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## Family Participation in Evaluation: How to Make it Work

In recent years, the use of participatory approaches in research and evaluation has gained momentum. Participatory approaches are believed to lead to studies that are more relevant to the needs of families. Ultimately, a goal of participatory approaches is to produce findings that will be used to improve services for families (Osher, van Kammen, & Zaro, 2001). The National Institute on Disability and Rehabilitation Research (NIDRR) has adopted a list of advantages of participatory action research, formulated by Turnbull, Friesen, and Ramirez (1998):

1. Increased relevance of research to the concerns of family members;
2. Increased rigor of research;
3. Increased benefit to researchers in minimizing logistical problems;
4. Increased utilization of research by families; and
5. Enhanced empowerment of researchers, families and other stakeholders (p.178).

Family involvement in children's mental health research and evaluation has received support from a variety of government agencies. NIDRR now encourages grantees to use participatory action research to involve families and consumers. Since 1993, system of care projects funded by the Center for Mental Health Services' Comprehensive Community Mental Health Services for Children and Their Families Program have been required to involve family members as participants in the evaluation of the projects. In addition, the Surgeon General's Report on Mental Health (U.S. Department of Health and Human Services, 1999), the National Action Agenda on Children's Mental Health (U.S. Department of Health and Human Services, 2001) and the President's

National New Freedom Commission on Mental Health (New Freedom Commission on Mental Health Subcommittee on Consumer Issues, 2003) have promoted family and consumer involvement in the research and evaluation of children's mental health services.

These developments have presented family members with opportunities to work on teams that are evaluating the services their children are receiving. Evaluation teams at system of care grant communities around the country employ family members on their teams in different capacities. Involving family members on evaluation teams has led to the development of new family-evaluator partnerships in systems of care, requiring evaluators to collaborate with family members in all aspects of the evaluation of services. Team members have reported a number of benefits of involving family members on evaluation and research teams. For example, system of care team members have reported that family members are more likely to gain the trust of research participants and to get accurate information from them (Osher & Telesford, 1996). In addition, family members have assisted in the design of user-friendly formats for findings, which facilitate the dissemination of results to wider audiences, especially other family members (Vander Stoep, Williams, Jones, Green, & Trupin, 1999).

In addition to these benefits, there are also challenges to family participation in evaluation teams. While more evaluators are now beginning to work with family members on evaluation teams, few have prior experience working with these family members in this capacity. Many evaluators have been traditionally trained to maintain control of the research process and distance themselves from the "subjects," those who are being researched (Sohng, 1992). However, in these family-evaluator teams, evaluators interact with family members as partners in the evaluation process. Without adequate training, the participatory approach can present challenges to evaluators. There are also challenges related to the lack of organizational supports for family participation in evaluation teams.

This presentation discussed findings from a qualitative study of evaluators' perspectives on collaboration with family members on evaluation teams. The purpose of the study was to gain understanding of the challenges facing evaluators and family evaluators working together and to identify effective strategies for building collaborative relationships in evaluation teams. Our presentation reported on evaluators' descriptions of challenges to collaboration and the strategies they reported using to address them. A family member employed by Clark County, Washington's system of care evaluation team described examples of the barriers the team has faced and the strategies they used to address them.

## **METHOD AND SAMPLE**

To find out evaluators' perspectives about working with family members on evaluation teams, we developed a qualitative survey. Open-ended questions were designed to provide understanding of the challenges facing evaluators and family members working together and effective strategies for collaboration. We identified evaluators through nominations by key informants and snowball sampling and conducted telephone or face-to-face interviews with them.

We asked evaluators questions about the roles that family evaluators have played on their evaluation teams, their training to work with family evaluators, the challenges they have faced, and the strategies they have used to overcome these challenges. The interviews were audio-taped, transcribed, and analyzed qualitatively using a grounded theory approach (Glaser & Strauss, 1967). Members of the team developed a coding scheme and independently coded the data, compared the coded sections of the interviews and negotiated the categorization of the data. The data was categorized according to themes, these themes were synthesized, and examples were identified to illustrate the themes.

Results are based on interviews with 20 evaluators from different parts of the U.S., most of whom were involved in the evaluations of systems of care funded by the Center for Mental Health Services'

Comprehensive Community Mental Health Services for Children and Their Families Program. Fourteen evaluators reported that they had Ph.D.'s, two were Ph.D. candidates, and four held Masters degrees. Sixteen were female and four were male, with a mean age of 41.4 ( $SD = 11.2$ , range 28-66). These evaluators reported working in the field of children's mental health for an average of 13.8 years ( $SD = 7.4$ , range 3-30) and 70 percent said they had some level of experience as a family member of a person with mental health needs or a consumer of mental health services.

## RESULTS

Evaluators were asked how well their training had prepared them for collaboration with family members. Fifty-five percent of the evaluators reported that were trained to maintain distance from research participants. Most evaluators reported that partnering with stakeholders on research and evaluation teams was not discussed in their academic training. In response to a question about how they learned to work with family members, 70 percent of the evaluators reported that they learned by doing the work. One evaluator said that what helped her to do the work was, "learning by doing...learning from others around here who are trying a lot of the same things."

Family members were described as being involved in a variety of evaluation activities, including:

- helping with the development of projects,
- developing instruments/surveys,
- collecting data,
- training other family evaluators,
- participating in the decision making,
- assisting with analysis of data,
- assisting with the interpretation of results
- presenting data, and
- helping with dissemination of results.

In response to a question about challenges in their work with family evaluators, evaluators described

several difficulties. The primary challenges described were recruitment and hiring difficulties; payment of adequate salaries; concerns about the impact of family members on research rigor; stakeholders' lack of appreciation for family evaluators' roles; and the tension between advocacy and research. Respondents also discussed the strategies developed to address these challenges. Examples of the challenges and some of the strategies used to address them are summarized below.

### Difficulty recruiting and hiring family members without relevant academic training

Some evaluators reported that it was difficult to hire family evaluators who did not have a degree due to hiring policies based on academic qualifications. Strategies that evaluators reported using were creating a job classification specifically for family members and hiring family members as consultants. The Clark County family evaluator reported that the team initially addressed this problem by hiring a family member as a consultant through a contract with a family support organization. This organization did not have to adhere to the restrictive policies regarding hiring and pay that constrained the university-based research team. Subsequently, she was paid via a personal services contract with the university. Later, when she had gained experience on the job, she was hired as a university-based research assistant.

### Paying family members adequate salaries

Several evaluators mentioned their inability to pay family evaluators salaries that were appropriate to the complexity of the work. As one evaluator commented, "We say on one hand that we value families as much as the work of professionals, but we never pay them as much... it's hard to pay them what they are worth." To address this challenge, evaluators reported developing contracts to pay family evaluators based on their skills and expertise, rather than based on academic qualifications. One evaluator reported that she had worked to get the family evaluators a pay increase based on their skills and expertise rather than degrees.

*Concerns about the effects of family evaluators on the rigor of the research.* Some evaluators reported stakeholders' concerns about the impact of family members with personal experience of receiving mental health services on the rigor of the research. They described community partners' fears that family participation on the evaluation team would compromise the quality of the research. A few respondents mentioned their initial fears that it would be difficult for family evaluators to maintain objectivity. In response, a number of evaluators commented that they had learned that obtaining objectivity is not really possible. One evaluator said, "I think that I was a little less flexible about [objectivity] than I am now, realizing that sometimes that fuzziness of boundaries actually benefits us researchers in a lot of ways." The Clark County family evaluator said that it had been necessary to continually emphasize the benefits of having family members on the research team to community stakeholders, while also encouraging objectivity. Evaluators reported that research rigor can be maintained through frequent open discussions in team meetings, training, sporadic supervision of interviews, and thorough verification of data. They suggested that these activities are especially important in the early stages of research.

### **Community stakeholders' lack of appreciation for family evaluators' roles**

Several respondents reported that community stakeholders, especially service providers, did not value the family member role on evaluation teams. Evaluators talked about the challenge of gaining respect for the family members as real members of the evaluation team. In some cases, respondents informed us that family members gained respect over time by demonstrating that they could do high quality work. Some evaluators reported educating stakeholders about the valuable contributions of family evaluators. One evaluator described helping community stakeholders to appreciate family members' roles by demonstrating that family participation improved the retention of participants and quality of findings. The Clark County family evaluator described the team's efforts to gain respect

for her role, including "professionalizing" the family evaluator role, mutual education, and naming everyone on the team as team members, regardless of status. She reported that the team demonstrated the importance of family members as core members of the evaluation team by ensuring that they attend meetings, participate in presentations, and are involved in interpretation of findings and writing reports.

### **Tension between advocacy and research rigor**

Several evaluators mentioned challenges related to family evaluators' desire to use preliminary data for advocacy. One respondent reported that a family evaluator became frustrated at seeing the data but not being able to use it. She said that she had talked with this family member to help her to accept the slower pace of change with research. Evaluators said that open communication about the tension between research and advocacy was helpful in dealing with this challenge. For example, one evaluator stated, "The other thing, I think, is the ability to negotiate things, like the advocacy and research issue. The willingness, we realize that we have to talk about this and we have to hash it out."

### **CONCLUSION**

According to participants in this study, family members play a variety of roles on evaluation teams at systems of care around the nation. Most respondents of this study reported that they had not received training on how to work with family members. Evaluators reported encountering a number of challenges in their work with family evaluators and they described strategies to overcome them. Next steps in the research agenda are to expand our understanding by exploring family evaluators' perspectives. We will examine evaluators' training needs related to collaboration and develop training materials to improve family-evaluator collaboration.

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