

Research Highlights

Topic: Participatory Action Research (PAR)

Santelli, B., Markey, U., Johnson, A., Turnbull, R., & Turnbull, A. (2001, March/April). The evolution of an unlikely partnership between researcher and culturally diverse families: Lessons learned. *TASH Newsletter*, 21-25.

BOTTOM LINE

The foundation of the PAR partnership between research partners from university and community settings is to fulfill their shared mission: to make a positive difference in the lives of individuals with disabilities and their families. Participatory action research (PAR) teams composed of researchers and culturally and linguistically diverse families from traditionally underserved communities typically yield both benefits and challenges when they engage in joint research, but PAR is mutually beneficial when it is built on mutual trust, understanding, and respect, and when it incorporates equal participation in all decision making. Lessons learned from the PAR partnership between the Beach Center on Disability and the Grassroots Consortium on Disabilities have led to a shared commitment and the development of best practices and are the focus of this article.

TIPS

- Forge new alliances by initiating and sustaining joint partnership activities that are meaningful for everyone with an active role in the PAR process.
- Seek to build mutual trust, understanding, and respect among the PAR partners, since they may have little prior shared history and experience with one another.
- Be sensitive to time factors. Allow time to get acquainted, time for different culturally dictated concepts of pace, time to accommodate competing demands of the PAR partners, and time for mutual education.
- Be sensitive to financial factors. Support fiscally disadvantaged participants by compensating them directly for their time and/or offering support for their programs (grant writing, and use of staff or resources).

TIPS
cont.

- Design research to be relevant, beneficial, and fundable, using methodologies that are both scientifically sound and comfortable for families.
- Provide opportunities for mutual learning, honest dialog, and ongoing partnership activities.
- Recognize the strengths each of the parties bring to the collaborative effort.

KEY FINDINGS

- Lessons learned and suggested best practices include
 - ◆ getting to know one another, following up, and planning shared activities help to establish and sustain viable and sustainable partnerships.
 - ◆ seeking an open dialog about the PAR process, thereby helping to establish predictability, trust, and mutually realistic expectations.
 - ◆ acknowledging that not all activities benefit partners equally all the time.
 - ◆ recognizing the strengths, perspectives, and diverse contributions of each PAR team member.
 - ◆ recognizing that the PAR partnership may slow the research process, but give partners the time needed to fully involve their members in the discussions.
 - ◆ understanding the contexts and realities of all PAR partners and how these impact the participation of community groups.
 - ◆ making leadership teams on both sides responsible for organization-wide communication and follow-up activities.
 - ◆ identifying and correcting of mistakes born of inexperience or misperceptions.
- PAR relationships are strengthened when the risks of being involved in ground-breaking research are recognized by all and underscore mutual commitments.
- Change and continued nurturing and support are steady ingredients in a quality PAR partnership.
- Establish the PAR partnership on a foundation of mutual trust, understanding, and respect through candid, open, give-and-take discussions among the parties.
- Institute equal participation in all decision making relative to a particular research study.
- Recognize the respective strengths of the PAR participants.

KEY FINDINGS
cont.

- Try to level the playing field through deliberate actions to overcome barriers which may prevent full participation by some participants.
- Provide opportunities for mutual learning and for developing positive relationships among all research participants.

RELATED
PUBLICATIONS

Markey, U.A. (2000). PARTnerships. *Journal of Positive Behavior Interventions*, 2(3), 188-189, 192.

Santelli, B., Ginsberg, C., Sullivan, S., & Niederhouser, C. (2002) A collaborative study of Parent to Parent support: Implications for positive behavioral support. In J. Lucyshyn, G. Dunlap, & R. W. Albin (Eds.), *Families and positive behavioral supports: Addressing the challenge of problem behaviors on family contexts* (pp. 439-456). Baltimore, MD: Paul H. Brookes.

Santelli, B., Singer, G.H.S., DiVenere, N., Ginsberg, C., & Powers, L. (1998). Participatory action research: Reflections on critical incidents in a PAR project. *Journal of the Association for Persons with Severe Handicaps*, 23(3), 211-222.

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