Family Participation in Systems of Care: Frequently Asked Questions (and Some Answers)

For a number of reasons, family participation in an integrated service delivery system for children and their families is increasingly the norm around the country. Among these reasons are that a number of federal and state laws require family participation in service planning and delivery; several federal and state family run organizations continue to advocate for family participation in service planning and delivery; and service providers are learning that services are more family centered, culturally appropriate, and relevant to families' unique needs and strengths when family members are actively involved in service planning and delivery.

As this transition to increased family participation has progressed, a growing body of research begins to document what is known about family participation in child and family service systems. Available research informs our understanding of the child and family outcomes affected by family participation, the possible processes by which outcomes are influenced, the challenges to implementing family participation, and strategies that promote family participation in service planning and delivery. This article provides an overview of the available research in these four areas and discusses research that is currently underway to improve our understanding of family participation in the children's system of care.

Does Family Partnership Impact Child and Family Outcomes?

A small body of research assesses the impact that family partnerships have upon child and family outcomes. It appears that children experience improved educational outcomes and well-being; and reduced length of stay in out-of-home placements and residential settings when their parents are involved.

Family participation in schools is associated with children's enhanced academic performance and school competence (Kohl, Lengua & McMahon, 2000). For children with autism, active involvement of parents in educational planning contributes to greater home-school consistency of behavioral and educational approaches and is believed to lead to better educational outcomes (Moroz, 1989). Youth with behavior problems whose parents participated in a program of intensive family support and intervention in their alternative school showed improvements in behavior, grade point average, attendance, and drop out rates, compared with a group of adolescents whose program did not include parent participation (Aeby, Manning, Thyer, & Carpenter-Aeby, 1999).

Family partnership also appears to reduce the length of stay in foster care, residential treatment, and psychiatric hospitals. Studies have shown parental visiting to be highly associated with shorter lengths of stay in foster care (Benedict & White, 1991; Davis, Landsverk, Newton & Ganger, 1996), although visiting may be a proxy indicator for more complex parent-child-agency relationships. Tam and Ho (1996) found parental involvement to be of paramount importance in the prospect of children and youth returning home form residential treatment. Byalin (1990) ascertained that psychiatric inpatient stays for adolescents were reduced from an average of more than a year to less than four months when parents were encouraged to take leadership at all stages of the intake, treatment, and discharge planning process. Parent participation on an interdisciplinary team in an adolescent psychiatric unit also led to considerable reductions in length of inpatient stay (Williams, 1988).

Finally, family partnership has been shown to improve child well being. For children in out-of-home placement, regular parent-child visits and contact with children in foster care are believed to maintain child well being (Davis, Landsverk, Newton, & Ganger, 1996). Cantos, Gries, & Slis (1997) also found that children who were visited regularly had lower total behavior problem scores and less depression and anxiety than did those who were not visited or had irregular contact with their parents. Regular parent-child visits and parents' contact with children in foster care facilitate continuity of care and parent-child attachments and help children cope with the stress of separation and placement (Davis, Landsverk, Newton, & Ganger, 1996).

How Does Family Partnership Impact the Service Delivery Process?

The process by which family participation influences child and family outcomes is not clearly established in the literature. However, the results of some studies suggest that family participation changes service providers' approaches to service delivery, service providers' views of their work, and the families' approaches to treatment, each of which may improve child and family outcomes.

Family participation may change service provider's approach to service delivery. Rzepnicki (1987) determined that caseworkers offered more appropriate and relevant services to families that participated in case planning. Research in residential settings showed that staff attitudes toward parents changed as the parents' involvement in the activities of the facility increased and as they were more involved in communication, planning, and decision making (Carlo, 1988; 1993a; and Williams, 1998). Carlo (1988 & 1993b) found that staff gained a better understanding of children and began to treat parents as team members and "experts" on their child as parents participated in parenting roles with their child at the facility and in organizing special events and everyday functions. Koren,

et.al, (1997) determined that increased family involvement in service delivery resulted in greater collaboration among professionals and service systems, and greater understanding of the challenges facing parents, resulting in more coordinated services and increased family satisfaction. Finally, Grolnick & Slowiaczek (1994) have shown that teachers who perceived that parents were concerned about their child paid more attention to that child.

Family participation may make service providers' jobs easier, which may result in better outcomes. For example, in a study of successful service strategies, Worthington, et al. (2001) found that family professional partnerships contributed to, among other things, improved provider empowerment. Blacher & Baker (1992) identified that family involvement might also benefit care providers by enhancing their job satisfaction, allowing brief respite, and reducing stress.

Family participation may also change the family's approach to treatment. Rzepnicki (1987) found that family participation may result in a family's greater commitment to the change process and increased motivation to work toward achievement of agreed upon goals. Rzepnicki (1987) also found that family participation in case planning is likely to result in increased family motivation to undertake problem-solving actions. Both Byalin (1990) and Worthington, et al. (2001) established that family participation results in increased family empowerment. Finally, Tam & Ho (1996) determined that if parents are encouraged to continue to exercise their authority and fulfill part of their responsibility while their child is in care, they may be reassured that they have not been squeezed out of the picture and may be more motivated to reunite the family.

How is Family Participation Supported or Impeded?

The literature suggests a number of things that can support and/or impede family participation. Barriers may include logistics for participation and

agency polices and procedures. Agency policies and procedures may also support family participation as well as staff attitudes and specialized training.

In a series of focus groups, parents of children placed in out-of-home care described agency policies and rules that restricted parent participation and parent-child contact; even when policies were supportive of family participation, they were not always implemented (Friesen, Kruzich, & Schultze, 1995). Families described institutional barriers and staff attitudes and behaviors, which restricted their participation in their children's out-of-home treatment. Institutional barriers included scheduling constraints on visits and meetings, and behavioral contingencies related to point and level systems that affected parent-child contact. Some parents felt that their participation was restricted by lack of communication by staff and even dishonesty in communications between staff and their children (Friesen, Kruzich, & Schultze, 1995). Clausen, et al. (1998) found that the lack of funds in California made it difficult for parents to attend meetings. Finally, Friesen et al. (2001) reported that caregivers of children both at home and in out-of-home care cited communication across agencies as a barrier to family.

While agency policies and procedures may impede family participation, they may also support family participation. Hess (1986) demonstrated that caseworkers employed by agencies with written policies identifying minimum standards for visiting frequency scheduled parental visits more consistently and more frequently than caseworkers in agencies with no written polices.

Staff may also be the greatest support to family participation. For example, parents of children in out-of- home care who participated in focus groups identified individual staff members as the most important supports of family participation (Friesen, Kruzich, & Schultze, 1995). Caregivers of children at home and in out-of-home care cited

staff behaviors as supports that increased their capacity to participate in their children's education and treatment (Friesen, Kruzich, Ogilvie, Pullman, Gordon, & Jivanjee, 2001). Specifically, the most important supports that increased caregivers' capacity to participate in their children's education and treatment were that "staff treated me with dignity and respect," "staff made me feel my participation was important," and "staff provided a contact person."

Caregivers of children at home and in out-of-home care reported negative staff attitudes to be a barrier to family participation when their children were placed in out-of-home care (Friesen, Kruzich, Ogilvie, Pullman, Gordon, & Jivanjee, 2001). In addition, Worthington et al. (2001) found some professionals to be reluctant to abandon traditional therapeutic roles which involve unequal sharing of power. Mother-blaming attitudes which maintain that mothers have responsibility for their children's mental health problems persist in training materials for social workers (Ruffolo, Sugamele, & Taylor-Brown, 1994) and in professional beliefs about parents (Johnson, Cournoyer, & Fisher, 1994; Johnson, Renaud, Schmidt, & Stanek, 1998). While staff attitudes either support or impede family participation, some research has shown that specialized training in family-centered practice influences staff attitudes toward family involvement. Coleman (1999) found specialized training in family- centered practice to predict more favorable staff attitudes toward family involvement. Sanchirico & Jablonka (2000) determined specialized training to be related to an increase in staff involvement in activities supporting parent child contact.

Finally, logistics for system functions (e.g., meetings) may be a barrier to family participation. In a survey of caregivers of children at home and in out-of- home care, Friesen at al. (2001) report that distance from the facility is a frequently identified barrier to family participation when their children were placed in out-of-home care.

After distance from the facility, caregivers of children at home and caregivers of children in out-of-home care cited work schedules as a barrier to family participation when their children were placed in out-of-home care (Friesen, Kruzich, Ogilvie, Pullman, Gordon, & Jivanjee, 2001).

What Can Service Providers Do to Facilitate Family Participation?

While there has been impressive progress in increasing family participation, there is still work to be done to fully involve families as partners in systems of care. To participate actively, family members must be "informed, educated, and persistent" (Clausen et al., 1998), but participation is a right of all parents, not only those who have these qualities. Providers may support families' participation by:

- Developing and maintaining a climate that is respectful of parents and supportive of participation.

- Offering real opportunities for participation. Sharing information.

- Providing training so that families are able to be full participants.

- Offering concrete assistance, such as child care, transportation, and reimbursement for expenses and time taken off work (Friesen & Koroloff, 1990).

As service providers continue their efforts to promote and welcome family participation in systems of care, achieving full family participation at all levels of the system of care remains a continuing challenge for the future (Stroul, Friedman, Hernandez, Roebuck, Lourie, & Koyanagi, 1996).

What Research is Currently Examining Family Participation?

Research is currently underway which will add to the existing knowledge base. Evaluations being conducted by MACRO International of the Comprehensive Community Mental Health Services for Children and Their Families Program include measurement of family participation in relation to outcomes. At the Research and Training Center on Family Support on Children's Mental Health, Walker (2001) is conducting a micro-level analysis of the specific behaviors of participants in wraparound service planning with a view to developing training materials for staff and families. Pottick and her associates (Pottick, Hansell, Gaboda, & Gutterman, 1993; Pottick, Coyne, Barber, & Hansell, 1997) are working to identify factors associated with length of stay and outcomes for children and adolescents in inpatient psychiatric services. Parents' perspectives on their children's mental health services and their satisfaction with interactions with staff are the focus of research and the development of measuring instruments by Gerkensmeyer and associates (Gerkensmeyer, McBride, Finke, & Austin, 1995; Gerkensmeyer, McBride, Feaster, & Austin, 1997).

Research from related disciplines is relevant in increasing understanding of the associations between family participation and treatment outcomes. For example, research in early intervention services has described possible paths by which family participation in family-centered services contributes to reduced family stress, increased support, and family empowerment (Thompson, Lobb, Elling, Herman, Jurkiewicz, & Hulleza, 1997). Findings from pediatric research in the treatment and control of juvenile diabetes indicate that mothers' sense of empowerment is associated with their children's treatment adherence and favorable levels of diabetes control (Florian & Elad, 1998).

We have reported that there is ongoing research in children's mental health to test hypotheses related to the influence of different types of family participation on outcomes for children and families and these findings might be used to make an even stronger case for the utility of family

participation. We conclude this discussion by recommending that the children's mental health field imitate the early intervention field by accepting that family participation is a fundamental element of family-centered service delivery (Bailey, McWilliam, Darkes, Hebbeler, Simeonsson, Spiker, & Wagner, 1998). Research based on this assumption will then be directed toward discovering optimal levels and kinds of participation and the policies and practices that are more likely to support high levels of family participation, family empowerment, and family satisfaction.

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