FAMILY PARTICIPATION IN OUT-OF-HOME TREATMENT SETTINGS: CHALLENGES AND OPPORTUNITIES FOR CHANGE

Throughout the life of the *Family Participation* project, the research team has struggled with the contradiction inherent in spending resources and energy studying families' experiences related to out-of-home settings when we are wholly committed to community based care, and to the principle that children should live at home with their families. We began the *Family Participation* project nearly ten years ago in response to a federal funding priority to examine "alternatives to living at home when family-based treatment is not an option." We believe that if sufficient resources and supports are provided, most families and children can be helped without out-of-home placement. We also know that thou-sands of children enter residential settings each year, and we believe that they and their families should not be ignored. For these reasons, we decided to explore family participation and other topics of immediate concern to families whose children were in out-of-home care.

Here we summarize three journal articles focusing on family members' experiences when their children are in out-of-home placement. The first article presents findings from four focus groups conducted with families whose children were in out-of-home placement, and features the perceptions of African American parents. The second and third articles present information obtained from 102 families whose children had been in out-of-home treatment for more than 30 days during the study period. Caregivers returned a questionnaire addressing family participation and other service delivery-related issues. The questionnaire was developed in part from issues and concerns raised by the focus group participants. Details on the study samples and research methods are included in the original articles, which are, or will be, available from the RTC. Together, these articles explore family participation in out-of-home services from the perspective of family members, and point to areas where practices, programs, and policy can be improved.

Focus Groups

The first article, "Family perspec-

tives on residential treatment: Voices of African American families" (Kruzich, Friesen, Williams-Murphy, & Longley, 2003) reports on four focus groups that were held at annual conferences of the Federation of Families for Children's Mental Health. Three of the focus groups were comprised primarily of European American parents, while the remaining group was comprised of African American parents. (In this article, we use "parents" to include other primary caregivers as well.) Participants provided rich information about their experiences while their children were in residential care, psychiatric hospitals, or group homes. Focus group members were asked to describe the nature of their contact with their children and involvement in education and treatment during the period of out-of-home care.

Common concerns. One common concern across all groups was initial and ongoing contact between parents and their children. Residential programs varied widely in the degree to which they encouraged or discouraged family involvement during the initial weeks or months of treatment. Some family members were told in advance that during an adjustment period there could be no contact with their children. One mother of a 5-year-old boy reported that she was told initially that there would be no contact, but that staff relented and let her have phone contact because her son was so young. Other parents reported not only that they were denied contact, but that their children were moved to different facilities without notification.

One of parents' most frequently expressed desires was to have contact with their children through visits and phone calls. Many family members expressed concern about the inflexibility of visiting rules and policies and lack of communication between the facility and home. Permission for children to have contact with their families was often contingent upon the child's behavior.

Many family members commented on the financial expense of maintaining contact, including long distance calls, travel costs, and meals during day visits.

All participants emphasized the importance of being involved in treatment decisions. Some were encouraged to be involved "right from the beginning," but others felt they had to be assertive and persistent in order to be involved.

Recommendations for improvement included increasing the extent to which caregivers were respected, valued, and involved in decision-making. A number of family members indicated a need for more flexibility and individualization. They also asked for meetings that included other family members, more program information, financial support for visiting and phone calls, and better interagency collaboration.

Unique concerns of African American family members. Members of the African American focus group expressed concern about separation of child from family and community. Many family members expressed apprehension about having to place their child in residential treatment. They were concerned that the staff would interpret the child's placement as relinquishing their child, and also that the child would feel abandoned. Many of the African American parents had doubts that their children could be well served in any out-of-home setting. Instead of focusing on improvements in residential care, the majority of comments focused on the need to redirect resources to families and communities. Members of the focus group also expressed concerns about the use of medication, including the effects of medication on their children, over-medication, the use of drugs as the sole treatment, and possible racist experimentation.

Racial and cultural dissimilarities between staff and families were also concerns. One mother said, "the people who work in the program

are not African Americans or Latinos. It is very demeaning when people speak about your family life, where you live, like it is some foreign country." The staff's lack of understanding was also seen as possibly leading to inappropriate treatment such as the concern expressed by one mother who feared that teaching her son to cry would result in his being bullied. Families also described instances where stereotypes of staff appeared to lead to differential treatment of their children, e.g., assuming that their problems were "social" rather than biological, giving more severe diagnoses, and punishing them for hairstyles, dress, and socializing with other African American youth.

The article concludes with recommendations for recruitment of staff from diverse backgrounds, staff training, and changes in agency policies and practices, especially with regard to increasing the cultural appropriateness of services.

Parent-Child Contact

The second article, "Preserving family bonds: Examining parent perspectives in the light of practice standards for out-of-home treatment," used the questionnaire data to examine parent-child contact when children were placed out of their homes for the purpose of mental health treatment. Support for the principle that parents and children should have regular and frequent contact resides in laws and court cases that address the rights of parents, in theories about attachment and bonding, and in research that

demonstrates the benefits of parent-child contact. However, it appears that practices with regard to parent-child contact often do not reflect this principle. The purpose of this analysis was to learn more about practices related to parent-child contact, and how parents' experiences compared to practices outlined in the current standards of national organizations such as the Council on Accreditation (COA) and the Joint Commission on Accreditation of Health Care Organizations (JCAHO).

Contact during the initial period of placement. In response to the concerns of focus group participants, the questionnaire specifically asked about parent-child contact during the period immediately following placement. The standards, however, did not address different stages of placement; rather, they addressed the entirety of a child's stay. The standards call for written policies guaranteeing the right of parents to communicate with and visit their children and to have the frequency, length, and location of visits and telephone calls specified in service plans developed in cooperation with parents.

Nearly 60% of parents reported that there was a limitation placed on contact with their children for an initial period of adjustment. These restrictions lasted 1-8 weeks, with no significant difference based on age of the child or treatment setting. Predictably, parents who did not have custody of their children were more likely to report such restrictions.

Frequency of parent-child contact. The standards emphasize both regularity and flexibility of contact. Parents reported that telephone contact occurred most frequently, with nearly 90% of parents reporting phone contact once a week or more. Sixty-three percent reported weekly visits on campus, 33 % off campus, and 24% reported weekly home visits. Younger children had more contact with their families, as did children in facilities closer to home. There were no significant differences in frequency of contact based on the child's sex, race, or severity of condition.

Standards addressing restrictions on contact. Regulatory bodies require that restrictions on contact be fully explained, disclosed prior to placement, demonstrate benefit to the individual served, and be determined with the participation of the individual and his/her family. Some standards require regular reviews of restrictions, and some limit the conditions under which restrictions on parent-child contact may be imposed.

Fifty-nine percent of parents reported that after an initial period of adjustment, subsequent parent-child contact was contingent upon the child's behavior. Nearly 80% of parents reported restriction on at least one type of contact. Parents of girls, single parents, and parents who did not have legal custody of their children were more likely to report restrictions. Over half of the caregivers reported restrictions of parent-child contact based on point and level systems. Differences between those who reported that contact with their child was based on the child's behavior and those who did not varied significantly by severity of the child's problems (children who had less severe problems were more likely to have contact with parents contingent on their behavior) and income (83% of parents who earned very low incomes reported that contact was contingent on the child's behavior vs. 54% of caregivers who reported more income). Sixteen percent of parents reported that contact was contingent upon the behavior of peers in the treatment unit. Parents' reports of the reasons for limiting contact included staff discretion, restrictive facility policies, behavior modification programs, and maintenance of a therapeutic environment. Some caregivers felt that limitations were imposed arbitrarily or for the convenience of staff.

Despite many good reasons to promote parent-child visits, many organizations still restrict such contact. Thus, there appears to be a gap between current practice and contemporary thinking that highlights the importance of actively preserving children's attachment to their parents and minimizing the stress and trauma of separation. In addition, many parents reported the use of point and level systems that made parent-child contact contingent on the child's or the peer group's behavior. Although we recognize that

contact with family is a potent reinforcer for many children, we believe that it is problematic to base a child's contact with family on his/her behavior, especially because point and level systems are usually not individualized. Recent changes to the behavior health care standards of JCAHO emphasize individualization of interventions, and prohibit group contingencies based on a single individual's behavior. Implementation of these changes, agency self-examinations of policies regarding parent-child contact, and staff training designed to shift staff attitudes about families should help to support healthy relationships between children and their families.

Barriers and Supports

The third article to emerge from the work of the *Family Participation* project is entitled "Family caregivers' perceptions of barriers to and supports of participation in their children's out-of-home treatment," The analyses presented in the article focus on barriers and supports to participation identified by respondents to the questionnaire. Using a list of all possible barriers, parents were asked to indicate which had been barriers for them, and which was the single most important barrier they had encountered. A similar procedure was used for supports. For analysis, the barriers were divided into two groups: parent/family circumstances and facility characteristics. *Distance from service providers* was the most frequently identified parent/family circumstance, and was identified as a barrier by 45% of respondents. It was also the barrier most frequently identified as "most important." The other parent/family circumstances most frequently identified as barriers were *parents' work schedules* and *cost of transportation*. The most frequently identified facility characteristic was *lack of communication between staff in different programs*, identified as a barrier by 39% of respon-

dents. The other facility characteristics most frequently identified as barriers were *lack of open communication, lack of opportunity or encouragement to participate in the child's treatment, inflexible visiting and meeting schedules,* and *lack of clarity about whom to contact with questions and concerns.*

Two categories of support—concrete and interpersonal supports—were identified. The most frequently mentioned concrete support provided by the treatment program, identified by 81% of respondents, was *provision of a contact person.* Other important concrete supports included *notification of family when there were concerns or problems, flexible scheduling of meetings, provision of information about rights and grievance procedures, comfortable and private space for meeting, prompt return of phone calls,* and *inclusion of parents' comments in the child's records.* Among interpersonal supports provided by the treatment program, the most frequently identified was *parent treated with dignity and respect.* Other important supports were *parent made to feel his or her participation was important, caregiver made to feel welcome, all family members encouraged to participate,* and *responsiveness to the family's cultural values.*

Parents who reported more barriers also reported less total contact with the child, less satisfaction with the amount of contact, and a lower rate of participation in service and educational planning. Mirroring the results related to barriers, having more supports for participation was associated with having more total contact with the child, more satisfaction with the amount of contact, and higher rates of participation in service and educational planning.

These results emphasize the importance of the policies and practices of placement facilities and the attitudes of staff members. Addressing some of the tangible barriers, such as distance and the cost of

transportation, will require additional resources. Learning whether family members feel welcome and as if they are being treated with respect requires that programs develop ways to get feedback from family members about how they experience the program and what would be most supportive of their participation.

References

Kruzich, J. M., Friesen, B. J., Williams-Murphy, T., & Longley, M. J. (2002). Voices of African American families: Perspectives on residential treatment. *Social Work, 47*(4), 461-470.

Kruzich, J. M., Jivanjee, P., Robinson, A. D., & Friesen, B. J. (2003). Family caregivers' perceptions of barriers to and support of participation in their Children's out-of-home treatment. *Psychiatric Services, 54*(11), 1513-1518.

Robinson, A. D., Kruzich, J. M., Friesen, B. J., Jivanjee, P., and Pullmann, M. (in press). Preserving family bonds: Examining parent perspectives in the light of practice standards for out-of-home treatment.

Barbara Friesen *is the director of the RTC.*