**Challenges**

* Fewer fathers than mothers in attendance at parent events
* The need to reach more families that have other issues such as drug use, mental health challenges, etc. How do we approach these families? We can’t solve all problems. We may need to solicit the help of other professionals and agencies.
* Events for impoverished families - child care issues, money for gas to attend meetings. Families may just be holding on, trying their best to stay positive and want and need the information but are either traumatized or unable to attend a meeting for financial and child care reasons. Example of a recent event: Families offered $50 stipend for gas to attend but no one showed up.
* Have high employment standards for Family Specialists. Being a parent is not the only qualification.
* Due to on-line information, families are not as dependent on specialists as in the past. How can the benefits of meeting with a trained specialist be better explained?
* Time is a big challenge for families. Many do not want to sacrifice time for long commutes to meetings.
* The value of face to face meetings is not understood. How can the benefits of a face to face meeting be better explained?

**What Works?**

* LA Project working with their state Parent Training and Information Center (PTI), Early Hearing Detection and Intervention (EHDI) and other organizations.
* Stay current on technology and research methods.
* Hands on approach and personal touch, i.e. a personal letter of introduction to all families. Inform families about upcoming events so they can plan and ask for feedback on the event. Ask if the event is of interest and worth their time to attend.
* Provide opportunities to meet in different state locations and be aware that what works in one locale may not work in another (rural vs urban).
* Annual family retreats are important face to face opportunities.
* Parent to parent connections provide a means to support families.
* Set a time line for the intake process. Try not to be intrusive and be sensitive to information overload.
* Think about how to go about providing more face to face opportunities for families. We forget how important face to face can be.
* As a parent of a child who is deaf-blind we always found family weekends important. Initially fathers and mothers were included in the family weekends but as time passed switched to only a mom’s weekend (25 to 30 moms gathered).
* Continually engage families through very brief, weekly informational email. Consider “e-mail blasts” such as those used by the CHARGE Syndrome Foundation.
* Assign a strong parent to be a volunteer state liaison between the project and families.
* Assign family mentors to younger families.
* Face to face meetings are critical and are the building blocks for future connections via distance technology.
* Sib shops should be part of any family event so siblings can play a larger role in the life of their brother/sister who is deaf-blind. Sib shops build strong connections and allow siblings to feel less isolated.
* Family includes extended family too. Be mindful of grandparents and others involved in the family’s life.
* Develop special events such as a golf outing for dads where they feel comfortable to share their feelings.
* Project Directors should be supportive of staff so they can meet the challenges of the job.
* State clear Family Specialist requirements and training.
* Family Specialists play a dual role within the project as both parent and professional, and need to be mindful of the role they play when speaking with another parent.
* Different skill sets in the project can be useful. A social worker stated that we don’t always need to fix a problem but rather meet the family where they are and bring a family dynamics perspective to the mix.
* Effective strategies: Facebook, National Conference Calls in English and Spanish, staff proficient in new technology and social media and financially supporting a family to attend conferences, such as the CHARGE Conference which is a wonderful model of parent support.
* Outreach as an effective tool.
* Make the initial connection and then continue to engage families on a small budget.

1. Organize an informal visit to a farm or other community outing or create opportunities for families to connect and share these ideas on Facebook.
2. Start small and connections will grow and take on a life of their own.
3. Gather and bring a picture of your child as a starting point and then ask families if they’d like to meet each other’s children and plan for another informal gathering and then plan a family weekend with sib shops.
4. When you gather families you learn about their connections that can support future gatherings.

**Next Steps:**

* Personal challenge: Over the next 6 weeks select one area from this list that you are not addressing and accomplish a concrete and realistic objective!
* Final Message: What idea(s) will you use in your project and make happen?

**Collaboration**

* State Projects working with their PTI and Early Hearing Detection and Intervention (EHDI) and other organizations, like in Louisiana.
* Partnering with family organizations already established within states is an effective strategy.
* Utilize our creativity skills to include parent networks in the planning of a two day event.
* In the past, the State Project in Oregon hosted the first parent weekend without children and they began with 3 families. Families became interested and now have families from all over the state. Parents do all the planning and the project does the paperwork. In their website, the webmaster handles the posting of the content and the parent pages are done by parent’s submissions.
* State Project in Georgia has a private Facebook page for families; once families get involved they reach out to each other.
* These questions were raised, “How can we share database information between projects to find parent to parent connections? How can states collaborate in a more formalized process?”
* Collaboration happens through listservs with project postings trying to find a parent of a child with a similar etiology or rare conditions outside their state to match with one of their families.
* NFADB has a national database of parents.
* NFADB can help and will try to increase resources to expand outreach. NFADB needs support volunteers to help carry out action plans.
* Remember: It’s not what NFADB can do for you but… what can you do for NFADB? Facebook pages should include about NFADB and their new website. Spread the word by including a link on your homepage, like Kentucky did.
* The new NFADB web site contains videos of parents talking to parents.
* Promote NFADB by asking families in your state to become members of NFADB. Kentucky Project sent out NFADB bumper stickers to all their families as a reminder.
* Share information about NFADB’s work with regional PTIs.
* Support families within your state/states to get together and become affiliates to NFADB.
* Share information about NFADB with all state project stakeholders.
* Can we think of different and concrete strategies to collaborate with regional PTIs and forming partnerships with NFADB representatives at the same time?
* Invite a NFADB representative to a regional PTI/State Project meeting.
* If state projects are not re-funded after this five year grant cycle it is important to remember that NFADB and the CHARGE Syndrome Foundation will continue to exist beyond the state projects.
* It was brought up that it would be helpful to know what each state project self-identifies as there project strengths and individual staff strengths. In an earlier session today on building network neurons it was suggested that NCDB website create a format for states to be able to easily identify other state project strengths (possibly through a drop down menu).
* It is important to reach out to Spanish speaking families. NCDB sponsors two national conference calls per month facilitated by NYDBC’s Family Specialist. There is one monthly call for Spanish speaking families that have a child with CHARGE and one monthly call for Spanish speaking families with children with other etiologies.
* The Children's Hospital in Georgia has a live on-line expert available for a few hours to answer any questions.
* State projects and family organizations are both critical. At any time feel free to connect and contact Sheri Stanger and Clara Berg to help with outreach to a local family.
* It’s important to get families together and increase partnerships.
* Good example of collaboration in Kentucky where the state project and the PTI will share two sites within the state. Having staff members work together makes problem-solving much easier and creates a “beautiful marriage” and by tapping into each other’s strengths and by discussing their greatest challenges.
* Establish a relationship with the PTI. Improve upon the PTI connection, an easy way to begin the relationship is to invite your state’s PTI director to lunch. Go beyond advisory board involvement.
* Partner with other professionals that possess specific skills to support a family.
* Either full or part time, the Family Specialist is an important collaborator within State Projects.
* Suggestion: At next years’ Deaf-Blind Summit – plan a special meeting for the Family Specialists on the day before the Summit.

**How Can We Use Our National Network to Replicate, Learn From, etc.**

* Plan National Webinars to share FE action plans with a 6 month follow-up.
* Share and read newsletters from other state projects, i.e. Oregon Project Newsletter at: <http://www.oregondb.org/index.html>.
* Explore how other projects/organizations distribute their information to families and if those materials are available on web sites and through social media.
* Is the distribution of information effective? How is the effectiveness measured?
* Self-identify individual project strengths and individual staff strengths and share via the NCDB web site as suggested at the Building Network Neurons session.
* Improve outreach: The CHARGE Syndrome Foundation State Parent Liaison Pilot Project to improve outreach, communication, understanding and sharing of resources and child find.
* Utilize NCDB’s resources and web site to create chat/private rooms for topic specific discussions. Motivate families and professionals to participate in free on line training.
* State Projects to create a private FB group for parents to facilitate the sharing of information.