

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

BRIEF

1

Using Focus Groups to Guide Interventions

Based on findings from the 2009-2010 National Survey of Children with Special Health Care Needs (NSCSHCN), there are an estimated 1,002,912 children with special health care needs (SHCN) whose families reported that they had difficulty using needed services because they could not get the information they needed. 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. There are currently 105 such centers, a national training and technical assistance center, and 6 regional networks implemented through the PACER Center to support those 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, U.S. 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

Racial, Ethnic and Language Disparities in Care

Responses to the 2009-2010 National Survey of Children with Special Health Care Needs (SHCN) 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 than 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 non-Hispanic white children with SHCN.

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 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 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.

Brief 1 will include:

1. The **benefits** of conducting focus groups along with some findings from these three centers that illustrate the usefulness of the time and effort of implementing the focus group approaches;
2. **Lessons learned** by the three centers about conducting focus groups; and
3. **Some “how-tos”** for other centers wanting to use focus groups to increase the number of underserved families who use their services.

1 Benefits and Findings

Benefits of Conducting Focus Groups

Preparing for and conducting focus groups is time-consuming hard work but well worth the effort. Aside from learning what you set out to discover from the focus group, there could be other benefits that you may not have expected. Here are a few benefits that the centers we worked with told us came from conducting their focus groups:

- A focus group is a nice opportunity to connect the faces to the parents who contribute a lot to the center but whom you have not met personally.
- Some non-users in the focus groups may become users and spread the word about the center.
- Parents feel like someone is listening to what they have to say.
- Focus groups are one good way to improve the center's services.
- The information gathered can be used for writing grants.
- Parents are able to exchange information with each other and by the end of the focus group they feel like it has been a support group for them.
- **Most importantly, the focus groups gathered important information they needed to develop a social marketing strategy to increase use of their centers by the populations of focus.**

What Did the Family-to-Family Centers Learn?

Here are some findings from the focus groups in Maryland, New Mexico, and North Carolina.

They may not apply specifically to your state, but will give you an idea about how valuable focus group information can be. As you read them, think about the implications for how a family-to-family center might want to promote their services—with whom and what aspects of the center should be highlighted.

- Across all three states, families said that they preferred to get information via one-on-one communication. They preferred this mode over getting information from the internet or other technology-based resources because they needed to explain their situation in order to get the right information. For some families, there was a culturally based preference for getting information through personal interaction or after building a relationship.
- Across all three states, both families who had used the centers and those who had not all said that the advantage of using a family-to-family center was that staff have lived experience as parents of children with special health care needs and disabilities and that they have the highly specialized information needed to access the right services.

- For families from some racial and ethnic backgrounds, the fact that family-to-family centers are funded by the government was a barrier to use. Lack of trust in the “system”, concern that government funded programs might have “strings attached” and worries about immigration status were discussed.
- Many families thought that family-to-family centers in these states (the same organization houses the F2F and PTI) only helped families with school related issues.
- Families most often talked about turning to other non-profit agencies (such as The ARC), healthcare providers, state early intervention programs and Head Start for information and help with their children's needs.
- Many families reported that while they would typically turn to other family members for help or advice, family attitudes about their children's disabilities—denial of the condition or a sense of shame or stigma about disabilities and special health care needs—left them on their own for these issues.

Centers will use these findings to develop more effective communication approaches to increase use of their Centers by underserved groups of families. (More to come in Briefs 2 and 3 of this series.)

2 Lessons Learned by the Three Centers About Conducting Focus Groups

After the centers finished their focus groups, there were a few lessons learned about the recruitment process. Here are some of the things they told us:

- **Time:** The process of recruiting and doing focus groups is very time consuming; anticipate that it will take 2-3 times longer than what you originally think it will take.
- **Facilitator as recruiter:** When the person who runs the focus group is also involved in recruitment, parents are more comfortable answering questions because they have already met them even if it was just over the phone.
- **Participants who speak another language:** If you want to do a focus group in English and you are recruiting parents who may also speak another language, be sure to speak to them in English over the phone to make sure they are fluent enough in English to participate in the focus group. Participating in focus groups takes a higher level of English-speaking proficiency that is more complicated than what you may be able to reach in a simple phone conversation. Therefore, you can also consider conducting the focus group in their native language.
- **Contacting center non-users:** When contacting parents who were not familiar with the Center it is difficult to make contact over the phone because often parents

think there is a catch to joining the focus groups or they think the person calling is a telemarketer. Start the conversation by stating who referred them. For example, *“Hello, John Smith suggested I call you because...”*

- **Picking a date and time:** It is better to decide on a date and time **before** recruiting parents. If you do the opposite (collect possible participants first and then decide on a date to hold the focus group) this will require you to have to contact the parents again to let them know when the focus group will be. You may end up losing a lot of parents if you are unable to reach them a second time.
- **Focus groups in the winter:** Depending on your location, choosing to hold focus groups in the winter may not be the best choice due to weather delays.

3 How to Conduct Focus Groups

Focus groups are a great way to gather a large amount of information from a specific group of people. To put it simply, a focus group is an interview with 6-10 people done at the same time. This brief contains specific information that the centers we worked with found useful. For further information on focus groups including tips on how to run them:

- www.dsamh.utah.gov/spf/pdf/how_to_conduct_a_focus_group.pdf
- www.globalhealthcommunication.org/tool_docs/60/handbook_for_excellence_in_focus_group_research_%28full_text%29.pdf

Developing Focus Group Questions

Before you can conduct your focus group, you have to come up with reasons for wanting to do a focus group. Is your center considering a new program that you would like parents to give you feedback on before its launch? Do you want to know which services parents find most valuable and which they use the least and why? Are you trying to reach a new community and would like to learn what their needs are?

Once you decide that a focus group is a good strategy to learn more about the families you serve and you have specific overall questions you want the focus group to answer, you must then develop the specific questions to ask during the focus group. Below are a few things to keep in mind when coming up with your questions:

- **Open-ended questions:** Focus group questions should be open-ended so that parents can answer them fully instead of with a “yes” or “no.”
- **First broad then narrow questions:** Start the focus group with broad questions and then narrow down to more specific questions. This helps the group warm up slowly so that by the time you get to the specific questions you are really interested in learning more about, parents are feeling more comfortable with answering questions and are more likely to give elaborate responses.
- **Number of questions:** Most focus groups last about an hour

and a half. A surprisingly small number of questions can fill up this time quickly. Around 15 questions should be the maximum.

- **Probes:** Many questions can be followed with probes. Probes are extra questions that follow a main question to get more specific information about the topic.

The Centers in the study used the following questions to learn more about how and where families sought information and how they viewed the family-to-family centers.

Questions Used in Focus Groups with Families Who Had NOT Used the Centers

1. When you feel you are at a loss or looking for some answers or help whom do you usually turn to? Why?
2. When you feel you are at a loss or looking for some answers or help for issues concerning your child with special needs, whom do you usually turn to? Why?
3. If you met another family who had a child with a special need and was struggling to get answers and help for their child or youth with special health care needs, what advice would you give them? Where would you send them for help? Why?
4. Have you ever heard about “name of your center”? **If Yes:** What have you heard about it? Would you use it? Why? Why not? For those who have used your Center ask
5. **Provide a brief description of the Center including services the Center offers. Repeat it out loud to the participants.** Now that you have read the description, what are some things that you like about it? What are some things that you don’t like about it? What kind of questions do you have about the services the Center offers? [**NOTE: DO NOT** answer the participants’ questions, you can answer them after the groups.]
6. What are some of the most important things that might make you want to work with a Family Resource Center like this? What are some things that you’d be looking for?
7. How do you think getting information from a Family Resource Center like “name of your center” might be different from getting it from friends, family, others in your community? What might be better? What might be worse?
8. Do you think getting help and information from a Family Resource Center like “name of your center” would be something that is comfortable for you and your family?
9. Do you think it would be easy or difficult to make contact and get help from a Family Resource Center like “name of your center”? Why?
10. Do you think that any particular technology that a Family Resource Center like “name of your center” might employ (describe what you have and ask about others) would make it easier or harder for you to use the Center?
11. **Distribute Fact Sheet or Brochure of the Center, Ask them to review it and then ask:** Pretend you got this brochure in the mail, what would you do with it next? What would be your next step?

Questions Used in Focus Groups with Families Who Had Used the Centers

1. When you feel you are at a loss or looking for some answers or help whom do you usually ask? Why?
2. When you feel you are at a loss or looking for some answers or help for issues concerning your child with special needs, whom do you usually turn to? Why?
3. If you met another family who had a child with a special need and was struggling to get answers and help for their child or youth with special health care needs, what advice would you give them? Where would you send them for help? Why?
4. When I say “name of your center”—what words, adjectives or phrases come to mind?
5. If you had to describe the Center to another family: What would you say?
6. What are some things you like about the “name of your center”? Why?
7. What are some things that you don’t like about the “name of your center”? Why?
8. What are some of the most important things that made you want to work with the “name of your center”? Why they are important
9. How is (or could be) getting information from “name of your center” different from getting it from friends, family, others in your community? What might be better? What might be worse?
10. Is getting help and information from “name of your center” something that is comfortable for you and your family?
11. Is it (or do you think is would be) easy or difficult to make contact and get help from “name of your center”? Why?
12. Does any of the technology the “name of your center” employs (describe what you have) make it easier or harder for you to use the Center?
13. **Distribute Fact Sheet or Brochure of the Center, Ask them to review it and then ask:** Pretend you got this brochure in the mail, what would you do with it next? What would be your next step?

Recruiting

After you have come up with your questions you will need to prepare for the focus group. This means you have to decide how you will recruit families to be a part of the focus group. Although it depends on the purpose of the focus group and what you are hoping to learn from it, it is usually better to also hear from people who do not already use the center. If you only recruit people who have used the center and are familiar with your services, they may only have great things to say and you may not hear a range of opinions. When thinking about where to recruit center non-users, consider places where families may naturally go, and whom they frequently turn to. Below are some of the ways that the centers in this study recruited for their focus groups:

- Check with the center database for potential participants and parents to spread the word about the focus group.
- Use community partners that you have relationships with and have them help with recruitment, especially when trying to reach non-users (have community partners vouch for the center).
- Use someone in the center that is very well-connected in the community to help with recruiting. Having someone from the center that is trusted in the community will go a long way when asking local non-profits and government agencies to help recruit or pass out flyers for the focus group.
- Person-to-person contact works best—this means call or visit

community partners in person when asking them to help with recruitment.

- Emails to various agencies and organizations **only** works with frequent follow up.
- Use person-to-person contact when directly recruiting parents—the parents that were called directly and asked to come to the focus groups were usually the only ones that actually showed up to the focus groups (not the ones that were asked to come by someone else not affiliated with the center or through another agency—this means if someone is helping you recruit, you should ask them to collect names and numbers so you can call the parent directly yourself).
- Attend health fairs, Head Start fairs and other resource fairs in the community you are trying to reach.
- Reach out to places that provide recreational activities: YMCA, sports leagues for children with special needs, other local recreation centers.
- Distribute the focus group flyer through the Center’s monthly newsletter.

There were also some lessons learned by the centers in the study about which tactics did not work with recruiting:

- Posting flyers around the community
- Ads in the newspaper
- The main thing to keep in mind when recruiting is that you can

make a flyer but do not expect it to work on its own. **Keep in mind that the flyer is only a recruitment tool and should not be your primary method of recruitment.** The flyer provides a brief summary for your recruiters or for describing your recruitment needs to your partners. One-on-one contact is the only way to assure that you will get participants to your focus group.

Developing a Focus Group Flyer

The flyer you develop to announce your focus group should be clear and to the point. It should only contain a few key pieces of information:

- Characteristics of who you are recruiting
- A general statement about why you are doing the focus group
- Where the focus group will be
- When it will take place
- Any incentives you will provide to participants
- Who you are: include your logo on the flyer

Logistics

When you have recruited parents for the focus group and are ready to move to the next step of actually conducting the focus group, there are still a few things to keep in mind. Below are some important things to consider before, during, and after the focus group.

BEFORE the focus group:

- **Child care:** Decide if you are going to provide child care. Children get bored and do not

Confidentiality in Focus Groups

Begin your focus group by creating a “safe space”. Similar to the phrase “What happens in Vegas stays in Vegas”, a safe place means that everything that is said during the focus group is not to be shared with anyone after the focus group. You will also need to explain that even though you are recording the focus group, you will not share the audio with anyone outside of the few people who are involved with the focus group and that the audio file will be destroyed once you have transcribed the information on the file. Another good idea to maintain confidentiality is to have parents assign themselves fictitious names so that their real names are never used. You should also make clear that their responses to the questions will in no way affect their relationship with and ability to get services from the center.

like to stay quiet for an hour and a half. They will almost always become a distraction to their parent, the facilitator, and other group members if they are brought to the focus group. You will need to decide if you will provide child care and if not, explain to parents **ahead of time** that they will need to arrange child care prior to coming to the focus group. You may want to take into account that possible expense when determining the type and amount of your incentives.

- **Incentives:** Decide if you are going to provide incentives to parents for participating in the focus group with cash, gift cards, or another way (free books, etc). Incentives usually help attract parents but if this is not possible simply saying that there will be refreshments will also help draw them in. Finally, parents also may find that helping other parents is an incentive.
- **Refreshments:** For many cultures, providing refreshments is an important part of welcoming people to an event. Offering refreshments during the focus groups can help draw parents in.
- **Recording:** A lot of information is shared during focus groups. If possible, record the focus group so that you do not have to count on someone capturing everything that was said through note-taking during the focus group. Make sure to get parents’ permission to record before turning on the recorder.
- **Start time:** Because there will always be late-comers, set the

time of the focus group to start 15 minutes later than the posted and announced time. For example, broadcast that the focus group will be from 3:00-4:45 pm, but do not actually begin the focus group until 3:15 pm to allow late-comers to come in without interrupting the focus group. Regardless of the time you start, make sure you finish at the time you said you would.

DURING the focus group:

- **Help during the focus group:** Have at least 2 people from the center at the focus group. Both people can set up the refreshments and greet parents as they come in. One person will be the one who will run the focus group and ask the questions (facilitator), the other person can take notes just in case the recorder fails and can also assist late-comers.
- **Recorder:** Don’t forget to check the recorder’s batteries, memory space, and test that it is working. And don’t forget to turn it on!
- **Distributing incentives:** If you will be providing incentives to parents for participating, the second person can take the lead in passing out the incentives at the end of the focus group.
- **Confidentiality:** Focus groups are only effective if the parents feel they can openly express their thoughts without consequences. Be sure to create a safe space by explaining the confidentiality rules of focus groups (see box).

AFTER the focus group:

- **Recording:** If you have recorded the focus group you will either want to listen to it again (maybe a few times) and take notes on what you hear. Or you may want to ask someone to transcribe the focus group so that there is a transcript available to read. You can then use the transcript to read and highlight sections that seem interesting and that show patterns of what people were saying in the focus group about a particular topic.

The information in this Brief on using focus groups is the first step in the process. Brief 2 of this series will illustrate how family-to-family centers can use the information from focus groups to create new approaches to marketing their centers designed to specifically increase visibility and use within populations of interest to them. Brief 3 will share how the centers in the study were able to track the impact of their new approaches.

Reference: National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 5/3/2012 from www.childhealthdata.org.

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.

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