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## **Family Participation in In- and Out-of- home Care: Preliminary Findings**

This project began in 1994, with the intent of conducting a study of family participation in residential treatment programs. In 1995 and 1996, focus groups with family members, residential treatment providers, and youth were conducted. Analysis of focus group data provided valuable information about experiences of family members and youth with residential programs; it also informed the conceptual framework (see Figure 1, page 146) and development of the survey instrument that was used in generating the data presented during this symposium. In 1998, the focus of the project was expanded to include investigation of families' experiences of participation while their child was living at home and receiving services. Survey instrument development continued through the summer of 1999. Sample recruitment and data collection took place in the fall of 1999.

### **Methodology**

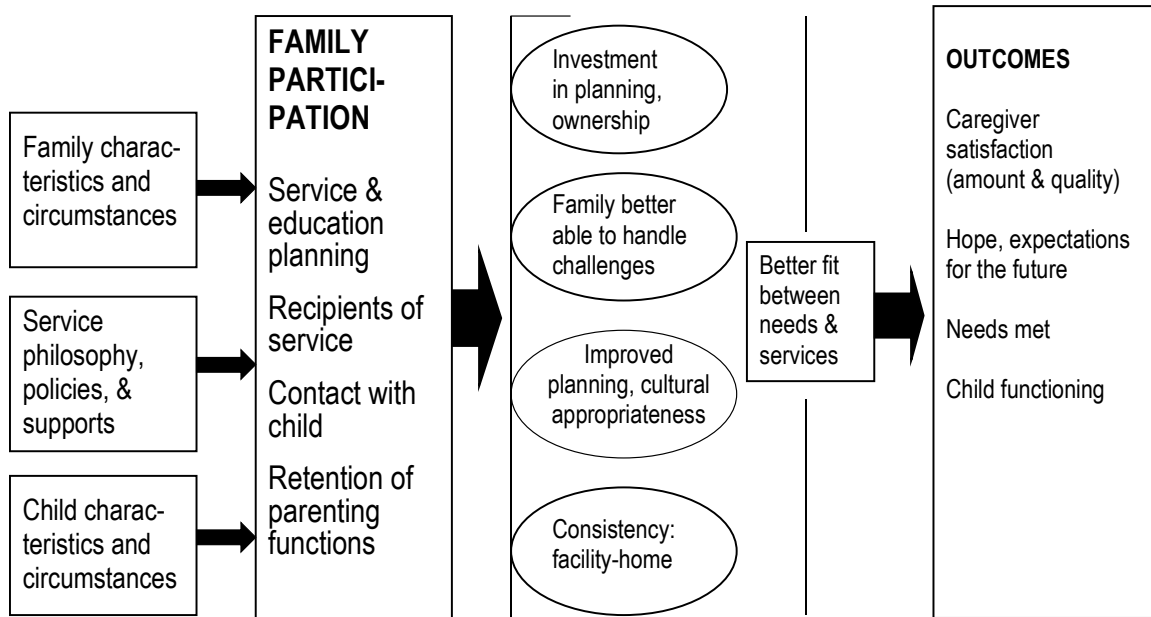
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This cross-sectional study utilized a convenience sample recruited through randomly selected family organizations within five regions of the United States. As part of the recruitment process, caregivers returned willingness forms that identified the research instrument they would receive (as the caregiver of a child who had received services at home during the time period surveyed, or as the caregiver of a child who had been in out-of-home care for at least 30 days during the research time period). Both the "in home" and

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**Figure 1. Conceptual Framework**



“out-of-home” instruments asked parallel questions about family and child characteristics, level of family participation in planning and receiving educational and treatment services, and family empowerment. The “out-of-home” version had additional questions pertaining to placement decisions and contact with the child or youth while in care. As an incentive for return and as compensation, respondents were offered their choice of two publications of the Research and Training Center. Sixty-one percent of those who expressed initial interest in participating in the study returned completed questionnaires.

provided the bulk of respondents to the study, this was an overwhelmingly female (95%), primarily White (88%; 5% African American), and well-educated (49% with a college or graduate degree) group of caregivers. Most were birth mothers (75%), although 12% were adoptive mothers; birth fathers and grandmothers each made up about 3% of the total sample. The majority (65%) were married. Most caregivers presently had legal custody of their child, while 4% of the children and youth were legal wards of the state or of a juvenile court, and another 6% were of the age of majority at the time the questionnaire was completed.

## Preliminary Findings

### Family and Child Characteristics

All told, 492 primary caregivers returned usable questionnaires. Of these, 372 were caregivers of children or youth who had received services while at home; 120 were caregivers of children or youth who had received out-of-home services during the time period measured by the study (September 1<sup>st</sup>, 1996 through August 31<sup>st</sup>, 1998). There were few significant differences between the two groups of caregivers, and thus the following demographics are for the sample as a whole. Reflecting the composition of the family support groups that

Regarding the children and youth whose (most recent) placement or (most important) treatment was used as the referent for questions regarding participation in treatment and education planning, there were several differences between the “in-home” and “out-of-home” groups, as noted in Table 1 (page 147).

Finally, the most common diagnoses reported by parents of the combined groups were as follows: Attention Deficit Disorder or Attention Deficit/Hyperactivity Disorder, 56%; Learning Disabilities, 32%; Oppositional Defiant Disorder, 29%; Bipolar Disorder, 27%; “Serious Emotional Disorder” (SED) or “Emotional or Behavioral Disorder,” 22%; Depression, 21%; and Developmental Disabilities, 20%.

**Table 1. In-Home and Out-of-Home Characteristics**

Variable	In-Home n = 371	Out-of-Home n = 120	Total n = 491
<b>Age Mean (Range)</b>	13.32 (4-22)	15.88 (3-23)	13.95 (3-23)
<b>Age of first mental health problem Mean (Range)</b>	4.94 (1-18)	5.94 (1-16)	5.18 (1-18)
<b>Age of first services Mean (Range)</b>	6.28 (1-17)	7.07 (2-16)	6.47 (1-17)
<b>Medication taken for mental health problem</b>	88.4%	97.5%	90.6%
<b>Gender</b>			
<b>Male</b>	75.5%	72.5%	74.7%
<b>Female</b>	24.5%	27.5%	25.3%
<b>Race/Ethnicity [% (n)]</b>			
<b>White/Caucasian</b>	82.7% (302)	78.4% (91)	81.7% (393)
<b>Black/African American</b>	5.5% ( 20)	8.6% (10)	6.2% ( 30)
<b>Asian &amp; Pacific Islander</b>	1.1% ( 4)	.0% ( 0)	.8% ( 4)
<b>Hispanic</b>	3.3% ( 12)	2.6% ( 3)	3.1% ( 15)
<b>Native American</b>	.5% ( 2)	3.4% ( 4)	1.2% ( 6)
<b>Biracial &amp; Multiracial</b>	6.3% ( 23)	6.9% ( 8)	6.4% ( 31)
<b>Other</b>	.5% ( 2)	.0% ( 0)	.4% ( 2)
<b>Diagnosis given to caregiver for child's condition</b>	95.7%	99.2%	96.5%

**Family Participation in Treatment and/or Service Planning and Review**

For this symposium, we focused on the degree to which families reported participation in, and to a lesser extent, review of treatment or service planning for their child. Responses to selected questions relevant to caregivers' participation are summarized in Table 2 (page 148). Overall, relatively high levels of participation were reported by families in this sample, with mean scores around 3 ("some") on a 4-point scale for most items. Of particular note are the aspects of service planning and review where statistically significant differences between "in" and "out-of-home" were present. Caregivers in the "out of home" group answered that there was less of a role for them in carrying out treatment plans ( $M = 2.77$  vs. 3.12), that the service planning fit their child's needs less well ( $M$

$= 2.82$  vs. 3.12), that they agreed with service planning to a lesser degree ( $M = 3.00$  vs. 3.22), that they were less able to influence planning for services ( $M = 2.75$  vs. 3.02), and that staff were less responsive to making changes in their child's service plan as a result of their suggestions ( $M = 2.50$  vs. 2.85).

**Supports and Barriers to Participation**

In addition, we reported on both quantitative and qualitative findings regarding barriers and supports to participation. Caregivers were asked to mark any relevant item from lists of potential supports and barriers they had experienced, and to then circle the "most important/greatest" barrier or support. They were also invited to describe "other" supports and barriers and to write comments about supports and/or barriers in general.

**Table 2. Participation Means for In-home and Out-of-home Services**  
**A lot = 4    Some = 3    A little = 2    Not at all = 1**

<b>Participation in Planning To What Extent...</b>	<b>In-home Mean</b>	<b>Out-of- home Mean</b>	<b>Total Mean</b>
Were you included in planning this treatment or service for your child?	3.12	2.97	3.09
Was your child included in planning for this service?	2.45	2.51	2.47
Were your ideas valued in planning this service for your child?	3.10	2.85	3.04
Were your family's values and culture taken into account when planning for your child?	2.94	2.79	2.90
Was there a role for you in carrying out the treatment or service?*	3.12	2.77	3.03
Did the service planning fit your child's needs?*	3.12	2.82	3.05
Did you agree with the service planning for your child?*	3.22	3.00	3.17
Were the needs/circumstances of your family considered in this planning?	3.02	2.77	2.96
Were you able to influence planning for this treatment or services?*	3.02	2.75	2.95
<b>Participation in Review of Service</b>			
How much did staff make changes in the service plan for your child as a result of your suggestions?*	2.85	2.50	2.76

\* Significant difference ( $p < .01$ ) between in-home and out-of-home.

**Table 3. Most Important Supports of Participation**

<b>Kind of Support</b>	<b>In-Home</b>	<b>Out-of- Home</b>	<b>Total</b>
Treated me with dignity and respect	11.3%	5.8%	10.0%
Made me feel my participation was important	9.4%	9.2%	9.3%
Provided a contact person	8.6%	10.8%	9.1%
Notified me with concerns	4.3%	15.8%	7.1%
Communicated with all relevant family members	5.4%	4.2%	5.1%
Encouraged all relevant family members to participate	4.6%	3.3%	4.3%
Supported transitions into or out of the service/program	4.6%	0.8%	3.7%
Other	3.2%	2.5%	3.0%
Added comments to records	2.4%	1.7%	2.2%
No response	36.3%	34.2%	35.8%

Taking a strengths-based approach, we described supports to participation first. The following “support” items were identified by at least half of our respondents (percentages are for the total sample): treated me with dignity and respect (72%), provided a contact person (64%), staff made me feel my participation was important (61%), I felt welcome at the program/service (58%), staff/provider returned phone calls (57%), provided a comfortable space (56%), flexible scheduling of meetings/appointments (52%), added my comments to records (50%), and notified me if they were concerned (50%). The “most important” supports of participation, summarized in Table 3 (page 148), revealed interesting differences between the two groups:

Regarding qualitative data, content analysis of caregivers’ comments revealed themes that both supported and went beyond the quantitative findings. Emergent themes around supports included advocacy by the family themselves; appropriate actions by school or education staff; accommodating, positive attitudes by professionals and a “program culture” that was family friendly; and open communication with professionals. The latter two themes in particular were illustrated in parents’ own words:

“Our family doctor and our pediatrician—a behavior specialist—were wonderful to work

with. They listen, believe what you say, and go out of their way to help us.”—Parent of a child receiving services while at home.

“We had a really good experience with staff at the residential treatment facility—we have learned to advocate as well as work as a team without offending staff so that doors close. Likewise, we’ve been open enough to suggestions so that we aren’t offended, thus keeping doors of communication open.”—Parent of a child receiving out-of-home services.

Caregivers reported lower incidence of barriers than supports; no single item was cited by more than 36% of the total sample. The most frequently-reported barriers included the following: lack of communication between staff in different programs (36%), my work schedule (31%), distance to services or program (26%), lack of open communication (22%), inflexible program/professional schedules (18%), negative staff attitudes (17%), no encouragement to participate (17%), unclear who to contact (16%), and the cost of transportation (15%). As in the case of supports, interesting—and predictable—differences arose between the two groups on their selection of “the greatest barrier to participation,” as Table 4 summarizes.

**Table 4. Most Important Barriers to Participation**

Kind of Barrier	In-Home	Out-of-Home	Total
My work schedule	12.9%	8.3%	11.8%
Lack of communication between staff in different programs or agencies	10.2%	8.3%	9.8%
Distance from service providers	4.8%	20.0%	8.5%
Other	10.2%	3.3%	8.5%
Negative staff attitudes about my family	6.2%	5.0%	5.9%
Lack of open communication	4.8%	4.3%	4.7%
Cost of child care	3.5%	0.0%	2.6%
Lack of opportunity or encouragement to participate	2.2%	3.3%	2.4%
Inflexible visiting and meeting schedules	2.2%	3.3%	2.4%
No response	35.5%	31.7%	34.6%

Families who responded to the invitation to write down their comments related to barriers and/or supports had a great deal to say about barriers in particular. Emergent themes from their comments included the lack of a family-centered philosophy, including unaccommodating, negative attitudes; barriers presented by poorly trained, and sometimes incompetent, staff; inappropriate (if not illegal) actions by school staff; a lack of service coordination and inadequate case management resulting in poor communication among service providers; strain on caregivers from multiple responsibilities and the sheer stress of caring for a child with an emotional or behavioral disorder; and system/provider “strain.” Illustrative examples of parents’ comments included the following:

“The plans for treatment and education were presented to me as ‘this is what we are doing and will be doing.’ My input was never a consideration.”—Parent of a child receiving out-of-home services.

“Communication is vital. I found out the nurse had records of his medication—teachers had no idea he was on anything—he was falling asleep in nearly *every* class. No one contacted me to ask or tell me about it.”—Parent of a child receiving services while at home.

“I have two young children with mental health diagnoses—scheduling is a problem, respite care is a problem, transportation is a problem.”—Parent of a child receiving services while at home.

### Improving Services and Supports to Children with SED and their Families

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As this presentation offered limited, preliminary findings, we were not able to offer clear cut recommendations for families, service providers, and policymakers. We were, however, able to identify a series of questions with clear implications for improving services and supports that ongoing analysis of this survey data will be able to address, including:

- ◆ What is the experience of families with regard to participation? In relation to treatment or service planning and review? In relation to educational planning/review? Are these experiences similar?

- ◆ What barriers to participation do families identify?
- ◆ What supports family participation?
- ◆ Does the experience and participation of families vary by custody status, living situation, demographic characteristics and/or other factors?
- ◆ What do families identify as goals they hope their children will achieve by age 21? How optimistic are families that their children will reach these goals? What might explain the differences among families with regard to goals and expectations?
- ◆ To what extent did service planning include attention to the needs of all family members? What services did families receive, and how helpful were they?
- ◆ What is the relationship between varying levels of family participation and family satisfaction, family empowerment, and the extent to which caregivers expect that their children will achieve important goals?

### Discussion / Consultation about Dissemination

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During the final portion of the presentation, participants were invited to offer feedback to the presenters on four questions (italicized below) related to dissemination of findings from the family participation study. A lively discussion brought out the following points, among others:

- ◆ Regarding *who needs to bear about the results of this study*, funders (like state legislatures), training institutions for service providers, residential treatment facilities, children’s mental health agencies and advisory/policy-making councils, professional groups, and family members themselves were all identified.
- ◆ In relation to *what form findings should be disseminated in*, participants came up with both traditional formats (conference presentations, newsletters) and emerging, creative formats (utilizing popular media like *Redbook* magazine, posting on “women’s websites” and e-mail listservs).
- ◆ Addressing *how this information can be used to make needed changes*, audience members suggested tying

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measures from the study into program evaluation and quality assurance loops. As one person expressed it, “If family satisfaction is in your contract, it becomes important.” The value of proving that “when parents are treated as partners, kids do better” was affirmed. We were advised to “think in terms of a public relations campaign,” using credible data to make people aware of the value of family participation.

- ◆ Finally, some participants spoke to *which aspects of needed change regarding family participation are most important to focus on*. Participants cited exploration of quantitative and qualitative findings around school/mental health system collaboration, looking at the power issues inherent in service provider/family relationships, and describing what “dignified” participatory treatment looks like for caregivers of varying backgrounds.

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