



HANDS &
VOICES™



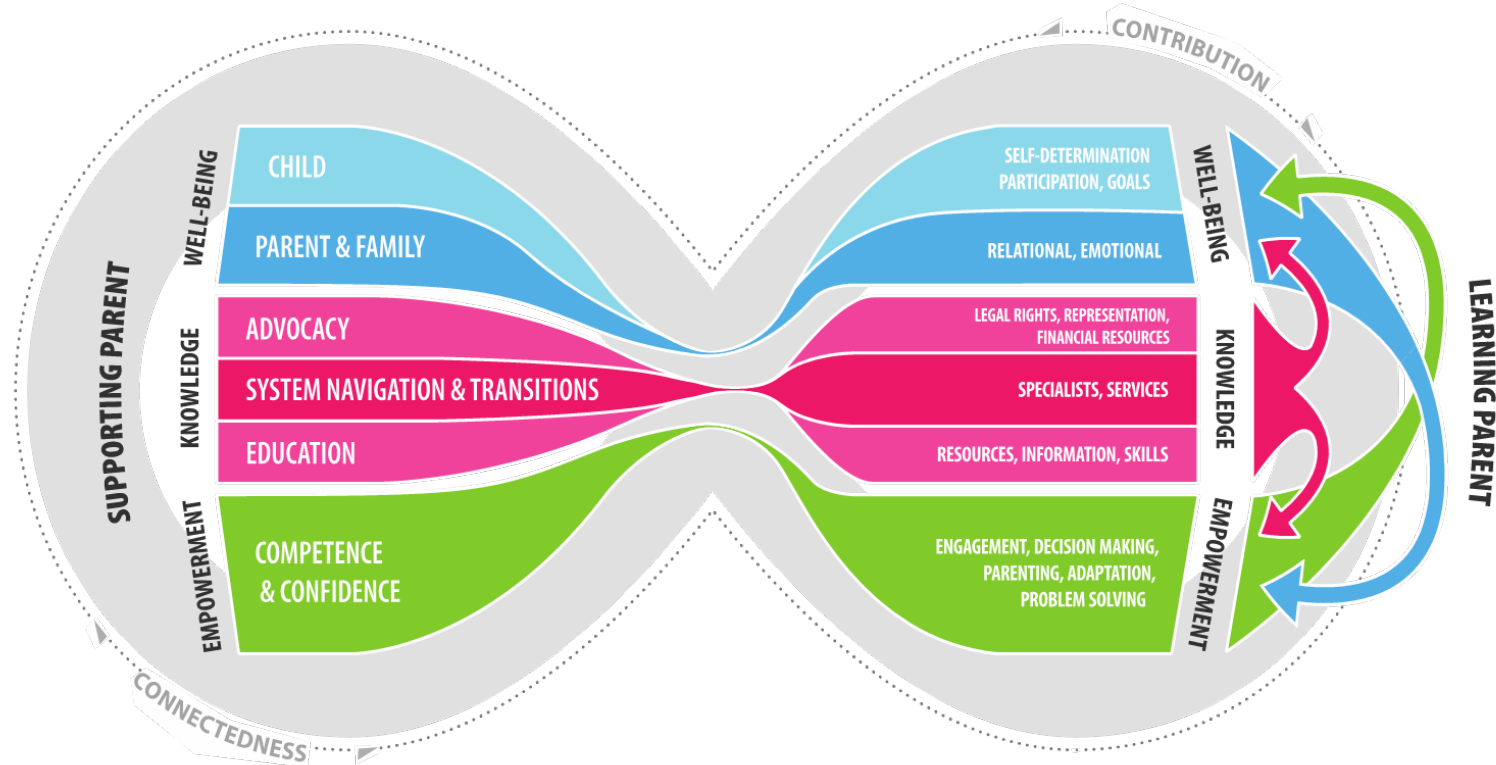
This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number UJ1MC30748-01-00 for Family Leadership In Language And Learning for \$1,500,00.00 This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Implementing an Evidence-Based Model of Parent-to-Parent Support

LISA KOVACS – FL3 CENTER DIRECTOR – HANDS & VOICES DIRECTOR OF PROGRAMS
LISAKOVACS@HANDSANDVOICES.ORG

Parent-to-parent support for parents with children who are Deaf or Hard of Hearing: **A conceptual framework**

Sheila Moodie, PhD, Rebecca Henderson, MSc. (MSc Project), Andrew Johnson, PhD



Publications:

Henderson, R., Johnson, A., & Moodie, S.T. (2014). A conceptual framework of parent-to-parent support for parents with children who are deaf or hard of hearing. *American Journal of Audiology*, 23(4), 437-448. doi: 10.1044/2014_AJA-14-0029

Henderson, R., Johnson, A., & Moodie, S.T. (submitted). A revised conceptual framework of parent-to-parent support for parents with children who are deaf or hard of hearing. *American Journal of Audiology*.

© Henderson, Johnson & Moodie

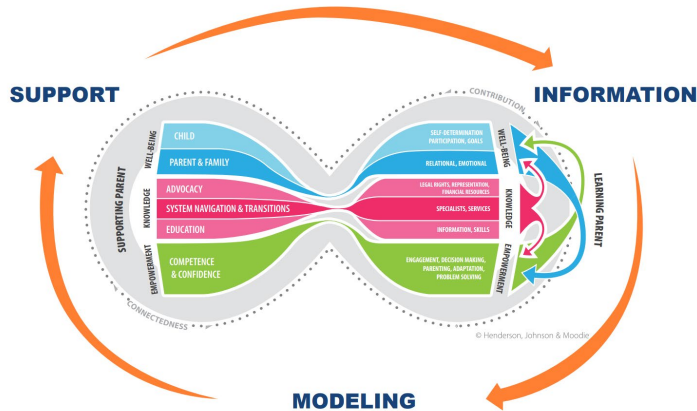


Hands & Voices Process for Implementation



**HANDS &
VOICES™**

HANDS & VOICES PARENT-TO-PARENT SUPPORT ACTIVITIES GUIDE



A guide for parent-to-parent support providers that includes family learning outcomes and parent-to-parent support activities developed from an evidence-based parent-to-parent support framework



**HANDS &
VOICES™**

Hands & Voices © 2019

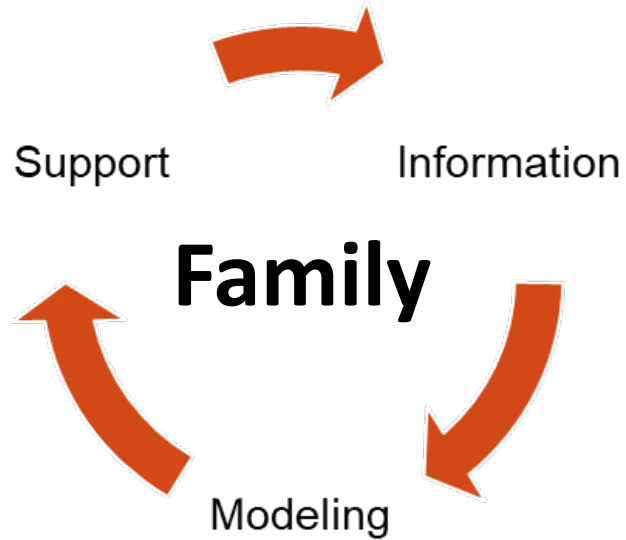


**GUIDE BY
YOUR SIDE™**



© Henderson, Johnson & Moodie

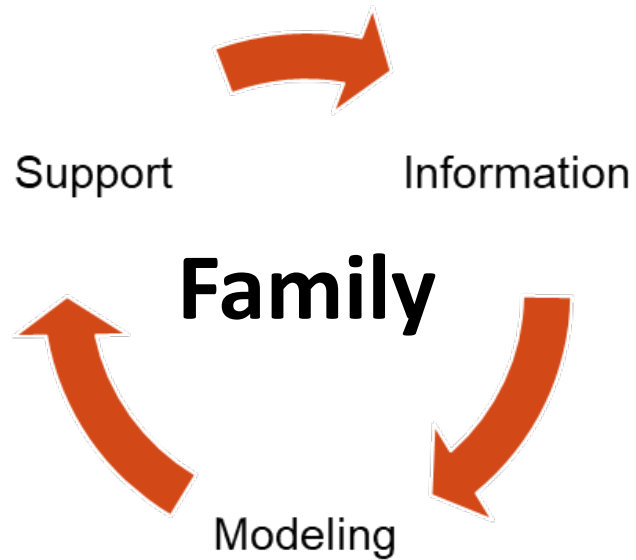
Construct-Well Being: Child



Component:

- 2. Participation:** involvement in hearing and Deaf communities, leisure and extracurricular activities, daycare/school, and ventures with family and friends.

Outcome	Parent/Family can name at least 2 deaf/hard of hearing family support organizations and their contact information (website, Facebook page, etc.).
Outcome	Parent/Family can name at least 1 opportunity/activity to learn about the Deaf Community in their area.
Outcome	Parent/Family can explain at least 2 strategies for incorporating their child into activities with friends, family, or other social activities.

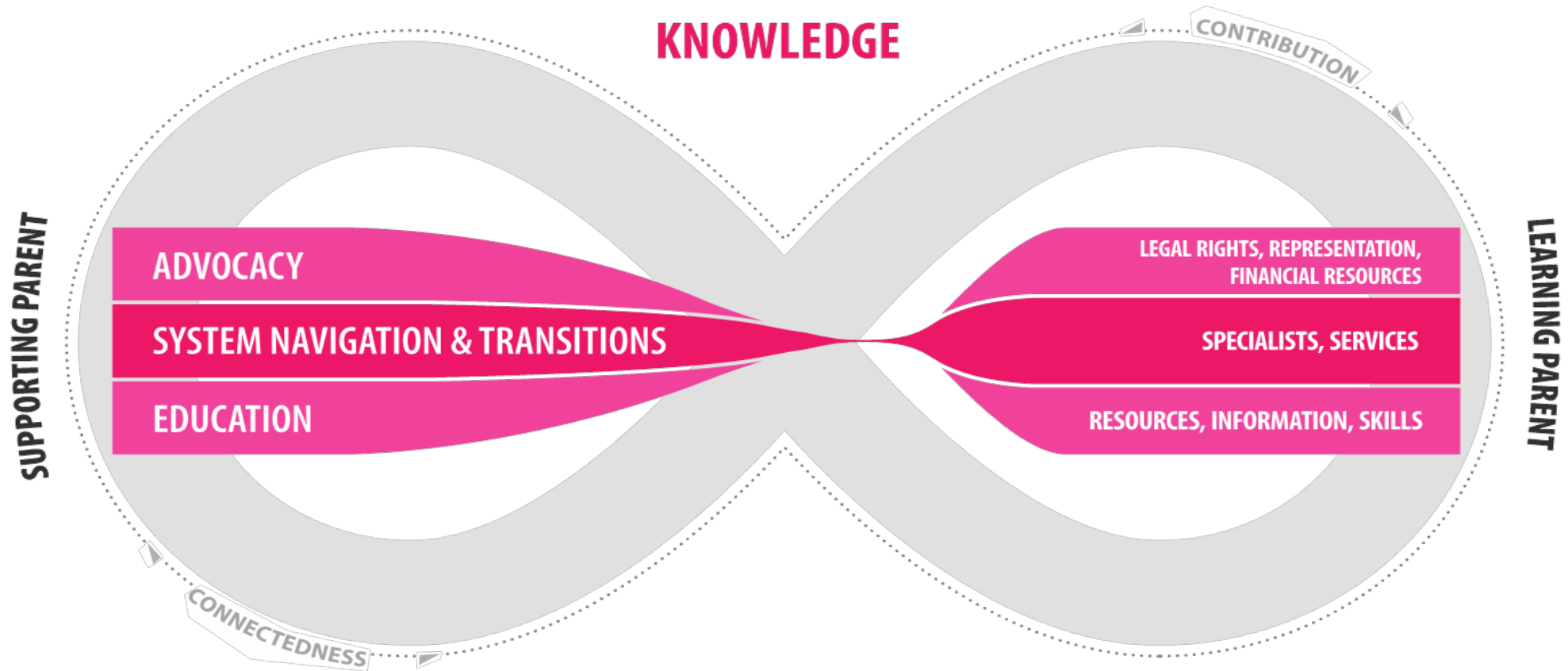


Construct-Well-Being: Parent & Family

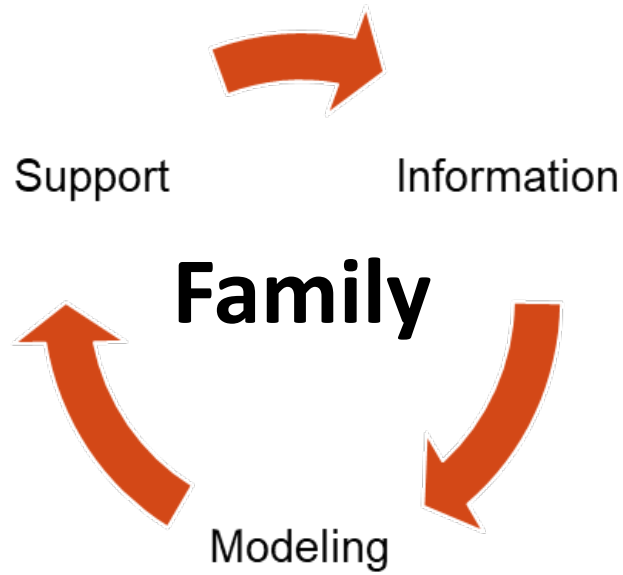
Component:

- 1. Relational:** Bonding with the child, family and parental cohesiveness, and communication between family members. Involvement in community and cultural networks, friends and religious institutions.

Outcome	Parent/Family can explain their child's hearing condition to others including family members, friends, and community.
Outcome	Parent/Family can identify challenges to their own well-being and name resources and knowledge to overcome the challenges.
Outcome	Parent/family can model appropriate communication methods/language with their child for family and community to provide full access and interaction with their child.



© Henderson, Johnson & Moodie

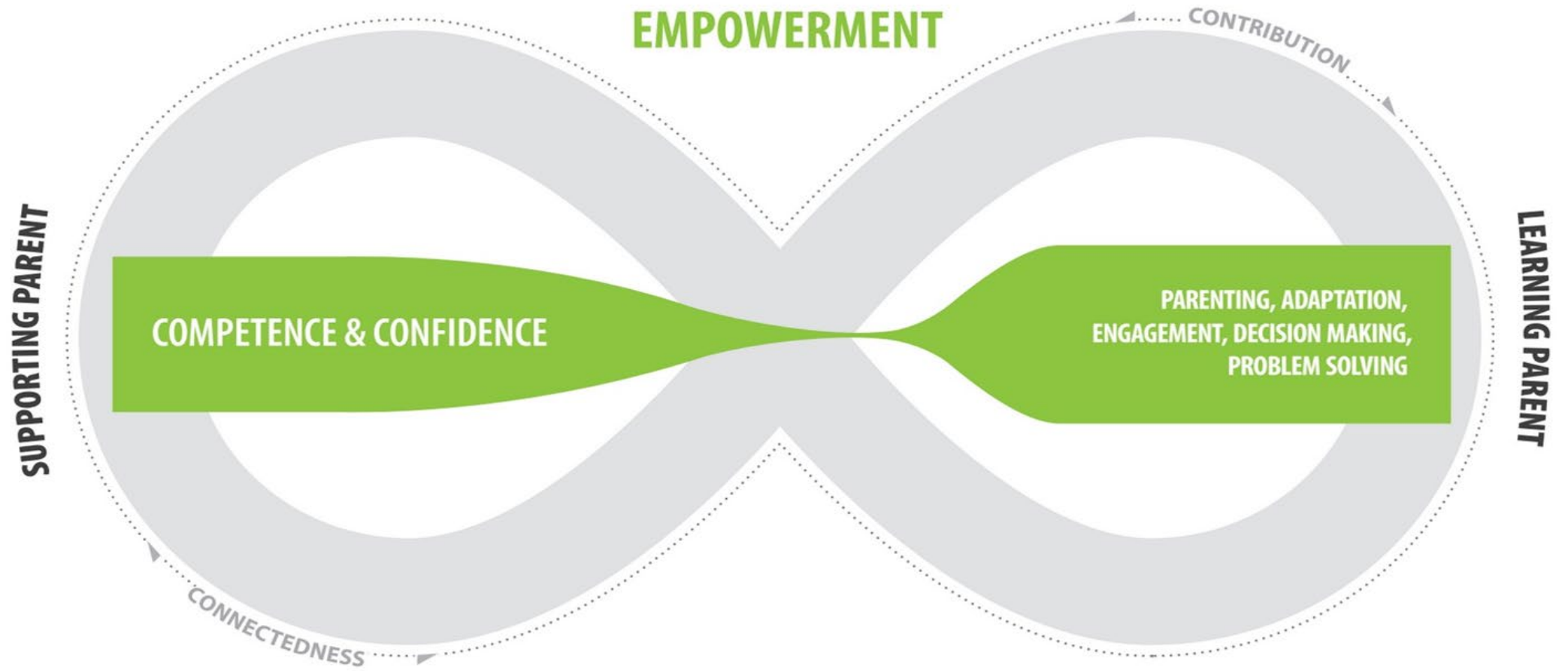


Construct-Knowledge: Systems Navigation & Transitions

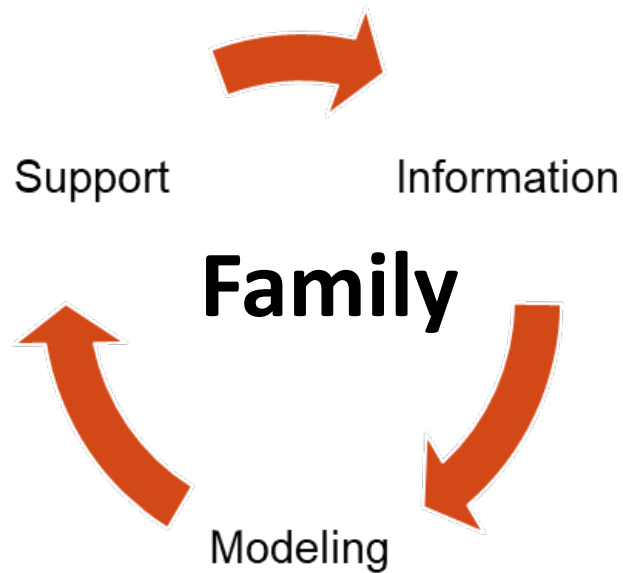
Component:

- 1. Specialists :** parent’s knowledge of navigating the systems and transitions to coordinate care with specialists, collaborate with stakeholders, provide a roadmap of care, understanding of the role of the specialist(s).

Outcome	Parent/Family can describe ways to learn about all the different specialists in order to make the most appropriate choice(s) for their child and family.
Outcome	Parent/Family can demonstrate their ability to request/advocate for specialized services to meet their child’s needs.
Outcome	Parent/Family can identify Early Intervention Specialists who will provide guidance to the family regarding transition into school age (Part B) services.



© Henderson, Johnson & Moodie



Construct- Empowerment: Competence & Confidence

Component:

2. **Decision Making** : parent-to-parent support that provides access to knowledge and resources, and the opportunity to cultivate ideas for informed choice and decision-making.

Outcome	Parent/Family can name at least two tools and/or training on informed decision-making, (ie. websites, CDC Guides, workshops).
Outcome	Parent/Family can explain the strategies they use to ensure they are an equal member on their child's Medical Care, Early Invention or School team.
Outcome	Parent/Family can name the on-going assessments their child will receive that will assist them with monitoring decisions/choices they've made.

SO WHAT'S NEXT?



2022 EHDl Learning Community

IMPACT OF FAMILY SUPPORT AND ENGAGEMENT (IFSE)

PARTICIPATING STATES- MN, MO, SC, VT, VA, WA

The purpose of the Impact of Family Support and Engagement (IFSE) Learning Community (LC) is to determine the most important domains (e.g., child/family well-being, knowledge, empowerment) of family support and how to measure those domains through a survey.



AIM: By September 8, 2022, the IFSE will develop and test a survey that measures the impact of family-to-family support for families with children who are DHH.

Each session included:

- Pre-work
- Review of LC aim and purpose
- Discussion and team decision making
- Next steps

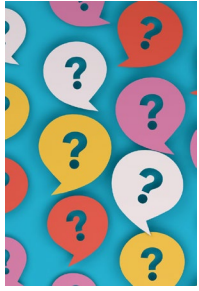


PDSA #1

- Tested with 2-3 families
- Select families you know will complete
- #completed

PDSA #2

- Tested with 8-10 families
- Random families
- Track method of delivery
- #completed



Survey Considerations & Lessons Learned

Considerations:

- Number of questions
- Time to complete survey
- Readability
- Demographic and content questions
- Questions for testers

Lessons Learned:

- Clear instructions that the survey is asking specifically about the **family's experience receiving support from a family-to-family support providers.**
- Families need **several reminders** through different delivery methods and sometimes a **personal ask** to respond to the survey – possibly even offer an **incentive.**

Impact of Family Support and Engagement (IFSE) Learning Community – Question Bank

Impact Questions:

IFSE recommended questions:

In 2016 an Evidence-based Conceptual Framework was developed by researchers from Western University, led by Dr. Sheila Moodie. The findings from a dual-stage scoping review and electronic Delphi study provide a conceptual framework that defines the vital contribution of parents in Early Hearing Detection and Intervention programs that will be a useful addition to these programs. In developing the framework, three overarching themes (**constructs**) are included (a) well-being, (b) knowledge, and (c) empowerment. These constructs are what the IFSE Learning Community used in developing family-to-family support **impact** questions. <http://aja.pubs.asha.org/article.aspx?articleid=2527221>

Construct # 1 Well-Being – Child and Family

All questions used the following Likert scale unless otherwise indicated (Strongly agree, Agree, Disagree, Strongly disagree) (adding N/A was also discussed as an option)

1. I have learned I am not alone, there are other families I can connect with and learn from.
2. I feel hopeful about my child’s future.
3. My ability to focus on everyday moments that bring joy to our family has improved.
4. Meeting an experienced parent, has provided me with encouragement in raising my own child who is Deaf or Hard of Hearing.
5. My overall well-being (for example; state of being comfortable, healthy, or happy) has improved because of the support I received.

Construct # 2 Knowledge – Advocacy, Systems Navigation, and Education

All questions used the following Likert scale unless otherwise indicated (Strongly agree, Agree, Disagree, Strongly disagree) (adding N/A was also discussed as an option)

1. I better understand the impact of a hearing loss/difference on my child’s development.
2. I have an increased understanding of the different language/communication options for children who are Deaf or Hard of Hearing.
3. I better understand my role in advocating for my child’s needs.
4. I have more knowledge of information and resources that will support my child/family.
5. Name the one most important piece of information you learned from your family-to-family support provider (Open comment box: 200-character limit).



IFSE – Question Bank



Resource Links:

https://www.handsandvoices.org/fl3/fl3-docs/Henderson_etal-2016-AJA_famfam-givesupport.pdf

<https://www.handsandvoices.org/fl3/fl3-docs/IFSEQuestionsBank2022-data.pdf>

Measuring the Impact of Family-to-Family Support: Tools and Lessons Learned from a Learning Community Webinar

11/10/22

[[Watch the Video](#)]

SO WHAT'S NEXT?



-
1. Revised version – Family Support Activities Guide
 2. Family Support Provider Checklist
 3. Training Webinars – Implementation Ideas

Questions



Thank You!

We hope to connect with you!

www.handsandvoices.org

fl3@handsandvoices.org

lisakovacs@handsandvoices.org