

2019 Hands & Voices Family Leadership in Language and Learning (FL3) Family-based Organization (FBO) Survey

The Family Leadership in Language and Learning (FL3) Family-based Organization (FBO) survey was created to obtain feedback from state-based Early Hearing Detection and Intervention (EHDI) contracted FBOs. As we head into Year 3 of this work, the FL3 Program asked EHDI FBOs to provide information about their FBO such as the programs provided, numbers of families served, etc. Results from this FL3 FBO survey provides the FL3 Program with feedback and information to inform progress made by the FL3 Program. Individual FBO responses are confidential and will not be shared. A summary of the FL3 FBO Survey results is shared here.

Summary

The FL3 FBO Survey was open for 3 weeks, from June 19, 2019 through July 10, 2019, and respondents were asked to reply based on activities conducted during Year 2 of the FL3 Program (April 1, 2018-March 31, 2019). The survey was emailed to 141 contacts from all FBOs on three separate occasions. There were 50 responses from 42 states/territories (71% response rate). Five territories participated and eight states had more than one response (FBO). Fifteen states/territories did not participate in this survey. Of the fifty respondents, twenty-four are associated with Hands & Voices and twenty-six are not. Examples of non-H&V FBO representation include F2F HICs, non-profit and for-profit organizations, etc.

Summary of Results

Of the FBOs who participated in this survey;

- 90% (45) indicated that their FBO has a website or webpage (Q#3)
 - 78% (39) indicated that their FBO website or webpage has information specifically for families who have D/HH children. Twelve percent of FBOs indicated that they do not have information specifically for families who have D/HH children. (Q#3)
- 86 % (43) indicated that they offer a Family-to-Family support program for families. (Q#3)
- 36% (18) indicated that they offer a D/HH Mentor/Role Model/Guide for families. (Q#3)
- 88% (44) indicated that their family leaders participate in Leadership training. (Q#3)
- 38% (19) indicated that their D/HH leaders participate in Leadership training. (Q#3)
- 44% (22) indicated that they led or participated in a QI initiative on the topic of active family engagement partnerships in EHDI systems. (Q#3)
- 70% (35) indicated that they receive direct referrals (individual family contacts) from their state or territory's EHDI Program; 26% (13) indicated that they do not receive these referrals. FBOs that do not receive contact information from their EHDI program report that they find families through other local families, providers (Audiologists, EI) and through marketing efforts via Facebook and other social media outlets.
- 82% (41) of FBOs report that 372 Family Leaders with D/HH children are being compensated to provide direct support to families with children who are D/HH by FBOs. Nine FBO respondents indicated that they do not compensate family leaders. (Q#4)
- 48% (24) of FBOs report that 124 D/HH Leaders are being compensated to provide direct support to families. Twenty-three FBO respondents indicated that they do not compensate D/HH leaders. (Q#5)
- 88% (44) of FBOs report that 4,581 families with D/HH children were provided direct support. Six FBOs did not provide direct support or were unaware of how many families were served. (Q#6)
- 40% (20) of FBOs report that 1,223 families were offered access to a D/HH Adult (Role model/Guide/Mentor). Twenty-eight FBOs did not provide access to D/HH adults or were unaware of how many families were served. (Q#7)

- When asked where their FBO Ranks on the Partnership Continuum with their EHDI Program; (Q#8)
 - 46% (23) indicated “Partnership – Families and professionals work from an agreement base of shared values; risks rewards, resources, accountability, vision, ideas and decision-making are shared through formalized processes, systems and methods”.
 - 32% (16) indicated “Collaboration – shared decision making exists; families and professionals feel like they are adding value to each other and their organizations”.
 - 10% (5) indicated “Cooperation – No fixed or long-term relationship is implied, acknowledgement of common issues, interests or agendas, no ongoing or formal commitment to each other”.
 - 6% (3) selected “Coexistence – parents and professionals don’t work together regularly, no dependency or need to collaborate regularly”.
 - 6% (3) selected “Networking – Informal discussions and information sharing is the standard, no collective vision, mission or tasks between parents and professionals”.
 - No respondents indicated that “No partnership exists”.
- 90% of respondents indicated that yes, they are the EHDI designated FBO for Year 3 (April 1, 2019-March31, 2020). Five FBOs (10%) indicated that they were not. Of those five, 3 were either in discussion, or only supported through July 31, 2019. (Q#11)
- **Table 1** below shows the FBO detailed responses indicating the FBOs current responsibilities for EHDI programs. While most organizations (82%) indicated they are “providing family support by trained parents who have children who are D/HH”, the nine organizations who did not select this response identified as a state Commission on D/HH, University Center on Disability, a hearing aid provider, or an organization that did not provide D/HH specific support. Connecting families to Deaf Adults and providing family support by families who had children with other special needs remains lower on the list.

What are your FBOs current responsibilities for EHDI? (Select all that apply)

Answer Choices	Responses	
Provide family support by trained parents who have children that are D/HH	82%	41
Participate on state EHDI mandated advisory board	70%	35
Participate in D/HH children-focused learning communities	66%	33
Provide a family representative on deafness-related projects	62%	31
Design and/or deliver leadership training (for example, advocacy training, IEP training)	58%	29
Connect families to Deaf adults such as deaf mentors, guides, or role models	50%	25
Provide family support by trained parents who have children with other special needs	46%	23
Lead D/HH children-focused learning communities	34%	17
Develop and administer EHDI state level needs assessment or gap analysis	24%	12

TABLE 1: FBO Current responsibilities

- **Table 2** below shows the kinds of contacts and outreach their FBO provides for EHDI programs. While most organizations (82%) are contacting families to offer support, 36% (9) are not contacting families to offer family to family support. Forty-six percent of organizations indicated that they contact families to offer support from D/HH adults, compared to Table 1 where 50% of the organizations connect families to Deaf adults.

What kind of contacts or outreach does your FBO make to help your EHDI program? (Select all that apply)

Answer Choices	Responses	
Contacts families to offer family- to- family support from your organization	82%	41
Contacts families to refer them to other community resources (for example, sign language classes, parenting classes)	72%	36
Contacts families to ensure children who are identified with a permanent hearing loss are referred to Early Intervention (EI)	48%	24
Contacts families to offer support from deaf and hard of hearing adults such as deaf mentors, guides, or role models	46%	23
Contacts families to ensure children who did not pass (aka refer) on their screening test get into an audiologist for a diagnosis	32%	16
Contacts families to ensure newborn hearing screening is complete	28%	14

TABLE 2: FBO contacts or outreach

- **Table 3** below indicates the type of resources offered by the FL3 that FBOs either participated in, utilized or shared with others. We were pleased to see the high percent of FBOs that indicated they participated in/ received our resources. Unfortunately for many of these items we don't know why the items used in our work or shared with others are considerably lower.

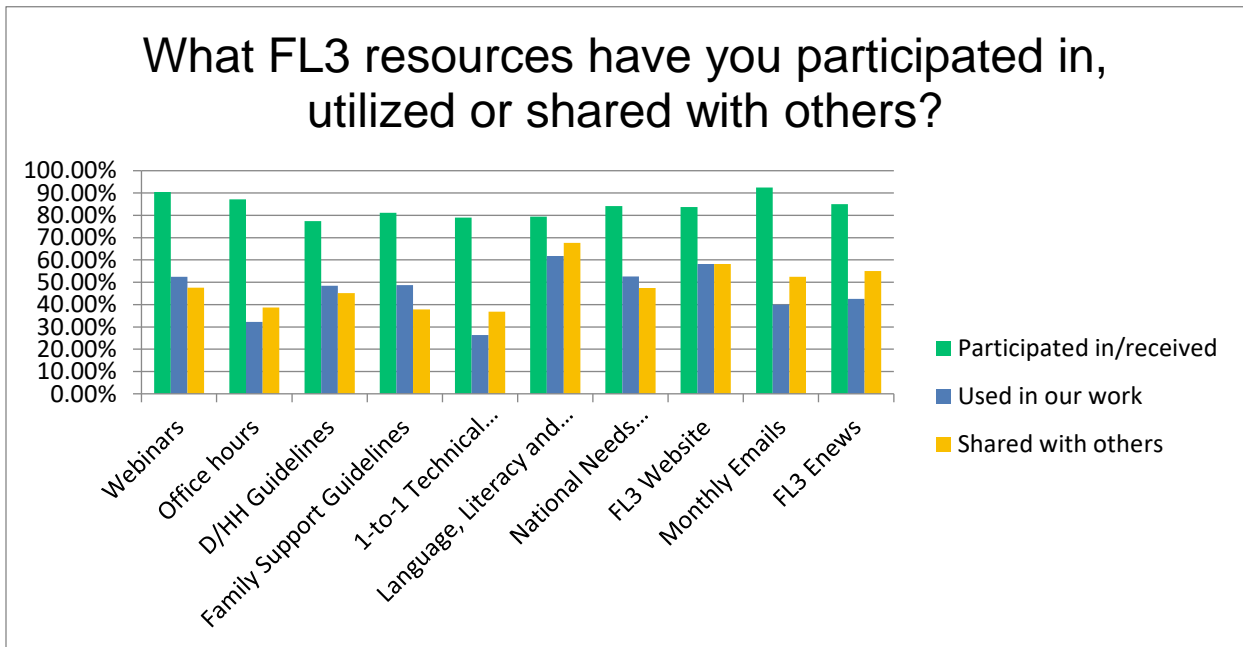


TABLE 3: FL3 resources FBOs participated in, utilized and/or shared with others

- **Table 4** below shows level of agreement with statement about how FL3 is doing providing supports and resources to FBOs. Of the seven areas listed, six of them had a positive response (Strongly agree or Agree) of more than 76%. Four of the items with positive responses were between 82-94%. While the lowest positive response was the FL3 timely response at 62% it is important to note that 32% (16 FBOs) indicated that this was N/A to them or they did not have questions.

Please indicate your agreement with these statements:

	Strongly agree		Agree		Neutral		Disagree		Strongly Disagree		N/A		Total	Weighted Average
	%	Count	%	Count	%	Count	%	Count	%	Count	%	Count		
FL3 responded timely to my questions	40.00%	20	22.00%	11	6.00%	3	0.00%	0	0.00%	0	32.00%	16	50	4.5
FL3 presented virtual sessions (Office Hours, Webinars, etc.) were well produced.	48.00%	24	24.00%	12	6.00%	3	0.00%	0	0.00%	0	22.00%	11	50	4.54
Products distributed by FL3 were well designed	47.92%	23	45.83%	22	0.00%	0	0.00%	0	0.00%	0	6.25%	3	48	4.51
Products developed by FL3 were unbiased regarding language and communication modality	59.18%	29	30.61%	15	6.12%	3	0.00%	0	0.00%	0	4.08%	2	49	4.55
Products developed by FL3 were useful and relevant to the work of our FBO	55.10%	27	30.61%	15	6.12%	3	2.04%	1	0.00%	0	6.12%	3	49	4.48
The FL3 website is easy to navigate	46.00%	23	36.00%	18	10.00%	5	2.00%	1	2.00%	1	4.00%	2	50	4.27
FL3 Communication was the right frequency	44.90%	22	30.61%	15	10.20%	5	2.04%	1	0.00%	0	12.24%	6	49	4.35

TABLE 4: FBO contacts or outreach

All Overall Comments (Q#14)

- Great
- We appreciate FL3 hosting pacific office hours this allows families to join at a reasonable time.
- I am looking forward to this year being a baseline and really exploding this current year!
- I love the website and all of the resources on it. We are working on finding adult D/HH guides and role models. At this time, we don't have a lot of requests for it yet.
- The relationship between the <organization> and the EHDl program has not been mutually beneficial. The staff for the EHDl program are housed in our <organization> but choose to function very independently.
- I need to learn more & strengthen local partnership
- Our FBO is working hard to support more and more families.
- I am very excited with partnership with EHDl. Beginning to work collaborate more with EHDl coordination. I feel now that our FBO is taking on a more active and visible role in supporting the DHH community. Only good things to come!
- We hope we can continue to do this work.
- Thank you for the individualize support and assistance, and the more generalized resources.
- Thank you for all you do!
- Especially appreciate the takeaways and the DHH Guidelines, the L2L training and the ASTra training this year!
- Overall, you have all done an exceptional job. Keep up the good work. You are appreciated.
- FL3 is a great resource.

Conclusions and Next Steps

This survey highlighted a several areas that the FL3 Program can assist FBOs in meeting the needs of families who have children who are D/HH. Based on feedback from the FBO survey, there is still work that can be done in the final months of this grant period. The FL3 Program will continue to disseminate information and resources via monthly emails, FL3 E-news, and FL3 website which includes a list of ideas, trusted links and resources as suggestions for inclusion on their FBO websites so that families will have access to these resources locally.

The FL3 Program will present a session on Early Intervention (EI) with designated partners at the Annual EHDl Meeting to assist FBOs as they contact families to ensure children who are identified with a permanent hearing loss are referred to EI timely. This presentation will highlight the Parent's Guide to EI Recommendations.

To boost FBOs skills in designing/delivering leadership training, the FL3 Program will share resources based on the H&V New Leaders Training during the FBO Meeting at the Annual EHDl Meeting in March 2020.

FL3 continues work on strengthening partnership activities at the national level with Directors of Speech and Hearing Programs in State and Welfare Agencies (DSHPSWA) to build effective collaborations between EHDl Programs, sharing information via Office Hours, and utilizing the Spotlight on Success to share best practices and successful strategies in state/territory EHDl systems.