

Research Highlights

Topic: Parent to Parent

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

BOTTOM LINE

This article describes how a participatory action research (PAR) team comprised of parent leaders of Parent to Parent programs and researchers worked collaboratively to design, implement, and disseminate efficacy research on Parent to Parent programs. The participants in the PAR process identified key elements of their success as having a shared vision, having a sufficient number of parents and researchers to ensure that voices were heard and roles clearly defined, trusting the legitimacy of parents' input, compensating all team members for their efforts, and encouraging all team members to take on the role of expert and to share their expertise.

TIPS

- Established a shared vision to reduce differing perspectives that sometimes exist between families and researchers.
- Include approximately the same numbers of parents and researchers on the PAR team and clearly defined roles.
- Value the expertise that each person brings with researchers knowing about methodology and parents knowing about key concerns for families, ways to approach families in research, and ways to help ensure that families benefit from the research.
- Compensate all team members in equal ways.
- Allow more time for decision-making given the collaborative nature of the process.

TIPS
cont.

- Recognize that additional funding is needed for planning meetings, conference calls, and ongoing communication.
- Provide opportunities for all team members to share in publications and presentations.

HIGHLIGHTS

- Parent to Parent leaders and researchers formed a collaborative team to develop research that would investigate the efficacy of Parent to Parent support.
 - ◆ Based on extensive discussions, the PAR team defined the goals of the project and the anticipated outcomes of Parent to Parent.
 - ◆ They developed questions collaboratively based on the goals and anticipated outcomes.
 - ◆ The team struggled to find a balance between the necessary rigor of a control group study and the necessity and urgency of meeting parents' needs. They reached a compromise that there would be a wait list group that would only need to wait for two months before being matched, and if any parents encountered an urgent need they could receive help and be dropped from the study. They considered eight weeks the minimum amount of time for Parent to Parent support to make a meaningful difference to the people who received it.
 - ◆ The team reviewed standard research measures, noted shortcomings especially from the perspectives of parents on the team, and decided on measures that were the most appropriate.
 - ◆ The team prepared a joint grant proposal which was submitted to a federal agency and funded.
 - ◆ The team collaborated to determine the specific procedures for recruiting parents, developing and distributing measures, managing data collection, and analyzing data.
 - ◆ The team worked together to identify key findings, plan presentations, write papers, and thoroughly disseminate research findings.
- The team identified the following key elements that contribute to the success of their PAR collaboration:
 - ◆ Establish a shared vision to reduce differing perspectives that sometimes exist between families and researchers.

HIGHLIGHTS

cont.

- ◆ Recognize that there is safety in numbers and clearly define roles.
- ◆ Trust the legitimacy of consumers' input into formal research.
- ◆ Compensate all team members and recognize, correct, and learn from the "Oops Factor".
- ◆ Encourage all PAR team members to take on the role of expert by sharing their own expertise, perspectives, and skills.
- Some of the challenges associated with the PAR process identified by team members include:
 - ◆ Given the nature of group decision-making, PAR projects take more time than those done in isolation.
 - ◆ Additional funding is needed for extra planning meetings and conference calls necessary for collaborative communication.
 - ◆ All PAR team members need to share in the rewards of research associated with presentations and papers.
 - ◆ PAR efforts need to be available in a variety of formats to reach diverse audiences.
 - ◆ PAR efforts need to be comprehensively documented and validated.

RELATED PUBLICATIONS

- Turnbull, A.P., Friesen, B.J., & Ramirez, C. (1998). Participatory action research as a model for conducting family research. *The Journal of The Association for Persons with Severe Handicaps*, 23(3), 178-188.
- Meyer, L.H., Park, H.S., Grenot-Scheyer, M., Schwartz, I., & Harry, B. (1998). Participatory research: New approaches to the research to practice dilemma. *The Journal of The Association for Persons with Severe Handicaps*, 23(3), 165-177
- Santelli, B., Ginsberg, C., Sullivan, S., & Niederhauser, C. (2002). A collaborative study of parent to parent programs: Implications for positive behavior support. In J.M. Lucyshyn, G. Dunlap, & R.W. Albin (Eds.), *Families & positive behavior support: Addressing problem behavior in family contexts*. Baltimore: Paul H. Brookes.

RELATED
PUBLICATIONS
cont.

Lamb-Parker, F., Greenfield, D.B., Fantuzzo, J.W., Clark, C., & Coolahan, K.C. (2002). Shared decision making in early childhood research: A foundation for successful community-university partnerships. In F. Lamb-Parker & C.G. Powell (Eds.), *NHSA Dialog: A Research-to-Practice Journal for the Early Intervention Field*, 5(2 & 3), 356-377.

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