

Meeting Minutes  
Family Task Force  
March 5, 2021  
12:00 – 1:00

Facilitator: Heather Abraham  
Notetaker: Arlene Stredler Brown

Attendees:

- Sara Kennedy: Colorado Hands & Voices & Parent
- Emily Augsburger: Parent
- Mah-rya Proper: Parent & Interpreter
- Geoff Goodside: Parent
- Cathy Cortese; Parent & Interpreter

Discussion:

1. Documents were sent for review. The plan is to look at HRSA definitions of family-to-family support and requirements for reporting.

For this past year, we established a structure with CO EHDI to establish our governance structure. All appreciate the work of the Family Task Force to help get The Ascent Program up and running. There has also been a good discussion about the role of families in the transition families experience when a child is identified as DHH and then transitions into early intervention.

Today, the goal is to get grounded in shared definitions and to look at data collection.

2. Link to documents being discussed:  
<https://drive.google.com/drive/folders/1AgjOuFKBxz3fZM541VN6JGeceuWo7OoT>

First document is the Family-centered Early Intervention definitions:

<https://docs.google.com/document/d/1vhhGEx8cHTa0dIH1jhM71KH2AToPNonM2eZ5JnIA10/edit>

Our task is to focus on reporting requirements and information from JCIH about family-centered best practice.

In the documents you will see a listing of the five family support organizations. While four of the five programs offer services to families, only Hands & Voices is family led.

Need to distinguish services to families that are professionally-led v. parent-led.

What, among family-to-family support is an “activity” v. “information sharing”?

#### Reporting:

- Goal: Increase by 20% the number of families referred to and enrolled in family-to-family support.
- Family-to-family support defined:
  - o The definition states that organizations are to be family led. On the list of five agencies that provide family support, only one – Hands & Voices – is led by families. And, consider that some programs are for families but do not necessarily address family-to-family support.
  - o Capacity needs to be addressed. Are there enough organizations/services to serve all families.
  - o How might the programs in Colorado collaborate to fulfill family-to-family supports?
  - o How do we engage more families in the conversation about family-to-family support? This is the work of CO EHDI in Year 2.
  - o How do we capture data from other agencies (e.g., CO AG Bell) for statewide reporting?
  - o Do we want to include other agencies like Rocky Mountain Cued Speech? Do we want to include programs that are not specific to DHH? The group seemed to focus on programs that were focused on birth – three.

#### Family-to-family support data fields include:

- Number *referred* to family-to-family support
- Number *engaged* in family-to-family support

#### Data Collection:

- Sara shared about data collection to date as it supports a baseline. Historically, we've identified 130-140 children/year. Some are LTF. At the height, H&V connected with 174 families in a year. Referrals came from CO-Hear Coordinators and most audiologists. This year, there has been ~50% of this number referred to H&V. Notably, a referral process was established in April 2020 that identified CO-Hear Coordinators as the point of contact; issued by CDHS and signed by Christy Scott and Ashley Renslow. What might be affecting lower numbers:
  - o COVID (with fewer children)
  - o Home birth rate
  - o Shifts in providers
  - o Self referrals have increased
  - o Referrals from CO-Hear Coordinators are equal to referrals from audiologists.
  - o Other unknown factors

What is causing this shift in referrals to H&V? Does there need to be more education about what is shared and whose responsibility it is to share it? Is the data collected in HIDS adequate? This data does not go directly to H&V.

EHDI Definitions as to eligible programs:

- Has an organized structure to support families (above and beyond an organization that offers information/resources)
- Organized for delivering services to children birth – 36 months
- Organization is family led.

Action Steps:

- Heather and Sara Kennedy to work together to look at the referral process. Who refers? How to establish baseline data? What year are we reporting?
- H&V concerned about sharing data without funding from the state.
- Focus on CLD families.
- Gather data from other organizations providing supports to families. Identify what is family-led v. professional-led activities.
- Look at services delivered in person v. remotely?
- Add CSDB (Early Years and/or Early Literacy Events)?
- How define activities that meet the definition?