



The Evolution of an Unlikely Partnership Between Researchers and Culturally Diverse Families: Lessons Learned

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Historically, partnerships between large, well-established organizations in the dominant culture and smaller, newly developing, community-based efforts on behalf of un/underserved families have been beset with challenges stemming from cultural differences, varying priorities, and a lack of trust (Kritek, 1994). Kritek (1994) describes how cultural discrimination results in people attempting to negotiate at an uneven table - one to which un/underserved families and representatives of veteran organizations, such as university-based researchers, come, ostensibly with equal power but actually ; with highly disparate power. Parent-directors of community-based family support centers operate within the context of un/under-funded community settings and provide support and information to families with multiple challenges. Their efforts often go unnoticed and unrewarded. Researchers often operate within the context of well-funded university settings, and conduct research as one of their many academic requirements and expectations. Universities reward

their published research with promotions and tenure. And more often than not, and sometimes with just cause, culturally and linguistically diverse families believe that researchers come to their community, conduct their research, and then leave - all without creating any direct and immediate benefit to the families.

How then does a partnership develop between a national coalition of parent-directed community-based family support and information programs serving culturally and linguistically diverse families who have children with disabilities and a well-funded research and training center? The Grassroots Consortium on Disabilities and the Beach Center on Families and Disability at The University of Kansas were well aware of the potential pitfalls as we embarked on a mission to establish a partnership built on a foundation of an enhanced mutual understanding,

trust, respect, and equal participation in all decision making.

THE PARTNERS

The Beach Center on Families and Disability

The Beach Center is a Rehabilitation Research and Training Center (RRTC) that has been funded since 1988 by NIDRR's Rehabilitation Research and Training Center Program. All of its research, training, technical assistance, and dissemination activities focus on family and policy issues related to disability, and its major commitment has always been to conduct research and training that will make a significant and sustainable difference in the lives of families who have a member with a disability by influencing individuals with disabilities and their families, service providers, researchers, and policymakers.

The Beach Center does not provide direct service to families on a day in, day out basis but, rather, the Center tries to make a difference in the lives of families by:

This partnership will provide a model for collaboration between sophisticated, highly developed research entities and families all across the nation in the interest of improving the quality of life for all children and adults with disabilities everywhere. The promise is that participatory action research (PAR) teams composed of researchers and culturally and linguistically diverse families will discover a new relationship that broadens the scope of their commitment to research as a means of social change and contributes to a deeper understanding of the critical role research plays in finding practical solutions for families.

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- providing families with research-based information that leads to resource: and skills for meeting their needs, and the motivation to use those data, resources, and skills for their benefit
- helping to change policy and practice so that the families' context responds to their needs and efforts

The Grassroots Consortium on Disabilities

The Grassroots Consortium on Disabilities is a national coalition of community-based, parent-directed, family support and information programs serving culturally and linguistically diverse families who have children with disabilities and other special needs and who are living in traditionally underserved communities. These are communities that have become isolated due to racism, discrimination, cultural and language differences, and/or because they are located in distressed urban or remote rural areas.

The services are individualized, flexible, and comprehensive and often include assistance with meeting basic life needs related to poverty along with the disability-related needs. Each program serves and represents traditionally and historically un/underserved individuals with special needs and their families, including families who are African-American, Asian, Hispanic, Native American, and European in their racial or national background, and/or who are migrant workers.

While each of the programs is unique in how it supports families, activities that are common to all of them include outreach, informing parents about the educational and legal rights of their children with disabilities, helping

through nonjudgmental, ongoing, one-to-one technical assistance delivered by parents who reside in the home communities, and sponsoring parent leadership and community development.

If research does not include culturally diverse families, will its results be relevant to culturally diverse families? And if these families are not involved in the research activities, how will the investigators know what questions this families want answered, what products to develop, what training methods to use, and what languages to publish in?

All of the Grassroots Consortium's programs have been developed and administered by culturally diverse parents of children and adults with disabilities who operate their programs on a shoe-string budget and who strive for the greatest possible personalization and responsiveness to underserved minority families. Most of the programs have at most 2 or 3 part-time staff, and many of the programs operate out of the parent director's home with access to a single computer and one telephone/fax line. Yet, despite few tangible resources, the 14 programs have, over the past six years alone, served over 150,000 families in over 50 communities; they have received Presidential, other national, and state-regional awards; their members serve on a host of state-regional disability policy-making entities; and the families served by the Consortium's programs report high levels of satisfaction with the services.

The Beach Center on Families and Disability and the Grassroots Consortium on Disabilities - unlikely research partners? Yes. Successful research partners? Yes. Still learning about each other and our research partnership and equally committed to its continuing evolution? Most definitely! Why? Because without the personal and professional wisdom of members of the Grassroots Consortium on

Disabilities on meeting the needs of un/underserved families affected by disability issues, the research, training, and dissemination activities conducted by the Beach Center will face unnecessary difficulties in being relevant and appropriate for families represented by the Grassroots Consortium on Disabilities. And, without the professional expertise in research methodology and the national visibility of the Beach Center, the best practices for meeting the needs of un/underserved families currently being implemented by the Grassroots Consortium on Disabilities may not be awarded the credibility among the research and service delivery communities that these practices deserve. Our partnership enhances the capacity of each of our organizations to fulfill our mutual mission - to make a positive difference in the lives of individuals with disabilities and their families. Our shared mission forms the foundation of our partnership.

Our shared belief in participatory action research (PAR) and our commitment to be fully participatory as a partnership is the indispensable means through which we have been working and will continue to work. Our use of PAR has helped to ensure that

(a) the Grassroots Consortium on Disabilities programs have had opportunities to expand their skills in the use of research and its results to directly benefit the families served; and

(b) the Beach Center has increased its multicultural competence and is conducting research that is more relevant, meaningful, and immediately beneficial to underserved families.

EVOLUTION OF THE PARTNERSHIP
Initial Outreach

The Beach Center staff member who serves as its liaison to parent groups nationally has for the last 12 years

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regularly attended national conferences of parent organizations such as the Parent Training and Information Centers and Parent-to-Parent. Generally at each of these national conferences, there is at least one session on multicultural issues. Attending these sessions afforded the Beach Center liaison with opportunities to learn more about the needs of and best practices for serving culturally and linguistically diverse families. A consistent Beach Center presence at these sessions also increased our own visibility with the parent leaders directing parent support programs serving traditionally underserved families. When the program directors of multicultural parent support and information programs were able to have, for the first time, a retreat of their own, the Beach Center liaison offered to attend to (a) learn more about these multicultural parent support and information programs, their families, their best practices, and their issues and challenges; (b) continue to build relationships with the directors of these programs; and (c) to enhance their awareness of the resources of the Beach Center - those developed out of our research and those we have because we are a national resource with national visibility and many national connections. The offer was accepted.

Parent-directors of more than a dozen multicultural family support programs attended the retreat. They came eager to share resources and mutual support. The Beach Center liaison had an opportunity to learn about the many strengths of these programs and their parent leaders. The parent-directors however, were cautious about the Beach Center's presence,

and asked challenging questions and shared candid observations about the activities of federally sponsored research centers (including, the Beach Center).

- If research does not include culturally diverse families, will its results be relevant to culturally diverse families?
- Since most of the families being served by their programs are dealing with incredible poverty, health, language, and cultural issues, will a center's products be useful?
- If researchers do not involve families in their activities, will the investigators know what questions the families want answered, what products to develop, what training methods to use, and what languages to publish in?

The Beach Center response was to really listen, hear them out, recognize our own shortcomings, and pledge our interest in strengthening our own efforts and supporting theirs.

Later in the meeting, the parent-directors decided to establish themselves as the Grassroots Consortium on Disabilities - believing that as a national coalition they could be more effective than as simply directors of individual community-based programs. A group discussion about ways to enhance their fundraising and organizational capacity generated many ideas. As the ideas surfaced, the parent-directors had an opportunity to hear how the Beach Center might be able to help their ideas become reality. They began to

understand some of the relevant strengths of the Beach Center. These frank discussions were the first real stepping stones of our evolving partnership. The level of candor that framed our discussions was possible because of the ground work laid during the earlier phase of the partnership. A sufficient comfort level allowed us to go beyond the usual polite discussions that are often a part of early relationships. The parent leaders felt comfortable enough to put their cards on the table and the Beach Center liaison felt comfortable enough to understand that not all of their anger was directed at the Beach Center and to accept their honest critique.

Expanding the Partnership

Over the next year, the Beach Center continued to connect in a variety of ways with the members of the Grassroots Consortium on Disabilities to demonstrate our commitment. Through a series of quarterly mailings to each Grassroots program, we shared additional information and resources. A series of conference calls (hosted by the Beach Center) and visits by Grassroots program directors to the Beach Center (paid for by the Beach Center), allowed us to identify the challenges and possible benefits of working together. We agreed to give it a try.

Our First Joint Activity

Since the Grassroots Consortium on Disabilities was working hard to establish itself as a national presence, its program directors were particularly interested in (a) documentation of Grassroots success stories, (b) validation of Grassroots strategies, and (c) funding

Figure 1: Partnership Strengths

Beach Center Strengths	Grassroots Consortium on Disability Strengths
Knowledge about research	Knowledge about underserved families
National visibility/connections	Connections to underserved families
Rich in majority culture resources -financial, organizational, professional training	Rich in minority culture resources – cultural awareness, sensitivity, credibility with families

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Figure 2 Challenges and Benefits of the Partnership

Challenges	Benefits
Establishing trust among partners with little experience with each other	Relevant research for all families
Framing partnership to meet the needs of two very different organizations that share a common mission, but have significantly differing levels of resources available to them to carry out their activities	Methodologies are scientifically rigorous and comfortable for families
Time to get to know one another; to allow for differing paces and competing demands of the partners; for mutual education that allows for informed and democratic decision-making	Increases researchers' access to families as participants and participatory action research (PAR) team members
Funding to equalize disparate resources and to support ongoing communication among all partners	Increases families' access to research-based results and products that reach families in more meaningful ways
Designing fundable, rigorous, immediately beneficial research	Mutual learning opportunities
Minimal support for the partnership from respective systems	Enhances capacity of both partners to accomplish their similar missions

to support its efforts. The Beach Center shared its interest in enhancing its own cultural competence and for involving culturally and linguistically diverse families in all phases of its research. Given these identified needs, we agreed, as a first project, to partner on the submission of a grant to NIDRR in the area of dissemination of research to underserved families.

The process of writing this grant involved one 3-day face-to-face meeting at the Beach Center with the Beach Center funding the travel expenses of the parent-leaders; multiple conference calls, and shared responsibilities for preparation of the grant itself. While the grant was not funded, through this process we learned a great deal about each other and our working environments, and how important a shared, intense, time-sensitive activity is to strengthening a partnership. We were living our partnership and no longer just talking about it. We also learned that there were some who had reservations about our partnership - some from within university settings who feared a potential loss of scientific rigor, and some from within

culturally diverse communities who feared a loss of autonomy for the Grassroots Consortium on Disabilities. Despite these reservations, our commitment to maintain and expand our partnership grew.

Ongoing Partnership Activities

Over the last five years, we have engaged in many more joint activities - activities that have, in turn, been of primary benefit to Grassroots or to the Beach Center, but all of which have had common and mutual benefits. With each shared activity, our partnership is strengthened, and our resolve to continue to work as partners is deepened.

LESSONS LEARNED AND SUGGESTED BEST PRACTICES

1. We created opportunities for sharing family and professional stories and getting to know one another as people.
2. The mailings that went out from the Beach Center after the retreat helped to maintain the progress made at the initial retreat.

With each subsequent mailing, members of the Grassroots Consortium on Disabilities had more reason to believe that the Beach Center had not just dropped in "for a touch of color."

3. Planning specific activities to - undertake together brought to the - surface issues that might otherwise have remained submerged. These issues could then be dealt with as they arose. The early grantwriting adventure helped us to understand more clearly our respective contexts, as well as our own differing paces for addressing issues and taking action.

4. We committed ourselves to open an honest dialogue about our PAR process and its promises and pitfalls.

5. We recognized and affirmed the strengths and perspectives that each team member brings to the table, and developed roles that take full advantage of these diverse contributions.

6. We worked to understand the contexts and realities of each of the partners, and recognize that our progress as a team may be slower as a result of these realities.

7. We allowed each partner time to involve all of its members fully in discussions about our partnership so that decisions were made with full participation and information.

8. We recognized that not all activities can equally benefit both partners all the time.

9. We identified a leadership team for each organization and a single point of contact for each organization. The leadership teams hold conference calls and/or face-to-face meetings to revisit our shared vision, define critical issues, determine priorities, and outline action plans. Each leadership team shares information about these discussions with the wider membership of its organization and solicits input. Input from the

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membership may mean that additional conversations are needed between the leadership teams. As decisions are made, each leadership team is responsible for follow-up activities.

10. Having developed a basis for trust, a belief in good intentions, and a commitment to the partnership, we weathered and learned from the "Ooops" factors. We identified and corrected mistakes that were made of inexperience or misperceptions.

11. By acknowledging that our efforts to break new ground came with possible risks for each partner as well, we strengthened our relationship and underscored our commitments to each other.

12. We continually nurtured and refined our partnerships and the relationships within them. The process of partnering evolves and changes with each adventure and requires time to assure the quality of the partnership as well as its joint activities.

SUMMARY

We end with two quotes. The first is from an earlier article co-authored by members of our partnership. *"This partnership will provide a model for collaboration between sophisticated, highly developed research entities and families all across this nation in the interest of improving the quality of life for all children and adults with disabilities everywhere. The promise is that PAR teams composed of researchers and culturally and linguistically diverse families will discover a new relationship that broadens the scope of their commitment to research as a means of social change and contributes to a deeper understanding of the critical role research plays in finding practical solutions for families.* (Markey, Santelli & Turnbull, 1998).

The second quote is from Martin Luther King, Jr.: *"Cowardice asks the question, is it safe? Expedience asks the question, is it politic? But conscience asks the question, is it right? And there comes a time when one must take a position that is neither safe, nor politic, nor popular, but he and she must make it because their conscience tells them it is right."* The members of our partnership made such a decision when we committed ourselves to this collaboration. It is the right thing to do for underserved families and for researchers.

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