



A Community of Support

**Connecting Families of
Children who are Deaf or
Hard of Hearing (D/HH)
with Individuals who are
D/HH**

2018

Developed by the Early
Hearing Detection &
Intervention Parent to
Parent Committee



A Community of Support: Connecting Families of Children who are Deaf or Hard of Hearing (D/HH) with Individuals who are D/HH

About this Guide

This Guide was developed by the Early Hearing Detection and Intervention (EHDI) Parent to Parent Committee, which is an interdisciplinary, inter-agency/inter-organizational and diverse parent/professional group. This committee

is open to anyone who is interested – professionals, parents, D/HH adults. For more information contact Terri Patterson, Co-chair for this committee: terri@handsandvoices.org

Purpose of this guide:

- To share information about the positive aspects of connecting families with deaf and hard of hearing adults and community members.
- To describe several ways systems can provide and facilitate these connections. These approaches can be used in any combination, and they can be used at different points in a family's experience. Families should be able to choose the combination(s) that suit their situation.

All families, regardless of degree of hearing loss/level or communication/language of the child, should have the opportunity to interact and learn from D/HH Adults; this may include formal to informal interaction, from high level interactivity to low, etc.

Why are Deaf Mentors/Models so important to families of children who are deaf or hard of hearing (D/HH)?

It is because families benefit from increased access to support, dependable mentorship, and a connection for the hearing parent with the D/HH community. The D/HH community includes a variety of deaf, Deaf, deafblind, and hard of hearing individuals, who can offer insightful guidance. Such individuals are typically adults who work with the family and provide various types of assistance through one-on-one interaction. Such interactions also provide a comforting sneak preview into the future of the families' children. It is about offering opportunities to families to learn different skills for developing effective communication and positive connections with their children.

A variety of terms are used to describe individuals in these roles: deaf mentors, deaf guides, role models and partners. The importance of Deaf Mentor programs was demonstrated in a study by C.W. Jackson (American Annals of the Deaf, 2011 Fall; 156(4):343-62). This study surveyed 456 parents who had children who were deaf or hard of hearing. About 80% of

parents agreed that deaf role models and mentors, as well as the access to adults who are deaf or hard of hearing, is either moderately or very important.

Deaf Mentor, Deaf/Hard of Hearing Role Model and Deaf/Hard of Hearing Guide are terms used throughout this document. The terms have been used interchangeably in the past. For helpful definitions of these categories, please refer to the Hands & Voices D/HH Guidelines, Page 1 - <http://www.handsandvoices.org/fl3/fl3-docs/DHH-Guidelines.pdf>

The Matrix

Potential Opportunities for Families

There are a variety of resources that local, state, and national agencies/organizations may provide. This matrix looks at a continuum of opportunities that could be developed and made available to families. These opportunities are not a one-size-fits-all list nor are the resources/supports mutually exclusive.

This matrix was created by an interdisciplinary group of parents, professionals, and deaf/hard of hearing adults. It can provide insight and guidance to any groups looking at establishing programs and/or opportunities for connecting families with D/HH adults.

Target Audience

- **Administrators and managers** can use this document for ideas on how to improve and enhance family support in their programs. This document can help them meet Goal 11 of the **Supplement to the JCIH Position Statement: Principles and Guidelines for Early Intervention after Confirmation That a Child Is Deaf or Hard of Hearing** (pediatrics.aapublications.org/content/131/4/e1324).
 - » Goal 11: “All Children Who Are D/HH and Their Families Have Access to Support, Mentorship, and Guidance From Individuals Who Are D/HH.”
- **Families** can use the document to help them become aware of and consider the services and supports that may be helpful to them, and to help them advocate for that support.
- **Teachers of the D/HH** can use this document as a basis to refer families to the continuum of opportunities provided in this matrix.

In short, this document can be used by anyone seeking to learn about or provide structured opportunities for families that will help those families form supportive relationships with individuals who are deaf or hard of hearing.

On the following pages you will find **two separate Matrix and Checklist documents**:

1. The first list (**Systems Matrix** Pages 3 – 7) is for those seeking to build, implement, and/or sustain a network of opportunities for families in their state/region.
2. The second list (**Parent Matrix** page 8-12) is for parents to use to consider the different opportunities that are most applicable to their individual family’s needs.

While the two are similar, each Matrix has been developed with some unique considerations.

The Systems Matrix

Planning Scale

This matrix uses a Likert Scale to assist in evaluating/assessing the user’s rating of importance/desire, as well as the availability of resources available and impact for each opportunity. Please rate each factor on a scale of 1 to 5 using the JCIH Self-Assessment tool provided below:

For each question in the self-assessment tool, you will see response options based on five levels of system capability. It is not uncommon for systems, even successful ones, to be at relatively low levels in certain areas.

1. **Nothing in Place**- EHDI partners/programs have not yet begun to address this component.
2. **Just Beginning**- EHDI system for this component is at an early stage or period.
3. **Making Good Progress**- EHDI System for this component has made satisfactory development, growth, or advancement.
4. **Established Practice**- EHDI System for this component conforms to accepted standards.
5. **Exemplary Practice**- should be considered as a model for other areas/states

	1	2	3	4	5	Would like to explore... (Desirability)
State-based Deaf Mentor/HH Role Model Programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Events	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Virtual Interactions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Recorded Videos	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Some points to consider when using the Service Matrix:

- Consider which stakeholders will be involved in completing this form (e.g. programs, partners)
- Decide how to monitor the effectiveness of the programming/activities pursued
- Discuss the funding mechanism(s)
- Describe how information will be shared among service providers
- Discuss who will give the family matrix to families, and when
- Discuss how families may use this matrix at different times in their journeys
- Discuss how this form may be used in conjunction with an IFSP/IEP Communication plan as an addendum

Next Steps:

For the opportunities you rated above, your team will now determine:

- What areas/opportunities/activities you would like to further explore.
- The desirability of pursuing and developing these activities in your state.

In the next section please choose your team's determined area(s) and discuss the included considerations. Please use the checklists to encourage further discussion around your state's developmental needs:

- Rate the advantages and limitations
- State/team's readiness and current status
- Determine your ability to implement your choice(s)

State-based Deaf Mentor/Hard of Hearing Role Model Programs

Meets JCIH Recommended Guidelines (link in introduction)

Approach:

- Home visits
- Supplement visits with technology

Program Resources Required:

- Substantial funding
- Compensation
- Training
- Event space
- Travel
- Interpreters
- Food
- Supplies

Benefits:

- Standardized training
- Families can be connected to mentors or role models for individualized support
- Mentors serve as language model for child
- Mentors may provide sign language instruction
- Mentors and role models can also provide services using less formal approaches
- May be able to bill for services (*sustainability?*)
- Opportunity to build relationship
- Mentor can provide access to resources
- No financial burden for families seeking high level of engagement

Challenges:

- Requires the most resources
- Recruiting/hiring diverse Mentors and Role Models
- Promoting awareness of program
- Time/Frequency- ongoing and structured/often
- Location may affect availability of resources
- May not be sustainable

Other Considerations:

Events

Approach:

- Family picnics
- Workshops
- Camps
- Play groups
- Outings

Program Resources Required:

- Minimal to moderate funding
- Compensation
- Training
- Event space
- Travel
- Interpreters
- Food/Supplies

Benefits

- Mentors and Role Models are organizers, instructors and facilitators
- Opportunities to interact with other families of children who are D/HH
- Opportunities for families/individuals to engage with the cultural diversity in their community
- Opportunity for siblings/extended family to be exposed to D/HH individuals

Challenges

- Promoting events
- Accessibility/transportation
- Recruiting/hiring diverse Mentors and Role Models
- Scheduling
- Lacks individualized support
- May not be frequent enough to provide adequate support
- May not be sustainable
- Time/Frequency- syncing with family scheduling and/or availability of family
- Family travel may be required

Other Considerations:

Virtual/Social Media Interaction

Approach

- Facebook groups
- Listserv
- Message boards
- Scheduled online meetings

Program Resources Required

- Minimal funding
- Compensation
- Technology
- Training
- Promotion of awareness of program

Benefits

- Mentors or Role Models as moderators and facilitators
- Travel/distance not an issue
- Virtual Interaction with other families of children who are D/HH from around the world who may provide information, support and/or insights
- Time/Frequency- at the discretion of the family
- Diversity of Role Model exposure

Challenges

- Child who is D/HH may not participate
- May not involve language instruction for child
- Difficult to provide access in a variety of languages
- Tech savvy and availability
- Knowledge of existence of program- depends on accessibility to technology

Other Considerations:

Recorded Videos

Approach

- Individual stories and experiences shared by Mentors and Role Models

Program Resources Required

- Minimal funding
- Compensation
- Video production

Benefits

- Families can access at their convenience
- Travel/distance not an issue
- Can be translated in a variety of languages
- Time/frequency-at the discretion of the family

Challenges

- Not interactive
- Child who is D/HH may not participate
- May not involve language instruction for child
- Requires tech savvy and availability/access
- Knowledge of existence of program is less likely

Other Considerations:

The PARENT Matrix

Parents: First review the different types of opportunities listed in the table below. Then use this table to summarize your thoughts about each opportunity.

Opportunity	Advantages	Challenges	Does this exist in my state?	Can I access this easily?	Would like to explore
State-based Deaf Mentor D/HH Role Model Programs			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know	
Events			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know	
Virtual Interaction			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know	
Recorded Videos			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know	
Other?			<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know	

Next Steps For the opportunities you rated above, your family can now determine (1) what areas/opportunities/activities you would like to explore further and then (2) your interest in pursuing these opportunities for your family. Please use the checklists to suggest further discussions about resources offered in your state.

Types of Opportunities

State-based Deaf Mentor/Hard of Hearing Role Model Programs

Approach:

- Home visits
- Supplement visits with technology

Benefits:

- Families can be connected to mentors or role models for individualized support
- Mentors serve as language model for child
- Mentors can provide sign language instruction
- Mentors and role models can also provide services using less formal approaches
- Opportunity to build relationship
- Mentor can provide access to resources
- No financial burden for families seeking high level of engagement

Challenges:

- Time/Frequency- ongoing and structured/often
- Location may affect availability of resources

Other Considerations:

Events

Approach:

- Family picnics
- Workshops
- Camps
- Play groups
- Outings

Benefits

- Opportunities to interact with other families of children who are D/HH
- Opportunities for siblings/extended family to be exposed to D/HH individuals
- Opportunities for families/individuals to engage with the cultural diversity in their community

Challenges

- Accessibility/transportation
- Scheduling
- Lacks individualized support
- May not be frequent enough to provide adequate support
- Time/Frequency- syncing with family scheduling/availability of family
- Family travel may be required

Other Considerations:

Virtual/Social Media Interaction

Approach

- Facebook groups
- Listserv
- Message boards
- Scheduled online meetings

Benefits

- Travel/distance not an issue
- Virtual Interaction with other families of children who are D/HH
- Time/Frequency- at the discretion of the family
- Diversity of Role Model exposure

Challenges

- Child who is D/HH may not participate
- May not involve language instruction for child
- Difficult to provide access in a variety of languages
- Tech savvy and availability
- Knowledge of existence of program- depends on accessibility to technology

Other Considerations:

Recorded Videos

Approach

- ❑ Individual stories and experiences shared by Mentors and Role Models

Benefits

- ❑ Families can access at their convenience
- ❑ Travel/distance not an issue
- ❑ Can be translated in a variety of languages
- ❑ Time/Frequency-at the discretion of the family

Challenges

- ❑ Not interactive
- ❑ Child who is D/HH may not participate
- ❑ May not involve language instruction for child
- ❑ Tech savvy and availability/access

Other Considerations:

For more information If you have any questions about this document, or want further explanation of its terms or content, contact www.handsandvoices.org (Click on your state on the map for state-specific support) or contact parentadvocate@handsandvoices.org

For further resources regarding D/HH Mentors/Role Models/Guides find a list here: <https://www.infanthearing.org/dhhadultinvolvement/index.html>

For current programs in your state: <https://www.infanthearing.org/dhhadultinvolvement/states/index.html>

For information on this topic from the Hands & Voices Family Leadership in Language and Learning:

<https://www.handsandvoices.org/fl3/topics/dhh-involvement.html>

<https://www.handsandvoices.org/fl3/topics/dhh-involvement/resources.html>