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?

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<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
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<tbody>
<tr>
<td>Yes, in place today</td>
<td>45.71%</td>
</tr>
<tr>
<td>No, our FBO tracks this data</td>
<td>28.57%</td>
</tr>
<tr>
<td>No, we don't have this</td>
<td>25.71%</td>
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Answered 35
Skipped 0
• Less than 50% (49%/17) of EHDI 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 EHDI program track the number of families enrolled in Family to Family support?**

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<tr>
<th>Answer Choices</th>
<th>Responses</th>
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<tbody>
<tr>
<td>Yes, in place today</td>
<td>48.57%</td>
</tr>
<tr>
<td>No, our FBO tracks this data</td>
<td>31.43%</td>
</tr>
<tr>
<td>No, we don't have this</td>
<td>20.00%</td>
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Answered 35  
Skipped 0

• Eleven percent (4) EHDI 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) EHDI 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 EHDI-designated FBO is referenced on their EHDI Program website, 37%/13 programs indicated that their FBO is not referenced on their state/territory website.

• When asked what programs EHDI offers to utilize D/HH adults to serve families,
  o 34%/12 programs indicated they have Deaf Mentor (ASL instruction, SKI HI, etc.),
  o 31%/11 have a Hands & Voices Guide By Your Side D/HH Guide program
  o 29%/10 offer a D/HH Role Models (School for the Deaf program, etc.)
  o 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 EHDI 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.
No EHDI programs indicated that they did not receive the Guidelines for D/HH Mentor/Guide/Role Model programs.


- 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 EHDI program is aware of.
  - Costs of early intervention services.
  - More support to families with older children of school age.

- When EHDI Coordinators were asked what best describes where their EHDI 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 EHDI 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 EHDI programs shared additional comments:
  - We will be adding our partnership with our FBO to our EHDI website
  - Our FBO shares the data they collect with our EHDI 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 EHDI 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 EHDI Programs in meeting the needs of families who have children who are D/HH; facilitating conversations about data collection needs of EHDI 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 EHDI 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 EHDI Programs, EHDI 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 EHDI systems.