

Building Family-to-Family Communities (F2FC) Pilot

Summary of Southeast Family Conference Calls

Team Members

Alabama – Arkansas – Florida – Virgin Islands – Georgia – Kentucky –
Louisiana – Mississippi – North Carolina – South Carolina – Tennessee – Texas
National Center on Deaf-Blindness – National Family Association for Deaf-Blind

Long Term Intention: Increasing State Capacity for Building Community Family Infrastructure

Because deaf-blindness is a low incidence disability, the families of children who are deaf-blind may have difficulty meeting and sharing resources with other families who share the challenges and blessings of having a child who is deaf-blind. The Southeast Regional Teaming Group desired to build capacity within the region and within each state to bring families together to talk and learn from each other. The Group proposed instituting a year-long series of family conference calls, facilitated by parent leaders, to help families: get to know one another; build trust and confidence in one another; rely upon each other for shared emotional support, expertise, and resources; and then be able to extend similar support to additional families of children with deaf-blindness.

To help perpetuate family connections within the region and within each state after the pilot period ends, the pilot strived to provide other opportunities for families to stay in contact and to build leaders within the small groups who can serve as family leaders after the pilot period. The F2FC Pilot project established a collaborative relationship with the National Family Association for the Deaf-Blind (NFADB) so families have the opportunity to meet and connect to other families across the nation.

Format and Process for the Pilot:

- A F2FC flyer and registration form was developed and shared with SDBP partners.
- SDBPs used the flyer to recruit families to participate in the year-long pilot.
- Two Family-to-Family Community (F2FC) groups were organized for the 12-month pilot period.
- Call Facilitators and Moderators were identified for each group.
- NFADB representatives developed and facilitated training for call Facilitators and Moderators.
- Facilitators sent out an email to their families, introducing themselves with a picture of their family, and inviting all participants to send an introduction of their family with a picture to the group.
- Call Schedule for each F2FC: (November 2014 through October 2015)
 - Two calls for the first month (one 90 minutes and one 60 minutes) to get to know each other and establish ground rules for their group.
 - One call per month for months 2-12 (60 minutes each)

- Facilitators of the F2FC groups were to identify potential leaders to receive additional advocacy training through NFADB, so that they may provide support for another family or facilitate F2FC groups regionally or in their own states when the pilot is concluded.
- NCDB created a private, shared Wiki on the NCDB website where participants could dialogue and share resources between call interactions and which could continue to be used after the pilot period ends. They were also to be encouraged to post to the Family Engagement Forum page on the NCDB website to share reflections, insights, or questions to the larger national community.
- Data on efficacy of the calls was collected and analyzed by the Southeast Regional Teaming Group and will be shared through NCDB's Family Engagement Initiative.

Cost of F2FC Toll Free Calls for Pilot:

NCDB hosted the toll-free calls for participants. It was estimated that a 60 minute call for 8 participants would cost \$28.80 per call. The actual cost was approximately \$40 for a 60 minute call with 8 participants.

Pilot Measures:

Plan: To measure progress toward pilot benchmarks and to cull dominant themes and family resources identified through the F2FC calls, a comprehensive evaluation plan was developed.

We planned to collect the following information during the pilot:

- **Communication Briefs:** A volunteer from of each F2FC group provides a verbal status report to the state projects/NFADB/NCDB audience of what has been successful or not successful about their own F2FC's experience at the 6- and 12-month point of the pilot year.
- **Quarterly Focus Groups:** Conduct a brief survey among the individual community members. (Include barriers, improve how, topic(s) relevance to own situation, etc.)
- **Consider numbers of interactions and consistency of each members' participation:**
 - i. Within each scheduled call
 - ii. Within online interactions
 - iii. Number of volunteers/outreach interactions
- **Other measures as determined during the course of the pilot.**

Result: While it was important to have an evaluation plan, it was also necessary to deviate from the original plan based upon the level of response and engagement from participants.

- The moderator completed a Call Log following each call to capture the participation of F2FC members, record overall themes discussed during the call, and to make notes of ideas/suggestions for future calls.
- For months 1-4 and at the end of the pilot, online surveys were sent to participants following each call. Initially, the response rate was satisfactory; however, after the fourth month, we were receiving no responses. The F2FC team decided to stop sending out surveys after each call and only sent one final survey at the end of the pilot period. For the surveys that were completed, participants rated the calls highly:

- quality (4.54/5), relevance (4.65/5), usefulness (4.41/5), beneficial (4.70/5)
- Mid-point Focus Groups were completed in April 2015 for each of the F2FCs. A volunteer from NFADB facilitated the calls, which were recorded and transcribed (without names) so that the F2FC could analyze the responses. Feedback from each of the F2FCs was summarized and shared with the Facilitators of each group.
- Final Focus Groups were completed in November 2015 for each of the F2FCs (facilitated by the same NFADB volunteer) and in December 2015 for the Facilitators and Moderators (facilitated by two F2FC project leaders). These three calls were recorded, transcribed, and analyzed.

Goals:

2. Connect Families

- Benchmark: Participating state projects would have one family participate in at least one F2FC group in the first year.
Result: Nine out of the twelve participating state projects were able to identify and recruit a family member to commit to participating in the F2FC Pilot Project for one year.
- Benchmark: Each state would develop a plan to establish its own state F2FC, or partner with another state to share a F2FC group by the end of the first year of the pilot.
Result: State projects will collaborate with Family Specialists, NFADB, and NCDB to determine the next steps. Possibilities include state call groups, group(s) of states call groups, and/or national call groups.

3. Build Relationships

- Benchmark: Family participation in 75% of calls during the pilot period.
Result: F2FC 1 had a 42% family member participation rate for calls; F2FC 2 had a 67% family member participation rate for calls.

4. Maintain/Expand State Capacity for Engaging Families

Benchmarks:

- At least one family from each F2FC group joins NFADB.
- At least one member of each F2FC group will engage in or support an NFADB, state DB project activity, or state advocacy group activity.
- The facilitators will identify at least one family member as a leader for each F2FC group.
- In collaboration with NCDB and NFADB, the F2FC leaders will participate in further training to facilitate state calls or provide individual support to another family.

Results:

- At least 4 of the 9 participating family members joined NFADB.

- Participants were involved in various opportunities within their own states; however, it was not clear that their participation in F2FC was the impetus for this.
- At least one leader emerged from the group, and this participant (with support from the SDBP) started a state call group.
- The SE group of SDBPs, along with the larger network of SDBPs, NCDB, and NFADB will work together to create a plan to expand/replicate the F2FC project.

F2FC Suggestions for Future

- Recruit additional Facilitators, possibly pairing one of the Facilitators of the pilot with someone new
- Continue to provide training to Facilitators through NFADB
- Multi-state call communities, 8-10 members
- Offer communities divided by age (infant-toddler, school-age, transition-age), medically-fragile/not, and perhaps by specific etiology
- 90 minute calls, monthly, options for time of day
- Phone-only calls with option for occasional video-chat (esp. at beginning) and/or option for group of families who want to use video-chat every call
- Easier ways to connect outside of calls- email, Facebook, etc.
- Combination of structured topic (determined by group) and open forum for support & brainstorming
- Round-table facilitation for all members to have opportunity to participate
- Initial creation of community, then closed so that members can build relationships, then open period for new members to join
- Explore options for free conference calls; partnership with state DB projects, NCDB, NFADB

Narrative Summary of F2FC Pilot Project

Registrations were received from 9 family members who were committed to participating in the year-long pilot. Two call groups were established, divided by their availability of day/time to participate in the calls. Initial calls began in November 2014 and continued through October 2015; one group had busy schedule during the summer and did not meet. F2FC 1 was comprised of 5 family members, 2 facilitators, and 1 moderator, and they hosted a total of 9 calls during the year. F2FC 2 was comprised of 4 family members, 2 facilitators, and 1 moderator, and they hosted a total of 13 calls during the year.

The calls were semi-structured in nature. They began with open discussions of participants sharing celebrations and challenges of raising a child who is deaf-blind. When a common theme/topic was identified, call facilitators or participants gathered resources to share during the next call and/or they invited a guest speaker to share information with their community. Topics included: communication, concept development, calendars, routines, behavior, siblings,

holidays, interveners, IEPs, working with professionals, the Cogswell-Macy Act, transition, self-determination, person-centered planning, and summer camps and activities. Participants agreed that some of the best conversations stemmed from a parent bringing a challenging situation to the group for brainstorming, sharing of resources, and simply being able to talk with other people who understood their point of view. Both groups made a point to include the sharing of celebrations, big or small, with the group during each call.

Connecting outside of the calls was not as prevalent as expected. Only one parent posted information and pictures on the private space of the NCDB website. Participants reported that they occasionally contacted each other via email or phone, usually related to a specific topic that they wanted to discuss. The feedback from the focus groups was that they didn't feel comfortable and/or have the time to learn how to use a new technology. They would have preferred a group email or private Facebook page- something that they already use.

The F2FC pilot was designed with the purpose of building relationships between families, in contrast to drop-in-styled calls/webinars that focus more on the sharing of specific information. The communities were small, so that participants would have the opportunity to come together regularly in order to build relationships and feel comfortable sharing personal information about their child and family. Mid-way during the pilot, one participant expressed desire to invite a new participant to join one of the communities. The F2FC project leaders discussed this with the facilitators of the group and also received input from members via email. At least one parent from the F2FC group expressed feeling uncomfortable with including someone new, because including a new parent changes the dynamic of the group and the relationships that have been established. Therefore, it was decided to keep the original group and structure of the pilot project intact. This was an unexpected situation, and it gave us the chance to later discuss how to handle the opportunity to invite new members to an existing community. During the focus groups, participants suggested that there could be an initial time period for members to join, then a closed period of time to get to know and trust one another. After an agreed-upon period of time, the group could then be opened again to include new members. That is one approach to membership; another could be that another F2FC group could be established if there are enough interested family members.

Another interesting topic that arose during the course of the pilot was video chat vs. phone-only calls. The pilot was originally designed to be a phone-only call option. A few months into the pilot, NCDB offered that groups could also use the video-chat option of the Adobe room. Call facilitators were asked to discuss this potential option with their groups, and a question was included in the online survey to assess participants' preferences. Several of the participants favored the video-chat format. However, there was not consensus among participants in either of the groups to use the video-chat format, and therefore, the calls remained phone-only. Further probing questions were included in the focus group calls, and as a whole, participants shared that they would like to have most of the calls be phone-only, with the option of meeting on video-chat occasionally (especially at the beginning). Many participants expressed that they didn't want to feel pressured to "look good" for the camera or that they were often multi-tasking during the call and could not sit in front of a computer the

entire time. For future offerings, if enough families are interested in the video-chat format, it could be offered as an option.

The F2FC groups were divided by the time/day that they were available to participate. This may not have been the best factor to decide the groups. During the course of the pilot, one family who had a child much younger than the rest of the group stopped participating; facilitators attributed this due to the age differences of the participants' children. During focus groups, participants suggested that there may be several factors that would decide how F2FC groups are formed: age of children (infant-toddler, school-age, transition-age); whether the child is medically fragile or not; perhaps specific etiologies of deaf-blindness, and also perhaps video-chat vs. phone-only interactions.

In summary, the Family-to-Family Communities Pilot Project was a success, in that it brought family members together across state lines to get to know one another, share information and resources, celebrate successes, offer support during challenges, and simply to lend an understanding ear. These are some comments that families shared about their participation in F2FC:

- "it was like this little hour of sanity where you could talk with people who kind of understood where you were..."
- "...being able to interact with other parents that have children with deaf-blindness as well as share information and stories and just the support..."
- "the bond is very critical because you build that trust and that relationship and you're opening up"

Through the process of the pilot project and the evaluative information that was gathered, we were able to learn what types of support families wanted and needed and their preferences for connecting with each other in innovative ways. Information about the F2FC project was shared in July 2015 at the DB Summit family engagement session and was presented again recently with the Family Engagement Coordinators via their January 2016 conference call. We plan to share information about F2FC with the larger network, via the NCDB Family Engagement space and possibly a webinar. We would like to replicate and expand the F2FC project in order to reach and support more families, and we will need to determine partnerships and structure for the continued F2FC project.