Parent-to-Parent Networks: Systems that Optimally Support Parents of Deaf and Hard-of Hearing Children

Cincinnati Children's · University of CINCINNATI · LEND Leadership Education in Neurodevelopmental and related Disabilities

Maria Matacia, Samantha Redmond, Katelyn Wargel, Lisa Hunter, Ph.D.

Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program; The Division of Developmental and Behavioral Pediatrics, Cincinnati Children's Hospital Medical Center, The University of Cincinnati University Center for Excellence in Developmental Disabilities

Background

- Parents of children who are Deaf or hard of hearing (D/HH) desire and benefit from support and community beyond clinical care to meet their child and family's needs. Parent-to-Parent (PTP) networks help provide that support and community.

- In formal PTP networks, a mentor parent who has a child who is Deaf or hard of hearing is paired with a mentee parent to provide support and insight based on their lived experiences.

- A conceptual framework of PTP support for parents of children who are Deaf or Hard of Hearing has been defined (Henderson, Johnson & Moodie, 2016). Best practices help make networks successful, resulting in a model of PTP mentoring that supports the growth of knowledge, empowerment, and well-being between mentor and mentee. Training and "match" are two factors that facilitate positive PTP relationships.

- While the literature identifies these factors as important, it is unclear how common they are in established PTP networks. Many states have PTP networks supported by Hands & Voices' (H&V) parenting network, Guide by Your Side (GBYS). Several states' PTP networks were established without the support of H&V. Some states also have Advocacy, Support, and Training (ASTra) Programs for education.

- In studying whether states' PTP networks encompass factors from the conceptual framework, we can identify gaps and better understand the current status of PTP networks.
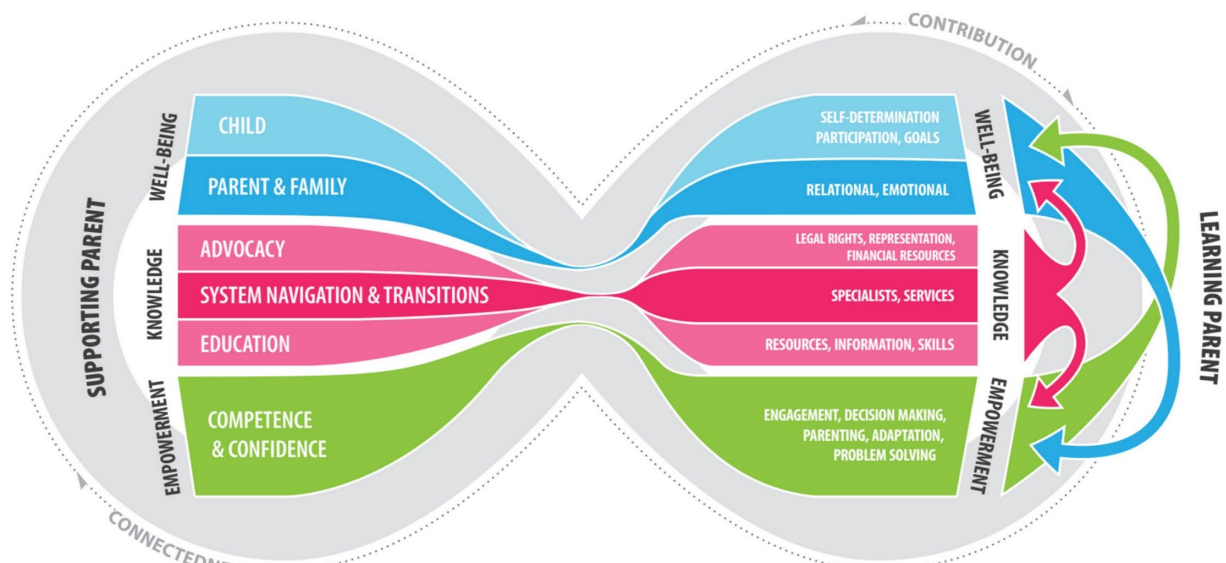
Figure 1. Conceptual framework of parent-to-parent support for parents of children who are Deaf or Hard of Hearing has been defined (Henderson, Johnson & Moodie, 2016).

Aims

The purpose of this study is to assess the various models used by H&V chapters GBYS and non-GBYS compared to non-H&V mentoring networks, and the extent to which the networks conform to the accepted structural framework for parent mentoring.

Research Questions:
- What are the models used by H&V state chapters and other PTP networks for parents of children who are D/HH?
- Do the models align with the accepted structural framework for PTP mentoring?
- What outcomes are measured, how is financial support sustained, and how diverse are the PTP networks?

Methods

Questionnaire Project:
1. We developed a survey to assess the various models used by PTP mentoring networks, their measured outcomes, and the extent to which the networks conform to the accepted structural framework for parent mentoring.
2. We sent the survey to be vetted by stakeholders to assess questionnaire clarity and accessibility.
3. The revised survey has been designed in REDCap and will be sent to program directors in all 50 states.
4. Collected data from H & V state chapters and other networks will be analyzed regarding the models of parent mentoring, financial supports, and outcome measures.

Website Project:
1.   A comprehensive web search for PTP support groups in each state was performed using the following Google Search terms:
    a. [State] parent support for deaf hard of hearing infants
    b. [State] newborn hearing screening
    c. [State] Hands & Voices
2. Data from this search was gathered in the following categories
    a. Top Organization in first search
    b. All Organizations available in the state
3. In a search for Hands & Voices state chapters, the following data was gathered:
    a. Programs provided specific to each chapter
    b. Resources listed specific to each chapter
    c. Number of staff listed and their background (i.e., as parents of deaf children)?
    d. Subjective assessment of diversity in the website pictures and content
4. A search of each state EHDI program was completed to assess which parent support organizations, if any, are listed as a resource
5. Data from all search criteria was then analyzed to assess the availability of PTP support resources that are readily available online to parents with children who are D/HH

References

Henderson, R., Johnson, A. & Moodie, S.T. (2016). Revised conceptual framework of parent-to-parent support for parents of children who are Deaf or Hard of Hearing: A modified Delphi study. *American Journal of Audiology, 25*(2), 110-126. doi: 10.1044/2016_AJA-15-0059

Moeller, M. P., Carr, G., Seaver, L., Stredler, Brown. A., & Holzinger, D. (2013). Best practices in family centered early intervention for children who are deaf or hard of hearing: An international consensus statement. Journal of Deaf Studies and Deaf Education, 18(4), 429-445

Bagatto, M., Moodie, Ss, Fitzpatrick, E., Kealey, C., Campbell, B., Aiken, S. (2020). Status of Early Hearing Detection and Intervention Programs in Canada: Results From a Country-Wide Survey. Canadian Journal of Speech-Language Pathology and Audiology, vol. 44(3).

Results

Top Line Internet Search "Parent support for deaf hard of hearing infants"
- Hands & Voices: 13%
- Family Voices or other DHH: 4%
- General State Parent Support: 9%
- Early Intervention Program: 11%
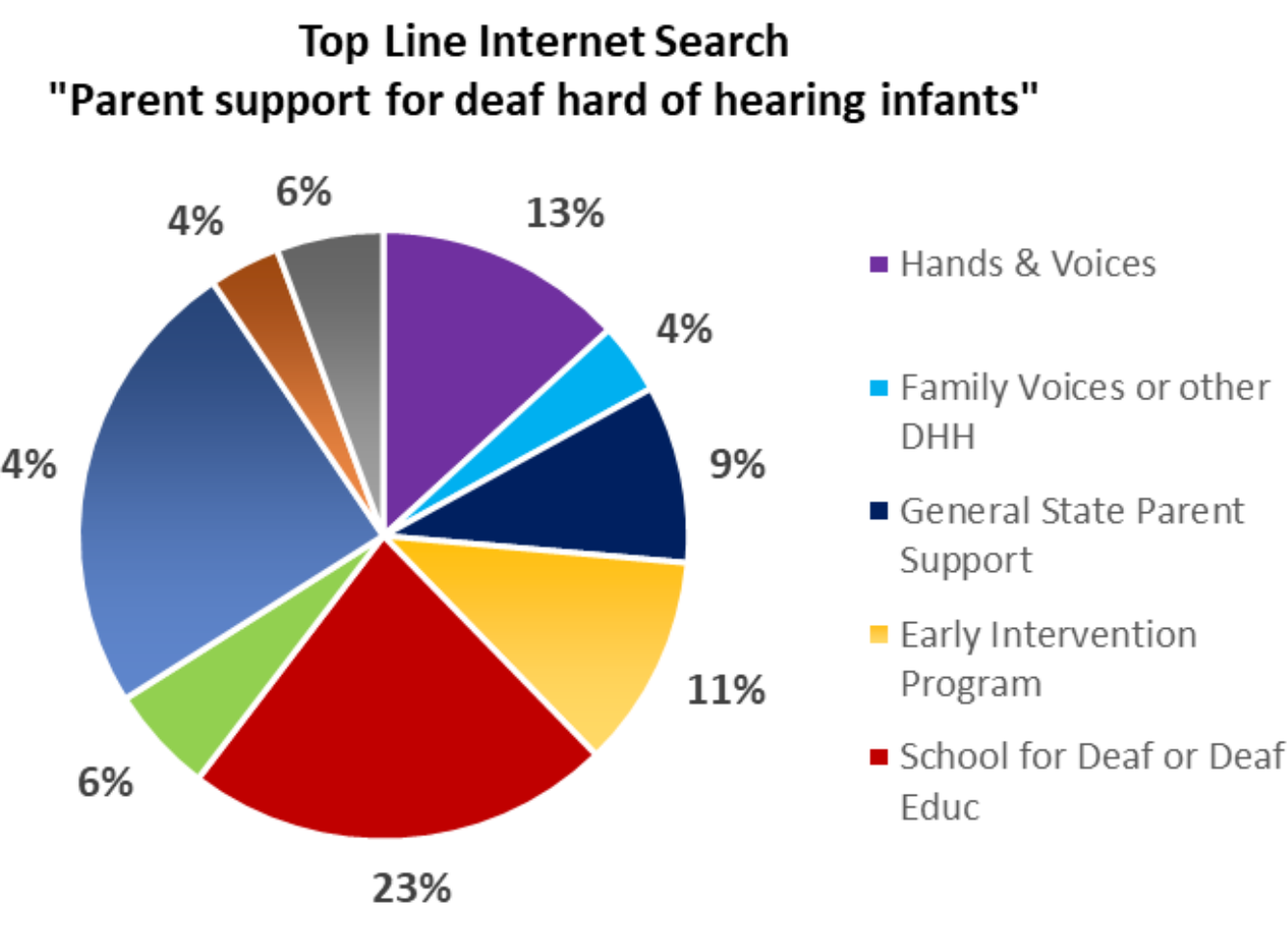- School for Deaf or Deaf Educ: 23%
- 6%, 24%, 4%, 6%

Figure 2. Search for "parent support for deaf hard of hearing infants" for all U.S. states and its territories: H&V=7; Family Voices or other DHH-P2P=2; General State Parent Support Program=5 states; Early Intervention program=6; School for the Deaf or State Deaf ; Assoc. For the Deaf=3; EHDI or Dept. Health program=13; Infant Hearing.org=2; Deaf Relay or Interpreters=3.

Hands and Voices State Chapters
- H & V Only: 30%
- H & V GBYS: 41%
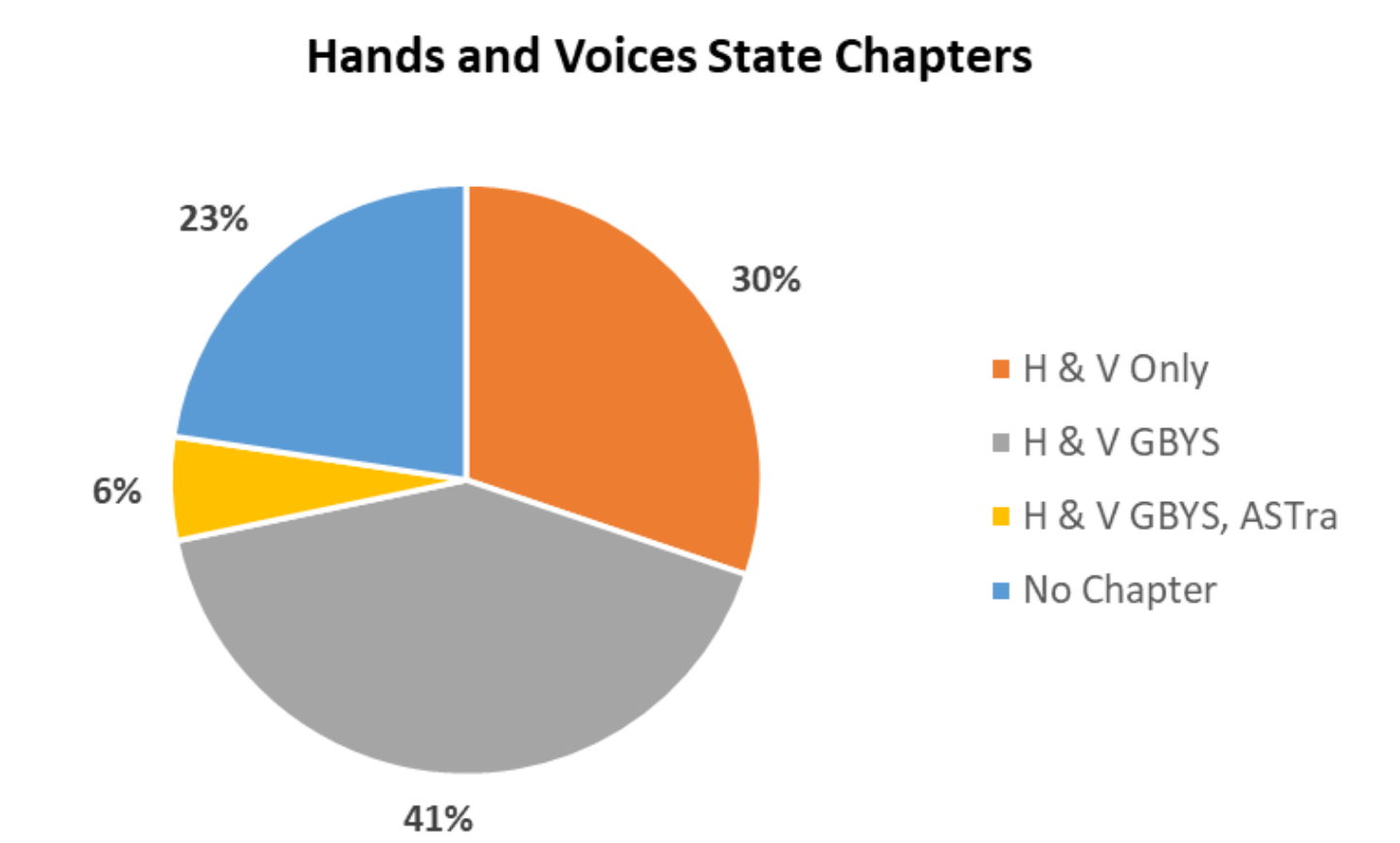- H & V GBYS, ASTra: 6%
- No Chapter: 23%

Figure 3. Status of H & V Websites: 39 states have a chapter website; 22 also have GBYS, and 3 also have ASTra program.

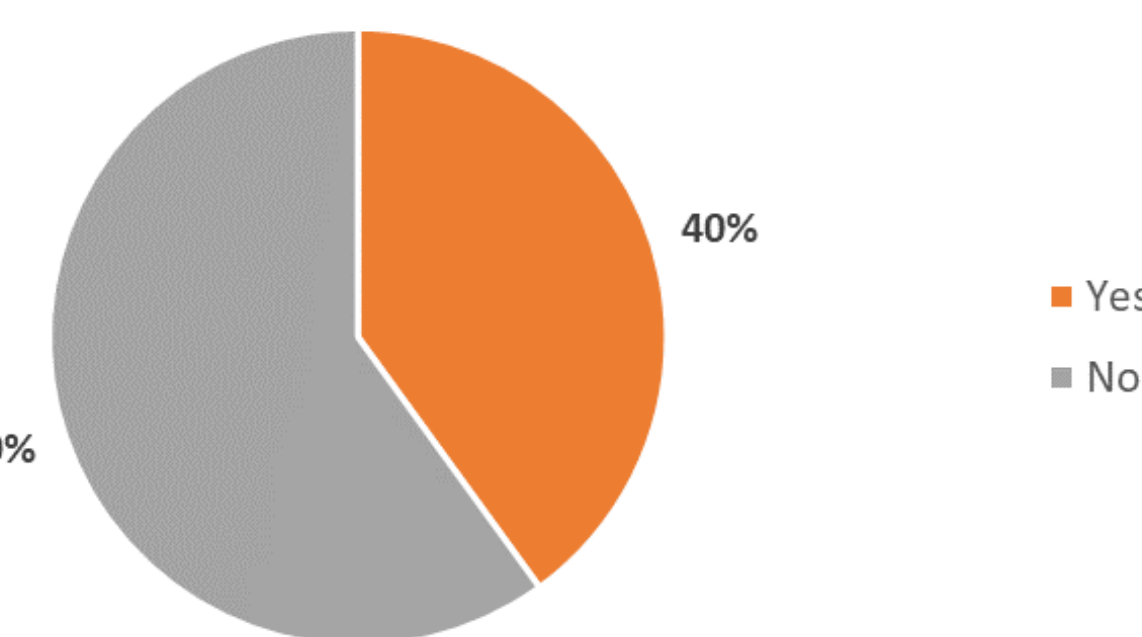EHDI Website Lists Parent Support Organization
- Yes: 40%
- No: 60%

Figure 4. Percentage of EHDI Program Websites that list a Parent Support Organization=20 states.

H&V		
Issue Type	States	Territories
Limited/No Existing Website	11/50	5/5
Website Problems (Broken Links, Navigation)	1/39	N/A
P2P Support Programs on Social Media Only	1/39	N/A
Lack of Diversity	11/39	N/A

EHDI		
Issue Type	States	Territories
Limited/No Exisiting Website	0/50	4/5
Website Problems (Broken Links, Navigation)	1/50	0/1
No Listing of P2P Support	25/50	0/1
Lack of Diversity	17/50	0/1

Table 1: Number of states and territories with website problems for H & V or EHDI.

Conclusions

Survey Project
- Feedback on the pilot survey indicates that PTP networks vary in the data they collect, and staff time and resources may be limited.
- To collect comprehensive data, the survey was modified to be clearer and more accessible, easy to complete, and adaptable to different organizations' outcome measures.

Website Project
Results indicate that it may be difficult for parents of children diagnosed with D/HH to identify local parent support. Parents new to this community may have difficulty navigating the online resources to identify family support, particularly if they are unaware that these networks exist. Many of the websites did not visually reflect racial, ethnic, or language diversity in parent mentors or families served, which may feel alienating or unwelcoming to families with diverse backgrounds. Our results suggest the following to raise awareness and better connect parents to PTP support::
- All EHDI websites should include links to local parent support resources
- Parent support organizations should ensure their websites are functional, easy to navigate, and welcoming to diverse families
- Providers could include resources about parent support when providing diagnostic results

Next Steps

1. Share the results of our website project with policy partners
2. Distribute the PTP organization survey nationally and collect responses
3. Analyze survey results and summarize findings for stakeholders, providing information about the processes that PTP organizations use and how that may be connected to funding, resources, and positive outcomes for families

Acknowledgements