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Is Caregiver Participation in Service Planning Related to Child Outcomes?

INTRODUCTION

There is little consistency among researchers regarding a uniform conceptual definition of caregiver participation and involvement in children's mental health services (Curtis & Singh, 1996). (The terms *participation* and *involvement* are used interchangeably here.) This consistency is lacking even in educational research (Baker & Soden, 1998), the discipline with the largest number of studies on caregiver participation. Traditional research in children's mental health has loosely defined caregiver participation in a number of ways, including caregiver compliance with services such as family therapy or parent training (Aeby, 1998; Ainsworth & Cowan, 1996; Kazdin, 1997) or amount of contact or visitation with a child receiving out-of-home treatment (Baker, Blacher, & Pfeiffer, 1996). A small amount of research has also focused on more non-traditional roles for caregivers. These include viewing caregivers as treatment providers who informally volunteer services such as case management and service coordination, and examining caregiver participation more globally by looking at family members as advocates and policymakers (Friesen & Stephens, 1998).

As the conceptual definition of caregiver participation is inconsistent, vague, or absent within and across disciplines, not surprisingly, the operational definition of participation is also inconsistent. Participation has been operationalized as caseworker and case record information on the number of times a child in out-of-home treatment was visited by their parent (Cantos & Gries, 1997), parent's perceptions of their involvement in planning

and/or treatment (Curtis & Singh, 1996; Wilson, 1999), and parent attendance at therapy and trainings (Aeby, 1998).

The specific caregiver role of participation in planning treatment and services has received some attention due to team-based planning processes such as wraparound (Epstein et al., 2003). However, there are few methodologically sound studies which examine the effectiveness of wraparound (Bickman, Smith, Lambert, & Andrade, 2003), and we found none that specifically examine the relationship between caregiver participation in planning services with child functioning.

This study expands the scant literature on the caregiver role of participation in treatment and service planning. We propose that the quality of participation is an important influence on youth functioning. We also examine the various child, caregiver, and family characteristics that may be related to high quality participation. In our view, high quality caregiver participation consists of the following characteristics: 1) Decision-making and authority is shared between the caregiver, service provider, and administrators; 2) Service providers, administrators, and caregivers must take on new and innovative roles—this includes transforming from the roles of service provider as ‘expert’ and the family as ‘client’ to an equal partnership; 3) Caregivers feel empowered; 4) There is a working level of trust among caregivers, service providers, and administrators. Our hypothesis is that high quality caregiver participation in service planning will lead to higher quality services and increased caregiver investment in treatment, which will lead to improvements in youth functioning.

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.

To measure child functioning for this analysis, we used three measures: 1) the caregiver-reported Child and Adolescent Functional Assessment Scale (CAFAS; Hodges, Doucette-Gates, & Liao, 1999), 2) the Child Behavior Checklist (CBCL), and 3) the youth self-report version of the CBCL, aptly titled the Youth Self Report (YSR; Achenbach, McConaughy, & Howell, 1987). These were completed at baseline and 6 month follow-up.

Six months after intake, caregivers 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?, and 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.

RESULTS

Fifty-three participants stated that they had received no services between intake and six-month follow-up. In most cases, this was because the family did not return for services or was discharged after the first few sessions. These participants were excluded from the analysis, leaving a sample size of 175.

Participants

Participants were 175 caregivers and 78 youth. Youth were 61% male and had an average age of 12.2 ($SD = 3.3$). Youth were 87.9% Caucasian, 7.3% Hispanic, 6.3% American Indian, 4.5% African American, and 1% Asian (numbers add to more than 100% because

multiple race/ethnicities could be endorsed). Most youth were in the custody of their biological mother only (50.3%), or two parents with at least one biological (24.3%). Caregiver respondents were mostly biological parents (75.1%), 94% female, with an average age of 39.9 ($SD = 8.8$). The mean range of family income was \$15,000-19,999.

Services received

Caregivers reported that their family or child received individual therapy (78%), medication (66%), case management (40%), wraparound (27%), family therapy (18%), group counseling (11%), and smaller numbers of other services.

Participation scores

Six months after intake, high levels of participation were reported; on a scale of 1 to 4, caregivers rated a mean score of 3.5. The distribution was negatively skewed (skewness = -1.6), so for analysis we divided caregivers into two groups that we named high-quality participation (HQP; score greater than 3) and low-quality participation (LQP; score of 3 or below). After this grouping, 73.1% ($n = 128$) of the sample was in the high-quality participation group.

Caregiver characteristics and participation

Several analyses were run examining possible relationships between caregiver characteristics and participation. Using the dichotomous independent variable of high/low quality participation, several t -tests were run with caregiver age, level of education, adequacy of transportation, adequacy of social support network, and caregiver strain as dependent variables. Two chi-square tests were run using caregiver's relationship to the child (birth parent, foster parent, extended family member, etc.) and gender as the dependent variables. None of the tests were significant ($p > .05$), revealing no relationships between caregiver variables and participation.

Child characteristics and participation

Similarly, several Analysis of Variances (ANOVAs) were run using the dichotomous independent variable of participation and the dependent variables of child

age, number of living situations during the previous 6 months, grade level, CBCL total problem score and subscales, BERS total score and subscales, CAFAS total score and subscales, Global Assessment of Functioning, and the YSR total problem score and subscales. Several chi-squares were also run featuring the dependent variables of race/ethnicity, gender, previous service usage, previous suicide attempts, self-reported criminal or aggressive behavior, current attendance in school, special education status, school detention, Individualized Education Plan status, juvenile justice detention, use of medication, ever been arrested, and lived in any restrictive setting during the previous 6 months. Most of these analyses were not significant ($p > .05$).

A few of the ANOVAs and chi-square tests were significant (see Table 1). HQP caregivers were significantly more likely to report at intake that their child was on psychotropic medication, and less likely to report that their child had been in a group home, shelter, or residential treatment at any time in the previous 6 months. Caregivers with high-quality participation scores at six month follow up were also more likely to report that their child had more problems in functioning at intake on several measures, including the CAFAS total score, the CAFAS community subscale, the CAFAS moods/emotions subscale, the CAFAS school subscale. HQPs were more likely to have youth that rated themselves as having more problems on the YSR externalizing subscale.

Family characteristics and participation

Several ANOVAs and chi-square tests were run examining the relationship between participation and family income, number of children in household, number of adults in household, family resources, and caregiver and youth ratings of family functioning from the Family Assessment Device (FAD; Miller, Bishop, Epstein, & Keitner, 1985). There were no significant relationships.

Table 1
Significant Relationships between Child Characteristics and Participation

Variable	<i>n</i>	Low part. mean / %	High part. mean / %	<i>F</i> / χ^2	<i>p</i>
CAFAS Total problems	173	115	133	4.3	.04
CAFAS Community	173	6.4	12.1	6.5	.011
CAFAS Mood/emotions	173	19.3	23.1	6.2	.014
CAFAS School	173	21.1	24.8	4.9	.028
YSR Externalizing	88	59	64	4.1	.046
Psychotropic medication at intake	173	35%	63%	10.9	<.001
Lived in group home, shelter, or residential treatment intake to 6 months	173	15.2%	5.5%	4.3	.037

Table 2
Significant Relationships between Satisfaction and Participation

Variable <i>n</i> = 173	Low part. mean	High part. mean	<i>F</i>	<i>p</i>
Overall satisfaction	3.1	4.0	21.1	<.001
Satisfaction with provider's respect for beliefs about mental health	3.6	4.2	11.7	<.001
Satisfaction with provider's understanding of cultural traditions	3.5	4.2	12.8	<.001
Satisfaction with provider's ability to find strength-based services	3.2	4.0	19.6	<.001
Satisfaction with level of involvement in planning	3.2	4.1	22.6	<.001
Satisfaction with number of times asked to participate in meetings	3.2	4.1	19.0	<.001
Satisfaction with child's progress	3.3	3.8	6.4	.012

Table 3
Means and Standard Deviations for Repeated Measures Analysis

Measure	Participation	Baseline M (SD)	6 month follow-up M (SD)
CAFAS	Low	114 (54)	105 (49)
	High	133 (48)	108 (52)
CBCL	Low	71 (11)	68 (13)
	High	74 (9)	70 (11)
YSR	Low	58 (10)	57 (14)
	High	64 (9)	60 (11)

Satisfaction and participation

Several ANOVAs were run using the dichotomous measure of participation at six month follow up as the independent variable and several caregiver rankings of satisfaction at six month follow up as the dependent variable. All of these were statistically significant, with HQPs more likely to rate themselves as satisfied (see Table 2).

Changes in functioning and participation

Three repeated-measures ANOVAs examining change over time were run using CAFAS, CBCL, and YSR total problem scores as dependent variables and blocked on the dichotomous measure of participation.

For the CAFAS total score, the within-subject main effect (baseline to six months) was significant: overall, youth's functioning scores improved over time, $F(1, 167) = 20, p < .001$. The within-by-between subjects interaction was also significant: from baseline to six month follow-up, those in the high-quality participation group reported that their youth improved more than those in the low-quality participation group, $F(1, 167) = 4.7, p = .032$.

For the CBCL total score, the within-subject main effect was significant: overall, youth's functioning scores improved over time, $F(1, 161) = 21.6, p < .001$. There was no significant interaction: high participators did not report that their child's functioning changed differently than low participators. For the YSR total score, there was not a significant main effect or interaction.

CONCLUSION/SUMMARY

This analysis found that caregivers' reports of their feelings on participation were not related to family demographics, including education, income, and age. Caregivers of all types felt like they had quality participation in planning their child's treatment. High-quality participators had youth with more problems at intake, were more satisfied with the services they received and, according to one measure of youth functioning (the CAFAS total score) high-quality participators had youth that improved at a faster rate than low participators. On the other two measures

(the CBCL total problem score and the YSR total problem score), youth functioning improved at the same rate for those in the high and low-quality participation groups.

This study is limited in several ways. First, the participation groups were naturally occurring and the measures were almost entirely caregiver self-report. Because of these two interrelated issues, the participation groups may not have been fully comparable; some evidence supports this. Although they did not differ on most demographic measures, caregivers in the HQP group were more likely to report that their child had more problems with functioning at intake. Second, the participation distribution was skewed towards high-quality participation. This may have been due to the fact that the participation measure was the last of a very lengthy (up to two hours long) interview process and participants were exhausted. Third, there were a large number of caregivers that reported receiving no services from intake to six months—53 (23%) of the 228 possible. Most of these participants probably received a small amount of services and, had we been able to complete the participation measure with them, may have altered the participation distribution.

Regardless of these limitations, these findings provide some support for the argument that high-quality participation is associated with improved services and treatment. Additionally, caregivers can feel like they are participating in planning their child's treatment regardless of their socioeconomic status and other family obligations.

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