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**Family Engagement Workgroup**

**Facilitators: Megan Cote (NCDB) & Jan Serak (Region 4 PTAC)**

**Attendees**

Tanni Anthony CO

Lyn Ayer OR

Brenda Baroncelli NCDB

Elizabeth Bell, NCDB

Edgenie Bellah TX

Clara Berg, NY & NFADB

Susan Brennan IA

Danna Conn TN

Carol Darrah GA

Jennifer Gonzales AR

Adam Graves TX

Sue Ann Houser PA

Melanie Knapp TX DBMAT

Thomas Lather OH

Molly McLaughlin MN

Mellanie Lee HI

Rebecca Obold-Geary KS

Amy Richards IL

Charity Rowland

Jana Villemez AR

Notetaker: Peggy Malloy, NCDB

**Megan intro**

Differing levels of resources in SDBPs lead to inequity in the availability (and knowledge and skills) of family specialists.

Families need training to:

* know about deaf-blindness
* be effective advocates for their children
* be prepared to work for state and national system change (if they want to)

Family specialists need:

* organized ways to work together and share information
* training to help them develop similar skill sets

**Review of existing initiatives (see also, handout)**

* Carol Darrah described F2FC Pilot
  + Pilot year ends in November and then they will evaluate how the group should proceed moving forward
  + May convene separate groups within states or with specific interests (e.g., based on child age, etiology)
* Megan talked about family specialist Mastermind calls. Clara added that the calls help you see all of the good people are doing and make you feel good about yourself.
  + In the context of this report, a discussion bubbled up regarding the role of a family support person within a db project? The group agreed that we need a joint job description.
  + A number of states mentioned already having one that they can share (CO, GA, HI, NM)
* Megan talked about familieslead.org. Let's figure out as a network what resources we have and add them to the site.
* Clara talked about the symposium. NFADB is planning to invite more families this time. The focus will again be on individualized supports, but will also include teachers of the deaf-blind.
* Megan talked about highlighting collaborations between parent centers and SDBPs. Have received forms back from 15 states. Jan pointed even if a state does not have a collaboration, they should let us know why that is, so we can help.
* Family matters stories
  + Thomas (OH) has 6 video stories that he will send to Megan.

**General discussion questions**

***What are the top five things that family specialists need?***

* Training about national, state, and local resources available to support families
* How to conduct train-the-trainer sessions on leadership
* Mentoring
  + Could set up each FS with a mentor partner
  + Programs to consider
    - Guide by Your Side
    - Hands and Voices
* Information about topics that will have sufficient value and interest to draw families to events
* Suggestions about how to learn more about what family specialists need
  + Have a discussion about how each state benefits from having a family specialist
  + Do a national needs assessment

***What are the 5 top things families in your state need (e.g., things they call you about)?***

* Why it is important to attend SDBP family events
  + Recommended video on how to create community: "Everything is better in community" (http://delight.us/everything-better-community/)
* Topical information about deaf-blindness and educational programming
  + Several state projects (OR—western states—TN, CO, AR) have done needs assessments on family needs and will send to Megan to synthesize.
  + Commonly-identified topics:
    - behavior
    - interveners
    - communication
    - etiologies
      * recommended website written by parents: "Complex child"
    - transition
    - how to be an effective partner with school teams
    - parent connections
    - training on individualized and unique supports for deaf-blindness (e.g., different roles such as interveners, SSPs, teachers of the deaf-blind)
* More local parent groups
* More info about early intervention for kids who are deaf-blind (the needs of parents of children in this age group differ from those of older kids)

***What do they families need that they don't know they need?***

* The first time meeting with parents is the hardest. Once they realize what they have to gain, it becomes easier. Anything you can do to get a parent for the first time to an event is crucial because then you will have them forever.
* Need opportunities to network together person-to-person. Families feel completely alone and talking to another family member is much more meaningful early on than talking to a professional.
* Don't worry so much about content and teaching, just organize a picnic. Anything to get families together.
* National communities of family leaders and state communities of families. National connections.
* Preparation for transition to adulthood. Help families coordinate among various state agencies (Thomas said Ohio has done work in this area). Family specialists need to have this kind of info to share with their families. Can we develop a tool that people can use in different states?

***What do families need to feel empowered in the following areas?***

1. Advocacy for own child
   1. Qualified personnel—parents need to understand that teachers of the deaf-blind and interveners are critical for their children
   2. Meeting basic needs—accessing food stamps, diapers (can't expect families to deal with complex educational issues if they are having trouble meeting basic needs)
   3. Remember that not all families have internet—some need print materials (easy-to-read) or info on a DVD
2. Mentoring of other families
   1. Info about person-centered planning
   2. Support (including funding) for getting to family events and childcare at these times
3. Working for systemic change
   1. Advocating to formalize interveners and teachers of the deaf-blind
   2. Educate families about how to participate in groups (see new guide).

**Action planning**

***Potential Partners***

* Within the db network
  + F2F network
  + Mastermind group
  + DB-MAT (a good resource for families even outside of TX)
  + NFADB
  + CHARGE
  + Spanish conference calls group
  + HKNC
  + Perkins
  + Communication Matrix CoP (community.communitionmatrix.org)
  + Needs to enroll family members. We can help Charity do this.
* Outside the network
  + Regional parent center trainings (there are 6 centers). It would be valuable to have someone from our network be at these trainings
  + CADRE
  + State agencies that are strong on specific topics
  + Hands and Voices
  + NAPVI
* People to ask to post on our family engagement forum
  + Millie Smith
  + Barbara Miles
  + Robbie Blaha
  + Bernadette van den Tillaart
  + Maybe one state a week could post to the forum (e.g., *Here are the top three things that are great for our families!*)

***Action steps***

* Symposium
  + What will family specialists do on their day? How do we get ready? Need a workgroup to have this conversation.
  + Be sure to emphasize to the speakers to focus on the things that are important for family specialists to know and not make it seem like they (the speakers) are the sole experts.
* familieslead.org also needs a work group
  + Tours
  + Conversation—what resources do you have that can augment the site?
  + Family leaders would like an interactive place to communicate with each other
* Get families to create a profile on nationaldb.org
* Families Matter
  + will need help collecting stories
  + if you are having trainings and can capture video, let Megan know
* National survey of family needs