

# Challenges in Conducting Family-Centered Mental Health Services Research

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*In this article, the authors provide an analysis of the challenges facing researchers as they respond to the ideas that guide family-centered services and incorporate these themes into research focused on improving services for children with emotional, behavioral, or mental disorders and their families. The concept of "family-centered services" has emerged only recently as a generally well understood set of practice principles. Traditional approaches to conducting mental health research have not yet responded to the fundamental changes in thinking about service delivery evoked by a family-centered service system. The authors examine the fit between traditional mental health research and family-centered services and provide an introduction to the articles in this special issue.*

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Changes in both philosophy and service delivery patterns associated with a "system of care" approach (Stroul & Friedman, 1986) to services for children with emotional, behavioral, and mental disorders and their families have accentuated the gap between the demands of traditional mental health research and the realities of service delivery. For example, traditional mental health research focuses on group performance, whereas a system of care model emphasizes individualization that involves levels of service flexibility, responsiveness, and dynamism that often fit very poorly with traditional research designs. Other important challenges are posed by system of care principles such as comprehensiveness, service coordination, and cultural competence. The fit between another core system of care principle, family-centered services, and research is the focus of this article.

Nearly 10 years ago the Association for the Care of Children's Health convened a panel of experts to identify and discuss key issues in family-centered research across a variety of health, mental health, and disability fields (McGonigel, 1988). The panel considered two key questions:

Can the same family-centered principles that guide intervention or treatment with children and families also guide research?

Can research be conducted in a way that is scientifically valid and yet acknowledges and adheres to principles of family-centered care?

One result of the panel deliberations was a set of four principles to guide research, which did the following:

1. Emphasized researcher-parent collaboration;
2. Acknowledged the diversity of families;
3. Underscored the need to respect and protect family privacy and autonomy;  
and
4. Encouraged complete sharing of information about the purpose and use of the proposed research and about possible benefits for families.

At an abstract level these four principles may appear to be a reasonable fit with the usual practice of mental health researchers. However, the development and refinement of ideas about family-centered services in children's mental health and reflection on current mental health research make apparent the need to reconsider these questions (Friesen, Koroloff, & Koren, 1993).

The difficulties in reconciling the competing demands between requirements of service delivery and field research are well known. A close examination suggests that the differences between traditional mental health research and family-centered services is more than just another example of this practice-research conflict and cannot

be wholly bridged by tinkering with the research design or educating providers and consumers. Rather, family-centered services represent a significant change in the service delivery system, introducing new ways of thinking about family members, new roles, and changes in power dynamics (Leaf, 1997). Traditional mental health research, which by its nature is conservative (Kytle & Millman, 1986), has not yet responded to this fundamental change in services that has evolved over the past 10 years. In the following discussion we provide a brief description of family-centered services and traditional mental health research, compare key elements of each, and discuss the challenges of conducting research in a family-centered services system. This discussion is intended to articulate the points of tension that arise in studying family-centered services and stimulate creative responses that preserve the necessary requirements of the research process while acknowledging the value base of family-centered services.

## FAMILY-CENTERED SERVICES

The concept of family-centered services has emerged only recently as a fairly well-understood set of practice principles (Shelton, Jeppson, & Johnson, 1987). One of the leading tenets is the emphasis on the central role of the family in all aspects of service (Bailey, Buysse, Smith, & Elam, 1992; Roberts & Magrab, 1991). The development of services, both formal and informal, is in response to the needs of the entire family, including the needs of the child with an emotional disorder (Friesen & Koroloff, 1990). Concepts such as family empowerment, family support, reduction in the burden of caregiving, and helping the family to live as normal a life as possible are key to understanding family-centered services.

Hunter and Friesen (1996) proposed three defining principles for family-centered services. First, family-centered services emanate from a theoretical basis best described as an expanded ecological view, one that incorporates family, extended family, friends, and community into the services delivery plan. Second, family-centered services are designed to support all family members in a way that makes ongoing caregiving possible. Third, within a family-centered perspective, parents and other family members are involved in all aspects of planning and evaluating the service delivery system, including the services for themselves and the services for other families. Within this perspective, professional providers no longer carry the entire burden of responsibility for designing and monitoring services but share this with family members who are viewed as equals in knowledge and expertise (McGonigel, 1988). The family-centered perspective may best be understood in contrast to a child-centered perspective that focuses on change in the child, or a program-centered perspective that focuses on change in groups of individuals who complete a program (Friesen & Huff, 1996). With a greater understanding of the underlying principles of family-centered services has come the realization that evaluating services under such a system severely tests the capability of traditional research approaches.

## TRADITIONAL MENTAL HEALTH RESEARCH

In order to further examine the challenges posed for traditional mental health research approaches by family-centered services, it is useful to consider a working definition of traditional mental health research. By this term, we refer to the primarily quantitative research tradition that employs increasing levels of rigor as the standard of quality. The "gold standard" for traditional mental health research (and in fact traditional research in most fields) calls for an experimental design with random assignment of subjects to a carefully controlled intervention, and assessment of both independent and dependent variables with commonly accepted standardized measures (Bickman, 1992). Research that does not meet these criteria is often labeled nonconclusive or exploratory and seen as a precursor to conducting the real work of research: the experimental study.

Traditional mental health research is compatible with the assumptions and goals of traditional mental health services, which have as their goal if not cure, then greatly improved functioning of the child. Central outcomes related to this goal include such dimensions as reduction or elimination of behavior problems, improved mood, regular school attendance, and age-appropriate academic performance. As Rosenblatt and Attkisson (1993) noted, a variety of goals, which may even conflict with each other, exist for mental health treatment. To the extent that the interventions employed to address these goals can be described and their implementation verified, traditional research designs are appropriate for testing whether those who received the interventions improved more than those who did not. Thus, traditional mental health services parallel the medical model, which starts with a diagnosis, prescribes a treatment, and then checks whether the treatment was successful. Traditional mental health services are focused on the individual "patient," view time periods as "episodes of illness," and have as their goal curing the individual and returning him or her to a normal life in society. This orientation to treatment is contrasted with the goal of family-centered services, which, in addition to being concerned with the child's functioning, aims to help the whole family to live as normal a life as possible while caring for the child with an emotional disorder.

## Comparing the Perspectives

In the following discussion, we contrast the above conceptions of traditional mental health research with the conceptualization of family-centered services presented earlier in this article. Although we present this discussion as a series of contrasts, our purpose is not to invite the reader to choose one, but to consider how the apparently conflicting demands of each can be reconciled. We cannot compare family-centered research with traditional mental health research because family-centered research or its conceptual sibling does not yet exist. In Table 1, we explicitly compare family-centered services and traditional mental health research on eight dimensions: (a) value orientation; (b) orientation to success and failure; (c) orientation to family; (d) orientation to prior research; (e) orientation to outcomes; (f) orientation to intervention; (g) orientation to self-report; and (h) orientation to advocacy and change goals. In addition, we identify a central challenge related to each dimension.

### Value Orientation

The value orientation of researchers is less well documented than the more explicit value system of family-centered services. In fact, researchers have historically been taught to be objective, and not to take sides or become too involved with the subjects of their study. Although some writers have questioned the feasibility of maintaining this objectivity (Kytle & Millman, 1986), most researchers hold objectivity as an implicit value that permeates their work. In a family-centered system of care, values are generally explicit, although it would not be correct to say that all values are stated or that everyone agrees on the values. Certain values are commonly held and include the following: (a) the service plan should include whatever it takes to support the needs of the family and child (rather than matching needs to existing services); (b) the family should not be blamed for causing the child's disorder; (c) family members should be included as a part of the planning and decision-making system; and (d) the service plan and service delivery should be individualized and look very different for different families, even families with children who have the same diagnosis. Values such as these have implications for the design and process of research.

The explicitness of the values and the passion with which they are held may override a commitment to objective research. For example, a provider who adheres to the "whatever it takes" value may find this approach in conflict with a research-driven request to control the flow of services to families in a comparison group or to control the extent and nature of the services received by the intervention groups. The traditional researcher's value for objectivity and control is in direct conflict with the family-centered philosophy of providing or developing whatever it takes. Thus, a primary challenge is to find a research design and data collection procedures that provide enough objectivity to satisfy researchers and policymakers but that also honor the explicit values of family-centered services.

### Orientation to Success and Failure

The next issue extends the discussion of values. Both orientation to success and orientation to failure provide good examples of situations in which the values of family-centered services and research may diverge. The purpose of traditional group research designs is to answer some version of the question, What intervention is most effective for the greatest number of people? The way this question is posed assumes that the intervention will be effective or successful for some families and children but not for others. In order to be conclusive, group research designs assume that at least one group of families (the control group) will not do well or at least will improve less. Traditional research also requires that the intervention be narrowed and controlled such that the maximum amount of discrimination, between intervention and control groups is achieved (Bickman, 1992). Thus, a tightly controlled intervention that is clearly successful for one group of families as compared to another group provides the maximum amount of information from a traditional research perspective.

This orientation to success and failure is in contrast to the approach of family-centered services, in which it is important that the maximum positive effect be achieved for each family and child. From this perspective, treatment failure should not be tolerated. There is an unconditional commitment to continue to pursue an acceptable set of supports until a successful constellation is found (VanDenBerg & Grealish, 1996). One of the challenges in bridging these two perspectives is determining how to construct a reasonable comparison for services delivered under a family-centered philosophy.

### Orientation to Family

The way family variables are viewed in the research design and analysis has changed considerably over the past several years (Summers, 1988). This progression is most clearly seen in the way that various measures regarding family functioning, family coping, or family pathology are used to explain why a child did or did not get better. Traditionally, the primary outcome of research in children's mental health has been the child's functioning, as measured by standardized child mental health measures, with a focus on whether the child's symptoms or condition improved (e.g., Bickman, Heflinger, Lambent, & Summerfelt, 1996). In these studies, various constructs related to family functioning were often used as contributing factors or mediating variables, to help explain why a child did or did not improve (e.g., how did family functioning contribute to the child's symptomatology?).

In the family-centered system of care, the family members who care for the child are viewed as experts on the needs of the child and family as well as a primary provider in the system of care (Henggeler, Schoenwald, & Munger, 1996). Given this orientation to the family, family-related variables become important in a different way. Now the family's view of service planning, access, and delivery are used as variables for explaining whether a constellation of services was successful. New constructs such as family empowerment (Koren, DeChillo, & Friesen, 1992), family satisfaction with the service plan (Young, Nicholson, & Davis, 1995), level of stress created in the family by the child's disability (Patterson, 1990), and the family's ability to continue to act as caregivers are seen as relevant outcomes. Because standardized measures do not exist for many of these constructs, one of the challenges for the researcher is to find ways to measure these ideas that have not been carefully measured in the past (Patterson, 1996; Summers, 1988). A major challenge lies in achieving an agreement about the ways in which measures of family characteristics and family functioning will be used in the analysis of data and reporting of results.

#### Orientation to Prior Research

Traditional mental health research depends on an established line of published empirical research literature. Proposals for funding begin with a review of the prior research. Proposed research designs and selected measures are supported by reference to use in prior research efforts, and interventions are usually tested in relation to research on similar interventions. Lack of research in an emerging area makes it difficult for researchers to test innovative research designs or attempt to measure new constructs because funding is rarely available to do exploratory research or to develop new instruments. Thus, historically developed research themes and procedures tend to be revised or adapted incrementally.

In the past few years, studies have begun to emerge that illuminate various aspects of family centeredness (Clarke, Schaefer, Burchard, & Welkowitz, 1992; Evans, Armstrong, & Kuppinger, 1996; Tannen, 1996), and some criteria for assessing family-centered services at the practitioner (Allen, Petr, & Brown, 1995) and system (Koroloff, Hunter, & Gordon, 1995) levels now exist. In general, however, most planners, providers, and family members have developed and evaluated family-centered services without much direction from the published literature, depending instead on an oral and experiential tradition. The challenge to both researchers and research funding involves ensuring that developments in family-centered services are based on available research and evaluation findings. This includes both increasing available knowledge and encouraging the application of relevant research findings. Another challenge involves finding ways to fund innovative research approaches such that a new literature base can emerge.

#### Orientation to Outcomes

The dominant assumption of traditional mental health services and related research is that children with serious emotional disorders are expected to achieve improved functioning, if not be cured of their disorder. This belief leads to outcomes that focus on changes in the child's behavior or symptoms. In contrast, family-centered services operate from assumptions that are usually found in a rehabilitation or disability framework. Under these assumptions, the goal for the family and child is the management of the disability and the reduction of negative impact on the child and the family. Another goal is to help the child achieve and maintain the best functioning possible. Within a disability framework, it is accepted that some children may improve, some may deteriorate in functioning, and some may not change. Further, children with emotional disorders often demonstrate cyclical patterns; they may improve and lose ground during a given period, thus appearing to show no change. Success of family-centered services is measured against principles such as the ability of all family members to have a reasonable quality of life as well as by improvements in the child's functioning. In addition, the group of children labeled "seriously emotionally disturbed" encompasses a wide range of disabilities with a variety of different levels of functioning and prognoses. The state of child mental health research is not yet refined enough to make

distinctions among those children who can be expected to improve dramatically in their functioning and those for whom this is not a reasonable expectation.

Deciding which outcomes to measure is a heavily political process (Kytle & Millman, 1986). In traditional mental health research, outcomes are often selected from a short list of measures that are psychometrically proven and frequently used. In addition, there is increasing attention to measurement of cost and cost benefit. This results in a set of outcomes that answers questions important to major funders and policymakers and fits well with the ongoing stream of research. In family-centered services, the outcomes of major importance are derived from the needs and goals of each family, without regard to costs. These two sets of preferred outcomes may overlap somewhat, but more often are markedly different. The central challenge for researchers in family-centered services is to develop a list of outcomes that includes the interests of family members along with those of the more commonly involved stakeholders.

Another issue related to outcomes is the appreciation for individual differences strongly held by proponents of a family-centered service system. Family members and practitioners within this system believe that service delivery and definition of outcome must accommodate the differences that exist among families and their children. Taken to the extreme, this might mean defining a different set of outcomes for each child and family. Ways of measuring individualized outcomes are underdeveloped, and researchers have little to turn to (Rosenblatt, 1996), with the exception of goal attainment scaling (Kiresuk & Sherman, 1968), an area of instrument development that has received minimal attention. Traditional mental health researchers, on the other hand,

prefer to adopt outcome measures that are standardized and commonly used in research projects. This allows researchers to compare their findings across groups and with findings of other studies, but does not allow for the exploration of outcomes that apply to only one or two families. Even more challenging is the critical need to develop a reliable measure of system-level concepts and constructs such as accessibility and service coordination (Burns, 1994; Stroul, McCormack, & Zaro, 1996). The challenge for the researcher in a family-centered system of care is to find or develop standardized measures that allow for generalizability of the results and at the same time to adopt some measures that capture individualized outcomes.

A final issue is the extent to which a designated outcome measure will remain appropriate over time. In traditional mental health research, outcomes are defined at the beginning of the research project and do not change during the research project. In family-centered services, the outcomes for the child and family may not be known at the beginning of the relationship with service providers and may change as more information is collected and various interventions are tried. Outcomes that are not recognized or defined at the beginning of services may emerge over time. This represents a major challenge to research in family-centered services. The researcher is faced with finding ways to work collaboratively and to develop an approach that accommodates the realities of practice and the family's situation along with the need for scientific rigor.

### Orientation to Intervention

As with outcomes, the way intervention is viewed by proponents of family-centered services may complicate the research endeavor. Research on services to children has always been plagued by the reality that children are often involved in multiple and overlapping services. They may be receiving services from several different systems (e.g., mental health, education, child welfare), have an individualized service plan in at least two systems, and be working with many formal and informal service providers. An additional complication, in family-centered services is the possibility that no two families will receive the same set of services or have the same goals for being involved with services. A single service or intervention (the one that the researcher wants to study) may be a small part of the child's life and have only minor impact on the child's functioning and the family's situation (Weisz, Han, & Valeri, 1996). The researcher's need to test small modifications of one intervention can easily result in misleading findings unless the centrality of that intervention to each family's life is taken into consideration. Further, family members and providers want to think about all aspects of the child's life and the family's life and will be uncomfortable and perhaps unwilling to participate in research that tries to partialize their experiences. The challenge to researchers is to find ways to identify and track all services that the family receives, both formal and informal, and weigh the contributions of each to outcomes.

### Orientation to Self-Report

Traditional researchers have long been concerned about the possibility of bias and the questionable validity of data collected solely through self-report. Family members' assessments of a child's behavior or of the family's situation could be influenced by caregiver feelings of stress and burden, recent incidents, or a desire to give "correct"

responses. Only assessment by an objective third party can be considered free from such influences. In particular, consumer satisfaction ratings, which are available only through self-report, are considered biased toward the socially accepted answer (Young et al., 1995), further contributing to the idea that consumers and family members cannot or will not give reliable information.

From the perspective of family-centered services, only the family members and in some cases the child have the information that is most important to assessing the acceptability and effectiveness of services. Family members alone know what they feel about concepts such as ease of access, coordination of services, and the capability of services to meet their needs. For them the question of whether to include self-report data is moot because there is no more legitimate source of data than themselves. Further, many family members contend that they are better judges of their children's symptoms' and behaviors than external observers such as teachers and therapists.

Ratings of behaviors by parents and those by outside persons often correspond only moderately (Greenbaum, Dedrick, Prange, & Friedman, 1994; Handen, Feldman, & Honigman, 1987). The differences may result from a variety of factors such as parents' greater familiarity with their child's behavior, the child's setting specific behaviors, and different standards and expectations for behavior. If systematic differences are found, however, the researcher cannot answer the question of which set of ratings, the parents' or the objective other set, is the most accurate and valid. This is a question of values. A related issue is the need to find ways to incorporate ratings from several family members into data collection and analysis protocols instead of using information from only one caregiver, usually the mother (Patterson, 1990). Resolving the debate over what is considered a reasonable outcome may go far toward answering questions about the use of self-report data. If concepts such as family satisfaction and coordination of services on a family-by-family basis are accepted as legitimate outcomes, then self-report data as a primary form of information may also gain more acceptance.

#### Orientation to Advocacy and Change Goals

Proponents of family-centered services feel a strong responsibility to advocate for needed changes in the service system and related policies (Harry, 1996). Family members, providers, and even

administrators and policymakers who come from this orientation may view modification of services and policies as a part of their personal and professional responsibility. They may believe that any information, including interim research results, should be directed toward the change effort. There are several major ramifications for the traditional researcher. First, advocating for modifications in treatment or system of services in the middle of a study would almost certainly disrupt the carefully controlled intervention, thus destroying the research effect. Second, when study conclusions are used for advocacy, researchers often feel that simplistic statements made for the purpose of causing system change misrepresent research findings about very complex issues. Finally, attempting to incorporate an advocacy agenda into the design of research is uncomfortable for most traditional mental health researchers because they believe that they should not enter the study with a preconceived notion about the probable effectiveness of a service. Advocacy, by its very nature, requires that one enthusiastically and publicly support a position. The central challenge for the researcher who is working within a family-centered services system is to acknowledge and support the change agenda of family members and providers without letting that change agenda bias the research effort. This kind of balance will not be easy to strike.

#### CONCLUSIONS

The panel convened by the Association for the Care of Children's Health (McGonigel, 1988) called for the development of new attitudes, skills, and methods so that researchers could better accommodate family-centered principles in their work. Five years later, a symposium on Family Research held by the Research and Training Center on Family Support and Children's Mental Health at Portland State University examined many of the same questions, specifically for the field of children's mental health (Friesen et al., 1993). Both groups made recommendations about the kinds of research questions that must be investigated within a family-centered services model (Friesen et al., 1993; McGonigel, 1988). These recommendations included the following:

- Research is needed that further defines family-centered care and explicates the elements critical to the success of this approach.
- Outcomes must be developed that expand beyond traditional questions of child and family functioning to include family-identified outcomes encompassing individual family perspectives.
- New research approaches need to be developed to accommodate the diversity of family characteristics and circumstances and the requirements of individualized services.

- Understanding service delivery requires examination of concepts such as family-professional collaboration, family empowerment, family support, and family participation in service planning.
- All outcomes and processes need to be examined within the changing service environment, including attention to the effects of blended and flexible funding and the potential for family-centered services in managed care.
- New and productive roles for family members as a part of the research team or as members of research review groups and research advisory boards need to be developed.

This issue of the *Journal of Emotional and Behavioral Disorders* begins to address many of these recommendations with six articles. In their article, McDonald, Gregoire, Poertner, and Early acknowledge the complex circumstances in which families care for children with emotional disorders. The focus on caregivers' well-being, as well as on the mental health of the child, is consistent with values of family-centered services. Johnson and Renaud confront the issue of etiology and the problem of blame in their study of professionals' beliefs about parents of children with emotional disorders. The authors provide an important foundation from which to examine family-professional relationships, professional training, and related concerns.

In their article, Koren, Paulson, Kinney, Yatchmenoff, Gordon, and DeChillo view interagency relationships through the eyes of family members, thus providing a family-specific assessment of service coordination. The importance of social support and the role of extended family in understanding adolescent mothers are explored by Caldwell, Antonucci, Jackson, Wolford, and Osofsky. Of particular interest is the authors' description of similarities and differences in mental health status and patterns of support between Black and White adolescent mothers. Heflinger, Bickman, Northrup, and Sonnichsen address family empowerment, a rarely studied concept in family-centered services, and evaluate an intervention specifically designed to promote family empowerment. These articles illustrate the processes and challenges of studying family-centered services with traditional research tools and contribute to the growing knowledge base addressing family issues in children's mental health services research.

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