



15

BRIEF

The Benefits and Challenges of Research Partnerships: Families and University Researchers Working Together

In the past decade, there have been dramatic changes in approaches to disability research, training and service delivery. A focus on accountability brought more attention to outcomes and the satisfaction of consumers and family members with services. A new model of conducting research, the participatory action research (PAR) model, encourages researchers and intended beneficiaries of research, such as families, to collaborate at all stages of the research process (Turnbull, Friesen & Ramirez, 1998). This model recognizes the value that families bring to research through their expertise, experience, and expectations. And a strong, widely recognized consumer and family movement in the disability arena has established mandates for family involvement at all levels of service planning and governance.

Increasingly, researchers are asked to be more accountable for how their studies will impact the lives of individuals with disabilities. They must ask the “so what?” question, that is how meaningful is this research; how will it improve lives? Although there has been significant research and development of best practices and evidence-based interventions for populations with disabilities, there is often a ten year

gap between developing these practices and implementing them in the field. Attention has turned to research-family/consumer partnerships as a way to help to bridge this “science to service” gap. With increasing support for consumer and family involvement, the question is no longer whether to develop partnerships when conducting research, but how best to do it.

This brief summarizes discussions on a national teleconference call, sponsored by the Consortium for Children and Youth with Disabilities and Special Health Care Needs, that examined three different approaches of engaging families as partners in the research process. The purpose of the call was to highlight some of the benefits and challenges of these partnerships, and to present strategies for implementing them. Each model was discussed by a team representing a partnership between university researchers and family members.

Three Approaches to Research Partnerships

♦ **An Interagency PAR Team:** This collaborative relationship involved the Beach Center on Families and Disability, a rehabilitation research and training center at the

University of Kansas, and the Grassroots Consortium on Disabilities, a national coalition of parent-directed, community-based, family support programs serving culturally and linguistically diverse families who have children with disabilities. This was a partnership between a large, well-established research organization in the dominant culture with a smaller, community-based effort focusing on underserved families of color. Bringing these two organizations together was an “unlikely partnership” (Santelli et al., 1998). However, their shared mission—to make a positive difference for individuals with disabilities and their families—formed the basis for their extensive partnership. These two centers came together through a shared research project and collaborated equally throughout every phase of the research, dissemination and utilization process. Parents and researchers together defined the research questions, developed a family-sensitive and scientifically credible research design, selected or created family friendly and psychometrically sound instruments, and analyzed and interpreted the data. Each partner came to recognize the resources

and expertise of the other (Santelli et al., 1998).

◆ **A Family Consultant:** A member of Family Voices, a national advocacy organization for families with children who have special health care needs, partnered with a research team at the Center for Child and Human Development at Georgetown University. This family member functioned as a consultant to the research team. She contributed to the conceptual design of the study, reviewed interview protocols, and participated as a team member in data collection at the homes of families who had children with disabilities and special health care needs. She was instrumental in gaining access to families who were hesitant about meeting with researchers. She ensured that the interview protocol was family-friendly, appropriate and respectful, and that the questions asked would have meaning and relevance to families. The family member was contracted for her time on specific tasks, while the daily tasks were carried out by the university.

◆ **A Family Advisory Committee:** The Institute for Health Policy Studies at Brandeis University created a family advisory committee to provide input into a survey research project. The Family Advisory Committee met regularly with the university research team and provided a family perspective on different components of the research, particularly on development of a survey, ensuring that it was appropriate for and understandable to families. The Family Advisory

Committee consisted of four parents of children with varying special health care needs to ensure different perspectives. The family advisors were paid advisors to the project. The research team also has a paid, fulltime researcher on staff that has a child with special needs and identifies both as a researcher and a family member. This staff member served as a liaison to the Family Advisory Committee.

Benefits of Research Partnerships

◆ **Improved Relevance.** Families know about problems they are experiencing, questions they want answered, products that may help them, training methods that are most effective for them and materials and language that they can understand. Involving them in identifying research priorities and topics assures the relevance of the research to the end-users. Generally, the selection of research topics has been within the purview of researchers or funders, as opposed to the families whose lives are most impacted by the research.

“Our basic view is that research is far more meaningful if the people who you hope will benefit from the results of it are involved from the get-go.... From my research, I got awards, I got promoted, I got grants but I don’t know that many changes happened in the quality of life (of) families and people with disabilities...we’ve got to do business in a different way.”

—UNIVERSITY RESEARCHER
ON PAR TEAM

“They [family advisors] looked through our survey, a very early draft of it, and said ‘where are the questions about dental services? Our kids need dental services.’ We were thinking more of primary care. But dental was a huge issue for these families and one that we really had not considered. As a result, we added a whole section to our survey because it was pertinent to every single one of them. And they gave us ideas of what areas of need there were and we structured all of the questions around what they had talked about.”

—UNIVERSITY RESEARCHER

◆ **Improved Rigor.** Partnerships with families in research may help increase feasibility and acceptability of research procedures, improve survey or interview protocols, and improve the accuracy of the data. Families can anticipate how other families may respond, and help design research questions that families understand. Additionally, families may facilitate entry into research-wary communities and increase recruitment and continued participation in a study. Family partners can connect researchers to communities and diverse families that would be otherwise inaccessible. Effective partnerships help identify the burden of the research on families and the feasibility of carrying out specific research designs. The discussions address the issue of balancing scientific rigor with respect for the needs, values and preferences of the families.

"The family advisory committee has really impacted both the methods by which the projects are being conducted and what we hope to be the outcome...one of the examples that comes to mind is the power of the family advisers to really shape the language that we use. It is very difficult to get the language right.... It's easy to drift into more stilted language and not language that is used in the family."

—UNIVERSITY RESEARCHER

"She really told us what she thought family members might hear in the way we were asking the questions. So she helped us form them in a way that they was understandable and got at the information we were looking for."

—UNIVERSITY RESEARCHER

"It was really important that I make the first call to the family and that I get to tell them that I'm a parent of a disabled child and I got to talk a little bit about my child, so we got to make the personal connection before we went to travel to their home. I think that made the families feel comfortable with us; we had no no-shows."

—FAMILY CONSULTANT
REGARDING INTERVIEWS WITH FAMILIES

◆ **Increased Use of Findings.**

Concerns are frequently expressed that research results are not disseminated to stakeholders in a timely way. Family caregivers, policy makers and advocates often do not receive findings which may help their decision making or program and policy planning. Research partnerships can help with more timely dissemination and

utilization of the research findings. These partnerships promote meaningful ways to package research products so they will be more accessible to families and the general public.

"We wanted the benefit of all the research conclusions that had been drawn already and never disseminated to our community. So we wanted to partner, we wanted people to come to our communities and tell us what these things were and help us find practical applications..."

—FAMILY RESEARCH PARTNER

"The family advisors have been extraordinarily helpful in making sure that what we produce, how it looks on the paper, the language that we use really will speak to the respondents that we're trying to reach."

—UNIVERSITY RESEARCHER

◆ **Mutual Learning Opportunities.**

These partnerships enable the families to have greater access to research-based results and products. Families are able to learn first-hand about the research process and to realize how their input can be a valuable part of the project, both in terms of relevance and rigor, and in how the research will ultimately be communicated to families. Professional researchers may gain a greater understanding of families' situations which potentially enhances their research questions.

For example, the PAR relationship between the Beach Center and the Grassroots Consortium enabled each

organization to learn from the other. The Beach Center's research became more relevant and appropriate to un/underserved families of color with the personal and professional wisdom of the Grassroots Consortium. The Consortium learned from the expertise in research methodology and the national visibility of the Beach Center which enabled their own research on best practices for meeting the needs of families of color to gain rigor and credibility.

"Being a member of the Family Advisory Committee has really helped me as a person, really helped me grow. It's helped my own self-respect that a group of people really value my opinion and that I can see the difference that my voice truly makes...this in turn helped me to advocate for my own children...and solve my own problems and issues."

—MEMBER, FAMILY ADVISORY
COMMITTEE

"I can honestly say to folks...that this partnership with (family partner) has been very transforming for us. It has gotten us out of our typical circles and networks and it's taught us far more about racism. (and) about the needs of families...so now we have research that has formulated the...survey where these families' voices are in from the outset."

—UNIVERSITY MEMBER
OF PAR TEAM

◆ **New Sense of Collegiality.**

Bringing family caregivers and professional researchers together is similar to bringing two different cultures together. Each group has their own language and vocabulary, customs, values, attitudes and behaviors.

Collaboration presents opportunities for shared understanding as well as culture clash. Participants must attend to the areas of conflict that arise, address issues of mistrust and differing goals, and clarify rules of conducting research and engaging families.

“Building true research partnerships certainly requires an enormous commitment in sharing, in risk taking, in planning, in time and in energy. But the potential reward for such partnerships is also enormous, no less than to produce research that’s most useful and relevant to the end user of research, to the consumers who are directly affected by the services...and one of the greatest benefits is we have a friendship that has been enriching personally and professionally...”

—UNIVERSITY MEMBER
OF PAR TEAM

Challenges in the Research Partnership

◆ **Tension Between Research and Advocacy.** Families and professional researchers may share the goal of improving the lives of individuals with disabilities. However, they may have different objectives in how research data is to be used. Families often want data for advocacy to influence policy. Timeliness and urgency of the data is critical. Professional researchers may have different objectives, using the data to build a research agenda and a list of journal publications. Professional researchers often want to take more time and deliberation in examining and publishing the findings.

“Researchers want credibility in the world of research, they want, of course, documentable results and, for us, we want those results first, so we’re in a different kind of time track. We want to tell a family this is what we’ve learned and this is how to apply it and not have it take years and years.”

—FAMILY RESEARCHER

“It was hard for me to sit at the table [with the family] and be a researcher, to listen to things without trying to want to help these families.... I wanted it [the research project] to have a benefit to the family. So when the interview was over...I got to advocate. I got to make some suggestions...”

—FAMILY CONSULTANT

◆ **Mistrust Among Partners.**

Family caregivers and research professionals historically have little contact with each other as colleagues and there may often be a mistrust of motives. Families have concerns that researchers are not asking relevant questions and may exploit the families’ community for their own purposes with little benefit for the family or community. Research professionals may be skeptical about the value of family contributions to their research agenda.

“...these researchers who came into our communities and did their little experiments, asked little questions, and then were never to be seen again. So along the way, we developed what we call the healthy mistrust of researchers...”

—FAMILY RESEARCH PARTNER

◆ **Institutional Barriers.** University structures are not readily conducive to research partnerships with families. Family partners comment on how difficult it is to understand consent forms. They request that these forms be written in language that families can readily understand. University Human Subjects Review committees are often guided more by legal considerations than ease of comprehension. Additionally, Institutional Review Boards may prohibit a family member from being part of a research interview team. University payment procedures may not be conducive to family participation. Families often need payment in advance of the work, however, some university procedures may make it difficult to provide advance payments.

“With some families that we’ve been involved with, we need to pay them up front if they’re coming to a meeting because they don’t have a credit card and they don’t have ways to cover their expenses and then be reimbursed. Our state system is not as flexible as we would like for it to be in making accommodations so that we can be respectful of some of the families from diverse backgrounds that have particular needs.”

—PROFESSIONAL MEMBER
OF PAR TEAM

◆ **Lack of Shared Language and Vocabulary.** Family members and professional researchers, in their respective arenas, use very different vocabulary. Research terminology may be unfamiliar and distancing for families and

advocacy language and policy terminology may be unfamiliar to researchers. This may promote barriers in communication and establishing shared agendas. Further, in terms of interview protocols and surveys, family partners may encourage use of language that is not too formal or filled with research terms whereas research professionals may be concerned about being too family-friendly and supportive and not sufficiently objective.

◆ **Use of Professional Titles.**

Professional titles and degrees may be distancing, symbolizing an unequal status between researchers and family partners. Use of formal titles may impede connecting person-to-person and establishing effective research partnerships.

“It’s all of these PhD’s and MD’s and all of this stuff that is really kind of aloof and not that we don’t respect you for the work you put in for your degrees, we do. But at the same time, we’re not going to bow to you for that.”

—FAMILY RESEARCH PARTNER

“It’s almost like a class distinction...her [Family research partner] educational background and her wisdom is so strong but there are not any letters invented in our society to connote that.”

—UNIVERSITY MEMBER
OF PAR TEAM

◆ **Inertia to Change.** Partnering with family members in the research process introduces new ways of working for professional researchers. It involves more

attention to logistics and building a mutually beneficial relationship, increased resources to find and support family researchers, and increased time for the project. It requires the professional to risk sharing some of their control. While the benefits of this investment in family research partnerships may include increased relevance and easier access to families, researchers often find few institutional incentives to change the way they conduct research.

Strategies to Establish and Sustain Effective Research Partnerships

- ◆ Develop a shared vision for the partnership that will result in more meaningful use of research results. This is most effective if partnerships are established at the very beginning of a project so that the vision informs all aspects of the research.
- ◆ Allow adequate time for partnerships to form and trust to develop and secure appropriate resources to support the partnership.
- ◆ Understand the heterogeneity of families and identify family partners who bring an experience and expertise relevant to the topic of the research; try to customize family expertise with the research topic. In recruiting family partners, be clear about the expectations of their participation in the research experience and clarify how this is different from advocacy or other types of family involvement activities.

- ◆ Reach out to communities that may benefit from the research and establish a presence in those communities. Share findings with communities as a means of developing ongoing relationships; connect with family groups as resources for accessing members who may be interested in research. Understand that each community may need an individualized approach to outreach, recruitment and research participation.
- ◆ Prepare family partners for the research environment; provide an orientation to the research purpose and procedures, the timelines and the expectations. Send materials in advance, and explain paperwork and the billing procedures.
- ◆ Give careful attention to logistics: plan timelines and activities convenient to families and seek regular feedback on how things are working.
- ◆ Nurture family partners by providing one-on-one support, linking family participants, and follow up with phone calls for encouragement and clarification. If family partners do not maintain their participation, follow up to identify why.
- ◆ Recognize the diversity of expertise in family-professional research partnerships. Develop the agenda for the research jointly so that each partner feels valued and recognized for their contribution.
- ◆ Recognize the value of family input by: paying family partners

for their time and respecting individual family needs for flexibility in payment methods;

- ◆ Identify and acknowledge changes that have been implemented based on family input.
- ◆ Prepare university researchers to work collaboratively with family members who have not been trained in the research process; include learning to trust the legitimacy of the family partner's input into formal research; and addressing concerns about how a family-professional research partnership may impact the scientific rigor of the study.
- ◆ Provide products and rewards from the research in the formats most meaningful to the various partners; journal articles and conference presentations may be important to professionals, while information kits, policy briefs or family trainings may be more useful to family partners.

Successful family-university research partnerships promote the sharing of expertise, perspectives and skills. Research projects stand to benefit from the collective knowledge gleaned from diverse perspectives. Building effective research partnerships has the potential to truly change the quality (or outcomes) of research on disabilities.

"...when we put all of our expertise on the table...we have something bigger than any of us individually."

—COMMENT FROM A PARTICIPANT OF
THE NATIONAL CONFERENCE CALL

"If we don't have multiple strategies for effective collaborations between researchers and families, we really will have missed many, many important opportunities."

—UNIVERSITY RESEARCHER

References

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This brief is one in a series that covers disability research on issues related to children and youth with disabilities and special health care needs. These research briefs and other publications can be obtained directly from the Consortium for Children and Youth with Disabilities and Special Health Care Needs.

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