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Caregiver Participation in Service Planning in a System of Care

INTRODUCTION

One of the principles of the system of care is the full participation of caregivers and family members in all aspects of planning and treatment. This principle is in contrast to more traditional research and practice, which tends to define caregiver participation as caregiver receipt of services, such as individual counseling, family therapy, or parent training (Aeby, 1998; Ainsworth & Cowan, 1996; Brown, 1991; Davids, 1975; Mandelbaum, 1977), or amount of contact or visitation with a child receiving out-of-home treatment (Baker, Blacher, & Pfeiffer, 1993). Perhaps due to traditional training and philosophy, staff serving children with mental health problems may be resistant of fully inclusive caregiver participation and show support for caregiver involvement when it is defined as receipt of services rather than as an essential partnership in planning or providing services (Alwon *et al.*, 2000; Baker, Heller, Blacher, & Pfeiffer, 1995).

There is a significant amount of research, especially in child welfare and education, which shows that caregiver participation, variously defined, is related to a wide variety of positive child outcomes. Child welfare or residential treatment research, which tends to define participation as caregiver receipt of services, visiting an out-of-home placement, or caregiver training, has found that participation is related to positive outcomes such as improved child behavior (Cantos & Gries, 1997), faster reunification, and shorter stays in foster care (Benedict & White, 1991; Mech, 1985). Research in education has defined participation as contact with the teacher, helping with homework, involvement in school activities or field trips, and attending Individualized Education Plan meetings. Positive outcomes in this area include improved school

attendance and performance (Aeby, 1998) and faster development of school skills (Marcon, 1999). Research that specifically examines the direct relationship between caregiver participation in planning and treatment and child outcomes is sparse in child welfare and education. Surprisingly, even research on the relationship between caregiver participation in Individualized Education Plans and child outcomes is difficult to locate, and the relationship between participation in planning and outcomes appears lacking in the children's mental health field, as well. This presentation examined the relationships between caregiver participation in planning mental health services and satisfaction with services, types of services received, and child functioning.

The data from this study comes from the Clark County Washington Children's System of Care evaluation. In 1999 the county received a Comprehensive Community Mental Health Services for Children and Their Families Program grant, funded by the federal Center for Mental Health Services.

METHOD

Families qualified for the evaluation if their child (5 to 17.5 years old) needed services in mental health and another service system (school, juvenile justice, child welfare, etc.), had a disability that was expected to last for more than one year, and had a Global Assessment of Functioning score below 50. Randomly selected caregivers and youth (11 to 18 years old) were interviewed after intake, and followed every six months for up to three years. Sixty-one percent of youth were male, and the average age of the youth at intake was 13 years. Reflective of Clark County's racial profile, most of the youth were white (84.5%), with much smaller percentages of biracial (6%), Hispanic (4%), African-American (3.5%), and Asian (2%) ethnicities. Caregivers participating in the interview were overwhelmingly female (93.5%), and the median range of family income was \$15,000-\$19,999 per year.

Caregivers and youth each completed a five-item version of the Family Participation Measure (FPM; Friesen & Pullmann, 2001). The FPM measures caregiver participation in planning services and

treatment. In this study, we asked caregivers to identify the service that best met their family's needs and rate their participation in this service. This study used five items of the FPM:

1. Were your ideas valued in planning this service for your child?
2. Were your family's values and culture taken into account when planning for your child?
3. Did you agree with the service planning for your child?
4. Were the needs/circumstances of your family considered in this planning?
5. Were you able to influence planning for this treatment or service?

Caregivers and youth only completed the measure if they reported that they had received mental health services or supports during the previous six months.

At intake and six-month follow-up, we asked caregivers about the amount of work they missed due to their child's services, the increased amount of work they were able to attend as a result of their child's services (this could be due to flexibility in scheduling meetings or improved child behavior), their levels of free time, and the amount of strain that they felt as a result of their child's functioning. Caregivers and youth were also asked to identify and rate their satisfaction with the services they received between baseline and six months. To measure child functioning for this analysis, we used the caregiver-reported Child and Adolescent Functional Assessment Scale (CAFAS; Hodges, Doucette-Gates, & Liao, 1999), the Child Behavior Checklist (CBCL), and the self-report version of the CBCL, the Youth Self Report (YSR; Achenbach, McConaughy, & Howell, 1987).

RESULTS

At the time of the analysis, we had completed intake and six-month follow up interviews with 124 caregivers and 67 youth. Of those, at six-month follow-up, 24 caregivers (19.4%) and 17 youth (25.4%) reported that their family did not receive services during the previous six months. In most cases, this

was because the family did not return for services or was discharged after the first few sessions.

Services Received

Of those that reported receiving services between intake and six months, the most commonly reported were traditional services such as individual therapy (89% reported), medication (70%), assessment/evaluation (66%), and case management (23%); these were reported more frequently than innovative services or supports such as family support (18%), wraparound (14%), family preservation (11%), and flexible funding (10%).

Participation

Because 24 families reported not receiving services and 10 did not answer at least four out of the five FPM questions, we had FPM data on 90 caregivers. These caregivers reported high levels of participation in planning: out of a range of 1 to 4, with 4 being the highest level of participation, the mean was 3.4. The distribution of scores was highly negatively skewed (skewness = -1.4), with 52% reporting that they had the highest level of participation possible.

We had complete participation information from 32 youth. The distribution of youth scores was less extreme, with a mean of 3 and a skewness of -.5. However, because both participation distributions were skewed, for analysis we divided the participants into two categories: high participation (above a score of 3) and low participation (a score of 3 or below). This put 71% ($n = 64$) of caregivers and 62% ($n = 20$) of youth into the high participation group. Participation scores were not significantly related to demographics, including the caregiver's age or level of education, family income, number of people in the family, or child's age.

Participation, free time, strain, and employment

A commonly mentioned reason for not encouraging caregiver participation is to prevent another potential stressful demand to a caregiver's already busy life. To test this assumption, we ran several statistical tests examining the differences between high and low participators on their ratings of missed work, free time,

and caregiver strain. Between high and low participators there was not a significant difference in the caregiver reported amount of missed work *caused by* services; however, high participators were significantly more likely to report that the services they received *helped* them miss fewer days of work (26% of those in the high participation group vs. none in the low participation group, $p < .05$). Thus, high participation scores were related to missing less work as a result of the services received.

Furthermore, participation did not appear to be an additional drain on the time of caregivers. An examination of caregivers' rating of the adequacy of their free time revealed no differences between high participators and low participators at baseline or six months. Finally, while high participation at six months was related to higher caregiver strain scores at both intake and six months, there were no significant differences in the trend of caregiver strain over time, from intake to six months. High and low participators reported their levels of caregiver strain decreased at equal rates. Thus high participation did not appear to be related to increased strain over time.

We believe that the single time point differences are a result of multicollinearity: caregivers in the high participation group had children with more problems in functioning, and our past research found that child functioning is the greatest single predictor of caregiver strain (Pullmann, Savage, & Koroloff, 2002). In all of the analyses above, we found no evidence supporting the assumption that high levels of participation in planning services is more burdensome than low levels of participation.

Participation and satisfaction

Caregivers in the high participation group were significantly more likely to report that the services their family received were helpful than those in the low participation group (95% vs. 81%, respectively; $p < .05$). Youth in the high participation group were also more likely to report that the services they received were helpful (94% vs. 47%; $p < .05$). Table 1 depicts caregiver and youth ratings of satisfaction with services, divided into high and low participators; it

shows that caregivers in the high participation group reported significantly higher levels of satisfaction with services on all seven general satisfaction questions, and youth reported significantly higher levels of satisfaction on six of the seven questions.

Table 1: Mean satisfaction ratings, split by levels of participation

Satisfaction with...	Caregiver mean satisfaction score (n = 90)		Youth mean satisfaction score (n = 32)	
	Low part.	High part.	Low part.	High part.
	(5 point scale; 5 is more satisfaction)			
services, overall	3.2	4.0**	3.2	4.1*
provider's respect for family's beliefs about mental health	3.7	4.2*	3.5	3.9
provider's understanding of cultural traditions	3.6	4.3*	3.5	4.2*
provider's ability to find strengths-based services	3.0	4.6**	3.4	4.2*
his/her level of involvement	3.1	4.1**	3.3	4.2*
number of times he/she was asked to participate in meetings	3.2	4.1**	3.0	4.1*
progress during previous six months	3.1	3.8*	3.3	4.2*

* $p < .05$; ** $p < .01$

Participation and child functioning

Six separate t-tests were performed on the functioning measures by level of participation. Results showed significant differences on the CAFAS at intake and the CBCL at six-month follow-up (See Table 2); in both cases caregivers in the high participation group had children with more problems. On two of the three measures of functioning, repeated measures ANOVAs revealed that youth with caregivers in the high participation group showed significantly higher rates of improved functioning (CAFAS, $p = .025$; YSR, $p = .066$; see Table 2). We allowed the significance level for the YSR to be slightly more liberal than the

traditional level of .05 because of low power due to the small sample size.

Table 2: Mean functioning scores, separated by level of participation and timeframe

	Mean intake score ¹	Mean six-month follow-up score ¹	Change ²
CAFAS			
High participation (n = 61)	128**	103	-25**
Low participation (n = 25)	97	96	-1
CBCL			
High participation (n = 62)	74	70**	-4
Low participation (n = 24)	69	64	-4
YSR			
High participation (n = 30)	65	59	-6*
Low participation (n = 14)	59	58	-1

* $p < .10$, ** $p < .05$

- 1 Mean scores between participation levels were compared with t-tests at intake and six months.
- 2 Changes over time between levels of participation were compared using repeated measures ANOVAs.

CONCLUSIONS

Caregiver participation in treatment and service planning is an understudied area in children's mental health, especially concerning its impact on child functioning. On two of our three measures of functioning, children who had caregivers with high levels of participation showed more improvement than children who had caregivers with low levels of participation. Additionally, we not only found this to be true between caregiver-reported measures (the CBCL and FPM), we also found this relationship to be true from separate reporters (the Youth Self Report and caregiver-reported FPM). While participation appeared to be related to improved youth functioning, it did not appear to be related to an increased burden for caregivers. High participators did not report an increased negative impact on their time, strain, or work

life, when compared with low participators. High participators, both caregivers and youth, also reported more satisfaction with the services they received and that the services they received were more helpful. These findings emphasize the importance of respecting, valuing, and fully involving caregivers and youth in the treatment and services planning process.

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