

Families as evaluators: Annotated bibliography of resources in print

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Research and Training Center on Family
Support and Children's Mental Health



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Federation of Families
For Children's Mental Health

**FAMILIES AS EVALUATORS:
ANNOTATED BIBLIOGRAPHY OF RESOURCES IN PRINT**

References specifically about Family Participation in Research and Evaluation

Friesen, B.J. & Stephens, B. (1998). Expanding family roles in the system of care: Research and practice. In M.H.Epstein, K. Kutash, & A. Duchnowski (Eds). *Outcomes for children and youth with behavioral and emotional disorders and their families: Programs and evaluation best practices* (pp. 231-259). Austin, TX: Pro-Ed, Inc.

This chapter provides an overview of the multiple roles of the family members of children with serious emotional disorders in systems of care and the implications of these roles for children's mental health research. Of particular interest is the section on family members as evaluators and researchers which identifies roles for family members in research and provides examples of their participation. While recognizing the challenges of including family members in research and evaluation, the authors conclude that this is an important part of expanding family participation with view to improving services for children and families.

Gawron, T., McCormack, M., & McKelvey, J. (1999). Evaluation: The measure of all things. In National Resource Network for Child and Family Mental Health Services at the Washington Business Group on Health (Ed.). *A compilation of lessons learned from the 22 grantees of the 1997 Comprehensive Community Mental Health Services for Children and their Families Program* (pp.37-43). Washington, DC: Center for Effective Collaboration and Practice, American Institutes for Research.

This short article describes the development of the evaluation of the Community Wraparound Initiative in Illinois, a system of care grant community funded by the Comprehensive Community-based Mental Health Services for Children and their Families Program of the Center for Mental Health Services. The description includes detailed information about steps taken to ensure data integrity, engage stakeholders, return findings to participants, and promote the sustainability of the Initiative. As a case study, the report provides a concrete example of the activities needed to assure an environment of continual learning on evaluation teams.

Koroloff, N.M. & Friesen, B.J. (1997). Challenges in conducting family-centered mental health services research. *Journal of Emotional and Behavioral Disorders*, 5(3), 130-137

The authors of this article note that mental health research is responding to changes in thinking about service delivery resulting from a family-centered service system. They compare family-centered services and traditional mental health research in the light of their orientations to values, success and failure, family, prior research, outcomes, intervention, self-report, and advocacy. Recommendations for the kinds of questions to be addressed in family-centered mental health services research are included. The article provides a useful analysis of the challenges facing researchers as they attempt to

incorporate ideas guiding family-centered services into research that is being conducted to improve services for children with serious emotional disorders and their families.

Markey, U., Santelli, B., & Turnbull, A.P. (1998). Participatory action research involving families from underserved communities and researchers: Respecting cultural and linguistic diversity. In Council for Exceptional Children (ed.). *Compendium: Writings on effective practice for culturally and linguistically diverse exceptional learners*, pp. 20-32. Reston, VA: Council for Exceptional Children, Division for Culturally and Linguistically Diverse Exceptional Learners.

Following a discussion of the history of harms done in the name of research in traditionally underserved communities, this article discusses the importance of participatory action research (PAR) to answer questions of concern to people in these communities. The authors discuss the challenges facing researchers and people who have been underserved because of cultural and linguistic differences who are attempting to work together. An example of a collaborative partnership between the Grassroots Consortium on Disabilities and the Beach Center on Families and Disability and the challenges facing the partners is presented. In their conclusion, the authors review the benefits of PAR for families in underserved communities and for researchers. This article draws attention to the prior history of distrust between members of culturally and linguistically diverse communities and researchers and gives explicit attention to strategies to build trust in the interests of producing meaningful research.

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

The author, an African American parent who directs a parent resource center for families of children with disabilities, describes a training and participatory action research (PAR) project conducted in partnership with a university-based research center (the Beach Center at the University of Kansas). The project team looked to the community, a traditionally underserved ethnically and racially diverse community, to shape the context of the study. The purpose of the PAR study was to examine the relationships between disability policies, partnerships between families and providers, partnerships among providers, and quality of life for families with a member who has a disability. The article describes the benefits of participating in a PAR study for all parties. Family participants received information about research-based best practices, while researchers learned about the effects of social and economic conditions on the integrity of research findings, and providers modified services based on the new information resulting from the project.

Osher, T.W. & Telesford, M. (1996). Involving families to improve research. In K. Hoagwood, P.S. Jensen, & C.B. Fisher (Eds.). *Ethical issues in mental health research with children and adolescents* (pp. 33-36). Mahwah, NJ: Lawrence Erlbaum.

This chapter discusses ethical issues in children's mental health research from families' perspective. The authors present a rationale for family participation in research and describe several possible roles for family members: as participants, advocates, research associates, consultants, and advisors. Written primarily for researchers, this chapter

presents persuasive arguments for family involvement in research and some useful strategies for assuring “family-friendly” research.

Osher, T., van Kammen, W., & Zaro, S.M. (2001). Family participation in evaluating systems of care: Family, research, and service system perspectives. *Journal of Emotional and Behavioral Disorders*, 9(1) 63-70.

Family participation in the evaluation of systems of care in grantee communities is required by the Comprehensive Community-Based Services for Children and their Families Program of the Center for Mental Health Services. This article reports on findings of a study of the extent to which families were involved in evaluation activities at system of care communities. Participants in the study reported on the activities on evaluation teams and the benefits of family participation. The results suggest several avenues for integrating family members into the evaluation of services for children and families.

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

In this article, participatory action research (PAR) is presented as a collaborative process among researchers and stakeholders throughout the entire sequence of research activities. PAR is a research approach that combines community participation, research, and action to support local insights to resolve community issues. The authors examine the potential advantages of PAR and the challenges that need to be addressed. They propose a model of PAR implementation levels consistent with the National Institute of Disability and Rehabilitation Research (NIDRR)’s model of collaborative research. In this model, family members play key roles in all stages of research, including leadership roles. Implementation and logistical issues are addressed and potentially effective strategies are presented. This article is recommended as essential reading for all stakeholders considering using participatory approaches in community-based research.

Vander Stoep, A., Williams, M., Jones, R., Green, L., & Trupin, E. (1999). Families as full research partners: What’s in it for us? *Journal of Behavioral Health Services and Research*, 16, 329-344.

Reporting on an innovative family-initiated evaluation of children’s mental health services, this article examines the tensions between the traditional requirements of scientific rigor and the expectations of community stakeholders in the research process. Steps in a collaborative research process in Washington state are described in detail. The role of parent evaluator is addressed and there is a discussion of the benefits of family participation in research. The article concludes with a review of lessons learned in the process and offers a set of “Principles of Community-based Research” approved at the University of Washington.

Woodbridge, M.W. & Huang, L.N. (2000). Using evaluation data to manage, improve, market, and sustain children’s services. *Systems of Care: Promising Practices in Children’s Mental Health, 2000 Series, Volume II*. Washington, DC: Center for Effective Collaboration and Practice, American Institutes for Research.

This report is one of a series of Promising Practices monographs based on research at system of care grant communities funded by the Center for Mental Health Services as part of the Comprehensive Community Mental Health Services for Children and Their Families Program. This volume describes a descriptive study of promising practices in the use of evaluation data at these grant communities. The report describes techniques used to develop an “evaluation culture” and gain buy-in from multiple stakeholders, including involving family members in the development, dissemination, and interpretation findings.

In addition to being available in print, this monograph may be downloaded at www.cecp.air.org/promisingpractices/200monographs/vol2.htm

General References about Community/Consumer Participation in Research and Evaluation

Balcazar, F.E., Keys, C.B., Kaplan, D.L., & Suarez-Balcazar, Y. (1998). Participatory action research and people with disabilities: Principles and challenges. *Canadian Journal of Rehabilitation Readaptation*, 12, 1-11.

This article describes the use of Participatory Action Research (PAR) as a strategy for people with disabilities to take active roles in designing and conducting research. The authors discuss the benefits of participatory research for all participants and the resulting improvements in the quality of the research process and research findings. The challenges of conducting participatory research are also examined and the authors provide examples of their experiences using participatory approaches. While the focus of this article is on adults with disabilities participating in research, many of the issues the authors address are parallel to those affecting family members and evaluators working together.

Fetterman, D. (2001). *Foundations of empowerment evaluation*. Thousand Oaks, CA: Sage Publications.

In this book, David Fetterman, the leading exponent of empowerment evaluation, presents a comprehensive overview of this approach. Empowerment evaluation is described as a participatory approach in which the external evaluator trains and coaches stakeholders to become actively involved in developing their own evaluation plan and conducting their own evaluations. The goal is for evaluation to become an integral part of ongoing program change and improvement. To engage in empowerment evaluation, it is assumed that the evaluator possesses the skills needed to engage stakeholders in evaluation in addition to working with a program that has a democratic work culture. This clearly written book provides a detailed outline of the concrete activities of empowerment evaluation: mission building, taking stock, and charting a future course. The use of examples brings empowerment concepts to life.

Greene, J.C. (1997). Evaluation as advocacy. *Evaluation Practice*, 18, 25-35.

The premise of this article is that advocacy is part of all evaluation, given that evaluations are guided by questions formulated by specific interested parties, usually policy makers, program administrators, staff, or consumers of services. Using three short case examples the author illustrates her position that an explicit stance of advocacy enhances fair judgments in evaluation. She recommends a framework of democratic pluralism to ensure

that the least franchised groups (usually program participants, their families, and surrounding communities) gain an equitable presence and voice in evaluation. The article provides a useful review of the range of evaluator positions on objectivity in evaluation, from a total commitment to complete objectivity to a respect for multiple perspectives shaped by people's social and cultural experiences and contexts.

Patton, M. (1997). *Utilization-focused evaluation: The new century text, third edition*. Thousand Oaks, CA: Sage Publications.

This comprehensive overview of utilization-focused evaluation is an update of Michael Patton's book, which was originally published in 1978. The utilization-oriented approach is focused on the use of evaluation by intended users. The book describes in detail the activities evaluators need to engage in from beginning to end to assure that evaluations are used to bring about change. Illustrated by many examples, the text addresses the realities and practicalities of utilization-oriented evaluation. It includes useful tables and flow charts to guide evaluation activities.

Schnoes, C.J. (2000). Empowerment evaluation applied: Experiences, analysis, and recommendations from a case study. *American Journal of Evaluation, 21*, 1-14. A case study of three Comprehensive Communities initiatives illustrates the application of the empowerment evaluation approach. In this article, issues related to the evaluator's role, stakeholder involvement, contextual variables, and the empowerment of participants through the evaluation process are addressed. Based on their experiences in this project, the authors conclude with recommendations regarding the circumstances expected to support the empowerment evaluation approach.

Secret, M., Jordan, A., & Ford, J. (1999). Empowerment evaluation as a social work strategy. *Social Work, 24*, 120-128.

This article reviews the principles of empowerment evaluation and presents a case study of the use of empowerment evaluation in a street outreach HIV-prevention program. The difficulty in maintaining the distinction and balance of program implementation and program evaluation is examined. The conclusion highlights the benefits and risks of using an empowerment approach to evaluation and provides a succinct overview of opposing arguments presented in the evaluation literature.

Sobeck, J.L., Chapleski, E.E., Fisher, C. (2003). Conducting research with American Indians: A case study of motives, methods, and results. *Journal of Ethnic and Cultural Diversity in Social Work, 12*(1), 69-84.

This article offers valuable advice to researchers engaged in research and evaluation with American Indian communities. The authors report on their experiences doing four research projects with American Indian communities and the lessons learned. After reviewing the historical reasons for American Indians to distrust researchers from outside their communities, the article describes legal, ethical, political and methodological shifts to Native communities gaining control over research. Research practices such as including Native people in the research team and viewing all team members as experts, determining research priorities with the local community, developing questions suited to

the local context, seeking review of questions for sensitivity, training community participants to collect data, and providing frequent reports of findings to participants resulted in successful research projects. The article concludes with a set of recommended strategies for conducting culturally competent research with American Indians.

Sohng, S.L. (1992). Consumers as research partners. *Journal of Progressive Human Services*, 3, 1-14.

Illustrated by two examples of participatory research, this article makes a case for an empowerment approach to consumer involvement in research. The author identifies strategies used to facilitate consumer participation and empowerment in each of the projects described in the article. Examples of strategies include frequent and clear communication, strength-oriented role and task assignment, consensus-building, training participants in research skills, redefining the problem in the local social context, and developing a network of support. The article concludes with a discussion of the challenges to implementing participatory research and the advantages as consumers become involved in determining the direction of future research inquiry.

Wallerstein, N. (1999). Power between evaluator and community: Research relationships within New Mexico's healthier communities. *Social Science and Medicine*, 49, 39-53.

As an examination of the participatory evaluation process of the Healthier Communities initiative in New Mexico, this article focuses on the contested power dynamics of the research relationship. The author provides a detailed description of the process of conducting this participatory evaluation. Her analysis demonstrates the "potential pitfalls, conflicts and pain" associated with community-based research led by a university-based researcher. By drawing on the lessons learned in this study, evaluators will be prepared to anticipate some of the challenges of participatory evaluation.