



HANDS &
VOICES™

TIPS FOR MEANINGFUL PARTICIPATION

TIPS FOR MEANINGFUL
PARTICIPATION BY PARENTS AND
ADULTS WHO ARE DEAF AND HARD
OF HEARING SERVING IN EARLY
HEARING DETECTION AND
INTERVENTION (EHDI) SYSTEMS*

**Specifically, Advisory Committees and Learning Communities*

“The goal of early hearing detection and intervention is to maximize the linguistic and communicative competence and literacy development for children who are deaf or hard of hearing.”ⁱ

Purpose:

Local EHDI Advisory Committees and Learning Communities are created to advise and assist the EHDI program in a state/territory to successfully implement program goals and to promote and improve effective collaboration between parents of children who are deaf and hard of hearing (D/HH) and the professionals who serve them.

Parents who have experienced the EHDI system for their own child/family and adults who are D/HH can provide rich input and expertise into the implementation and improvement in one or more of the following areas: medical, educational, and other services to families.ⁱⁱ They will have a range of experiences with the EHDI system. Some may be very experienced and represent a vast stakeholder group, while others may have limited knowledge in one or more of the following areas: medical, educational and other services for families. Additionally, personal experience of the individual may have occurred in the distant past and/or limited to certain geographic locations.



The goal of this guidance is to:

- Ensure participation by diverse parents and adults who are D/HH through intentional planning during recruiting, onboarding and facilitating meetings.
- Aid parents and individuals who are D/HH to enter the relationship with clear expectations of how they will participate.
- Foster parent and adult satisfaction in serving in these roles by seeking, valuing, implementing and gaining feedback about their meaningful and active engagement.

Assessment/Gap Analysis of Diversity of Committee/Learning Community:

Committee/Community representation may be determined by local statute, by-law's or guidelines and could include stakeholders in the newborn hearing screening and intervention system such as audiologists, speech-language pathologists, primary care providers, nurses, early interventionists/educators for deaf and hard of hearing, ENTs, geneticists, diverse parents of children who are D/HH and diverse individuals who are D/HH who are representative of the diversity of the families served. The following are considerations for the assessment of membership:

- Parents and individuals who are D/HH will comprise 25% of the EHDI advisory membership and learning communities should include a family member of a deaf or hard of hearing child, per Maternal Child Health Bureau (MCHB) 2017 grant requirements.ⁱⁱⁱ
- Committee/Community members will demonstrate a diversity of experience and expertise, including language and communication modes used at home and in practice and educational methodology for children who are D/HH. Diversity can include but is not limited to hearing loss that occurred at birth or occurred later, unilateral, and bilateral, all degrees from minimal to profound, sensorineural, auditory neuropathy, conductive and mixed, DeafBlind, and D/HH Plus additional health concerns. Diversity in the age of children represented and socio-economic backgrounds is also helpful. To ensure this diversity, more than one parent and more than one individual who is D/HH is needed. However, keep in mind that a diverse group is not meant to “represent” certain modalities, experiences, and such—more important is the ability to understand the complexities that families with D/HH children face and the ability to honor a family’s journey. Parents and D/HH individuals have their own personal journeys and bring a unique perspective to the systems that serve families with D/HH children.
- Recurring (annual) assessment of membership by parents of D/HH children and individuals who are D/HH will provide an opportunity to ensure program balance/minimum requirements as membership changes.
- An effective advisory member can:
 - See beyond their own experiences to understand and represent the needs of other families
 - Respect and honor the perspectives of others
 - Understand and practice support without bias



- Demonstrate empathy and genuineness
- Work in partnership with others
- Share their experiences, perspectives, and expertise with respect to differing views
- Collaborate on planning, execution, and delivery of services to serve every family
- Contribute to the decision-making process to benefit families

Recruitment of Parents and Individuals who are D/HH:

EHDI systems benefit from developing a plan for how parents of children who are D/HH and individuals who are D/HH will be recruited. After assessing the number and diversity of current representation and gaps, the Committee/Community could:

- Form a new member subcommittee to aid with recruitment, including members who are parents and individuals who are D/HH.
- Reach out to modality-specific consumer groups (parent/adult), education programs, organizations, unbiased consumer groups, and past members.
- Have an application process (possibly including references) or interview to assess the individual's personal experience, knowledge base and ability to respect the diverse perspectives serving on the Committee/Community.
- Share the time commitment for participation.
- Provide participation stipend or reimbursement for child care, travel or other related expenses.
- Create virtual participation opportunities when in-person attendance is not possible.
- Meeting location, dates and times should optimize participation by parents and adults who are D/HH.

Maximizing Communication Access:

Communication access should be provided at all meetings and in accordance to committee member's needs. This can include providing/ensuring:

- Sign Language Interpreters/Transliterators, Cued Speech Transliterators (Qualified/Certified according to state regulations), Real time captioning and Remote Real Time Captioning, Enlarged print or other accommodations. Members should be asked their preferred form of access, room configuration and providers, within limitations.
- Communication Ground Rules for all meetings and interactions, such as the Hands & Voices Communication Ground Rules. This includes clear communication by permitting one comment at a time, asking participants raise hands and wait to be called upon to share, allowing time for parents and participants who are D/HH to contribute to discussions.
- Room is equipped with sufficient lighting, ample microphones/good acoustics, elimination of window glare, seating in a semi-circle or V-shape whenever possible, unobstructed views to visual information, set up and test and assistive technology prior to start of the meeting.



- Virtual options for participation or subcommittee work also needs to be accessible with the preferred method of the individual.

Onboarding Parents and Individuals who are D/HH:

All new members will benefit from an orientation that provides background and time for question and answer, separate from the meeting time. Components should include:

- Overview of EHDI System and Services such as:
 - Statistics about how many children are identified annually
 - Number of children with mild, moderate, severe, profound, unilateral, etc.
 - Other demographic information
- List of EHDI System terminology and acronyms commonly used.
- Defining the scope/purpose and limitations of the Committee/Learning Community.
- Discussion of a foundation of respect for all perspectives and informed parent choice in decision-making.
- Description of stakeholders and representation on the Committee/Community, including what stakeholder group each member represents and expectation to report information back to constituency.
- Explanation of meeting/voting procedures and by-law's (encouraged as applicable).
- Training about how to ask questions/share information that is relevant for parents in general, rather than sharing information about a parent or adult's personal experience that may not apply to a larger constituency.
- Conduct during meetings and representation of the committee/community outside meetings.
- Establishment of a buddy system where new members are teamed with an experienced parent or individual who is D/HH.

Meaningful Participation of Parents and Individuals who are D/HH:

Meaningful participation can be defined as: contributing to development of the agenda, consistent attendance/participation, discussion at meetings or in subcommittee work, and serving in a leadership role. To maximize engagement, the Committee/Community can take simple steps to actively seek parent and D/HH adult input including:

- Attention to meeting agendas items to be relevant topics for parents and adults to contribute. During meetings, parents and adults will be invited to share their perspective.
- Consideration of a standing agenda item where parents and adults share relevant portions of their personal story (or another parent or D/HH youth or adult) to bring focus to the purpose of the committee/community's work.



- Commitment and encouragement of parents and individuals who are D/HH to serve in a Committee/Community in a leadership capacity, whenever appropriate.

On-Going Assessment of Engagement:

Feedback from parents and adults who are D/HH after onboarding and thereafter on a regular schedule provides opportunities to ensure their needs and those of the Committee/Community are met. Here are some topics to consider:

- Satisfaction with the onboarding process.
- Quality of communication access and meeting format.
- Ability to meaningfully participate and contribute to meetings/discussions/projects.

“Diversity and inclusion, which are the real grounds for creativity, must remain at the center of what we do.” - Marco Bizzarri



ⁱ JCIH 2007 Position Statement, Pediatrics Vol. 120 No. 4 October 1, 2007 p. 898
<http://pediatrics.aappublications.org/content/pediatrics/120/4/898.full.pdf?download=true>

ⁱⁱ Supplement to the JCIH 2007 Position Statement, Pediatrics Vol 131, Issue 3, April 2013 Goals #8 and 10
<http://pediatrics.aappublications.org/content/pediatrics/131/4/e1324.full.pdf?download=true>

ⁱⁱⁱ HRSA-17-059: Universal Newborn Hearing Screening and Intervention Program
<https://mchb.hrsa.gov/fundingopportunities/?id=26775015-d525-4b9a-a65e-65200fa397a3>