements	Examples/Comments
APPROPRIATE REFERRALS & RESOURCES (DHH/DB)		APPROPRIATE REFERRALS & RESOURCES (BVI/DB)	
<ul> <li>16. El program staff is knowledgeable about the complexity of additional needs that a child who is D/HH might have.</li> <li>17. El staff refers families to other appropriate local, regional, state, and national resources.</li> </ul>	<ul> <li>El staff has knowledge of etiologies associated with hearing loss and other disabilities (e.g., Down syndrome, cytomegalovirus/CMV, CHARGE syndrome).</li> <li>Families are routinely referred to Genetic Clinics during early intervention.</li> <li>Families are informed of D/HH resources (e.g., CDHL, WSDS, ODHH/regional service centers for the DHH, annual Spring Family Camp, Infant Early Childhood Conference, National EHDI meeting).</li> <li>Children who are D/HH are routinely screened and monitored for visual impairment.</li> <li>Families of children with combined vision and hearing loss are referred to WSDS (Deaf-Blind Project) for additional resources: www.wsdsonline.org</li> </ul>	<ul> <li>16. El program staff is knowledgeable about the complexity of additional needs of a child with BVI.</li> <li>17. El program staff refers families to other appropriate local, regional, state and national resources.</li> </ul>	<ul> <li>Staff has knowledge of etiologies of medical conditions correlated with BVI and additional disabilities (such as neurological conditions, Down syndrome, cerebral palsy, CHARGE syndrome, etc.)</li> <li>Staff has knowledge regarding the risk factors for CVI.</li> <li>Children with BVI are routinely screened and monitored for hearing loss.</li> <li>Families of children with combined vision and hearing loss are referred to WSDS and the national deaf-blind registry.</li> <li>The consulting TVI assists in registering the child with Ogden Resource Center (WSSB) as part of the APH Federal Quota process.</li> <li>Families are informed of BVI state resources such as Department of Services for the Blind (DSB), Washington Sensory Disabilities Services (WSDS), Washington Talking Book &amp; Braille Library (WTBBL), and Washington State School for the Blind (WSSB).</li> <li>Families are informed of BVI national web resources such as FamilyConnect.org, NAPVI, and Wonderbaby.org, as well as local state such as the parent Facebook page "Blind Sided in WA."</li> </ul>

Elements	Examples/Comments	Elements	Examples/Comments
PLANNING FOR TRANSITION (DHH/DB)		PLANNING FOR TRANSITION (BVI/DB)	
18. Planning for transition always includes input from a D/HH specialist or CDHL (see p. 1).	The TOD on the IFSP team participates in planning transition to preschool.	18. EI program includes input from TVI during transition planning.	The TVI on the IFSP team     participates in planning for     transition to preschool.
19. If child has additional needs (e.g., deaf-blindness), an appropriate specialist is on the IEP team.	If possible, the receiving TOD in the child's home school district (or receiving district) is included also in transition planning.	19. If child has additional needs (e.g., deaf-blindness), an appropriate specialist is on the IEP team.	If possible, the receiving TVI in the child's home school district is also included in transition planning.
References		<u>References</u>	
Joint Committee on Infant Hearing (2013). Supplement to the JCIH 2007 position statement: Principles and guidelines for early intervention after confirmation that a child is deaf or hard of hearing. <i>Pediatrics, 131</i> , e1324-e1349.  Moeller, M.P., Carr, G., Seaver, L., Stredler-Brown, A. & Holzinger, D. (2013). Best practices in family-centered early intervention for children who are deaf or hard of hearing: An international consensus statement. <i>Journal of Deaf Studies and Deaf Education (18:4),</i> 429-445.		Moore, S., Riggio, M., Robinson (2003). Family-centered practic	es for infants and young children on paper of the Division on Visual tional Children. Arlington, VA:

# 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)
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.		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.	
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.		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.	

2. REFERRALS TO RESOURCES: Deaf/Hard of	ring (DHH)  2. REFERRALS TO RESOURCES: Blind/Visually Impaired (I	2. REFERRALS TO RESOURCES: Blind/Visually Impaired (BVI)	
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Early support for infants/toddlers with sensory disabilities must begin as soon as possible following identification.

2.a PRE-IFSP: For all infants and toddlers who are DHH, BVI, or DB, complete a Registry Form and submit via button on form: <a href="http://www.wssb.wa.gov/b3">http://www.wssb.wa.gov/b3</a>

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.

# For infants/toddlers who are deaf/hard of hearing: 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.

Families decide on their priorities. We help locate specialty services as needed, whether they are provided in person or via distance technology.

# Here's how CDHL can help:

- 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.
- Explain technologies (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.

# Here's how WSSB can help:

- 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.
- Explain, in understandable language, vision conditions and recommended treatment options (e.g., patching, glasses).
- Guide family's learning of strategies to <u>promote concept</u> <u>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:
Regional Service Centers of the Deaf and Hard of Hearing located around the state offer education and training, among other services. To learn more:	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.dshs.wa.gov/altsa/odhh/regional-service-centers	http://www.dsb.wa.gov/services/childrenandfamilies.shtml

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.

# 2.b Are there concerns about <u>child's vision</u>, in addition to hearing loss?

2.b Are there concerns about <u>child's hearing</u>, in addition to visual impairment?

Contact Katie Humes WSDS/Deaf-Blind Project: 800-572-7000 (or) khumes@psesd.org (or) wsds@psesd.org www.wsdsonline.org

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.

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:

- 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

Please contact WSDS/Deaf-Blind Project for more information.

### 2.c Parent-to-Parent Support (DHH/DB) 2.c Parent-to-Parent Support (BVI/DB) Parent-to-Parent Support: Christine Griffin 425-268-7087 Parent-to-Parent Support: Contact Guide-By-Your-Side gbys@wahandsandvoices.org **National Association for Parents of the Visually Impaired** (GBYS) to request a visit or (NAPVI): www.napvi.org www.wahandsandvoices.org phone conversation with an "We believe that if parents obtain the support and information they need they will become the best advocates for their children. experienced parent. When parents join together with common concerns, they have a Trained Parent Guides provide unbiased emotional support and powerful voice that can make significant changes and information to families with deaf/hard of hearing children. GBYS is a improvements for the services and education of ALL children with program of "Hands and Voices," a national parent organization with a visual impairments." Washington State chapter. Lighthouse Guild also offers a National Tele-Support Network Here's how Guide By Your Side can help: that can connect you with parents of children with the same eye • Family members can get support and learn from experienced condition as your child. You can share resources, experiences, strength and hope. To register call 800-562-6265 or parents. • Learn about all communication options and resources. email parentgroups@lighthouseguild.org Link up with other families and family events. Get tools to navigate challenging systems. American Foundation for the Blind (AFB): Family Connect http://www.familyconnect.org/parentsitehome.aspx **Hands & Voices National Organization** "On Family Connect you'll find videos, personal http://www.handsandvoices.org/index.htm stories, events, news, and an online community that can offer tips and support from other parents of children who are blind or **Hands & Voices Washington State Chapter** visually impaired." http://www.wahandsandvoices.org/ National Federation of the Blind (NFB): www.nfb.org "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."

Hard of Hearing

### 3. AREAS OF UNDERSTANDING FOR ALL FAMILIES

### **Deaf/Hard of Hearing**

# Parent Notebook for Families of Children Who are Deaf or

At the time their child's hearing loss is diagnosed, families should receive a copy of: *Parent Notebook for Families of Children Who are Deaf or Hard of Hearing*<sup>1</sup>. 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.

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.

**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.

See Parent Notebook sections: Your Child's Hearing; Tests.

- 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.

# **Blind/Visually Impaired**

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.

- 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 braillist). 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.

<sup>&</sup>lt;sup>1</sup> 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: <a href="http://www.doh.wa.gov/Portals/1/Documents/Pubs/344-017">http://www.doh.wa.gov/Portals/1/Documents/Pubs/344-017</a> EHDDIResourceGuideEng.pdf and download a copy.

# **Deaf/Hard of Hearing**

**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.

Parent Notebook sections: Getting Started; Communication Options.

- 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.

**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.

Parent Notebook sections: Communication Options.

 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.

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# **Blind/Visually Impaired**

AREA 2. The family/caregivers understand early infant/caregiver 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.

- 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 nonverbal) 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.

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.

 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.

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### **Deaf/Hard of Hearing Blind/Visually Impaired** The child and family's IFSP will include outcomes to encourage Parents often need time to process new information and vocabulary from the audiologist, as well as how to care for and compensatory skills to accommodate for the visual impairment check their child's amplification system. and use of other senses during daily activities. Young children also need support in using HAs, as the auditory Members of IFSP team who are not trained in visual impairment stimulation will be a new experience for their brain. Also, HAs are will collaborate with TVI to learn about the sensory modalities of very small and may be pulled out of ears to mouth and play with. the child and become knowledge about the potential differences in concept development of individual children. 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. Tip: Communication modality is not chosen based on the hearing technology a child uses.

**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**.

Parent Notebook sections: Communication Options.

- 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.

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.

**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.

- 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**

**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.

Parent Notebook sections: Your Child's Team; Advocacy; Staying Organized.

- 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.

TIP: The Statewide Center on Childhood Deafness & Hearing Loss (CDHL) can provide evaluation services or support with assessments.

# **Blind/Visually Impaired**

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.

- 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.

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.

- 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**

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.

We strongly support the philosophy that families need time—

- 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.

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.

- 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.

We strongly support the philosophy that families need time—

- 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.

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.

- 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.