

**FROM RESEARCH
TO REAL LIFE:**
Increasing Visibility
and Use of Family-
to-Family Centers

**BRIEF
2**

Using Key Informant Interviews to Guide Marketing Plans

Based on findings from the 2009-2010 National Survey of Children with Special Health Care Needs, there are an estimated 1,002,912 children with SHCN whose families reported that they had difficulty using needed services because they could not get the information they needed (National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10). In addition, lack of information and need for support in navigating the complex system of services can be one factor that feeds racial and ethnic disparities in access to care for children and youth with special health care needs.

Family-to-family information and advocacy centers play a key role in connecting families to that needed information and support. To address the documented need for information and support for families of children with SHCN, federally-funded, centers were created within states, expressly designed to give families knowledge and support. For over 40 years, the Office of Special Education Programs within the Department of Education has funded Parent Training and Information Centers. In addition, as a requirement of the Affordable Care Act of 2010, the Maternal and Child Health Bureau of the Health Resources and Services Administration initiated funding for a Family to Family Health and Information Center in each state and a national training and technical assistance center through Family Voices to support those projects. Ongoing evaluations of family-to-family centers reflect their value to those families that use their services, yet many families still do not access these family centers.

If you work in a family-to-family center, consider the following:

- How often do you hear from families that contact your center, “I didn’t realize you existed!”?
- Are there groups of families that you wish you could reach more effectively—diverse cultural, racial, or ethnic groups? Families of transition age youth? Rural families? Families who speak a language other than English?
- Do the demographics of the families you serve reflect the racial and ethnic make-up of your state?

What can state-wide family-to-family information and advocacy centers do to connect with families that need their services, but have not yet found them?

Georgetown University Center for Child and Human Development and three state-wide family-to-family centers (Exceptional Children’s Assistance Center in North Carolina, Parents’ Place of Maryland and Parents Reaching Out in New Mexico) are partners in research funded by the Maternal and Child Health Bureau, Health Resources and Services Administration, US Department of Health and Human Services to study how and where families of children with special health care needs seek information and ways in which family-to-family centers can learn how to reach more families in their states. The study is based on the idea that families typically turn to family, friends, co-workers, agencies or doctors and other care providers that they already know and trust when they want information and advice about raising their children. If their usual networks do not know about or feel positively about using family-to-family centers, families may never reach out for those services.

The study has three phases:

1. Focus groups with families who had already used their services and with families who had never used the services of a state-wide, family-to-family center to learn more about what families know about their centers, how families like to receive

Racial, Ethnic and Language Disparities in Care

Responses to the 2009-2010 National Survey of Children with Special Health Care Needs indicate that Hispanic, black, and other non-white, non-Hispanic children are significantly more likely to have families who report that they had one or more unmet need for healthcare services in the year preceding the survey than white children and are significantly more likely that those who are white non-Hispanic to report that:

1. they did not receive needed elements of care coordination;
2. they did not receive coordinated, ongoing, comprehensive care within a medical home; and
3. they usually or always are frustrated in getting care for their children.

Finally, a key to effective care of special health care needs is identifying the problems early and throughout the life course, yet based on responses to the 2009-2020 NSCSHCN Hispanic families with SHCN are significantly less likely to report that their children receive early and continuous screening services than white children with SHCN.

- information, and to whom they typically turn for help.
2. Key informant interviews with health care providers and others in the natural support and communication networks of the families in the focus groups to learn what they knew about the family-to-family centers, how they viewed the centers, how best to communicate with the centers and whether they referred families for services from the centers.
3. A communication/social marketing plan that is directed to both families and those in the natural social and communication networks of families the centers wanted to reach more effectively.

This series of *From Research to Real Life* briefs will share information from each of these three phases so that all family-to-

family centers can profit from what the centers in the study are learning.

Using Key Informant Interviews to Enhance Focus Group Findings—What Do Families’ Social Communication Networks Think about Family-to-family Centers?

From Research to Reality Brief 1 described how gathering information from focus groups can help family-to-family centers understand more about populations they want to reach. In the three states in the study, they learned about why families thought that the family-to-family center was a better place to seek information than other possible places and people; when they most need information, how they like to get information, and what aspects of family-to-family centers might be barriers to using them. In addition, families reported about whom they typically trusted and turned to when they needed

support and information—their social communication network.

Brief 2 includes:

1. Definition and understanding of the **social communication networks** of families in the focus groups;
2. How to conduct key informant interviews with members of social communication networks; and
3. How to interpret findings from key informant interviews.

1 What are social communication networks and why are they important?

Social communication networks are the individuals and groups that people regularly talk with about important issues in their life. People tend to go back to the same people over and over for support, information and advice (Case, 2000; Harris & Dewdney, 1994) such as friends, relatives or co-workers. In addition, these kinds of networks tend to occur in places where people regularly meet and spend time such as barber shops, hair salons, at the playgroup, in church, or in the work lunchroom where there are opportunities for them to exchange information. (Pettigrew 1996, 1999) For families of children with special health care needs, information needs are very specialized and people in those usual groups and places, may not be where they seek information and help for those needs.

Based on the theory of diffusion of innovations (Rogers, 2003) families will decide to use your center if they are aware of its existence and if they think it meets the following criteria:

- it is better than other ways of getting information and support;
- it feels comfortable and compatible with their needs and values;
- it is easy to get help from your center;
- they can try it out and have no long-term obligation; and
- they or others in their social communication network know families who have tried it and liked it.

Families' social communication networks are important to all of these factors. They must know about your center if they are to make families aware of their existence. In addition, their perceptions and attitudes about your center will inform families in their decision-making process. It is essential that social marketing efforts by family-to-family centers capitalize on these social communication networks and make sure that they are informed about what the centers offer. In addition, their understanding of what your center offers and their opinions about the quality and usefulness of your center will be communicated to families and can either increase the likelihood that a family would contact a center for make it unlikely that they would turn there for help. Thus understanding their views is key to how you might plan your marketing activities.

2 What did the Family-to-family Centers Learn from Social Network Members?

Social network members' views about the family-to-family centers in this study were very similar to those expressed by families in the focus groups. These findings are particular to these three centers, but will give you an idea of how valuable information from social communication networks can be. The following summarizes key information that helped the centers begin to create and implement their marketing strategies.

When families turn to them for information and help:

- Diagnosis or new diagnosis*,
- Need resources or help with funding of services,
- Problems with services at school*.

The advantage of families using family-to-family centers in comparison with other resources:

- Staffed by families who have children with special health care needs who have faced similar problems*,
- Knowledgeable staff*,
- Provide training to help families become effective advocates*,
- No cost*,
- Help with advocacy,
- No waiting lists.

Possible barriers to encouraging families to use family-to-family centers:

- Unsure what they offer*,
- Think the location is

- inconvenient/think families have to go in-person to the center*,
- Think they only work on school related issues*,
 - Do not receive feedback about families they refer,
 - Not sure how/if they serve all immigrant families *, and
 - Think may lose their government funding*.

How social network members want to learn about and get information from family centers:

- One-on-one meeting*,
- internet*,
- email.

**These views were also mentioned by the family members in the focus groups.*

In Brief III you will learn how this information and the information from the focus groups can help inform how to market your center to families. **You can see from the information gained by the three centers in the study, they will have to more clearly articulate what they do for families, highlight their advantages and clear up possible misconceptions held by members of social communication networks.**

3 How to Learn from Social Network Members—Key Informant Interviews

From Research to Real Life Brief 1 describes the focus group process used to gain information from families about who comprises their social network—whom they turn to for information and support related to caring for their

A key informant interview is a structured conversation with an individual who has knowledge or experience about the topic you are trying to understand. Sometimes the person has been identified by others as a key person—in our study we interviewed people mentioned by families in the focus group. Other times the key informant might be chosen because of their position or long-time experience with an issue.

children with special health care needs. The places families most frequently mentioned were their children’s doctors, teachers or community agencies and organizations that provided services and supports to them. Understanding their perspectives on what families need, how they support families with information and how they view family-to-family centers was accomplished in the second phase of this research study. **Often the people, who have important information to help with developing social marketing plan for your center, cannot be organized to come to a focus group meeting. In those situations, choosing important individuals to participate in key informant interviews is an effective way to get the information you need.** Choose individuals who are frequently mentioned in focus groups as important members of families’ social communication networks or who you know are important supports to families you want to reach. In this research study,

health care providers and staff at community agencies frequently mentioned by families were recruited to be interviewed.

Lessons Learned by the Three Centers about Conducting Key Informant Interviews

While the idea of doing key informant interviews seemed simple, actually completing the interviews was sometimes challenging. Contacting and scheduling key informant interviews took tremendous persistence. The people they wanted to interview were busy and the healthcare professionals, in particular, did not always have control over their schedules. As a result, they suggest the following:

- The first hurdle is actually making contact with the person for the interview. It helped if the caller or someone in the family-to-family center already had a relationship with the person or their organization. When that did not exist, having families who knew the person contact them to give them a “heads-up” about the request could open doors.
- It is important to figure out who controls the person’s schedule. If there is someone else who helps with scheduling, it is a good idea to get them involved in choosing the time.
- When recruiting, make the importance of the interviewee’s input to better serving families very clear. It helps them see the value of giving you their time.
- It is important to be clear about the nature of the interview and the time it will take, so potential

interviewees can make an informed decision.

- Make the process as convenient as possible. This may mean going where they are—in some cases the centers in the study hung out in the hospital cafeteria to catch doctors there.
- Needless to say, being flexible about time is vital. You have to work with their schedule. Also be prepared for multiple rescheduling of calls. It is important, however, to have a deadline for completion and if a particular person cannot seem to schedule within that time frame, go on to alternates.
- Don't take it personally—it frequently happens that people will miss interviews and never let you know that they needed to change the time.
- Ask what approach—in person or on the phone—is best.

How to conduct Key Informant Interviews to Inform Your Marketing Plan

Key informant interviews are good way to learn about the views and opinions of important people in your state who will help families get to your center. Below are some steps to consider:

- **Decide what information you want from your key informants.** Think about what you already know about their ideas or opinions. Do you want to confirm that information? Do you want to find out something entirely new? Do you want to see if their opinions and ideas

have changed since the last time you sought information?

- **Decide what sorts of people/organizations you want to include.** This means knowing something about the people you hope to interview and what kinds of perspectives they will bring.
 - Try to think about people who know your center well and those who may not. Include people who may not have a totally positive view of your center—we often learn important lessons from our “nay-sayers.”
 - Think about characteristics such as professional background, gender, race and ethnicity, age, and how long they have been serving families in your state.

Key informant interviews are most useful when you have input from people who have different roles, different backgrounds or levels of experience. As noted, for the study, those key informants were chosen from a list of resources families in the focus groups mentioned. You can use a similar approach or you can regularly ask current users of your services who referred them to you. By looking at that information, you can think about who are key referral points in your state. **You can also look to see who is missing from the list.** Are there agencies that work with families who have children with special health care needs that **do not** refer to you? It is important to understand why, because as members of the

social communication networks of families, they may not be supporting families to use your center. Based on this information create your list of potential interviewees.

- **Choose your final list.** Make sure you have people with different roles and perspectives on your list. Have an “A” list and have back-ups for each sector you want to include, in case your first choices cannot or will not participate.
- **Decide what kind of interview you want to do.** Will it be in person? On the phone? Will you want to be able to use both approaches to meet the needs of those interviewed?
- **Decide what questions you want to ask.** From five to ten questions is a good number. Make them open-ended questions and think about follow-up questions to get the information you will need. Think about asking your most important questions first, in case you run out of time. Your questions may be complex, so try to break them into shorter, simpler questions for the interview. See Table 1 below for the questions used in the key informant interviews for the research project. You may find some of these useful.
- **Decide who will do the interviews and provide them with information and training on conducting the interview.** If you can find someone who is not part of your center staff to do the

interviews, it may make it easier for informants to be open, but this is often not possible. Thus, it is important that interviewers be clear about their roles. Be sure interviewers know to react impartially to information and not become defensive about criticisms or misconceptions about your program. They

should not use this interview as an opportunity to educate the informant about your project, but can offer a follow-up after the interview to provide more information.

- **Recruit and schedule those you want to interview.** Email, call or ask in person. This may take a

great deal of persistence. In addition, informants may be busy and not have complete control over their time—expect cancellations and rescheduling. Just be clear about your time line and know when to move on to an alternative informant. As noted above, having an ongoing relationship with the person or having someone who does make the ask leads to greater success. Develop and provide a concise but clear explanation about:

- Why you want to learn this information
- Why their perspective is important to you
- What you hope will be improved or changed using their input
- How you will share the information with them, with funders, etc.
- What they will be asked to do—in person interview, phone, etc.; how long it may take; how you will capture the information (take notes, tape the interview)
- How confidentiality will be protected (See below)
- Your time line—if they cannot meet this time line, you will want to go to an alternate informant that comes from the same sector of your list.

- **Conduct and record the interviews.** Decide if you will tape interviews (always ask for permission from the informant) or you or someone with you will take notes.

Table 1. Key Informant Interview Questions

1. What kinds of information do you feel families with children and youth with special health care needs need to help them to ensure that they get good medical care, services, and supports? Are these available to them?
2. How are you typically able to help them? (What kind of information do you offer or what resources do you provide?) Do you feel this information or resources are sufficient to help the family? How so? OR Why not?
3. What difficulties, if any, do you have in locating information that might be helpful to families with children with special needs? What kind of information do you wish you had at your fingertips?
4. As far as you know, what kinds of resources are available to the families of children with special care needs in the community? As far as you know, how hard or is it for them to access these services? What makes it hard/easy?
5. Have you heard about XXX Center (name of your Family-to-Family Center) in our state? **IF YES:**
 - a. What do you know about them? Have you ever suggested that a family you know use them? What is your impression of their ability to help the families you refer to them?
 - b. Is getting help and information from a Family-to-family Center something that is comfortable for you and the families you support?
 - c. How does this center fit with how families should get help?
 - d. How does this fit with your ideas of privacy?
 - e. How do you think families that you support view getting help from an organization run by families? From families that may have a different background than theirs? About getting help from a program that is sponsored by the government?

IF NOT: PROVIDE A BRIEF DESCRIPTION OF THE CENTER AND SERVICES AND POPULATION THEY SERVE and the questions above.
6. What kind of things can the Center provide to make the referral easier for you?
7. How do you like to get information to share with families? What technologies do you use to get and use information?

- **Compile and organize the information.** For the research project we had the interviews transcribed and then used a formal method for identifying themes and issues. You can use a less formal method. Have several staff members read/listen to the interviews and think about what themes and issues seem to come up frequently. Then discuss what was noticed and organize that information into categories such as strengths, barriers, etc. Think about any differences in what is mentioned based on the informant's position or background and how you can use that information to better market your center. **Brief III will describe how to use this information to develop a marketing plan.**

Confidentiality in Key Informant Interviews

Explaining your approach to confidentiality is critical to making informants comfortable to share their views. If they are staff in agencies, they may not want their name or their agency's name publically associated with a particular perspective or opinion that is very important to you in improving your marketing approaches. Others informants are probably well-known in the community and may not want their perspectives shared by you. Because our project was research and we knew we would be sharing the information publically, we were very clear that no names or names of particular agencies or health care practices would be mentioned. In addition, any information within the interview that might identify the informant was omitted in reports and articles. If you are doing these interviews for your own use, you can assure informants that it is for internal use only. That said, **it is extremely important that any staff who know the identity of the informants be well versed on confidentiality.** It can be easy to mention to others comments about the informants such as "Can you believe what X said?" Those sorts of lapses in confidentiality are bad for your center's reputation and will make it very difficult to get cooperation in the future.

The best approach is for staff doing the interviews to understand confidentiality well. Then remove any personally identifying information from the interview transcripts or tapes. Have the interviewer avoid using the informants name after the beginning of the interview to make this easier. Sometimes it is impossible to mask the identity of an informant. In those cases be extra careful in how information is shared or ask the informant if they are comfortable with you identifying them in that process.

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The **Georgetown University Center for Child and Human Development (GUCCHD)** was established over four decades ago. The GUCCHD's mission is to improve the quality of life for all children and youth, children with special needs, adults with developmental and other disabilities, and their families. A division of Georgetown University's Department of Pediatrics, the Center is founded on an interdisciplinary approach to service, training, research, community outreach, technical assistance, and public policy.



Founded in 1990, **The Parents' Place of Maryland** was created by parents of children and youth with disabilities to help other parents and families facing

similar challenges. The Parents' Place is staffed primarily by parents of children with disabilities and works in coalition with many statewide disability organizations. Our staff help families obtain appropriate education, health care, and services for their children with disabilities; work to improve education and health care for all children; train and inform parents and professionals on a variety of topics; and connect children with disabilities to community resources that address their needs.



Exceptional Children's Assistance Center (ECAC) is a private non-profit parent organization committed to improving the lives and education of ALL children through a special emphasis on children with disabilities. ECAC affirms the right

of all individuals, from all backgrounds and cultures, with or without disabilities, to an appropriate education and other needed services. We seek to make that right a reality by providing information, education, outreach, and support to and for families with children across the state of North Carolina.



Founded in 1981 by families who had children with special health and developmental needs,

Parents Reaching Out (PRO) is a statewide non-profit organization that works with parents, caregivers, educators and other professionals to promote healthy, positive and caring experiences for New Mexico families and children. Through partnerships with funding from federal and state agencies, donations and the valuable time of our volunteers, PRO develops materials, programs, workshops to effect positive change for families in New Mexico.

For further information about this project contact:

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