2014

Addressing Disparities in Access to Information for Hispanic Families of Children with Special Health Care Needs

Suzanne M. Bronheim , *Georgetown University Medical Center*, suzanne.bronheim@georgetown.edu

Sandra Soto , *San Diego State University/University of California San Diego*, sosa@gmail.com

Bruno J. Anthony , *Georgetown University Medical Center*, bja280@gmail.com

Follow this and additional works at: https://digitalscholarship.unlv.edu/jhdrp

Part of the Public Health Commons

Addressing Disparities in Access to Information for Hispanic Families of Children with Special Health Care Needs

Abstract

Objectives: Utilizing a diffusion of innovation (DOI) framework, the study seeks to increase access to information for Hispanic families of children with special health care needs (SHCN) by increasing their use of Family-to-family Centers (F2Fs) in their states. **Methods:** Focus groups were implemented of both English-speaking and Spanish-speaking Hispanic families in two states with a confirming Delphi procedure exploring factors within DOI framework related to using F2Fs and the nature of current family communication networks. **Results:** Families seeking information at key change points turn to formal sources, although Spanish-speaking families, noted that due to language barriers, they also turned to family and friends. Families prefer getting information in one-on-one encounters rather than via technologies. F2Fs being staffed by parents of children with SHCN is a relative advantage over other sources of information and race or ethnicity of the staff was not an essential feature in using F2Fs, although services in Spanish was. Findings indicated that cultural values might impede turning outside the family for support and that concerns about federally funded programs serving all families or being suddenly cut impacted families views of using F2Fs. **Conclusions:** Increasing the use of F2Fs by Hispanic families will entail increasing awareness and acceptance of the centers by their social networks and by social marketing efforts that focus on factors identified. In addition, at the policy level, there needs to be a recognition of the strong preference for person-to-person support rather than technological approaches, which has fiscal implications.

Keywords

Children with special health care needs; Hispanic; access; disparities

Cover Page Footnote

29 Addressing Disparities in Access to Information for Hispanic Families of Children with
Special Health Care Needs
Bronheim et al.

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

Suzanne M. Bronheim, PhD, Georgetown University
Sandra Soto, MPH, BSN, San Diego State University/University of California
Bruno J. Anthony, PhD, Georgetown University

ABSTRACT

Objectives: Utilizing a diffusion of innovation (DOI) framework, the study seeks to increase access to information for Hispanic families of children with special health care (SHN) needs by increasing their use of Family-to-family Centers (F2Fs) in their states. Methods: Focus groups were implemented of both English-speaking and Spanish-speaking Hispanic families in two states with a confirming Delphi procedure exploring factors within DOI framework related to using F2Fs and the nature of current family communication networks. Results: Families seeking information at key change points turn to formal sources, although Spanish-speaking families, noted that due to language barriers, they also turned to family and friends. Families prefer getting information in one-on-one encounters rather than via technologies. F2Fs being staffed by parents of children with SHN is a relative advantage over other sources of information and race or ethnicity of the staff was not an essential feature in using F2Fs, although services in Spanish was. Findings indicated that cultural values might impede turning outside the family for support and that concerns about federally funded programs serving all families or being suddenly cut impacted families views of using F2Fs. Conclusions: Increasing the use of F2Fs by Hispanic families will entail increasing awareness and acceptance of the centers by their social networks and by social marketing efforts that focus on factors identified. In addition, at the policy level, there needs to be a recognition of the strong preference for person-to-person support rather than technological approaches, which has fiscal implications.

Keywords: Children with special health care needs; Hispanic; access

INTRODUCTION

National surveys estimate that from 13-20 percent of children and youth in the United States have special health care needs (SHCN) (Bethell, Read, Blumberg, & Newacheck, 2008). Children with SHCN are those who have or are at increased risk for a chronic physical,

30 Addressing Disparities in Access to Information for Hispanic Families of Children with
Special Health Care Needs
Bronheim et al.

developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (McPherson, et al., 1998). Hispanic children with SHCN have greater levels of chronic health conditions and associated functional difficulties and experience poorer outcomes than white children (Berry, Bloom, Foley & Palfry, 2010; Newacheck, Hung, & Wright, 2002). Documented variation in use of services likely contributes to these (Mulvhil, et al., 2007; Raphael, Zhang, Liu, Tapia, & Giardinao, 2009; Rosenberg, Zhang, & Robinson, 2008). Families of Hispanic children with SHCN (28.4%) are significantly more likely than non-Hispanic white children (20.7%) to report that they had one or more unmet need for healthcare services. They are also significantly less likely to report that they received all needed elements of care coordination (Hispanic children 39.8% vs. non-Hispanic white children 45.1%). They were also more likely to report that they did not receive coordinated, ongoing, comprehensive care within a medical home (Hispanic children 68.8% vs. non-Hispanic white children 51.2%), and were usually or always are frustrated in getting care for their children (Hispanic children 13.2% vs. non-Hispanic white children 8.3%) (National Survey of Children with Special Health Care Needs, 2009-2010). Also, Hispanic families have reported that they experienced difficulties using services because of language, communication or cultural problems with providers (Ngui and Flores, 2006).

The unmet needs for services reported by Hispanic families may be moderated by differences in health literacy--the capacity to obtain health information, communicate with health care providers, and navigate the health care system as well as conventional literacy skills (Institute of Medicine, 2004). Families raising children with SHCN have the same needs for knowledge, but also need specialized accurate information about their child's condition and effective interventions. Federally-funded family-to-family (F2F) centers were created to improve the health literacy of families with children with SHCN to enhance knowledge and support; however, families from culturally/linguistically diverse backgrounds access these centers less frequently. This report presents the results of formative, qualitative research, interpreted within the Diffusion of Innovation (DOI; Rogers, 2003) model, to inform strategies to increase use of F2F centers by Hispanic families.

Disparities in Access to Information for Hispanic Children with SHCN

All families raising children need knowledge about how to best support their children's health, mental health and overall well-being. Because information and services concerning SHCN are complex, health literacy demands for families are substantial and they need extra, expert help in gaining that knowledge and most especially how to navigate the poorly coordinated systems of services. Families also require support in finding ways of financing those services to be informed decision makers. A key tenet underlying work with families of children with SHCN is that providing information, referrals and support will enhance access to needed services and thus improve outcomes. Many families of children with SHCN report having difficulty using needed services because they could not get the information they needed. However, significantly more Hispanic children (12.4%) than non-Hispanic white children (7.3%) had families reporting this problem (Child and Adolescent Health Measurement Initiative [CAMHI], 2011). Disparities in access to and processing of high quality information that supports families in seeking and utilizing needed services (i.e., health literacy) is one potential source of the unmet service needs reported by Hispanic families with children with SHCN.

Family-to-family Centers Address Information Needs

31 Addressing Disparities in Access to Information for Hispanic Families of Children with
    Special Health Care Needs
    Bronheim et al.

To address the documented need for information and support for families of children with SHCN, federally-funded, family to family centers were created within states, expressly designed to give families knowledge and support to address needs within the education and health related systems of services and supports. Family-to-Family Health Information Centers (F2F HICs) are non-profit, family-staffed organizations that help families of children and youth with SHCN and the professionals who serve them. Evaluations of these F2F centers indicate that large numbers of families are being served, and, that when connected to a center, families report receiving and using information provided to address their children's service needs. In the two states included in this study 100% of families using the centers rated their experience from useful to extremely useful (Alliance National Parent Technical Assistance Center, 2011; Family Voices, 2014). Although providing a valued service to many families, these centers and the resources they provide may not reach the families who need them the most, particularly those from culturally/linguistically diverse backgrounds (Banks and Miller, 2005; Klingner, Blanchett, & Harry, 2007). Hovart, Weininger and Larueau (2003) reported that minority and low income families are more likely to act alone or with extended family rather than responding to collective parent networks. A key approach to increasing access to high quality and highly specialized information needed by Hispanic families with SHCN to enhance their health literacy is to increase their use of F2Fs.

Using F2F Centers: Adopting an Innovation

Initiating and sustaining use of F2Fs by Hispanic families who have not accessed them constitutes what Rogers (2003) has called adopting an innovation. Innovations are defined as ideas, beliefs, knowledge, practices, programs, and technologies that are perceived as new by individuals, groups or organizations. Diffusion is the process by which an innovation is communicated through certain channels over time among members of a social network.

Rogers posits three stages of diffusion of innovations through social networks like F2F centers: *awareness*, *persuasion*, the *decision* to use the innovation. To inform a social marketing approach and increase adoption of use of F2Fs, the findings reported here focus on the first two stages. This study explored the extent and nature of Hispanic families' awareness of F2Fs in their states, as well as these four aspects of the centers that persuaded potential users to consider using their services:

- *relative advantage* over other ways to get information;
- *compatibility* between the characteristics of an innovation and the needs, existing values and past experiences of the potential adopter (Wejnert, 2002);
- the *complexity* of requirements and procedures of using F2Fs;
- *trialability,* which refers to the fact that an adopter does not need to commit to full adoption; and
- *observability* or knowing other families in their social networks who have used and liked the services of F2Fs.

Social Networks of Hispanic Families with Children with SHCN Impact Access to Information

Hispanic families with children with SHCN increasing their adoption of F2Fs, through efforts to increase awareness and positive perceptions of these centers, requires an understanding of their relevant preferred communication channels. Previous studies of parents in general have

32 Addressing Disparities in Access to Information for Hispanic Families of Children with
Special Health Care Needs
Bronheim et al.

reported that families turn most frequently to informal sources for parenting information (Berkule-Silberman, Dreyer, Humberman, Klass, & Mendelsohn, 2010; Nichols, Nixon, Pudney & Jurvansuu, 2009). There is very little in the literature, however, about where Hispanic families of children with SHCN turn for general support, and even fewer that directly address the issue of where they seek information about how and where to meet their children's special needs. Bailey, et al. (1999) reported that Hispanic families with children with developmental disabilities rely heavily on extended family members and religion for emotional and instrumental support and that they placed a high priority on the expertise of professionals because of the knowledge they can glean from them. Ganotti, Kaplan, and Handwerker (2004) noted, however, that Latino parents viewed the role of professionals primarily as service providers. Additionally, Denney, Itkonen and Okamoto (2007) emphasize the importance of looking at within groups' differences within the Hispanic population, including the language spoken and cultural differences—when exploring needs and experiences within the service delivery system.

This paper reports the results of formative, qualitative research from the first phase of a collaborative study by a university center and three F2Fs to develop strategies to increase the use of their centers by Hispanic and African American populations using a diffusion of innovation (DOI) model based social marketing approach. (Rogers, 2003) This first phase used focus groups to explore the social networks, communication channels and perceptions of F2Fs framed by the DOI model with an array of Hispanic families from diverse backgrounds and with and without English proficiency. These findings will be utilized to inform the next phases of the project—key informant interviews with individuals and programs identified by families as key members of their social networks and a test of social marketing approaches to increase the utilization of the F2Fs in the study by Hispanic families.

METHODS
Sample

Focus group subjects were Hispanic parents (or primary caregivers) of children and youth with SHCN from New Mexico and Maryland. A sample from these two states was selected to address the diversity within the Hispanic population in terms of countries of origin and length of the existence of a Hispanic community within the state. In New Mexico 83% of the Hispanic population is native born compared with only 49% in Maryland. There are also differences in country of origin with 63% of Hispanics in New Mexico of Mexican origin compared with only 19% in Maryland (Pew Research Center, 2011). In Maryland the Hispanic population is largely from Central America, South America and the Caribbean. There is also a sizeable Puerto Rican population in Maryland that differs culturally from the New Mexico Hispanic population (Maryland Department of Health and Mental Hygiene, 2014).

Two cohorts of subjects were recruited at each site representing parents who had used the services of the F2F and those who had not used those services. In addition, for each of those cohorts, there were two groups—one conducted in Spanish and one conducted in English based on participant preference for language. Table 1 presents the numbers of focus group subjects based on location, language status and use of the F2F. At each site, there was diversity within groups based on age of the child and SHCN (emotional/behavioral, developmental, or chronic illness).

33 Addressing Disparities in Access to Information for Hispanic Families of Children with
Special Health Care Needs
Bronheim et al.

Table 1. Location, Language Status and Center User Status of Focus Group Participants N=65

Center	Focus Group Population	Number of participants
NM	English-speaking users	11
	English-speaking non-users	13
	Spanish- speaking rural users	8
	Spanish-speaking rural non-users	12
MD	Spanish-speaking users	5
	Spanish-speaking non-users	5
	English-speaking users	5
	English-speaking non-users	6

Focus group participants, who had used the F2Fs, were recruited by the F2Fs after reviewing their databases for potential participants and via one-on-one encounters at center events or programs. Participants who had not used the F2F previously were recruited through community organizations, faith based groups, and existing ethnic specific organizations that were not specifically focused on children with SHCN. In addition, a screening criterion for inclusion was that the family was not connected with another F2F support organization related to their child's SHCN. Thus the sample of non-users of the center were within the mainstream of their communities, but not connected to an F2F or similar support.

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 in order to have a representative group provide feedback on the themes from the focus groups. Parents who participated in the focus groups were excluded as potential confirmation process participants. See Table 2 for the demographic description of Confirmation process participants.

Table 2. Location and Language Status of Delphi-like Process Participants N=30

Center	Delphi Population	# Completed
NM	English-speaking	10
	Spanish-speaking	10
MD	Spanish-speaking	5
	English-speaking	5

This research was conducted under the supervision of the IRB at Georgetown University. All investigators at the F2Fs involved in recruiting parents and/or conducting focus groups received CITI training on protection of human subjects.

Procedure

Phase 1: Focus Groups. Focus groups were led by ethnicity concordant staff of the F2F centers bilingual in Spanish and English. Research staff provided training to the leaders on implementation of the focus groups. Each group discussion was audiotaped and transcribed, substituting study names for first names used during the group. For groups conducted in Spanish, audiotapes were first transcribed by a trained professional translator. Those transcriptions were reviewed in comparison with the audiotapes by a bilingual member of the research team for accuracy. The Spanish transcripts were then rendered in English by the trained professional translator and again reviewed by the bilingual staff member. In addition, a co-leader in the focus group took notes to augment the transcripts.

The focus group 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 protocol, the focus group questions were based the DOI framework. The Spanish language versions of the protocol were not word-for-word translations of the English questions, but developed in Spanish by the Spanish-speaking focus group leaders.

Phase 2: Confirmation Process. In order to confirm themes identified from the focus group samples, a Delphi-like process was implemented. Key themes identified in the focus groups related to how parents seek information and how they have or might interact with F2Fs were utilized to create a voting document completed by subjects. Two questionnaires were created per center. An English version containing the themes from the user and non-user focus groups conducted in English and a Spanish version containing the themes from the two groups conducted in Spanish. In order to address potential literacy limitations of the sample, subjects were provided the voting document in paper format and then site investigators reviewed each item verbally with the subject either in person or on the phone.

Participants were asked to rate their agreement with statements based on the focus group themes on a 1 to 5 Likert scale, where 1=strongly disagree, 3=neutral, and 5=strongly agree.

Data Analysis for Phase 1-Focus Groups. The verbatim transcripts were transcribed into Microsoft Word with conventions appropriate for analysis by ATLAS.ti. Examination of the

interview data employed a *framework approach* (Miles and Huberman, 1994) used in the authors' previous work, (Anthony and Foster, 2000) rather than a purely *grounded theory* strategy, because of the more structured characteristics of the interview protocol 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. This process drew on *a priori* issues and questions, detailed above, as well as respondents' views and experiences raised in the focus groups to produce a preliminary codebook, consisting of the code, a brief definition, a full definition, guidelines for when to use the code (including linguistic cues), guidelines for when not to use the code, and examples. After coding, the codes were mapped to form theoretical networks and themes were interrelated to inform the explanation of the results.

   Data Analysis for Phase 2—Confirmation Process. Median score and Inter-Quartile Range (IQR) was calculated for each item. The median indicates the central tendency of the scores and is the most accurate representation of central tendency when interpreting data collected using Likert scales.

RESULTS

   Below are the results from the focus groups organized by key themes. Tables 3 and 4 present the median score on the follow-up survey items, indicating the level of agreement with the statement and the level of consensus, reflected by the IQR. An IQR of greater than 1 reflects low dispersion of ratings and high consensus.

36 Addressing Disparities in Access to Information for Hispanic Families of Children with
Special Health Care Needs
Bronheim et al.

Table 3. Mean, Median and IQR values for combined English-speaking Delphi-like Process

Question	Mean	Median	IQR
Where do families turn to?			
Pediatrician	4.7	5	0*
Teacher	4.2	4	1*
Therapist (physical therapy, occupational therapy, speech therapy)	4.8	5	0*
School social worker	4.1	4.5	1*
Preferred format			
One on one on the phone	4.6	5	0*
Internet	4.1	5	1*
Written information if easy to read	4.4	5	1*
Texting	3.8	5	3
Email	4.4	5	1*
When do families seek information and resources?			
When their child's needs are not met by the school	4.8	5	0*
Relative advantage			
Advice is based on experience from parents and backed by up-to-date facts	4.3	5	1*
F2F already understands what parents are going through because they also have CSHN	4.4	5	1*
F2F is knowledgeable about resources families may need	4.5	5	1*
F2F is free of charge	3.7	3	2
Trialibility			
Would walk away from F2F if they did not think it was right for them or their child	4.1	4	0*

*IQR values of 1 or less indicate high consensus. Note: Number of questions in Delphi procedure depended on themes identified in focus groups.

37 Addressing Disparities in Access to Information for Hispanic Families of Children with
   Special Health Care Needs
   Bronheim et al.

Table 4. Mean, Median and IQR values for combined Spanish-speaking Delphi-like Process

Question	Mean	Median	IQR
Where do families turn to?			
Pediatrician	4.5	5	1*
Teacher	3.3	4	2
Relatives		4	1*
Head Start		3	3
Preferred format			
One on one	4.9	5	0*
Internet	3.9	5	1*
When do families seek information and resources?			
When their child's needs are not met by the school	4.8	5	0*
Relative advantage			
F2F already understands what parents are going through because they also have CSHN	4.8	5	1*
F2F is knowledgeable about resources families may need	4.6	5	1*
Parents have opportunity to get help and support other parents		5	1*
F2F knowledgeable about services, laws and how to access resources	4.7	5	0*
Compatibility			
Race/ethnic concordance not important—experience as parents is	3.8	4	1*
Hispanic bilingual staff important for communication	4.6	5	1*
Trialibility			
Would walk away from F2F if they did not think it was right for them or their child	4.4	4	1*

*IQR values of 1 or less indicate high consensus. Note: Number of questions in Delphi procedure depended on themes identified in focus groups.

<u>When do parents of children with SHCN seek information related to the care of those children?</u>
        Based on focus group findings, families reach 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. Across all groups, difficulties at school were cited as a trigger for seeking support and information. Confirmation process respondents echoed the latter finding (see Tables 3 and 4).
        English-speaking, but not Spanish-speaking parents also described seeking information and resources when their child had a new diagnosis or started a new treatment.
<u>From whom do parents seek information related to care of their children with SHCN?</u>
Healthcare and education systems provided the most important and trusted sources of information for Hispanic parents. Across all the samples, the pediatrician or primary care provider was an important point of contact for information, although this resource was more frequently mentioned by English-speaking subjects. Similarly, both English-speaking and

38 Addressing Disparities in Access to Information for Hispanic Families of Children with
Special Health Care Needs
Bronheim et al.

Spanish-speaking confirmation process participants strongly agreed on the importance of medical providers although consensus, was greater among English speakers.

> *"[I go to] his pediatrician, just because she seems to know where a lot of the services are that I'm still looking for, and I trust her. She is very honest with me."*

Teachers were the second major source of information for parents although more frequently mentioned by Spanish-speaking parents than English-speaking parents. Spanish-speaking 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.

Spanish-speaking parents, viewed friends and family as important resources and they did so with high consensus.

> *"Well, I turn to friends and also well…so I feel supported because they inform you where to go. I haven´t lived in Chaparral for a long time and that is why I turn to friends."*

> *"I turn to the relatives because sometimes at the doctor´s office they don´t speak Spanish. It is almost always in English and if I want to be able to tell them what the children have they don´t understand me; they can´t give me an answer either. I think that is why I seek the relatives´ advice."*

In addition, 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 children with SHCN. Church or faith-based organizations were only mentioned once across all groups.

Channels of Communication--How do families prefer to receive information?

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.

> *"Contact using technology would be easier but in person it's best to get the information we need in person. Technology is good, but it is not personal, you need to personalize it and that cannot be done."*

> *"It's just sometimes, you know, like when you feel you have an urge to talk to somebody, because you know that your person that you've been in contact with so much, you just need that voice. You just need that re-encouragement and that's what you get."*

The internet as a resource was cited positively by English-speakers, but the internet as a resource was not mentioned by Spanish-speaking parents. When asked about their use of the internet for searching for information and resources, Spanish-speaking parents either said they

39 Addressing Disparities in Access to Information for Hispanic Families of Children with
   Special Health Care Needs
   Bronheim et al.

did not have access to the internet or they said there were not enough web pages in Spanish to be utilized it in any productive way.

> *"… if you don´t have access to the internet and you don´t know English, you can´t have access to any information and I don´t know all the services that we could obtain, because we can´t find them in Spanish."*

The internet as a resource was cited positively by English-speakers. However, families reported turning to on-line resources for a narrow set of purposes--to research descriptions of new medications their child had been prescribed, explanations of diagnoses their child had received, and to look for and vet potential resources before making direct contact with them; they tended not to use internet resources for specific, personalized advice about obtaining services and supports for their children or dealing with new challenges in the service system. Yet even within the groups of English-speaking participants, there were differences based on socio- economic status that impacted access to and use of the internet.

> *"For those of us that are on even lower end of technology; I can't afford an Internet. I can't afford a computer.… I know I'm not the only one out there that just can't afford to keep up with technology. So I think it's important to be able to reach those of us that are below the economic abilities to even check Facebook."*

Other electronic methods such as email and texting were mentioned by English speakers as possible ways to receive information, with strongly and consistent agreement for the value of email. Digital resources were not mentioned by Spanish-speaking parents.

<u>What are families' perceptions of F2Fs affecting adoption?</u>

Relative Advantage. Parents valued the fact that the F2Fs are run and staffed by family members of children with SHCN. Confirmation process participants showed strong agreement with this theme, and reached consensus. This sense of "like me" may have also contributed to some participants noting that they thus trusted the information they received—F2F staff would not mislead them.

> *"Your staff is very qualified and is made of people who are also parents of children with special needs, so they understand our suffering as parents and understand why we get so upset, and we ask so much of the program."*

40 Addressing Disparities in Access to Information for Hispanic Families of Children with
Special Health Care Needs
Bronheim et al.

> *"And I really liked that connection, because you could actually talk to a
> parent who has the same kinds of problems; maybe not specifically, but
> just in the order of things, you know. Knowing she's been there, she's
> done that, she knows where to go. She was a good resource for me."*

Families also noted that F2Fs can not only provide information, but F2F staff can also teach them the knowledge and skills they need to advocate for themselves and provide helpful hints that can lead to action. Also, some noted that using an F2F saves time, because families can find what they need in one place.

Compatibility. Parents shared a number of factors which influence the acceptability of using an F2F. First, seeking advice and support outside of the family conflicted with their own or their extended family's beliefs and values. Sometimes parents said their extended families believe their children's needs to be private matters that can and should be handled within the family unit. Instances where the family did not want parents to seek outside help were offered by groups in both states from English-speakers and Spanish-speakers.

> *"It's just very -- I don't know what it is with that, but I think, just for me
> reaching out on my own, they just didn't like how I was handling things.
> And that I was actually seeking advice from someone else other than
> them."*

Also, family members can deny the reality of the child's condition. Parents noted that often there are family members, usually the husband or another male in the family who may not see anything wrong with the child and thinks that the parent is over reacting in seeking help from outsiders.

> *"…my husband, who is very traditional, very, you know, 'Oh no, nothing's
> wrong with my child'. He's just like that. You know, that's just him…
> And I find the same thing with my brothers. They kind of have this, like,
> 'Well, that's just him'. No. 'He just acts like that'; like nothing's wrong.
> They almost want to just have a blind eye to the problem."*
>
> *"When you have a big family, there's a certain sense of pride in your
> lineage. 'There's nothing wrong with my lineage. Nothing like that could
> have come from my lineage.' …And that's part of the reason, because you
> can get ostracized from your family pretty much."*

A second issue related to compatibility raised by parents was the acceptability of seeking services from a government-funded organization, such as F2Fs. Spanish-speaking parents who had no previous contact with the centers expressed the belief that government-sponsored organizations may be prohibitive for those who are undocumented or who lack Medicaid or other insurance.

> *"Well, when they receive government funding, some people…that I´ve seen or
> heard of, feel bad because they don´t give them assistance, they don´t say hello to
> them, just because they don´t have any insurance…many people complain that
> people from a different race do receive help, just because they are citizens…"*

English-speaking 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.

41 Addressing Disparities in Access to Information for Hispanic Families of Children with
Special Health Care Needs
Bronheim et al.

> *"…it makes me feel that [the center] is vulnerable; that it could disappear overnight. And just as much as we're all being introduced to it and we could get into it, and it could be something that would benefit us, it could be easily taken away."*

> *"Don't get me used to your help and then say now we can't afford it. I want stability"*

Finally, racial and ethnic concordance with F2F staff was not consistently viewed to be a necessary feature of the services they receive; however it was noted to be desirable.

> *"I really feel that, as parents of children with special needs, we recognize the culture of disability before we recognize the culture of this ethnicity. I think we all become one because our children have these needs, and skin color is the least to do with it."*

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.

> *"Sure, I think [getting help from staff that are a different race or ethnicity] is fine, but I would also like to have Hispanic or Latin parents because we could communicate better with them."*

Other factors. Ease of access and use was an important factor that might affect uptake of F2F services. Parents emphasized the difficulty and time requirements of juggling all the services required by their child (e.g. speech therapy, counseling, physician visits). Connecting with another yet another service, like F2Fs, would be limited by these other demands.

> *"I heard great things about it. And then I just kind of kept putting it off, because so many doctor's appointments, so many therapies; you know how it is."*

In this vein, 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.

DISCUSSION

Families with children with SHCN need high quality and highly specialized information that will enable them to access complex and poorly coordinated services and be meaningful partners in decision-making about their children's care. Findings from the focus groups and the confirmation process provide important guidelines that can inform social marketing approaches to further the adoption of F2Fs to address disparities in health literacy experienced by Hispanic families with children with SHCN.

Social Networks

Social networks are key to adoption of innovations in two ways. First, members of the network can play a role in making families aware of the potential innovation. Second, their acceptance and approval of the innovation, in this case use of F2Fs, is central to the final

42 Addressing Disparities in Access to Information for Hispanic Families of Children with
Special Health Care Needs
Bronheim et al.

decision-making stage of adoption. We found, like other reports that Hispanic families turn to formal supports such as their pediatricians, other professionals and an array of community organizations and agencies (Bailey, et al., 1999; Correa, Bonilla, & Reyes-MacPherson, 2011). Within this 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, and the issue of 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.

Channels of Communication

Hispanic families are most likely to seek information when experiencing concern and uncertainty about their children with SHCN—e.g. a new diagnosis, a change in the child's status or a barrier to the child receiving needed services. Families noted that, at those moments, they preferred having one-to-one contact with an individual rather than receiving information from the internet or other electronic media. While web-based information was seen as helpful to answer general questions, it did not meet their needs when they were confused about the information they required to make decisions. Moreover, for Spanish-speaking families and those with low incomes noted limited access to and difficulties navigating the internet due to limited English proficiency. As a result both information sharing and marketing efforts must also be directed to members of families' social networks, since electronic communication channels may not be effective.

Findings related to preferred channels of communication have implications at the policy level for those agencies that support F2Fs. Current funding may not be adequate to provide the person-to-person services and language access 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 F2Fs may actually impede adoption of their services by Hispanic families. In order to address the disparities in access to services and information that impact health literacy for Hispanic families of children with SHCN, there may need to be both an increase in available funding and a refocusing of how resources are required to be utilized.

Implications for Social Marketing of F2Fs

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 outer 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. Finally, marketing efforts should communicate that there are no eligibility requirements, including having citizenship or residency documentation, to use the free services.

Families had two concerns related to *compatibility* of F2Fs with their values and needs. First, resistance from family members to going outside the family for support may affect adoption of use of F2Fs. Marketing efforts may need to address this issue directly or identify ways to engage those in the social networks of families to increase their acceptance of the innovation of using F2Fs. Second, while families felt that ethnic concordance with F2F staff was

43 Addressing Disparities in Access to Information for Hispanic Families of Children with
Special Health Care Needs
Bronheim et al.

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.

Families noted two issues that might make it difficult to use F2Fs. First, families noted that the myriad of tasks they already faced in caring for their children with SHCN might prevent them from working with new service or organization. Marketing efforts will need to focus on ease of use—one place to call, no eligibility requirements, no cost to the families, etc.--to reduce these concerns. Second, families had concerns that because F2Fs are federally funded programs, documentation related to immigration status would be required to use them. Again marketing messages will need to assure families that anyone can use the services of F2Fs.

In addition, findings indicate that marketing of F2Fs should include a clear message about how to connect with a person and should provide a simple message about connecting with F2Fs when families need help. Detailed information about the variety of programs and services offered may add to confusion at those moments when families perceive they need help, but are not sure what form that help might take.

Finally, families did not express concerns about trialability. They noted that they would feel comfortable not using F2F services after contacting them if they did not want to continue. Marketing messages might emphasize that service use is driven by family need and not a specific program model.

Implications for Changes in F2F Practices and Structures

Both F2Fs that participated in the study learned that there needed to be changes in how they both delivered services and partnered with other community organizations already serving the Hispanic communities in their states. These changes included requiring all staff (from receptionists to parent support workers and trainers) in the New Mexico F2F to be bilingual in Spanish and English so they could quickly respond to family needs and any contact with the Center could be in Spanish. In addition, F2Fs learned that overcoming concerns about use of the centers could be addressed by building new partnerships with community organizations that the Hispanic families they hoped to serve trusted. These partners brought new resources to the table to promote F2Fs and to normalize the use of such a service.

Limitations of the Study and Implications for Future Research

The study sample included families from two states and varied countries of origin, however, differences in beliefs and approaches among Hispanic families can be great. Thus, these findings cannot be interpreted as a definitive profile of all Hispanic families. Even within these groups, there was noted lack of consensus on issues raised in focus groups and then tested with the confirmation process procedure subjects. Thus, each F2F may need to revisit these findings with families they are directly serving. At the same time, the themes presented surfaced repeatedly across the groups from both states and, as noted, across language spoken and reflect previous findings in the literature (Bailey, et al., 1999; Correa et al., 2011; Shapiro and Tittle, 1990; Rehm, 2000). What is needed next is to understand more about what those noted within families' communication networks know about F2Fs and their attitudes about F2Fs, since those networks play a key role in the decision-making process of families.

The authors are implementing a second phase of this study which includes key informant interviews with individuals and agencies or organizations noted by focus group participants to learn how to market the F2Fs to them. This step is critical, because families identified reaching

44 Addressing Disparities in Access to Information for Hispanic Families of Children with
   Special Health Care Needs
   Bronheim et al.

out to these network members in those crisis times when they are most likely to seek information. In addition, with the information from those future interviews and the focus groups, each F2F will develop and implement a social marketing plan designed to increase utilization by Hispanic families in the state and data about new families contacting the center will be used to evaluate its impact.

Additionally, this study demonstrated the effectiveness of partnerships between university research centers and F2Fs to implement community participatory research to address an important area of racial and ethnic disparities in healthcare for children with SHCN. Future efforts to build the capacity of F2Fs to more effectively reach families from diverse racial and ethnic groups can be an important component of addressing disparities in healthcare related to health literacy.

ACKNOWLEDGEMENTS

REFERENCES

Alliance National Parent Technical Assistance Center (2011). Parents Centers Helping Families: Outcome Data 2009-2010. Minneapolis, MN: PACER Center. Retrieved from http://eric.ed.gov/?id=ED529792

Anthony, B. & Foster, L.F. (2000). Listening to families. *Attention, 6,* 61-70.

Bailey Jr, D. B., Skinner, D., Correa, V., Arcia, E., Reyes-Blanes, M. E., Rodriguez, P., . . . Skinner, M. (1999). Needs and supports reported by Latino families of young children with developmental disabilities. *American Journal on Mental Retardation, 104*(5), 437-451.

Banks, S. & Miller, D. (2005). Empowering indigenous families who have children with disabilities: an innovative outreach model. *Disability Studies Quarterly, 25*(2). Retrieved from http://dsq-sds.org/article/view/544/721

Berkule-Silberman, S. B., Dreyer, B. P., Huberman, H. S., Klass, P. E., & Mendelsohn, A. L. (2010). Sources of parenting information in low SES mothers. *Clinical Pediatrics*, *49*(6), 560-568.

Berry, J. G., Bloom, S., Foley, S., & Palfrey, J. S. (2010). Health inequity in children and youth with chronic health conditions. *Pediatrics*, *126*(Supplement 3), S111-S119.

Bethell, C. D., Read, D., Blumberg, S. J., & Newacheck, P. W. (2008). What is the prevalence of children with special health care needs? Toward an understanding of variations in findings and methods across three national surveys. *Maternal and Child Health Journal*, *12*(1), 1-14.

Child and Adolescent Health Measurement Initiative. (2011) *National Survey of Children with Special Health Care Needs 2009/2010.* Data Resource Center for Child and Adolescent Health. Retrieved from www.childhealthdata.org

45 Addressing Disparities in Access to Information for Hispanic Families of Children with
Special Health Care Needs
Bronheim et al.

Correa, V. I., Bonilla, Z. E., & Reyes-MacPherson, M. E. (2011). Support networks of single
Puerto Rican mothers of children with disabilities. *Journal of Child and Family Studies*, *20*(1), 66-77.

Denney M.K., Itkonen T, Okamoto Y. (2007). Early intervention systems of care for Latino
families and their young children with special needs: Salient themes and guiding
implications. *Infants & Young Children. 20*(4), 326-335.

Family Voices, Inc. (2014) *Activities and Accomplishments of Family to Family Health
Information Centers*. Albuquerque, NM: Family Voices, Inc. Retrieved from:
http://simplebooklet.com/2014F2FHICActivitiesBooklet#page=0

Ganotti, M., Kaplan, L., Handwerker, P., Groce, N. (2004). Cultural influences on healthcare:
Difference in perceived unmet needs and expectations of providers by Latino and Euro-
American parents of children with Special Health Care Needs. *Journal of Developmental
and Behavioral Pediatrics, 25*(3), 156-165.

Kindig, D. A., Panzer, A. M., & Nielsen-Bohlman, L. (Eds.). (2004). *Health Literacy: A
Prescription to End Confusion*. Washington, DC: National Academies Press.

Klingner, J., Blanchett, W.J., Harry, B. (2007). Race, culture and developmental disabilities. In
Odom, S.L., Horner, R.H., Snell, M.E., Blacher, J, editors. *Handbook of Developmental
Disabilities (*pp 55-79*).* New York: Guilford Press. 55-70.

Maryland Department of Health and Mental Hygiene (2013) *Hispanics in Maryland: Health
Data and Resources.* Baltimore, MD: Maryland Department of Health and Mental
Hygiene. Retrieved from http://dhmh.maryland.gov/mhhd/Documents/Maryland-
Hispanic-Health-Disparity-Data.pdf

Horvat, E.M., Weininger, E.B., Lareau, A. (2003). Social ties to social capital: Class differences
in the relations between schools and parent networks. *American Educational Research
Journal*. 2(40), 319-351.

McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P.W., Perrin, J.M.,
Shonkoff, J.P., Strickland, B. (1998). A new definition of children with special health
care needs. *Pediatrics, 102* (1), 137–140.

Miles, M. B., & Huberman, A. M. (1994). *Qualitative Data Analysis: An Expanded Sourcebook*.
Thousand Oaks, CA: Sage.

Mulvihill, B.A., Altarac, M., Swaminathan, S., Kirby, R.S., Kulczycki, A., Ellis, D.E. (2007).
Does access to a medical home differ according to child and family characteristics,
including special-health-care-needs status, among children in Alabama? *Pediatrics, 119i*
(Supplement 1)*,* S107–S113.

Newacheck, P.W., Hung, Y.Y., Wright, K.K. (2002). Racial and ethnic disparities in access to
care for children with special health care needs. *Ambulatory Pediatrics, 2,* 247–254.

Ngui, E.M., Flores, G. (2006). Satisfaction with care and ease of using health care services
among parents of children with special health care needs: the role of race/ethnicity,
insurance, language and adequacy of family centered care. *Pediatrics. 117*(4)*,* 1184-
1196.

Nichols, S., Nixon, H., Pudney, V., & Jurvansuu, S. (2009). Parents resourcing children's early
development and learning. *Early Years*, *29*(2), 147-161.

Pew Research Center (2011) *Hispanic Trends Project Demographic Profile of Hispanics in
Maryland*. Retrieved from: http://www.pewhispanic.org/states/state/md/

46 Addressing Disparities in Access to Information for Hispanic Families of Children with
Special Health Care Needs
Bronheim et al.

Pew Research Center (2011) *Hispanic Trends Project Demographic Profile of Hispanics in New Mexico*. Retrieved from http://www.pewhispanic.org/states/state/nm/

Raphael, J.L, Zhang, Y., Liu, H., Tapia, C.D., & Giardino, A.P. (2009). Association of medical home care and disparities in emergency care utilization among children with special health care needs. *Academic Pediatrics, 9* (4)*, 242–248.*

Rehm RS. (2000). Parental encouragement, protection, and advocacy for Mexican-American children with chronic conditions. *Journal of Pediatric Nursing, 15*(2), 89-98.

Rogers, E. (2003) *Diffusion of Innovations. 5th ed.* New York: Free Press.

Rosenberg, S.A., Zhang, D. & Robinson, C.C. (2008). Services for young children: prevalence of developmental delays and participation in early intervention, *Pediatrics, 121* (6)*,* e1503-e1509. doi: 10.1542/peds.2007-1680

Shapiro, J. & Tittle, K. (1990). Maternal adaptation to child disability in a Hispanic population. *Family Relations, 39*(2), 179-185.

Weiss, R. S. (1994). *Learning From Strangers: The Art and Method of Qualitative Interview Studies.* New York: The Free Press.

Wejnert, B. (2002). Integrating models of diffusion of innovations: a conceptual framework. *Annual Review of Sociology, 28,* 297-326.