IFSE Learning Community Purpose and Aim

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.

Demographic Questions:

IFSE recommended questions:

1. How did you learn about the survey? (Email, Text message, Phone, Other (please specify))
2. State/Territory where you live? (please select)
3. How do you identify your place of residence? (Urban, Suburban, Rural, prefer not to answer)
4. I identify as (select all that apply): (White or Caucasian, Black or African American, Asian or Asian American, Native American, Pacific Islander, prefer not to answer, other (please specify))
5. What language(s) are used in the home? (please select all that apply) (ASL, Cued Language, Chinese, English, French, Spanish, prefer not to answer, other (please specify))
6. Relationship to the child: (Father, Mother, Grandparent, Foster Parent, prefer not to answer, other (please specify))
7. Please select the highest education level completed: (Master’s or higher degree, Bachelor’s degree, Associate degree, Trade/technical, vocational training, High school graduate or equivalent, less than high school equivalence, prefer not to answer)

Optional additional demographic questions:

1. Age of the child (0-3 years, 3-5 years, 5-10 years, 10 plus years)
2. Hearing level of the child (right ear: typical, mild, moderate, moderate-severe, severe, severe-profound, profound / left ear: typical, mild, moderate, moderate-severe, severe, severe-profound, profound)
3. Family size/ Household income
4. How did you learn about the family-to-family support program (Family-to-Family Support Organization, Hospital Hearing Screener, Audiologist, Physician, Early Intervention, EHDI program, School, D/HH Provider, Internet, other, please specify)
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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](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).
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Construct # 3 Empowerment – Competence and Confidence

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. My original concern(s) have decreased by connecting with the family-to-family support provider.
2. I am confident in how to use the information provided to me by the family-to-family support organization.
3. I am more prepared to explain my child’s needs to family and friends.
4. I am more prepared to discuss my child’s needs with professionals.
5. I know how to contact my family-to-family support provider.

Optional satisfaction questions: IFSE did not include satisfaction questions

1. Family Support provider’s ability to share knowledge with you about local/regional/national resources
2. Family Support provider’s ability to share information about connecting with other families, either individually or through community events
3. Family Support provider’s ability to listen and be supportive
4. Family Support provider’s sensitivity to your unique family needs, culture and/or language
5. Family Support provider’s ability to share information with you in an objective and unbiased way?
   a. Communication options
   b. Technology options
   c. EI and school options
6. Were you satisfied with how long it took to be contacted?
7. Did you receive enough resource materials to meet your needs?
8. Materials provided were high quality.
9. The information I received was relevant.
10. The information I received was useful.
11. What did you like the most about your Family Support provider?
12. Did the "Family Notebook," provide you with the necessary resources and information?
13. How many visits/sessions did you have with the family support provider?
14. Would you recommend the family-to-family support program to another family?
15. What did you learn from the family support provider that was different from professionals on your child’s team?
16. Please leave a quote about how the program has benefitted you and your family.