

2019 Hands & Voices Family Leadership in Language and Learning (FL3) EHDI Coordinator Survey

The Family Leadership in Language and Learning (FL3) EHDI Coordinator survey was created to obtain feedback from Early Hearing Detection and Intervention (EHDI) Programs. As we wind up Year 3 of this work, the FL3 Program asked EHDI Coordinators to provide current information that will assist us in providing future supports and resources to EHDI Coordinators and/or Programs as well as provide us with information for comparisons to previous data collected via other surveys. Additionally, this information will assist us in our FL3 annual report to the Health Resources Services Administration (HRSA), Maternal Child Health Bureau (MCHB). Only summarized results will be shared, individual responses will be kept confidential and will not be shared.

Summary

The FL3 EHDI Coordinator Survey was open for 3 weeks, from December 18, 2019 through January 10, 2020, and respondents were asked to reply based on their current program activities. The survey was emailed to 80 contacts from all 59 state/territory EHDI programs on two separate occasions. Individual responses were received from 35 states/territories (59% response rate), including four territories. Twenty-four states/territories did not participate in this survey.

Summary of Results

Of the EHDI Coordinators who responded to the survey.

- Respondents indicate 721 (average 21) **individuals** participate on their EHDI Advisory committees. The highest number of participants indicated was 45, lowest was 8 participants.
- Respondents indicate that 158 (average 5) **parent/family members** participate on their EHDI Advisory Committees. The highest number of participants was 12, lowest was 8. One program indicated that they don't have an EHDI Advisory group but convene a stakeholders' meeting to share information.
- Respondents indicate that 93 (average 3) **D/HH Adults** participate on their EHDI Advisory Committees. The highest number of participants was 12, lowest was 1. Seven programs indicated Zero D/HH Adult participants. One program indicated that; *"asking committee members to identify as D/HH or as parents of D/HH is problematic and sometimes controversial."*
- Less than 50% (46%/16) of EHDI programs track the number of **families referred** to Family to Family support. The rest indicated that they do not have this data (26%/9) or their FBO tracks this data (29%/10).

Does your EHDI program track the number of families referred to Family to Family support?

Answer Choices	Responses	
Yes, in place today	45.71%	16
No, our FBO tracks this data	28.57%	10
No, we don't have this	25.71%	9
	Answered	35
	Skipped	0

- Less than 50% (49%/17) of EHDl programs track the number of **families enrolled in** Family to family support. The rest indicated that they do not have this data (20%/7) or their FBO tracks this data (31%/11).

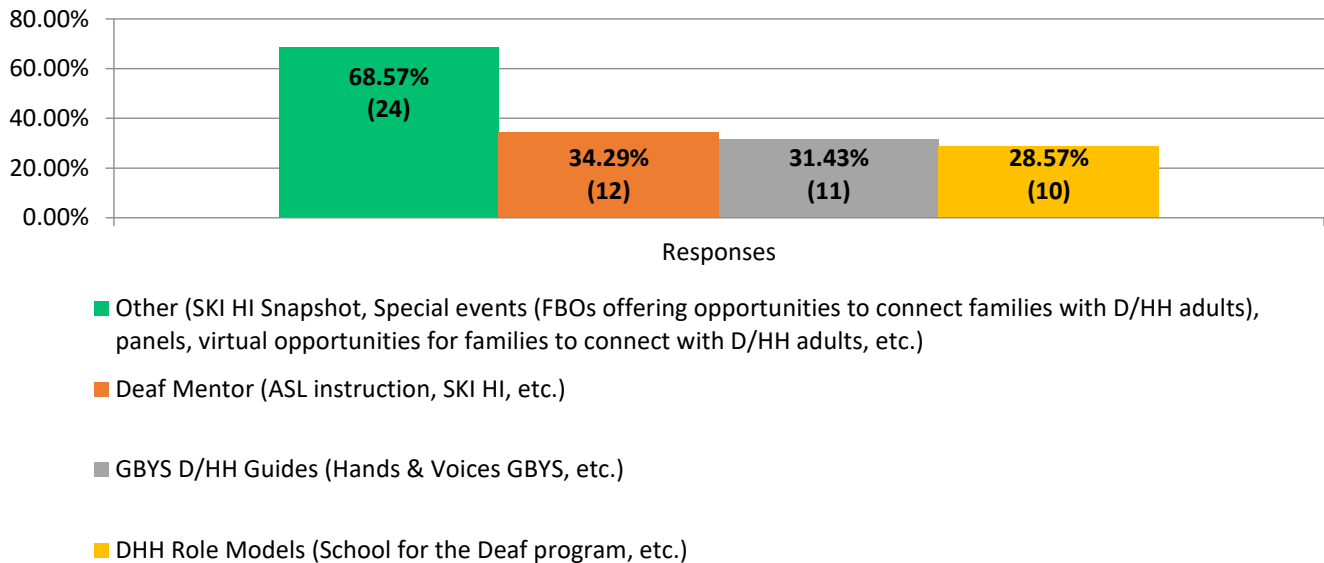
Does your EHDl program track the number of families enrolled in Family to Family support?

Answer Choices	Responses	
Yes, in place today	48.57%	17
No, our FBO tracks this data	31.43%	11
No, we don't have this	20.00%	7

Answered 35
Skipped 0

- Eleven percent (4) EHDl programs track the number of families **referred** to D/HH Adult Support today. While 26%/9 programs get this data via their FBO, a much higher number 63%/22 of programs do not have this kind of information.
- Fourteen percent (5) EHDl programs indicated that they track the number of families **enrolled in** D/HH Adult support today. While 20%/7 programs get this data from their FBO, 66%/23 programs do not have this kind of data.
- Fifty-seven percent (20 programs) have indicated that their EHDl-designated FBO is referenced on their EHDl Program website, 37%/13 programs indicated that their FBO is not referenced on their state/territory website.
- When asked what programs EHDl offers to utilize D/HH adults to serve families,
 - 34%/12 programs indicated they have Deaf Mentor (ASL instruction, SKI HI, etc.),
 - 31%/11 have a Hands & Voices Guide By Your Side D/HH Guide program
 - 29%/10 offer a D/HH Role Models (School for the Deaf program, etc.)
 - Fifteen (62%) of the 24 programs that indicated "Other" did not select Deaf Mentor/Guide/ Role Model as an option. Of those fifteen, 6 programs indicated that while the EHDl program doesn't formally offer these supports, they are aware of organizations who provide D/HH Adult supports either formally or informally refer families to them.

What programs do you currently have to serve families utilizing Deaf and Hard of hearing adults (check all that apply)?



- No EHDl programs indicated that they did not receive the Guidelines for D/HH Mentor/Guide/Role Model programs.

A set of Guidelines for D/HH Mentor/Guide/Role Model Programs was created and distributed in the past: <https://www.handsandvoices.org/fl3/fl3-docs/DHH-Guidelines.pdf>.

Answer Choices	Responses	
I have received the Guidelines but not yet reviewed them	32.35%	11
I have utilized the Guidelines in my state/territory	32.35%	11
I am not aware of the Guidelines	23.53%	8
I have not received the Guidelines	0.00%	0
Answered		34
Skipped		1

- Freeform answers to the question about what D/HH services do your family's request that you do not currently provide included the following comments.
 - Rural areas in some states cause limited service offerings (ASL instruction, LSL support, connection to other families and to D/HH Adults, etc.) than are offered in more populated areas.
 - Inadequate support for families who choose Cochlear implants or hearing aids due to limited availability of professionals to support them as well as technology not being covered by insurance
 - Nothing the EHDl program is aware of
 - Costs of early intervention services
 - More support to families with older children of school age
- When EHDl Coordinators were asked what best describes where their EHDl Program ranks on the partnership Continuum with their FBO the majority (83%/29) considered their relationship to be that of a Partnership; where 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. One EHDl program indicated that they are thankful for the relationship with their FBO and that the relationship is making a difference for families.

All Overall Comments

- Fourteen EHDl programs shared additional comments:
 - We will be adding our partnership with our FBO to our EHDl website
 - Our FBO shares the data they collect with our EHDl program
 - Working to establish family support program and connections to D/HH Adults
 - A territory responded that while it has taken some time to develop this partnership with their FBO, they are working hard to get the word out and support families while establishing the formalities
 - Our state does not have an Advisory Committee but rather a stakeholder group that is sharing information and does not provide formal recommendations or actionable items
 - One EHDl program indicated that asking committee members to identify as D\HH or as parents of D\HH is problematic and, in some instances, controversial. Members are volunteers and we do not wish to violate anyone's privacy or to give the impression to prospective members that they are not welcome if not D\HH or parents of D\HH. Additionally, some members do not want to be thought of as D\HH first, rather as a person, doctor, audiologist, etc. We make it clear all are welcome, and we do have both parents and D\HH as active members.

Conclusions and Next Steps

This survey highlighted several areas that the FL3 Program can assist EHDl Programs in meeting the needs of families who have children who are D/HH; facilitating conversations about data collection needs of EHDl programs compared to data collected by FBOs around referral and enrollment into family to family support services and D/HH Adult to family support services. The FL3 Program will continue to disseminate information and resources via monthly emails, FL3 E-news, and the FL3 website which includes a list of ideas, trusted links and resources as suggestions for inclusion on their EHDl Program websites so that families will have access to these resources locally.

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, EHDl designated FBOs, sharing information via E-News, Office Hours, and utilizing the Spotlight on Success to share best practices and successful strategies in state/territory EHDl systems.