

Family Early Hearing Detection and Intervention Data Project (FEHDI)

This is a draft document and changes may be made pending further review.

Participants:

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The purpose of this working group¹ is to create a draft of definitions for the HRSA EHD objective to “*increase by 20% from baseline the **number of families enrolled in family-to-family support services by 6 months of age***”. This work includes identifying data that the EHD programs need to monitor enrollment in family support so that they can report progress on this objective to their funders. Family support organizations (or Family-based Organizations [FBOs]) also need specific data to be able to provide data to EHD programs on the work they are doing to support families. In some EHD programs this support is provided “in-house” by EHD parent staff and not provided by other organizations. In addition, a data entry form will be created to assist in pulling the data from EHD systems, by child, to track specific items for this measure. This data may change (data will vary depending on when data was pulled and birth date range), and parents/caregivers can re-engage at any time. Standard data collection of the following dates across EHD programs is vital to improving the EHD system and meeting the needs of families we serve:

- Date of Birth (DOB)
- Date of Screening (DOS)
- Date of Diagnosis (DOD)
- Date of Early Intervention referral (DOEI Ref)
- Date of Early Intervention enrollment (DOEI EN)
- Date of referral to FBO (DOR2FBO)
- Date of enrollment with FBO (DOE WFBO)

Each EHD program and FBO will determine their own standard operating procedures (SOP) where data collection is concerned.

Definitions

EHD Programs currently differ in their specific definitions of these terms. Definitions are offered here as a guideline and may need to be adjusted on a program-by-program basis as determined by the individual programs. Adopting uniform definitions will allow EHD programs to compare across states/territories and looking at national progress in these areas.

¹ This project was supported in part by HRSA MCHB UNHSI program and CDC NCBDDD EHD program.

The Joint Committee on Infant Hearing (JCIH) 2019 Statement provides information on best practices through literature reviews and expert consensus opinion on screening; identification; and audiological, medical, and educational management of infants and young children and their families through early intervention and family support.²

Family to family Support - definition should remain broad and include all of the types of outreach and connections; must be support from a trained parent/caregiver of a child who is D/HH (*i.e., has a child with a hearing loss/atypical hearing*) providing support to families with a child who is D/HH (*i.e., has a child with a hearing loss/atypical hearing*); family support could include any parent, primary caregiver or guardian. Some states/territories may use the terminology “parent-to-parent” support which in this context is synonymous with family-to-family support. Standardized training will be determined through collaboration between the EHDI Program and FBO.^{3, 4}

Family-based Organization (FBO) – Any family-led organization that utilizes family leaders/partners and is connected with the EHDI program to provide family to family support. For purposes of this document, we will use this term to describe the provider of family-to-family support.⁵

Atypical hearing – this terminology is used to describe a suspected/confirmed diagnosis of permanent hearing loss. An attempt was made to parallel CDC Hearing Screening and Follow-up Survey (HSFS) terminology for consistency⁶.

Referred

- **Referred** is the receipt (sharing per program agreement protocol) of contact and pertinent information from an entity (e.g., EHDI or EI program, another family, or provider) to the FBO for any child with suspected or confirmed permanent atypical hearing in one or both ears. The information is received for the purpose of offering, providing, and/or enrolling in family-to-family support.
- **Referral Sent date**: the date the entity (e.g., EHDI or EI program, another family, or provider) shares the referral information with the FBO. (data field H: Date Referral sent to FBO)
- **Referral confirmation date** (received/ assumed responsibility/acknowledgement): the date the FBO acknowledges the receipt of the referral information. (data field I: Date Referral received by FBO)

NOTES/COMMENTS:

- ✓ Contact information is pertinent information that is needed to connect with a family to provide support.
- ✓ There may be “other” circumstances that may impact connecting with families (e.g., home hospice/medically fragile, other medical issues, language, housing situations etc.) and may be important to know when communicating with families.
- ✓ This definition refers to children identified with a suspected/confirmed diagnosis of permanent atypical hearing. Per programmatic agreement (between EHDI program and FBO) referrals may also occur at the time of “did not pass” (referred on) the newborn hearing screening.

² (2019). Year 2019 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. Journal of Early Hearing Detection and Intervention, 4(2), 1-44. DOI: 10.15142/fptk-b748. Retrieved from <https://digitalcommons.usu.edu/jehdi/vol4/iss2/1>

³ Early Hearing Detection and Intervention Program NOFO, HRSA-20-047, page 5. Family-to-Family and DHH Adult Consumer-to-Family Support. <https://www.hrsa.gov/grants/find-funding/hrsa-20-047>

⁴ Family Leadership in Language and Learning Center NOFO, HRSA-20-051, Page 11-footer. Family-to-family Support Program. <https://www.hrsa.gov/grants/find-funding/hrsa-20-051>.

⁵ Hands & Voices Family Leadership in Language and Learning (FL3), Support Guidelines for Addressing the Needs of Families Who Have Children Who are Deaf/Hard of Hearing, page 1. <https://www.handsandvoices.org/fl3/fl3-docs/Fam-Fam-support-guidelines-8-30-2018.pdf>

⁶ 2016 CDC EHDI Hearing Screening and Follow-up Survey (HSFS) Explanations. <https://www.cdc.gov/ncbddd/hearingloss/2016-data/13-2016-HSFS-Explanations-508.pdf>

Enrolled

- **Enrolled** is the two-way verbal and/or written acceptance (as agreed upon between the EHDI program and the FBO) to participate in family-to-family support services followed with documentation by the FBO into the designated data system(s). (data field column N: Date of enrollment into FBO) (data field is column **N**: Date of Enrollment in FBO)

NOTES/COMMENTS:

- ✓ An acceptance is defined as a two-way conversation through text, email, social media, phone, or in-person (or other agreed upon forms of communication) in which both parties communicate, and both parties are willing to communicate more in the future.

Declined

- During two-way communication, the family chooses not to participate (refuses) in offered services. (data field is column **R**: Date of Decline/Refuse)

Types of Contacts

- **Contact made** - Is when a two-way communication has occurred. Communication could be via phone, email, text/instant messaging, home/clinic visit, or participation in a family support event. This does not include 1-way attempts by the FBO that are not acknowledged by the family. (data field column **K**: Initial date contact made to family)
- **Contacted but Unresponsive** - There was two-way (back/forth) communication between the FBO and the parent or guardian, however, there was no action taken by the parent or guardian to follow-up, engage, enroll, or participate with the services after the initial contact. (data field column **L**: Contact made but unresponsive)
- **Declined/Refused** - A documented two-way communication was completed but the parent or guardian declined/refused either in writing or verbally to participate in family-to-family support services (A family may re-engage at a later time when the file would be “re-activated” and documented as a subsequent contact. (data field column **Q**: Date Support Discontinued)
- **Unacknowledged** - A documented (one way) provision of information in a verbal or written format with the child’s legal parent or guardian that informs about the availability of family-to-family support services.
- **Unable to Contact** - Unable to complete attempted correspondence with the parents or guardians due to insufficient contact information. (data field column **M**: Unable to contact)

NOTES/COMMENTS:

- ✓ The metric is ENROLLED in family-to-family support; it is important to also document the informal outreach that occurs; each program will need to clearly define their enrollment for activities at the organization level and then see if it meets the metric for family-to-family support. Distinction between joining a Facebook group (to stay in touch) vs. 1-on-1 paid support.
- ✓ Based on the family needs at the time, a continuum of support from one time to multiple: frequency (scale). Newsletters, Facebook groups, to ongoing 1-to-1 support.
- ✓ Passive vs. active engagement; collection for data reporting and programmatic for supporting families (use of QI, to improve).

Support-Discontinued

- **Discontinued Support** - voluntary or involuntary ending of outreach or support services due to one or more of the following: (Reason for discontinuing; choose one) (data field **P**: Reason for Discontinue)
 - Family decision to terminate services
 - Documentation of no response to program outreach for a time period designated by the FBO protocol
 - Family has moved out of jurisdiction
 - Child has aged out or transitioned to other services
 - Child no longer has a diagnosis of atypical hearing
 - Inactive (period is TBD by EHDI Prog/FBO)
 - Deceased infant/child
 - Outdated contact information

NOTES/COMMENTS:

- ✓ EHDI Programs/FBOs will define their own SOP for number of contacts/lengths of time for contacting, etc.

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