

The Support Matrix: Identifying and Implementing Opportunities for Families to Connect with Individuals who are D/HH

EHDI Parent to Parent Committee

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Who WE Are

- Michele Berke
 - Raised in a Deaf family
 - Parent/grandparent of Deaf children
 - Student Outcomes Specialist at the California School for the Deaf
 - Committee member
- Janet DesGeorges
 - Parent of an adult daughter who is Deaf/Hard of Hearing
 - Executive Director, Hands & Voices Headquarters
 - Committee co-chair
- Danelle Gournaris
 - Deaf Adult
 - Deaf and Hard of Hearing Mentor Family Program Manager, Minnesota
 - Committee member
- Terri Patterson
 - Parent of a young adult son who is Deaf/Hard of Hearing
 - Director of Chapter Support, Hands & Voices Headquarters
 - Committee co-chair

Who We Are

The EHDI P2P Committee

- Hosted by the CDC
 - CDC provides a liaison, the resources to produce our products, and has them available to the public at no cost via their website.
- We are an interdisciplinary, inter-agency/inter-organizational and diverse parent/professional group
 - Open to anyone who is interested – professionals, parents, D/HH adults.
- Monthly Meetings
 - We work for one hour a month together by phone.
- Process for choosing projects/products
 - We "pick" a project, which usually evolves into a "tool" or resource/checklist.

Correlative and Unique Projects

FL3 DHH Guidelines: Guidelines for Deaf And Hard of Hearing Mentor/Guide/ Role Model Programs

- The 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. Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing (pediatrics.aappublications.org/content/131/4/e1324). :
 - *"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. ..."*
- **NCHAM DHH Learning Community (2011 – present)**
- This learning community originally consisted of representatives from nine programs that met the following criteria:
 - Participation was by invitation only. The size of the group was small in order to facilitate collaboration.
 - Programs were well established.
 - Programs were diverse in their model and types of services.
 - Programs were willing to work together in a collaborative manner for at least 6 months.
- Has recently begun to meet again and work towards new efforts.

JCIH Guidelines

All children who are D/HH and their families have access to support, Mentorship, and guidance from individuals who are D/HH and represent the diversity of the EHDI population (e.g. deaf culture, hard of hearing, cochlear implant and hearing aid users, unilateral hearing loss, auditory neural hearing loss, and cultural diversity.)

When we first received our son's diagnosis,
I looked at the doctor,
he was hearing...
I looked at the audiologist,
she was hearing...
And as we walked out,
I looked back at the receptionist
and she was hearing.
I had no idea what this
(raising a deaf child)
would look like
until you, (Deaf adult) walked in the door.

-- *Shelley Strickfaden -parent*



The Why

- **Why are Deaf Mentors/Models so important to families of children who are deaf or hard of hearing (D/HH)?**
- Families benefit from increased access to support, dependable mentorship, and a connection for the hearing parent with the D/HH community which includes a variety of deaf, Deaf, deafblind, hard of hearing individuals, as well as insightful guidance.
- Such individuals are typically adults who interact 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.
- The importance of Deaf Mentor programs was demonstrated in a study by Jackson, C.W. (*American Annals of the Deaf*, 2011 Fall; 156(4):343-62).
 - Surveyed 456 parents who had children who were deaf or hard of hearing.
 - Approximately 80% of parents agreed that deaf role models and mentors, as well as having access to adults who are deaf or hard of hearing, was either moderately or very important.

Need
more on
Why?

Lifetrack's Family Mentor Program Fact Sheet

- Results of the needs assessment of families with young children who are Deaf and hard of hearing in Minnesota and next steps for program expansions.
 - Mentoring and support
 - Mentoring Program structure
 - Characteristics of mentors
- <http://www.lifetrack-mn.org/news/blog/2015-09-14/mentoring-needs-minnesota-families-children-who-are-deaf-and-hard-hearing>
- Key Findings include: high satisfaction of families; quality of life improvement reported, more effective communication....

Target Audience

- **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.
- **Administrators and managers** can use this document for ideas on how to improve and enhance family support in their programs, as well as meet Goal 11.
- **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 to form supportive relationships with individuals who are deaf or hard of hearing.

The Current Project

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

- How did we choose this project?
- Considerations may differ between:
 - A System
 - A Family
- What does the Matrix look at:
 - A spectrum of opportunities for engagement
 - The resources required/recommended for systems implementation
 - Benefits and challenges for systems implementation, as well as family participation
 - Considerations for family participation
- It leads the reader to learn more and explore the vetted information developed by the FL3 D/HH Advisory group
 - It is **NOT** a set of guidelines on **how** to provide, but rather suggests a variety of options/opportunities to further explore
 - It may act as a complimentary tool to other resources, guidelines, documents

The Purpose

- To share information about the positive aspects of connecting families with D/HH adults and community members.
- To describe several ways systems can provide and facilitate these connections.
 - These opportunities 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 suits their situation.
- **All families**, regardless of degree of hearing loss/level or communication/language of the child, should have the opportunity to engage with and learn from D/HH Adults.
 - This may include formal to informal interaction, from high level interactivity to low, etc.
- 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.**



The Matrix

Systems Matrix

Systems Opportunities

Parent Matrix

Parent Opportunities

Systems Matrix

PLANNING SCALE

This matrix utilizes 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 4 using the JCIH Self-Assessment tool provided below:

For each question in the self-assessment tool, you will see response options based on four 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- EHDl system has not yet begun to address this component.

2 – Just Beginning- EHDl system for this component is at an early stage or period.

3 – Making Good Progress- EHDl System for this component has made satisfactory development, growth, or advancement.

4 – Established Practice- EHDl System for this component conforms to accepted standards.

	1	2	3	4	Would like to explore... (Desirability)
State-based Deaf Mentor/ HH Role Model Programs					
Events					
Virtual Interactions					
Recorded Videos					
Other					

Systems Matrix

Next Steps:

- Once scored, teams can determine what areas/opportunities/activities they would like to further explore and determine the desirability of pursuing and developing these activities in their state.
- Can utilize the checklists to encourage further discussion around state's developmental needs:
 - rate the advantages and limitations
 - state/team's readiness and current status
 - ability to implement

Systems Matrix

- A continuum of opportunities for state-based programs:
 - Deaf/HH Role Model Program (state-based, regional, or local)
 - Events
 - Virtual/Social Media Interaction
 - Recorded videos
- Each has:
 - Varying degree of resources needed
 - Different levels of family commitment
 - Benefits and challenges

Systems Matrix Checklist Sample

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

Approach:

- Home visits
- Supplement visits with technology
- ★ Meets **JCIH Recommended Guidelines** (link in introduction)

Program Resources Required:

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

Other Considerations:

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

The PARENT Matrix

PARENT SCALE

This table can be used by parents to summarize their thoughts about each opportunity listed in the next section.

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					
Events					
Virtual Interaction					
Recorded Videos					
Other?					

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

Parent Matrix Checklists: How it differs

- Checklists have been modified slightly from the systems matrix
- More individualized for consideration (vs. systems level considerations)
- Which type of support is best? - Committee considerations and conclusions
- Useful tool to complete with: Early Intervention providers, parent supporters/guides, as a family.



We want to hear from YOU

5-7 minutes for small group review and report back out



Next Steps

- Formatting the Matrix document
- Vetting it through the CDC for recommendations on
 - Language level
 - Formatting suggestions
- Final review by the EHDI P2P Committee
- Dissemination and sharing
- Determine our next project- join us!

Cool resources

- Lifetrack:
- [Http://www.lifetrack-mn.org/news/blog/2015-09-14/mentoring-needs-minnesota-families-children-who-are-deaf-and-hard-hearing](http://www.lifetrack-mn.org/news/blog/2015-09-14/mentoring-needs-minnesota-families-children-who-are-deaf-and-hard-hearing)
- Hands & Voices
 - Deaf/Hard of Hearing Adults/Stories
 - http://www.handsandvoices.org/resources/dhh_adults.html

Thank you.

- **Contact Information**

- Michele Berke- mberke@c sdf-cde.ca.gov
- Janet DesGeorges- janet@handsandvoices.org
- Danelle Gournaris- DanelleG@lifetrack-mn.org
- Terri Patterson- terri@handsandvoices.org

- **Interested in joining?**

- Please contact Janet@handsandvoices.org
- We meet the 3rd Wednesday of every month at 2pm EST