

Truths Converging: Empirical Support for Intuitive Understanding

Ann P. Turnbull
Jean Ann Summers
Betsy Santelli
Ursula Markey
University of Kansas

In an article about participatory action research published in 1998, one of the authors of this commentary remarked that there was no empirical documentation of the efficacy of research in which the various stakeholders are involved throughout the process of planning and conducting the study (Turnbull, Friesen, & Ramirez, 1998). Now, we are delighted to see that Faith Lamb-Parker et al. have gone a long way toward correcting this deficit. We should also congratulate the ACYF/Head Start Bureau for the creation of the community-university partnership funding initiatives, with their accompanying requirements for researchers, practitioners, and parents to develop and carry out research in partnership. These community-university partnership funding initiatives created the sufficient and appropriately similar pool of partnerships necessary for an empirical study to occur.

This survey of 60 community-university partnerships is an affirmation for those who have advocated shared decision making in the conduct of research. The creation of a strategy to measure the degree to which decision making is shared (by averaging ratings of degree of participation across five groups) is in itself a contribution to the field. But the best news is that the results of this study suggest that a high level of shared decision making is associated with a number of beneficial characteristics of effective partnerships, including a greater sense of involvement among the partners in all phases of the study, a greater sense of satisfaction with the research process, and a perception by the participants that the research was valuable to them. Participants in partnerships with high levels of shared decision making appeared to spend more time working on issues such as protecting participant rights and sensitivity to participants' culture in the 1st year, and in the 2nd year spent time on more concrete, "down to business" issues such as specific research and choice of measures and procedures. In contrast, projects with low levels of shared decision making were spending more time in their 2nd year working on problems that were impeding the progress of the project. These findings suggest that initial investment of time and effort into forging a meaningful process-always time consuming-may, in the end, be more than worth it in terms of effective and timely completion of the project.

Correspondence should be addressed to Ann P Turnbull, Beach Center on Disability, University of Kansas, 3111 Haworth Hall, Lawrence, Kansas 66045; e-mail: tumbull@ku.edu.

This is not to say that shared decision making is easy to achieve--far from it! In our own partnership experience involving the Beach Center on Disability at The University of Kansas (a university-based center focusing on research, technical assistance, and policy analysis related to disability and family issues) and the Grassroots Consortium on Disability (a national coalition of community-based, parent-directed family support and information programs serving culturally and linguistically diverse families who have children with disabilities), we learned early that good intentions were insufficient in overcoming the barriers that typically exist between the research world and families living in traditionally underserved communities (Markey, Santelli, & Turnbull, 1998; Santelli, Markey, Johnson, Turnbull, & Turnbull, 2001). Those of us at the university were not prepared for the anger built-up over decades that existed in the hearts and minds of families from underserved communities toward the "research establishment." Grassroots partners indicated that they were accustomed to researchers "dropping in for a touch of color" and then leaving to meet their own unique academic needs. They expected that a partnership with the Beach Center would be one more such disappointing experience. Yet as our partnership grew over the years, we learned about each other's worlds, and we discovered insights and innovations that would have been impossible from homogeneous vantage points. In time, we all realized the mutual benefits of the partnership--for each of us as partners and more importantly for the families as beneficiaries of our collaborative efforts. The key factor, however, that we would underscore that has made the most difference in the quality of our partnership was being upfront and "out on the table" from the outset about our visions, suspicions, fears, and hopes. As we have reflected as a group about our partnership experience, we came up with 12 lessons we have learned that we believe form the foundation for our reliable alliance. These principles, highlighted in Table 1, are clearly consistent with the findings of Lamb-Parker et al. in terms of attributes that are related to a high degree of shared decision making.

**Table 1. Lessons Learned From the Beach Center
Grassroots Consortium on Disabilities Partnership**

-
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 initial retreat helped to maintain the progress made at that 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."
-

(Table 1. continued on next page)

-
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 grant writing venture 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 and honest dialogue about our participatory action research 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 to 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 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 "Oops" factors. We identified and corrected mistakes that were made of inexperience and 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 venture and requires time to assure the quality of the partnership as well as its joint activities (Santelli et al., 2001).
-

As we noted, Lamb-Parker's study leads to the conclusion that the intensive effort required to build an effective partnership is well worth it. The next step for research about partnership formation is further study to determine whether there are lasting outcomes to the development of partnerships that are characterized by the qualities and the interim outcomes Lamb-Parker et al. describe. More longitudinal study will be needed to learn whether partnerships with shared decision making produce enhanced long-term outcomes. That is, does research reach a higher standard of rigor (measured by the quality of final reports and acceptance in peer-reviewed journals) when conducted in an atmosphere of shared decision making? Does research conducted in an atmosphere of shared decision making produce results that are more easily incorporated into practice and produce lasting change in services? And finally, the bottom line, does research conducted by meaningful partnerships produce positive results in child and family quality of life?

Some years ago, one of the authors of this commentary was involved as part of a parent-professional team delivering in-service training about family issues to a number of professional audiences. As the professional member of the training team, she would often field questions by saying, "The research says . . ." The parent member of the team would then respond, "Well, the research says that, but it's also true." The lesson this researcher carried away from that partnership is that "truth" means different things to different people. For researchers and policy makers, "truth" may mean empirically derived and tested results. For practitioners, "truth" may be visible evidence in the form of change and growth when a given practice is used. For parents, "truth" may be a sense of resonance or a "ringing true" with the experience of everyday life. Perhaps, for "truth" to be accepted and utilized to improve lives of children and families, it must be all of these things. As we reflect on our own research partnership, we believe this "triple truth" is in the process of coming to fruition. We are delighted to finally have evidence that what is "truth" according to our practice and our life, experiences is also "true" according to research.

REFERENCES

- Markey, U., Santelli, B., & Turnbull, A. P. (1998). Participatory action research involving families from underserved communities and researchers: Respecting cultural and linguistic diversity. In B. A. Ford (Ed.), *Compendium: Writings on effective practice for culturally and linguistically diverse exceptional learners*. Reston, VA: Council for Exceptional Children, Division for Culturally and Linguistically Diverse Exceptional Learners.
- Santelli, B., Markey, U., Johnson, A., Turnbull, R., & Turnbull, A. (2001). The evolution of an unlikely partnership between researchers and culturally diverse families: Lessons learned. *TASH Newsletter*, March/April.
- Turnbull, A. P., Friesen, B. J., & Ramirez, C. (1998). Participatory action research as a model of conducting family research. *Journal of The Association for Persons with Severe Handicaps*, 23(3), 178-188.