



## DATA TRENDS: #3

Summaries of research on mental health services for children and adolescents and their families



### Families as Researchers and Evaluators

Source: Carpenter, B. (1997). Empowering parents: The use of the parent as researcher paradigm in early intervention. *Journal of Child and Family Studies*, 6(4), 391-398.

Federation of Families for Children's Mental Health. (July, 1999). The world of evaluation: How to make it yours. Unpublished training manual. Alexandria, VA: Federation of Families for Children's Mental Health, 1021 Prince St., 22314-2971.

Turnbull, A.P., Friesen, B.J., Ramirez, C. (1998). Participatory action research as a model for conducting family research. *Journal of the Association for Persons with Severe Handicaps*, 23(3), 178-188.

Empowering caregivers of children with emotional and behavioral disorders to participate in the entire process of services is a challenging task. There have been several interventions attempting to increase caregiver involvement, but these interventions usually define the caregiver's role as an "advisor" to the "professionals" who make the ultimate decisions. Several researchers are now calling to increase caregivers' roles in the entire process of service provision, including evaluation and research. Barry Carpenter (1997) argues that an over-reliance on professionals disempowers parents, causing families and professionals to view each other with distrust, disrespect, and blame. Adding parent voices empowers the caregiver to shift the focus of research to more fully encompass the day-to-day experience of caregiving—for instance, research on caregiver stress now includes a focus on positive aspects such as coping and enrichment (see Data Trends, PSU #2).

Turnbull, et al. (1998) call for complete inclusion of parents in the research process. Using the Participatory Action Research (PAR) model, they outline six levels of families' participation in research. Moving from least to most involvement, these are:

- *Level 1:* Families as research participants
- *Level 2:* Families as advisory board members
- *Level 3:* Families as occasional reviewers and consultants
- *Level 4:* Researchers as leaders and families as ongoing advisors
- *Level 5:* Researchers and families as co-researchers
- *Level 6:* Families as research leaders and researchers as ongoing advisors

They outline five advantages of families as researchers: 1) Increased relevance of research; 2) Increased rigor of research; 3) Increased benefit to researchers in minimizing logistical problems; 4) Increased utilization of research by families; 5) Enhanced empowerment of researchers, families, and other stakeholders. However, they describe five challenges of families as researchers: 1) Increased time in planning and conducting research; 2) Researchers feeling criticized by parents; 3) Increased funding required to cover PAR costs; 4) The lack of family homogeneity; and 5) Increased need to change institutional rules. These challenges are being met by incorporating training for families as researchers. For example, the Federation of Families for Children's Mental Health is currently providing a three-day training on the "world of evaluation," specifically created to introduce evaluation methods to family members of children with mental health issues. This work will help the role of families as researchers and evaluators continue to expand and evolve.

---

Prepared by the Research and Training Center for Family Support and Children's Mental Health, Portland State University, 1912 SW 6<sup>th</sup>, Rm. 120, Portland, OR 97201, (503) 725-4040 in collaboration with the Research and Training Center for Children's Mental Health, University of South Florida. Contact [frieseb@rri.pdx.edu](mailto:frieseb@rri.pdx.edu), or [www.rtc.pdx.edu](http://www.rtc.pdx.edu).

Funds to support this activity come from the Child, Adolescent and Family Branch, Federal Center for Mental Health Services, Substance Abuse Mental Health Services Administration