



# WASHINGTON STATE EHDDI LEARNING COMMUNITY

## Best practices: Family-centered Care and Communication

***Draft: This best practices document was developed by group of WA EHDDI stakeholders and is currently being distributed to the greater WA EHDDI community for input. Please contribute comments to [wselc@uw.edu](mailto:wselc@uw.edu).***

**Overview:** Stakeholders in the WA EHDDI (Early Hearing Loss Detection, Diagnosis and Intervention) system have crucial roles in supporting each family that navigates the process of learning about their child's hearing and the importance of access to language and communication. The quality of care and the effectiveness of conversations between stakeholders and families impacts the outcomes for children and their families. EHDDI stakeholders include newborn hearing screeners, audiologists, family resource coordinators, early intervention providers, family mentors, and adults who are Deaf or hard of hearing.

### **The family**

The EHDDI process involves a series of steps of detection, diagnosis, and intervention. From the perspective of the family, the process involves initially wondering about their child's hearing and then, for some families, learning that their child is deaf or hard of hearing. As the family learns about childhood hearing loss and how it impacts their child, they discover the many opportunities for addressing the child's hearing levels with different communication approaches and/or hearing technology. The family members experience joys and challenges that are common to all families as well as those that are unique to raising a child who is deaf or hard of hearing. The family supports their child's inherent right to live, love, play and pursue their dreams within their community, and as parents, how they will achieve these goals for their child within their family. Family culture plays an important role in every family, and culture is composed of a multitude of components that impact family values and decisions on this journey. Cultural factors that may have the most relevance in EHDDI process include: view of medical and educational professions, view of deafness, view of child development, parenting style, family education, family socioeconomic level, and community and family support.

### **Family-centered care**

During the early period of information gathering and decision-making, families are supported by EHDDI stakeholders who present and discuss unbiased information. In the WA EHDDI system, we work together in the best interest of the child and the family. Services and supports follow the family's vision and priorities and build on family strengths. We are all respected for our skills, strengths, and expertise. We engage with each family in making informed decisions about which resources and supports are best suited for meeting their needs at a given time. Stakeholders help the family navigate the EHDDI system, moving from each phase as smoothly as possible to allow the family to be engaged and included in their child's growth and development. A family's involvement looks different depending on their culture and background, though ultimately for a child to be successful and have positive outcomes, a family must be involved participants. Care includes all members of the family and their circle of support. Families feel supported by those who provide quality care, discussion of child- and family-centered opportunities,



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and emotional support to them on their journey of raising their child who is deaf or hard of hearing. Families benefit when we recognize that families also need support outside of the family-professional relationship. We provide resources and encourage families to seek support from 1) other families who have children who are deaf or hard of hearing, 2) Deaf and hard of hearing adults, 3) existing communities surrounding a family. By providing these supports and resources families can begin to envision what they want and don't want for their child in order to reach their desired goals and outcomes for their child's future and ultimately what the child chooses for his/her future.

#### **Culturally-sensitive care**

Cultural competency is an intricate part of providing family-centered care to the diverse families in Washington State. Stakeholders honor the cultures and traditions of each family. We are engaged in a process of developing awareness, sensitivity and skills in interacting with people of diverse cultures. Lastly, we have awareness of the variety of Deaf and hard-of-hearing communities and cultures.

#### **Crucial conversations**

Stakeholders and families are involved in many conversations about the impact of a child's hearing levels and discussions about choices to address the child's hearing. Families benefit when we offer clear and concise discussion of information and options in child-centered family-friendly phrasing that is individualized to the family's unique needs. Conversations with families involve sharing information, but we also use skills of active listening to attend to families' questions, concerns, and comments and provide emotional support. We create a partnership when we build rapport and support families where they are along their journey. When we ask families questions about their perspective, we strive to view the child from the family's perspective and seek to understand their values and goals for their child.

The first step in the EHDDI process is informing families of results of newborn hearing screening. Newborn hearing screeners convey the importance of returning for follow-up screening and provide resources about follow-up with an audiologist, as needed. Professionals who provide newborn hearing screenings and re-screenings support families in this early part of the process by not over interpreting a baby not passing a screening as indicative of permanent hearing issue or by downplaying the baby not passing a screening as likely indicative of a temporary issue, but instead explaining that either is possible. Screeners inform families that further detailed hearing assessments with an audiologist will provide more information.

It falls to the audiologist to inform parents of the child's hearing levels following an evaluation. The audiologist is responsible for describing the impact of the hearing levels on the child's language, learning, and social-emotional development. Audiologists are most effective when conversations include family-friendly terminology and provide the amount of detail that the family needs at the moment, based on their questions and comments. Audiologists recognize that diagnostic test details that are



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important to the audiologist are not necessary details for the family in the first stages of learning about their child's hearing status, and that families are more interested in what the child can and cannot hear and how hearing loss will impact their child's communication and development. Families benefit from stakeholders who provide them with a balance between realistic expectations that their child will be impacted by hearing loss along with realistic hope that their child will develop and grow to be a happy and successful adult.

Audiologists, family resource coordinators and early intervention providers make up a family's professional support team that provides families with information about communication and technology opportunities. Trained parents and Deaf and hard-of-hearing adults make up the community-based support team for the family in their decision-making and planning. All individuals present and discuss all opportunities without bias. Professional and family support programs respect family choices and support families to make informed decisions. Information is provided with the intention of illuminating the parent perspective of the child, rather than changing or swaying their perspective. Stakeholders support the development of informed, independent, and involved families. With these supports over time, families can explore what is working for them and identify barriers for their goals for their child and learn to advocate for their child's needs.

#### **Shared vocabulary**

We strive to use vocabulary that is clear to families and respectful to the family and the child. Using the phrasing of "the baby did not pass the newborn hearing screening" instead of "referred on newborn hearing screening" is preferred, as the term "refer" can be confusing. The terms "hearing levels" and "hearing differences" provide a more neutral description of the range of hearing levels, whereas "hearing loss" has a place in describing a diagnosis. "Child who is deaf or hard of hearing" instead of "hearing impaired child" is an example of using person first terminology. Using terms such as "evaluation" and "measure" instead of "test" conveys that audiological assessments provide information about a child's hearing and are not graded tests. "Meeting age-expected milestones" preferable for describing a child's developmental progress. "Hearing technology" and "hearing devices" are good collective terms that encompass a range of devices that children use. "Opportunities" describes a variety of choices families can make, whereas "options" implies that families must choose one over another.



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### **Resources**

[American Speech Language Hearing Association guidelines for audiologists providing informational and adjustment counseling to families of infants and young children birth to 5 years of age. \(2008\).](#)

[NCHAM ebook: A Resource Guide for Early Hearing Detection and Intervention. Chapter 13: Family Support and Cultural Competence. DesGeorges, J. Chapter 11 Parent Counseling in the Information Age: The Rules & Roles Have Changed, Schmetz, L. \(2019\).](#)

[CDC: Hearing Loss in Children: Family Decision Making](#)

[Charting the Life Course Framework.](#)

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