Final Report
Increasing Access to Information and Support for Families of Children with Special Health Care Needs
Georgetown University Center for Child and Human Development
R40MC17176
Submitted by Suzanne Bronheim, Ph.D., PI
I. Introduction

A. Nature Of The Research Problem

Families of CYSHCN require high quality information that will allow them to be informed decision-makers and effective navigators of a complex and poorly coordinated system of services and supports. Yet, in national surveys and state level studies, families of children with disabilities repeatedly report that they cannot get the high quality information they need. This situation is striking because the Maternal and Child Health Bureau (MCHB) as well as the Department of Education fund high quality Family-to-family centers (F2Fs) within states that are expressly designed to give families the knowledge and support they need. Of particular concern is the significant reported disparity between non-Hispanic white families and African American and Hispanic families in access to needed information. The challenge is how to connect families who are not accessing these services so that they will receive the high quality knowledge they need. The problem is that the typical ways that families seek information about raising their children do not include looking to a government funded, state or regional organization. To do so would be, in the parlance of communication theory, adopting an innovation. Diffusion of Innovation theory posits that adopting an innovation means that families have to be aware of it, find it acceptable, be able to try it out and to adapt it to their needs and the theory provides a framework for addressing those issues. A key to adoption is awareness and acceptance of the innovation in natural social networks.

B. Purpose, Scope, And Methods Of The Investigation

The purpose of this project was to develop and evaluate an approach to increase access to information and support for African American and Hispanic families of children and youth with special health care needs (CYSHCN) from a range of geographic locations and backgrounds that is grounded in Diffusion of Innovation theory, reflects the principles of cultural and linguistic competence and can be implemented by existing F2F centers. The methodology consisted of a series of focus groups and a Delphi procedure to explore African American and Hispanic families’ (English and Spanish speaking) perceptions of F2Fs and the nature of the social networks they access for information and advice in raising their CYSHCN. These were followed by a series of key informant interviews of members of those social networks and care providers to explore their perceptions of F2Fs. This data was used to inform and test a Diffusion of Innovation based social marketing approach to increase the number of families from the target populations that connect with the parent centers in the study. The study employed a community participatory research model of a partnership between three state family-to-family centers and a university research team.

C. Nature Of The Findings

While families, healthcare providers and other members of the social networks of families with CYSHCN saw many advantages in using F2Fs, they often noted that current information and marketing efforts did not provide them with clear information about what F2Fs could provide and the advantages of adopting their use. In their view, F2F marketing efforts need to focus less on what they do and more on those aspects of F2Fs identified as likely leading to adoption. In addition, changes in how F2Fs are staffed to support Spanish-speaking families and how they communicate with healthcare providers could also increase adoption of F2F use by African American and Hispanic families.

II. Review of the Literature

On the 2005-2006 National Survey of Children with Special Health Care Needs (NSCSHN), there are an estimated 680,000 CYSHCN whose families reported that they had
difficulty using needed services, because they could not get the information they needed (CAHMI, 2008a). Hispanic children and African American children were significantly more likely than white CYSHCN to have families who reported that they lack information to gain access to services (CAHMI, 2008a). A similar pattern of racial and ethnic disparities was noted on the 2003 National Survey of Children’s Health; families who reported that they had concerns about their young children’s development also felt they did not get the information they needed from their healthcare providers (CAHMI, 2008b). While pattern similarity cannot imply causality, the reduced of knowledge and information in minority populations is mirrored in poorer access to services and outcomes. (CAHMI, 2008a).

Families seeking knowledge about parenting rely most frequently on what may be termed informal sources of information. Yet, the highly specialized knowledge that families with a child with special health care needs need is not readily available within those natural social networks. While families may turn to health care providers for information, only 56.1% reporting always getting information they needed from health care providers (CAHMI, 2008a). Seeking help in raising one’s child from a statewide organization and from people not in one’s social network is a new idea—an innovation for many families, particularly those from racial/ethnic minorities. To facilitate the use of organizations like F2Fs, the perceptions of African American and Hispanic families with CYSHNC and their social networks about seeking help and about F2Fs were explored, within a Diffusion of Innovation framework, to create and test effective marketing strategies that could increase use of these centers and potentially impact disparities in access to information.

III. Study Design and Methods

A. Study Design

This project was a multi-site study with data collection and intervention at three Family-to-family Centers: Parents’ Place of Maryland (PPDM); Exceptional Children’s Assistance Center (ECAC) in North Carolina and Parents’ Reaching Out (PRO) in New Mexico. There were three sub-studies:

Identifying knowledge seeking patterns of families and their social systems. In Phase 1 we conducted a set of focus groups with members of families with CYSHCN led by race/ethnicity/language concordant staff of the F2F Centers to elicit opinions from participants about their feelings and experience with gaining knowledge from Family-to-family Centers and any associated technology. In Phase 2, results were confirmed with a Delphi type confirmation procedure.

Determining Observability in Sample Population of Social and Provider Networks. Key informant interviews were conducted with healthcare providers and other groups or programs identified by families in Sub-study 1 as key sources of information in their social networks.

Creating and testing customized communication plans to increase recognition and use of F2F Centers. In Phase 1, each F2F center site chose to focus marketing efforts on one of the populations studied in that state and used the data from the first two studies to develop a diffusion of innovation based marketing plan using the information gained in the first two sub-studies. The impact of the plan was documented using encounter data from each Center.

B. Population Studied

Two groups of individuals participated in this research study. The first consisted of urban and rural African American families and Hispanic families (both English speaking and Spanish speaking) of CYSHNC in Maryland, New Mexico and North Carolina. The sample included both families who had used the Centers and those who had not. Forty African American
parents of children with SHCN participated in the focus groups: 28 living in an urban environment and 12 from a rural environment. Sixty-five Hispanic family members participated: 35 who participated in English and 30 who participated in Spanish language focus groups. A second group of participants completed key informant interviews. This group consisted of healthcare providers practicing in the geographical area served by site and non-healthcare sources of services, support and information noted in focus group data.

C. Sample Selection

Family recruitment and selection. Two cohorts of family members were recruited at each site representing parents who had used the services of the F2F and those who had not used those services. Families with contact with the Center were recruited from families served within the past 6 months. Families who have had no contact with the Center were recruited through community organizations, faith based groups, existing ethnic specific organizations that were not specifically focused on children with special needs and social networks of Center staff. Families with a personal relationship to Center staff were not included. All participating families were provided a stipend. Selection criteria for participants in the Delphi-like confirmation process were identical to that of the focus group samples and similar recruitment methods were implemented.

Social network recruitment and selection. F2F centers identified providers from healthcare practices in the area, and 10 were recruited. Subjects received a stipend for their participation. Organizations or individuals identified in the social network of at least three families in the focus groups were selected for recruitment, and 7-9 in each state agreed to participate in key informant interviews.

D. Instruments Used

The focus group and key informant interview protocols were collaboratively developed by the research team and F2F staff representing the study populations using the method of Weiss (1994) to develop the substantive framework for the focus groups with questions. The Spanish language versions of the protocol were not word-for-word translations of the English questions, but developed by the Spanish-speaking focus group leaders. Discussion points included perceptions of F2Fs related to the stages of diffusion based on DOI concepts – awareness and persuasion (relative advantage, compatibility, complexity, trialability and observability in social networks). Preferred methods of getting information were also explored. In addition, families were also asked to review existing marketing materials and social network informants were asked about experiences in referring families to F2Fs. Delphi procedure questionnaires were constructed using statements reflecting themes from the focus group data. Impact data was collected through the systems in place in each Center to track contacts.

E. Statistical Techniques Employed

Analysis of the focus group and interview data employed a framework approach (Miles & Huberman, 1994) rather than a purely grounded theory strategy, because of the more structured characteristics of the protocols in this study. In the first phase, at least two members of the research team separately examined the transcripts to develop an initial thematic framework, identifying key concepts and themes by which the data can be examined and referenced to produce a preliminary codebook. After coding, the codes were mapped to form theoretical networks and themes were interrelated to inform the explanation of the results. Delphi procedure data was analyzed according to convention by calculating the Median score and Inter-Quartile Range (IQR) for each item. To examine contact data from individuals of groups targeted by the diffusion plan before and after implementation, we used chi-square analysis in order to
test whether the proportion of contacts initiated by individuals from the targeted groups differs before and after implementation and whether there was a significant difference in the proportions of contacts from different groups over the two periods.

VI. Detailed Findings
A. Sub-Study 1. Identifying Knowledge Seeking Patterns Of Families And Their Social Systems.

In Phase 1 we conducted a set of focus groups, led by race/ethnicity/language concordant staff of the F2F Centers, with family members to elicit opinions from participants about their feelings and experience with gaining knowledge from F2F Centers and any associated technology. In Phase 2, results were confirmed with a stage Delphi procedure. Families reported the following information seeking characteristics.

**When do parents of CYSHCN seek information related to the care of those children?**
African American families reported reaching out to others for information when their child’s school is not providing sufficient supports to which their child is entitled, when they have questions about which resources are available and when their child is transitioning from one type of care to another. Parents living in an urban environment cited their child receiving a new diagnosis and a change in behavior as a trigger for seeking support and information. Similarly, Hispanic families, in both the English and Spanish speaking groups reported reaching out to others for information when there is a change in their child’s status or a problem or barrier to their child receiving needed services.

**To whom do parents of CYSHCN turn when seeking information related to care of those children?** Based on focus group findings, there are commonalities across samples in whom they turn to for information. A pediatrician or primary care provider was the most frequently mentioned point of contact for information and resources, although this resource was more frequently mentioned by English-speaking Hispanic than Spanish-speaking families.

Teachers were a second source of information and were more frequently mentioned by urban African American parents than rural African American parents. For Hispanic parents teachers were the second major source of information for parents although more frequently mentioned by Spanish-speaking parents than English-speaking parents. Spanish-speaking Delphi confirmation process participants, however, gave a wide range of responses with some respondents indicating reluctance to obtain information from teachers. Although English-speaking confirmation process participants achieved high consensus, their endorsement of teachers as a good resource was less strong.

Family as a source of information was as important as support groups for all focus group participants. In the Delphi process, African American participants agreed that “Family is important when looking for advice and information concerning their child with special needs”, though there was more consensus among rural than urban participants (IQR=0.00 vs. IQR=1.00): Hispanic Spanish-speaking parents, viewed friends and family as important resources and they did so with high consensus.

Finally, in each location families noted an array of community agencies and non-profit organizations such as the ARC or Head Start from whom they had sought information. These sources of information were highly specific to the geographic location. Of note, Spanish speaking families mentioned community ethnic support organizations that were not specific to CYSHN. Church or faith organizations were only mentioned once across all groups.
How do families prefer to receive information?-- Channels of Communication. In the digital age, the meaning of social networks and the potential sources for information and support have widened. However, when parents were asked in focus groups and through confirmation process questionnaires how they preferred to receive information related to the care of their children, the most commonly noted approach was one-on-one either face-to-face or via the telephone. Parents in the confirmation process sample strongly agreed and had virtual unanimous consensus. Parents who reported using the internet, however, turned to those resources for a narrow set of purposes, also turning to specific websites -- to research the diagnoses their child has been given, and to look for and vet potential resources before making direct contact with them — rather than specific, personalized advice about obtaining services and supports for their children or dealing with new challenges in the service system. For Hispanic families, English speakers turned to the internet for the more narrow sets of purposes, but there were differences based on socio economic status that impacted access to and use of the internet. Hispanic families who spoke Spanish noted language barriers as well as lack of access to the internet as limits to its usefulness as a source of information and advice.

Families’ perceptions of F2Fs. Perceptions as sources of information and support in relation to adoption of this innovation are described below.

Awareness of F2Fs. Families who had not used the services of F2Fs noted that they were unsure of what the centers offered them. In their review of current marketing or informational materials, families noted that there was information about the F2Fs, but not enough specific information about what they would gain for contacting a center.

Persuasion to use F2Fs. Both families who had and had not used the F2Fs had similar perceptions about the factors that support persuasion to use them. (Note: families who had not used the F2Fs were provided a description.)

- Relative advantage. Focus group participants perceived a key relative advantage of using F2Fs for information and advice was that the F2F centers are run and staffed by family members of children with SHCN. This theme, that F2F center staff members are people just like the parents they serve, was the most prominent theme repeated throughout the focus groups. Among all Delphi participants, they strongly agreed (median=5) with this theme, “Compared to family and friends, the staff at ECAC already understand what parents are going through because they also have children with special needs” and reached a strong consensus (IQR=1.00). In addition, families noted that F2F centers not only provide information, but teach them the knowledge and skills they need to advocate for themselves.

- Compatibility. Focus group participants noted issues that might interfere with deciding to use F2Fs that need to be addressed in marketing efforts.

  - Compatibility with parents and extended family beliefs and values. The concept of expanding one’s social network to include a F2F center comprised of individuals beyond the typical family and community circles of CSHN is one that may or may not be compatible with parents’ or extended families’ values and beliefs. Parents shared a number of experiences where their extended family was in conflict with the decision to seek support outside the family. In these cases, parents said the extended family believes their children’s needs are private matters that can and should be handled within the family unit. Another factor related to family beliefs that impacted compatibility with using an F2F center was family denial about the child’s condition.
Parents noted that often there are family members who may not see anything wrong with the child and think that the parent should teach the child discipline instead.

- **Seeking services from a federally-funded organization.** F2F centers are federally funded programs and focus groups explored families’ beliefs and values related to the compatibility of using a service funded in this way. Some parents noted a belief that there was the inherent risk that funding may be pulled from the organization at any moment due to federal budget cuts and parents would then be at a loss without the organization. In addition, the focus groups expressed some concerns about the process when government is involved since sometimes the process could be slow and cumbersome to the extent that they might go look somewhere else to get help. Spanish-speaking parents who had no previous contact with the centers expressed the belief that government-sponsored organizations may be unavailable to those who are undocumented or who lack Medicaid or other insurance.

- **Compatibility based on racial, ethnic or language concordance.** Another component of compatibility that parents were asked about was the importance of being served by individuals who were of the same ethnic or racial background as them. Racial and ethnic concordance was not viewed to be a necessary feature of the services they receive, a finding that was confirmed by all groups. However Spanish-speaking parents frequently mentioned that a strong indicator of whether the center was compatible with their needs was if there was Spanish-speaking staff available for them, a belief strongly agreed with by the confirmation panels with a high degree of consensus.

- **Complexity** Focus group participants were asked if they thought F2Fs would be easy or difficult to use and why. The most often noted factor was that they might be inconveniently located (although all centers provide services state-wide through local representatives and/or phone contact). Additionally, parents noted that they are often overwhelmed and having one more place to call might be a burden.

- **Trialability** A key to adoption of a new innovation is its trialability. Parents felt that the F2F centers did not require mandatory involvement once a commitment to use their services was made. Rather, supported by the consistent responses from the Delphi panels, it was clear that parents believe that they do not need to fully commit to the centers if they do not think they are the best choice for their family.

**B. Sub-Study 2. Determining Observability In Sample Population Of Social And Provider Networks**

Key informant interviews were conducted with healthcare providers and other groups or programs identified in phase one by families as key sources of information in their social networks.

Both healthcare providers and other named sources of information and support in the three states reported perceptions about F2Fs that matched those of the families in the focus groups. They were unsure of the specific services provided by F2Fs. They had positive perceptions overall noting the advantage of families staffing the centers and helping other families gain the skills to advocate for themselves. Like the families, providers, wanted one-on-one interactions with the F2Fs as a way to learn about them and feel comfortable making referrals to them. They also noted that having a particular contact in the F2F to share with families would help address the issue noted by families of the overload of tasks and calling the F2F being one more potential burden. Finally, healthcare providers noted a specific set of
barriers to referring families to F2Fs which included: a lack of awareness or knowledge about the range of specific services offered by F2Fs and a lack of such information on current marketing and informational materials and a lack of feedback about those families they have referred. Recommendations for increasing their likelihood of referring families to F2Fs included: formalizing the referral process to increase the efficacy of the services provided and create a way to provide consistent feedback to the healthcare providers; and F2Fs developing stronger working relationships with providers to help them improve their own skills in advocating for families.

C. Study 3. Creating And Testing Customized Communication Plans To Increase Recognition And Use Of F2fcents.

Because there were delays in implementing the data collection in Studies 1 and 2, the implementation of this third study did not begin until the final year of the grant. We are continuing to collect encounter data from the three sites. Preliminary findings are promising. The Maryland site is reporting a 10% increase in African American families using their services after implementing the marketing/outreach plan informed by the qualitative phases of this study. As we have access to data from the other centers, final statistical analysis will be performed and results reported in additional publications.

V. Discussion and Interpretation of Findings

A. Conclusions To Be Drawn From Findings

African American and Hispanic families in the three states studied turn to health care professionals and other professionals providing services to their CYSHCN. They do, when they learn about what F2Fs offer, see clear advantages in using those services over other sources. First, F2Fs are staffed by “parents like me” who understand their needs and have a high degree of knowledge about services and systems. Second, F2Fs help them learn to advocate for themselves. Finally F2F services are free. Lack of awareness of what F2Fs offer could be a limiting factor in a adopting their use. It appears that F2Fs can increase use of their centers by African American and Hispanic families with marketing efforts focused less on listing their activities and purpose and more on those aspects of F2Fs identified as likely leading to adoption. This study also indicates that healthcare providers, as key members of African American and Hispanic families’ social networks related to caring for their children with SHCN, value the F2F model of family-to-family support and recognize that F2Fs play a unique role in providing families support, knowledge, and skills to advocate within those systems. The study has, however also identified barriers to healthcare providers recommending F2Fs to families and to more effectively including them as collaborators in delivering the care coordination component of the medical home model. These include lack of knowledge about the specific services provided, need for face-to-face contact to fully embrace them as a resource they use, and lack of a formalized referral and feedback process that is in line with their experiences in the medical services system.

B. Explanation Of Study Limitations

The study sample included families from three states and varied environments, however, within group differences for African-American and Hispanic parents are apparent. Thus, these findings cannot be interpreted as a definitive profile of all African-American or Hispanic families. Even within these groups, there was noted lack of consensus on issues raised in focus groups and then tested with the confirmation procedure subjects. The sample of healthcare providers was not randomly selected and reflects perceptions of health care providers who serve the African American and Hispanic populations of focus in the first phase of this study. Not all were primary
care providers and the extent to which these providers implement the medical home model was not assessed. However, given the consistency of the themes identified by the sample that represented three states, there is ample reason to view the results as a guide to future studies on the topics identified and as providing direction for those working to enhance the collaboration between healthcare providers and F2Fs. Most importantly, with the promise shown in preliminary results of the impact of this approach, this study has demonstrated an approach that can be used by other F2Fs to increase the use of their centers by underserved populations.

C. Comparisons With Findings Of Other Studies

We found, like other investigators, that Hispanic families, in general, and with children with special needs turn to formal supports such as their pediatricians, other professionals and an array of community organizations and agencies. (Bailey, et al., 1999; Correa, et al., 2011) Within our study population, however, Spanish-speaking families, who had the greatest disparities in access related to insufficient information, tended to turn more to friends and family. Such informal systems addressed language barriers or, for those who had recently immigrated to the United States, being less integrated into their communities and thus not knowing about resources to help them and their children. Making sure that these resources are aware of F2Fs and have positive perceptions of them will support families adopting use of F2Fs. There is very little in the literature on African American families of CYSHCN, however, our findings relating to are similar to McMiller, et al (1996); Bussing, Schoenberg, & Perwien (1998) who reported that in seeking help for their children with mental health problems African American parents were more likely than Caucasian parents to seek contact with professionals. Cauce, et al (2002), however, found that for social and emotional problems African American parents would rather reach out to relatives or immediate members of the family.

D. Possible application of findings to actual MCH health care delivery situations

F2F marketing efforts need to focus less on what they do and more on those aspects of F2Fs identified as likely leading to adoption. Social marketing efforts need to communicate to families the most important advantages of using F2Fs identified by parents to gain information they need to increase their health literacy relative to other sources. First, F2Fs are staffed by family members who have “lived experience” of dealing with complex systems and the impact of a child with SCHN on the family and specialized knowledge of how to navigate those systems. Second, families perceived that F2Fs not only provided information, but also improved health literacy by increasing families’ knowledge and skills in dealing with their children’s needs and the service system. Marketing efforts should communicate that there are no eligibility requirements, including having citizenship or residency documentation, to use the free services. While families felt that ethnic concordance with F2F staff was not critical to their using the Centers (the shared experience of having a child with SHCN was more salient), Spanish speaking families noted that having language concordant staff was of great importance. Thus F2Fs will need to address language access issues in their marketing efforts. Finally, families noted that one-on-one interactions were key to meeting their information and advice needs. With limited funding and staff, F2Fs will need to 1) engage and train volunteer members of the communities as ambassadors for the program and sources of information and 2) support and partner with existing organizations supporting African American and Hispanic families. Increased collaboration between medical homes and other healthcare providers to support African American and Hispanic families’ adoption of F2Fs could be facilitated by formalizing the referral process and creating a way to provide consistent feedback to the healthcare
providers; helping providers improve their own skills in advocating for families; and creating opportunities for providers to have direct face-to-face contact with F2F staff.

**E. Policy implications**

The findings from this study also have implications at the policy level for those agencies that support F2F centers and create the required activities and structures for them. Current funding may not be adequate to provide the person-to-person services that families identified as key to utilizing these centers and an increasing focus on utilizing web-based or electronic access to information and support through F2F centers may actually impede adoption of their services by African-American and Hispanic families. In order to effectively address the disparities in access to services and information for African-American and Hispanic families of CYSHCN, there may need to be both an increase in available funding and a refocusing of how resources are required to be utilized. One possible focus is the promotion of activities that create effective networks of family leaders as ambassadors throughout the state who can provide some of the person-to-person first contact with the F2Fs that will then lead families to use the array of resources available, including electronic resources.

**F. Suggestions for further research**

Future research is needed to replicate the effectiveness of this model on enhancing use of F2Fs by African American and Hispanic families of children with special healthcare needs. In particular, using the lessons learned by the three study sites to change how they marketed their centers, engaged community ambassadors and partnered with members of the social networks of families that were common sources of information and advice (healthcare and other providers in particular) in other states to test the model is needed. Given the importance of both F2Fs and medical homes as part of the systems serving CYSHCN and their families, of interest in future studies would be the extent to which healthcare practices that have demonstrated the adoption of the medical home model work with F2Fs and exploration of how they have created those relationships.

**VI. List of Products**

**Presentations**

March 2011

*University of South Florida, Child and Family Studies Annual Children’s Mental Health Research and Policy Conference*

“Increasing Access to Information and Support for Racially and Ethnically Diverse Families of Children with Special Needs”

Sandra Soto, Josie Thomas, Bruno Anthony, and Suzanne Bronheim

November 2013

*APHA 142 Annual Meeting and Exposition*

“Addressing Disparities in Access to Information for Hispanic Families of Children with Special Health Care Needs: Increasing Use of Family-to-family Centers”

Suzanne Bronheim, Sandra Soto, Josie Thomas, and Bruno Anthony

November 2013

*AUCD 2013 Conference: Promoting Inclusion in an Increasingly Diverse World*


Suzanne Bronheim
**Products for the Field**

From Research to Real Life: Increasing Visibility and Use of Family-to-family Centers

Brief 1: Using Focus Groups to Guide Interventions

[http://gucchd.georgetown.edu/products/Revised%20F2F_Brief1.pdf](http://gucchd.georgetown.edu/products/Revised%20F2F_Brief1.pdf)

Brief 2: Using Key Informant Interviews to Guide Marketing Plans

[http://gucchd.georgetown.edu/products/F2F_Brief2.pdf](http://gucchd.georgetown.edu/products/F2F_Brief2.pdf)

Brief 3: Creating Effective Marketing Campaigns from Data

[http://gucchd.georgetown.edu/products/F2F_Brief3.pdf](http://gucchd.georgetown.edu/products/F2F_Brief3.pdf)

**Articles for Peer Reviewed Journals**

The following articles have been submitted:


The article was submitted in 5/13. Revisions were requested and made. Reviewers indicated that changes addressed their concerns. Awaiting final notification about acceptance.

Anthony, B., Bronheim, S., Soto, S., Karavanov, A. Addressing disparities in access to support for families of children with special health care needs. *Progress in Community Health Partnerships: Research, Education and Action.* The article was submitted and under review.

Bronheim, B., Can, E. and Anthony, B. Medical home and family support collaboration in addressing access disparities for children with Special Health Care Needs. *Journal of Children’s Services.* This article has been submitted and is awaiting reviewer scores.

In preparation:

Anthony, B., Can, E., Bronheim, B. Disparities in access to information for African American families of Children with Special Health Care Needs. Plan to submit to *Ethnicity and Inequalities in Health and Social Care.*