

HANDS & VOICES

FAMILY LEADERSHIP IN
LANGUAGE & LEARNING (FL3)

DHH GUIDELINES

GUIDELINES FOR
DEAF AND HARD
OF HEARING
MENTOR/GUIDE/
ROLE MODEL PROGRAMS



HANDS &
VOICES™

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I. Introduction

The inclusion of Deaf and Hard of Hearing (D/HH) adults in the lives of families with children who are D/HH can have a profound impact for everyone involved; child, parent, professionals and D/HH adults. Trained D/HH adults who act as mentors, guides or role models are uniquely qualified to provide families with a positive and hopeful perspective from their day-to-day, real life experiences as a D/HH person living in a hearing world. In sharing these experiences and insights, D/HH mentors/guides/role models may be able to articulate what a young child cannot, which brings an important perspective and credibility to the team discussion of the child's needs, extending beyond academics.

When the parent of a child newly identified as deaf or hard of hearing looks ahead, they may tend to focus on what is missing. The D/HH mentor/guide/role model has an opportunity to present to the family a perspective of optimism. By sharing stories, experiences and asking questions, the D/HH mentor/guide/role model may help the family take a step beyond that first awkward moment of how to "talk to a Deaf or Hard of Hearing person." The D/HH mentor/guide/role model can build a relationship with the family and support the bond between the parent and child. What is desired for all families, hearing or not, is the ability for their children to form and maintain lifelong relationships. Initiating a connection with an adult who is D/HH starts the family on the path of building new social networks, ones they may not have ever pursued without knowing their child was deaf or hard of hearing.

The following guidelines are intended to offer suggestions for EHDI systems as to recommended practices in provision of D/HH mentor/guide/role model services to families/children. Strength and support for families and access to mentorship programs can be found in Goal 11 of the Joint Commission on Infant Hearing (JCIH)¹ * position statement:

"Goal 11 (pg. e1338) All children who are D/HH and their families have access to support, mentorship, and guidance from individuals who are D/HH. This goal intends that families have access to meaningful interactions with adults who are deaf or hard of hearing who have the knowledge and skills to mentor, support, and guide families in culturally and linguistically sensitive ways and to serve as communication/language and social role models and mentors for deaf and hard of hearing children and their families."

These recommendations are advised by the FL3 D/HH Advisory Committee² and contributed to by members of the NCHAM Adult Involvement Learning Community³ and other community stakeholders.

II. Working Definitions of Terms

A. Deaf Mentors

The term "Deaf Mentor" or "deaf mentor" is a trademarked title referring to the staff using the Deaf Mentor Curriculum provided by the SKI HI Institute. SKI-HI Deaf Mentors are adults

who are Deaf or Hard of Hearing themselves and may be staff in the SKI-HI “Snapshots” Program. This program provides a series of visits (up to 6) to help the family understand more about life as a deaf or hard of hearing individual, including their life story, adaptations that are a part of a deaf person’s life, and things that are unique to being deaf or hard of hearing. The families have the option to meet as many Deaf Mentors as they like. If families have a desire to learn and use American Sign Language and learn more about the Deaf Community, then families can receive SKI-HI Deaf Mentor services on an ongoing basis, typically weekly. A SKI-HI Deaf Mentor is trained in ASL instruction and interacts with the child and family using ASL, shows family members how to use ASL through informal interaction and formal ASL lessons, teaches the family about Deaf Culture and introduces them to the local Deaf Community.

B. Deaf/Hard of Hearing Adult Role Models

Adult Role Models are adults who are deaf and hard of hearing. They may communicate via Listening and Spoken Language (LSL), Cued Speech/Cued English, and/or American Sign Language. They provide children who are deaf and hard of hearing and their families with insight into life experiences as an adult who is deaf or hard of hearing. In their position as an Adult Role Model, they do not teach ASL. The full range of hearing levels, communication modalities, technology use, educational placement are ideal for diverse staffing of a comprehensive Adult Role Model program. Role models typically are more likely to engage with a family on a short-term basis.

C. Deaf/Hard of Hearing Guides

A program of Hands & Voices, Guide By Your Side (GBYS) – D/HH Guides are a diverse group of D/HH adults who compliment the work of Parent Guides by working alongside them. D/HH Guides share with children and families their unique life experiences, use of technology, how they navigate social situations, how they developed their personal identity, etc. D/HH Guides undergo the similar training as Hands & Voices Parent Guides and all Guides are under the supervision of a local GBYS Coordinator as well as provided opportunities for ongoing training and networking through Hands & Voices Headquarters.

D. D/HH

Deaf/Hard of Hearing (D/HH) is intended to be inclusive of all children and adults who are deaf and hard of hearing whether from birth or hearing loss 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.

E. Language Instruction

In this document, specifically describing programming that provides direct language instruction, such as American Sign Language (ASL), may be necessary. If needed, the term “language instruction” will be used.

III. Assessment of Community/Family Needs

A. Rationale

To provide D/HH mentor/guide/role model services meeting the needs of all families/children, assessing the services that already exist is critical. This practice will identify strengths, avoid duplication and competition for funding, while identifying gaps and creating programming complementary and supportive to existing services.

B. Recommendations

1. A local stakeholder group⁴ who are an advisory group composed of a critical mass of members who are D/HH, especially those with experience with Early Intervention (EI) services and programs, along with representatives from the state EHDI system and EI providers with expertise and skill in providing services to families of infants and toddlers who are D/HH and parents of children who are deaf and hard of hearing. This stakeholder group will participate in and review local and other needs assessment information to gain more input to make decisions about how to proceed based on:
 - a. Families' needs are met with current programs and funding is adequate.
 - b. Families' needs are met with current programs, but funding is not adequate.
 - c. Families' needs are not met with current programs and additional programming is needed, and adequate funding exists.
 - d. Families' needs are not met with current programs and additional programming is needed, and adequate funding does not exist.
2. Initiate local needs assessments by conducting surveys, focus groups and/or interviews with families, stakeholders, and D/HH adults to determine what services exist and what families need.
3. Review needs assessments done by other sources such as the NCHAM Adult Involvement Learning Community⁵ and Lifetrack's Wilder Assessment.

IV. Funding for Programs

A. Rationale

Adequate, sustainable funding is important for the ability of states and territories to deliver services directly to all families, according to their needs, providing flexibility and options. Funding should be adequate to provide services to all families regardless of their geographic location, language of origin in the home, socio-economic status, child's communication modality, level of hearing, etc. Funding is used to hire coordinators, Mentors/Guides/Role Models, provide ongoing training, and program evaluation.

B. Recommendations

1. Collaboratively identify potential funding mechanisms for sustainable support services to families from individuals who are D/HH. ^{7·8}
2. Adequate funding to offer all families of newly identified children with the opportunity to access trained adult role models or guides in a formal program, preferably, at no cost to families.
3. Funding should allow for participation of all parents, no matter where they are located in the state or territory.
4. Funding to support **paid** staff at all positions: Coordinator, Mentors/Guides/Role Models, etc.
5. Funding to support **paid** training for all positions
6. Funding to cover expenses for travel etc.
7. Funding to provide program evaluation including client satisfaction surveying and reporting.
8. Funding should support participation of families whose first language is not English.
9. Adequate funding to offer all families of newly identified children who wish to acquire American Sign Language skills, the opportunity to access deaf mentors/Deaf Mentors who can provide instruction in group or on an individual basis.⁹

V. Program Coordinator

A. Rationale

The Program Coordinator plays a critical role in establishing mentoring services that meet the needs of families, is responsive to client feedback and community need, using information obtained from the assessment recommendations in section III, overseeing comprehensive and on-going staff support, financial oversight, program evaluation and reporting.

B. Recommendations

1. Coordinator is preferred to be an adult who is D/HH
2. Position has a written job description outlining responsibilities such as:
 - a. Responsible for establishing policies and procedures
 - b. Responsible for hiring and managing staff
 - c. Responsible for initial and on-going training for staff

- d. Responsible for financial oversight of the program in context to how the program is structured and funded
 - e. Responsible for program evaluation and reporting
3. Coordinator is accountable to a larger stakeholder community/advisory council who can provide feedback about the effectiveness of the program
 4. Coordinator has an annual performance review and plan for on-going professional development.

VI. Program Design/Services Provided

A. Rationale

Opportunities for families to meet D/HH adults may vary from state to state. Clear communication about what kinds of services are available are helpful for parents to understand and for professionals to refer appropriately.

B. Recommendations

1. Established policies and procedures, including:
 - a. D/HH mentor/guide/role model services abides by the policies and procedures outlined in their contract and by the agencies and organizations where the program is housed.
 - b. Determination by local stakeholders about when D/HH mentor/guide/role model services will be offered, what ages of children will be served, how often services will be offered to families, as well as a referral system, and how this service differs from other D/HH mentor/guide/role model services available.
 - c. A procedure for responding to parent inquiry, assisting with application process which is simple, easy and avoids unnecessary barriers to enrollment
 - d. Careful determination of which staff will provide services to a family based on the family's needs/interest. The program will provide families sufficient background information about the mentors/guides/role models for the families to make informed decisions about whom to meet
 - e. Procedure for scheduling meetings between families and D/HH mentor/guide/role models including confirmation of appointments, rescheduling, documentation
 - f. Guidelines for successful initial and follow up calls, home visits, etc. including how to convey personal background information in an unbiased manner
 - g. Strength-based programming and support for positive child/parent relationships
 - h. Develop systems that ensure that neither geographic location nor socioeconomic sta-

tus limits access to competent and skilled language instructors. State systems should consider utilization of all technology, including computer and videophones, to support teaching families¹⁰

- i. Ensure access and cultural sensitivity to families whose first language is not English
- j. Develop and implement guidelines that address providing families with access to D/HH individuals who can provide family support (these guidelines should outline the background and training necessary for support personnel/role models who are themselves D/HH to interact with families of infants/children newly identified as D/HH; these systems should guarantee that families have access to the services regardless of audiologic status (hearing levels or type) and the geographic location of the family)¹¹
- k. Safety of D/HH mentors and families and especially children, including mandatory reporting considerations¹²
- l. Delineation of the types of services offered: language instruction versus life experience coaching as described under “definition of terms”
- m. If a curriculum is followed, citation and training on the curriculum is established
- n. Collaboration with other programs, such as early intervention, local Hands & Voices chapters and other family-based organizations such as Family Voices, advocacy centers and health information centers
- o. At the end of services, programs provide resources for families to stay engaged with adult role models/guides and/or deaf mentors/Deaf Mentors on an informal basis
- p. For families communicating in various modalities, they will be offered opportunities to meet with other families who use that modality with the intention of lifelong learning and community for child and family
- q. Periodic review of staffing, policies, procedures and the services provided to reflect current practices and responses of parent satisfaction feedback. This may include modifying service delivery to provide better program access to families and meeting family’s needs
- r. Program Coordinator and D/HH mentor/guide/role models are integrated into local, state and national systems by serving on Advisory boards, serving in leadership positions etc.¹³

VII. Hiring Practices

A. Rationale

The strength of a program lies in its strong people with positive attitudes and their ability to respect the needs, values and perspectives of families. Strong individuals can share their stories with humor, grace, and a sense of purpose.

B. Recommendations

1. Ensure the D/HH mentors represent the diversity of the EHDI population (e.g., deaf culture, hard of hearing, cochlear implant and hearing aid users, unilateral, auditory neural, cultural diversity).¹⁴
2. Recruitment efforts are made to ensure staff diversity
3. Written job description for staff detailing job requirements, candidate qualifications and scope of work
4. Hiring practices are in accordance with the agencies and organizations where the D/HH mentor/guide/role model services are housed
5. Interview questions will assess the applicant's ability to provide services according to expectations
6. Ensure that program staff can accept, without judgment, a family's choices for communication, educational placement, technology use, etc.¹⁵

VIII. Training Practices

A. Rationale

Quality Deaf Mentor and DHH Guide and Role Model programs have training programs in place to provide a standard of care for services. This practice ensures families receive services by D/HH mentors/guides/role models who understand and honor the complexity of a family's journey and adhere to a consistent level of professionalism.

B. Recommendations

1. Training for D/HH mentor/guide/role models will be provided by individuals with the necessary qualifications to effectively train staff in:
 - a. Unbiased delivery of services/respect for parent choice, including honoring a family's decision around technology use or not, language and communication modality or educational placement of the child ¹⁶
 - b. How the mentor/guide/role model describes their personal background to help the family understand the circumstances surrounding their language acquisition/communication, educational placement, technology choices, etc.
 - c. How mentor/guide/role model will share positive experiences from their life to explain their story, refrain from sharing negative experiences or specifying specific people/programs/names related to negative experiences
 - d. How to determine limitations of one's own experience and when to refer families to someone else with more expertise in a particular modality or experience

- e. Services provided to families delivered with adherence to confidentiality and safety rules
- f. Appropriate expectations/professionalism by staff (appointments kept, professional boundaries established and maintained, staying within the scope of mentor/guide/role model job description despite professional background in another area)
- g. Necessary documentation and reporting of activities to meet program and grant requirements and to provide families with strategies and progress updates
- h. Referral process to other D/HH mentor/guide/role models and outside programs
- i. For ASL or cued speech instructors, age-appropriate strategies and techniques for teaching sign language or cued speech to families¹⁷ and assessing language development by child and families

IX. On-Going Professional Development

A. Rationale

Quality Deaf Mentor and DHH Guide and Role Model programs have established practices and processes for on-going support for staff professional development, staff performance reviews, for continuous maintenance/updating of services and assisting families in transitioning out of the program. This practice will ensure the programs continuously evolve just as the needs of the families they serve may change over time. The Program Coordinator will oversee this process with consultation from an advisory group.

B. Recommendations

1. Consultation with an advisory group composed of a critical mass of members who are D/HH, especially those with experience with EI services and programs, along with representatives from the state EHDI system and EI providers with expertise and skill in providing services to families of infants and toddlers who are D/HH and parents of children who are D/HH who continue to help identify funding mechanisms, review guidelines for the program, continue to review leadership training protocol and curriculum for role models and ensure a quality mentoring and monitoring system for role models¹⁸
2. Ongoing program oversight by program leadership trained in management of human and financial resources
3. Ongoing professional training for program leadership and staff including providing opportunities for staff to meet other adults with diverse life experiences and families who have chosen diverse communication, educational placement and technology use for their children who are deaf and hard of hearing as well as exposure to vetted research about diverse communication among children who are deaf and hard of hearing, oppor-

tunities to attend workshops, conferences (local, statewide and national)

4. Annual formal evaluation of leadership and staff provide opportunities to assess the strengths and need for professional development, can ensure alignment with the program's goals and offer feedback from team members to the design and delivery of services
5. Participation in national network of coordinators and trained staff, encouraging engagement outside the communication modality of the coordinator and staff
6. Ongoing use of a quality assurance program for ASL instructors of parents/ families. The program should (1) assess their fluency in and knowledge of ASL (existing models for such assessment include the ASL Teachers Association, the Registry of Interpreters for the Deaf, and the ASL Proficiency Interview) and (2) determine their ability to tailor the instruction so that families are prepared to communicate with infants and very young children¹⁹

X. Evaluation and Reporting

A. Rationale

Assessment of family satisfaction with the services they receive is critical to ensure programs are responding to family's needs and continually improving services. Programs also required to report their activities and family satisfaction to their funding sources and can assist their EHDI system in meeting their grant requirements by reporting data.

B. Recommendations

1. Data collection on all program activities (number of families served, number of presentations given, number of events staff attended, etc.)
2. Formal process to collect customer satisfaction data including questions about the professionalism of staff, respect for parent choice, delivery of unbiased information, staff punctuality and attendance at scheduled meetings, etc.
3. Report of measures of program effectiveness/program goals met
4. If a satisfaction survey identifies dissatisfaction with services or breach of unbiased delivery of services, process for addressing issue and an appropriate resolution for the family
5. Report on Language instructors: States and territories report the percentage of families and children who can access ASL learning opportunities from a skilled, fluent ASL user. All families who chose ASL will have access to trained and skilled ASL instructors who use effective ASL learning programs for families with young children who are D/HH. Families who elect to use sign systems or cued speech also have access to users with fluency²⁰

6. Assistance to EHDI Program in reporting all families have access to professionals/individuals in a variety of different roles who are themselves D/HH²¹

XI. Appendix

Examples provided are of complementary and supporting documents from various organizations who are willing to share excerpts or entire documents with permission (needs assessments, funding sources, job descriptions etc.)

1. JCIH 2013 Supplement
 - » <http://pediatrics.aappublications.org/content/early/2013/03/18/peds.2013-0008>
2. “Families with Young Children who are Deaf and Hard of Hearing in Minnesota: A Mentoring Needs Assessment Conducted for Lifetrack, June 2015”
 - » <https://www.wilder.org/Wilder-Research/Publications/Studies/Lifetrack%20-%20Families%20with%20Young%20Children%20who%20are%20Deaf%20and%20Hard%20of%20Hearing%20in%20Minnesota/Families%20with%20Young%20Children%20who%20are%20Deaf%20and%20Hard%20of%20Hearing%20in%20Minnesota%20-%20A%20Mentoring%20Needs%20Assessment.pdf>
3. Funding Tip Sheet
 - » <http://www.infanthearing.org/dhhadultinvolvement/docs/tools/Funding%20Tip-sheet%20for%20DHH%20Adult%20Involvement%20Programs-8-14.pdf>
4. Research and Published Literature via NCHAM Adult Involvement Learning Community
 - » <http://www.infanthearing.org/dhhadultinvolvement/research.html>
5. Resources and Tools via NCHAM Adult Involvement Learning Community
 - » <http://www.infanthearing.org/dhhadultinvolvement/resources.html>
6. Deaf Mentor Job Description, Maine Early Intervention Program
 - » <http://www.mecdhh.org/uploads/Pdfs/DeafMentorASLTrainerFall2015.pdf>
7. D/HH Guide Job Description, Texas Hands & Voices
 - » <http://www.infanthearing.org/dhhadultinvolvement/docs/texas/DHH-Guide-Job-Description-2014.pdf>
8. D/HH Role Model Job Description, Minnesota Lifetrack Program
 - » <http://www.lifetrack-mn.org/about/careers/deaf-hard-hearing-adult-role-model>

End Notes

1. “The mission of the Joint Committee on Infant Hearing (JCIH) is to address issues that are important to the early identification, intervention, and follow-up care of infants and young children with hearing loss.” For more information:
<https://www.asha.org/aud/JCIH-History/>
2. In 2013, the Early Intervention Supplement to the Joint Committee on Infant Hearing Position statement 2007 was published:
<http://pediatrics.aappublications.org/content/early/2013/03/18/peds.2013-0008>
3. FL3 DHH Advisory Committee Members:
<http://handsandvoices.org/fl3/about-us/dhh-advisory.html>
<http://www.infanthearing.org/dhhadultinvolvement/examples.html>
4. Goal 11 of JCIH 2013 Supplement
<http://www.infanthearing.org/dhhadultinvolvement/>
<https://tinyurl.com/ybcgafy6>
5. Goal 11 of JCIH 2013 Supplement
6. NCHAM Adult Involvement Learning Community Funding Resource document
7. ASL taught by Deaf adults who are fluent in ASL is the focus here. The assumption is that each EHDI system will have adequate funding to support a family’s pursuit of Listening and Spoken Language and Cued Speech, but not necessarily taught by an adult who is D/HH. Goal 3b of JCIH.
8. Goal 3 of JCIH 2013 Supplement
9. Goal 11 of JCIH 2013 Supplement
10. For more information about Hands & Voices O.U.R. Project, visit: <http://handsandvoices.org/resources/OUR/index.htm>
11. Goal 10 of JCIH 2013 Supplement
12. Goal 11 of JCIH 2013 Supplement
13. JCIH 2013 Supplement
14. Goal 3a of JCIH 2013 Supplement
15. Goal 11 of JCIH 2013 Supplement
16. JCIH 2013 Supplement
17. Goal 3a of JCIH 2013 Supplement
18. JCIH 2013 Supplement
19. JCIH 2013 Supplement

