



FAMILY EHDI (FEHDI) DATA PROJECT

Enrolling families into family-to-family
support

Today's Discussion

- Background
- NOFO Reference point
- Development
- FEHDI Tools
- Roundtable Discussions
- Next steps





“Without data
you’re just
another person
with an opinion.”

- W. Edwards Deming,
Data Scientist

Starting Point of this work – HRSA NOFO

EHDI Program Objective

Using data from year 1 as baseline data:

Increase by **20 percent** from baseline the **number of families enrolled in family-to-family support services** by no later than 6 months of age. (page 2 of 2020 NOFO under program objectives).



Definitions

Family Support

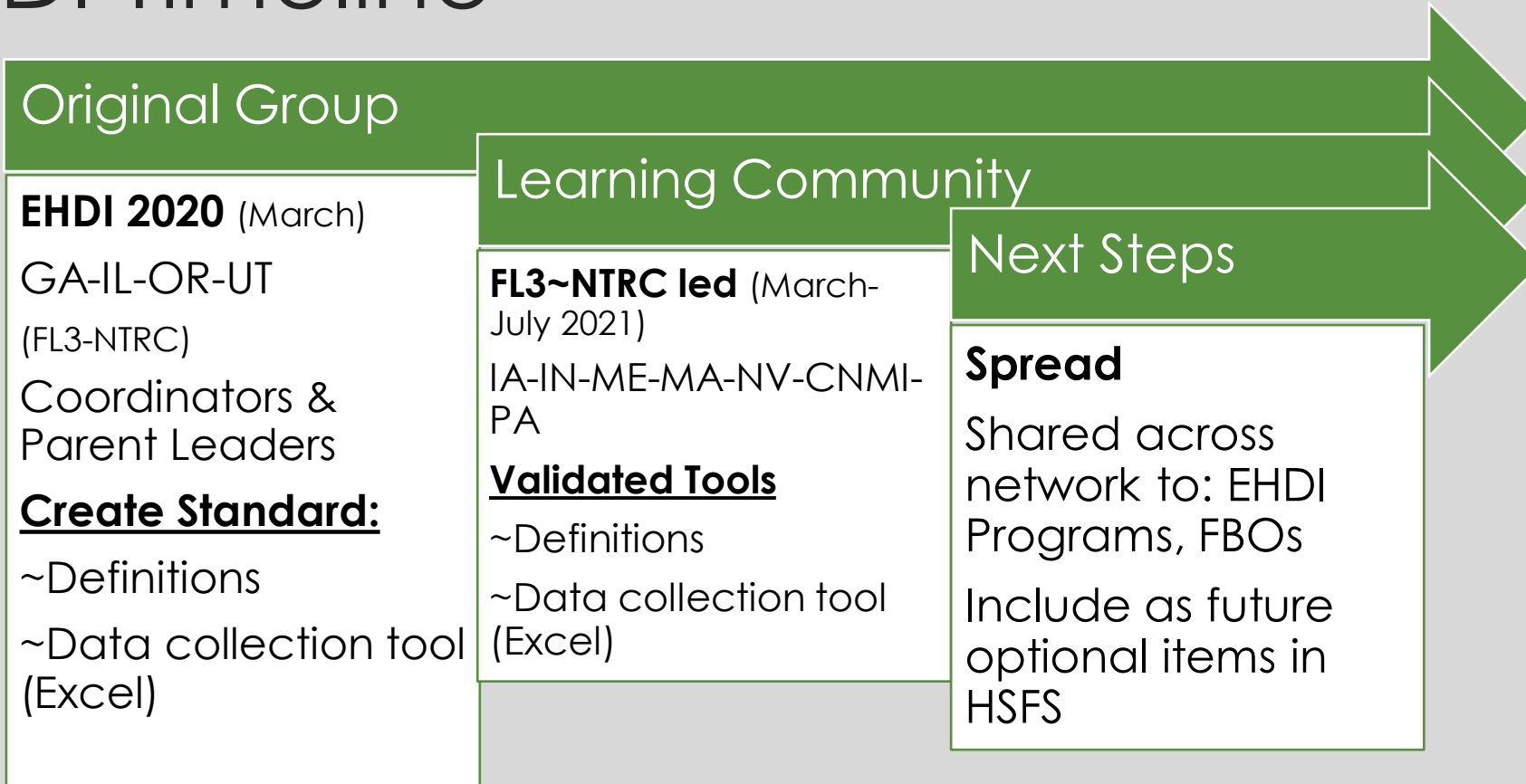
For the purposes of this NOFO, **family support** is defined as *“the practices that ensure that the holistic nature of the process for families is sustained through the timelines, policies, and procedures by the varying entities that the family encounters through hearing screening, diagnosis, EI, and beyond.”* (State NOFO/HRSA-20-047, page 1 footer).

Definitions

Family-to-family Support Program

*For the purposes of this NOFO, a “**family-to-family support program**” consists of services and supports provided in response to the needs of a given family through a family-led organization or program. Types of support and services provided will be based on the capacity of the family-led organization or program and may include but are not be limited to: direct parent-to-parent support, information, education, technical assistance, training, and referral. (page 11, footer)*

FEHDI Timeline



What are we trying to accomplish?

How will we know that a change is an improvement?

What change can we make that will result in improvement?

Aim

Measures

Ideas/Changes



The Model for Improvement



- Created by Associates in Process Improvement, 2009

Family Early Hearing Detection and Intervention Data Project (FEHDI)

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

Participants:

- Illinois – Ginger Mullin/EHDI Coordinator and DSHP/SHWA Representative, Carrie Ballou/Parent Partner, Gabrielle Biers/EHDI Staff
- Georgia – Brandt Culpepper/EHDI Coordinator and DSHP/SHWA Representative, Desbonda Washington/Parent Partner
- Utah – Stephanie McCann/EHDI Coordinator, Katie Greene/Parent Partner, Jackie Hennrichsen/Parent Partner
- Oregon – Heather Morrow-Almeida/EHDI Coordinator and DSHP/SHWA Representative, Amada Bales/Parent Partner and Molly Swafford/EHDI Staff
- H&V FL3 Center – Vicki Hunting
- NCHAM – Alyson Ward

The purpose of this working group¹ is to create a draft of definitions for the HRSA EHDI 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 EHDI 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 EHDI programs on the work they are doing to support families. In some EHDI programs this support is provided “in-house” by EHDI parent staff and not provided by other organizations. In addition, a data entry form will be created to assist in pulling the data from EHDI 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 EHDI programs is vital to improving the EHDI system and meeting the needs of families we serve:

- Date of Birth (DOB)
- Date of Screening (DOS)
- Date of Diagnosis (DD)
- Date of Early Intervention referral (DOEI Ref)
- Date of Early Intervention enrollment (DOEI EN)
- Date of referral to FBO (DOE2FBO)
- Date of enrollment with FBO (DOE WFBO)

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

Definitions

EHDI 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 EHDI programs to compare across states/territories and looking at national progress in these areas.

¹ This project was supported in part by HRSA MCHB LNHSD program and CDC NCBDDD EHDI program.
Last update: December 10, 2020

The Joint Committee on Infant Hearing (JCIH) 2019 Statement on the current best practices and expert consensus opinion on screening, identification, and intervention of infants and young children and their families through family support - definition should remain broad and include support from a trained parent/caregiver of a child who is providing support to families with a child who is D/HH (could include any parent, primary caregiver or guardian-to-parent support which in this context is determined through collaboration between the EI program and the parent/caregiver).

Family Support (FS) - Any family-led organization that provides family-to-family support. For purposes of this project, FS is used to describe a suspected hearing screening and follow-up program agreement with another family, or providing in one or both ears in a family-to-family support (e.g., EHDI or EI program referral services, shared responsibility, etc.).

Family-based Organization (FBO) - Any family-led organization that provides family-to-family support. For purposes of this project, FBO is used to describe a suspected hearing screening and follow-up program agreement with another family, or providing in one or both ears in a family-to-family support (e.g., EHDI or EI program referral services, shared responsibility, etc.).

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)

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

Types of Contacts

- **Contact made** - Is when a two-way communication has occurred. Communication text/instant messaging, home/clinic visit, or participation in a family support service attempt by the FBO that are not acknowledged by the family. (data field R)
- **Contacted but Unresponsive** - There was two-way (back/forth) communication or guardian, however, there was no action taken by the parent or guardian to participate with the services after the initial contact. (data field S)
- **Declined/Refused** - A documented two-way communication where the parent or guardian declines/refused either in writing or verbally to participate at a later time when the file would be re-engaged. (data field T)
- **Unacknowledged** - A documented (one way) communication where the parent or guardian does not respond to the FBO protocol. (data field U)
- **Unable to Contact** - Unable to complete contact due to insufficient contact information. (data field V)

NOTES/COMMENTS:

- ✓ The metric is ENROLLMENT that occurs; each program and then service group (for Baseline)

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 Discontinued)
 - Family decision to discontinue services
 - Documentation of no response to program outreach for a time period designated by the FBO protocol
 - Family has moved out of jurisdiction
 - Child no longer has a diagnosis of atypical hearing
 - Inactive (period is TBD by EHDI Program/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.

Workbook Tool

Date of Report:
Reporting Period (Babies born between):
of babies Referred by 3 Months of Age:
babies enrolled in family-to-family support by no later than 6 mos of age:

EHDI Program sends to FBO

Child Information		Screening	Diagnosis		
Unique ID# (MRN/EHR#)	Additional Unique ID# (MRN/EHR#)	Date of screening (final inpatient or final outpatient) MM/DD/YYYY	Date of Initial Dx	Date of Final / Confirmed Dx (may or may not be the same as initial Dx date)	Age (days) of diagnosis - Date of INITIAL DX minus DOB (Calculated Age) 90 days
abc123		08/20/2020	08/28/2020	08/28/2020	27
def456		08/20/2020	09/20/2020	09/25/2020	5
ghi789		07/01/2020	08/01/2020	12/15/2020	152
0 jkl012		07/15/2020	09/15/2020	09/15/2020	41


FBO (Family to family support) reports back to the EHDI Program

Date REFERRAL sent to FBO	Date REFERRAL received by FBO	Age of referral to FBO - Referral Date minus DOB (Calculated Age) 180 days	Initial Date Contact made to family	Contact made but unresponsive (Y, N/A, Pending)	Unable to contact (Y, N/A, Pending)	Date of Enrollment in FBO	Age of enrollment in FBO Date of Enrollment minus DOB (Calculated Age)	Reason for discontinue (choose one)	Date Support Discontinued	Date of Decline/Refuse
08/30/2020	08/31/2020	29	09/05/2020	N/A	N/A	09/05/2020	35			
09/26/2020	09/27/2020	11	09/28/2020	Yes	Pending			Outdated contact		
07/07/2020	07/09/2020	6	07/10/2020	N/A	Yes	07/10/2020	9	Family decision to terminate services	09/30/2020	
09/20/2020	09/20/2020	67	09/22/2020	N/A	N/A					09/22/2020

Parent Perspective



- FEHDI definitions allow us to compare apples to apples
- Information tracking
 - Spreadsheet or state system
 - Collection source (intake form)
- Agreement to share information
- FEHDI is a springboard to information gathering
- Goal of support by 6 months
 - Future support




*“I HAVE GREATLY **ENJOYED** SERVING ON THE FEHDI COMMITTEE. WHEN THERE IS A NEW EHDI PERFORMANCE METRIC, IT IS SO IMPORTANT TO HELP EACH OTHER IN FIGURING OUT HOW BEST TO ACCOMPLISH THIS NEW GOAL AND REPORT ON IT IN A CONSISTENT FASHION ACROSS THE STATES AND TERRITORIES - SO THAT WE ARE **ALL ON THE SAME PAGE** AND THE NATIONAL NUMBERS REALLY HAVE MEANING.”*

~ Participant Quote



“WORKING ON THE FEHDI PROJECT HAS GIVEN ME **A NEW UNDERSTANDING AND APPRECIATION** FOR THE INNER-WORKINGS OF PROGRAM DEVELOPMENT AND GRANT FUNDING. I’M SO THANKFUL TO HAVE A GLIMPSE INTO OTHER EHDI PROGRAMS AND THE WAY THEY **PARTNER WITH FAMILY SUPPORT** PROGRAMS! THE PERSONAL AND PROFESSIONALISM OF THIS GROUP HAS BEEN VERY EDIFYING TO ME AND THE WAY I LEAD MY PROGRAM!”

~ Participant Quote



“I FELT A **SENSE OF UNITY** AS WE ALL CAME TOGETHER TO DISCUSS PARAMETERS AND DEFINITIONS. IT WAS REFRESHING TO BE PART OF SOMETHING THAT COULD MAKE REPORTING NOT ONLY EASIER TO FIGURE OUT BUT TO HAVE **CONSISTENCY** BETWEEN STATES. THIS HOPEFULLY WILL ALLOW US TO SEE ACROSS THE NATION HOW WE ARE DOING, **CELEBRATE** OUR SUCCESSES AND **EVALUATE** AREAS TO IMPROVE. I HAVE HOPE THAT THIS WILL BRING MORE PARENT PARTNERS TO THE TABLE AS A PART OF A LARGER TEAM CREATING CONNECTIONS, DEVELOPING ROLES, A **SENSE OF PURPOSE AND A MINDSET OF QUALITY IMPROVEMENT.**”

~ Participant Quote

Maybe stories are just data with a soul.

~ Brene Brown



What's Next



Make Tools accessible



Continue to spread the learning



Continue discussions with Federal Partners and other EHDl system stakeholders

Roundtable Discussions:



1. How did you establish baseline? How are you measuring success?
2. What are your experiences with data sharing between EHDl and your family-based organization(s)?
3. What opportunities or challenges have you experienced in tracking enrollment into family-to-family support?
4. What capacity is needed in your EHDl Program and/or family-based organization(s) to fully implement FEHDl data tracking?



THANK YOU

<https://www.infanthearing.org/webinars/2021/family-support-data.html>