

Chapter Eight

Family Involvement & Perspectives

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Predicting Family Participation in Service and Treatment Planning for Children in Out-of-Home Care

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Introduction

Full participation of caregivers in planning, implementing, and evaluating services for their children with emotional, behavioral, or mental disorders is a fundamental principle of the system of care philosophy (Stroul & Friedman, 1996; U.S. Department of Health and Human Services, 1999a). As ideas about family participation have become more developed over the last two decades (Koroloff, Friesen, Reilly, & Rinkin, 1996; Friesen & Stephens, 1998), research and evaluation efforts related to family participation in children's mental health have also increased.

With a view to maximizing the effectiveness of family participation, researchers have worked on defining family participation (Cone, DeLawyer, & Wolfe, 1985; Singh, Cohen, & Nicholson, 1992), described the nature, amount and/or quality of family participation (Baker, Blacher, & Pfeiffer, 1993; Curtis & Singh, 1996; Schacht, Pandiani, & Maynard, 1996), investigated family and system-level outcomes associated with family participation (Tam & Ho, 1996; Williams, 1998), and have worked to understand factors that may support or inhibit participation (Baker & Blacher, 1993; Johnson, 1998). The research has been concerned with family participation across settings (i.e., when children are either living at home and receiving services or in out-of-home placements).

For children in out-of-home settings, achieving meaningful family participation may be complicated by family circumstances or agency practices. Among the studies that attempt to explain family participation, some studies have focused almost exclusively on family characteristics such as income, parents' education, or family structure (Cone et al., 1985; Fantuzzo, Tigue, & Childs, 2000). Studies of this type do not add much to advancing family participation, in that they focus on variables that are not amenable to change through intervention. This approach can be seen as implicitly blaming family, in that it appears to place the responsibility for participation entirely with the family, and does not acknowledge the responsibility of programs or facilities.

Researchers have examined the relationship between family participation and organizational, system, or policy variables including Baker et al. (1993), who looked at issues such as distance from the facility, visiting policies, and staff attitudes, and Johnson (1998) who examined differential treatment of families depending on whether or not their children's care was funded privately or with public funds, and Alwon, et al. (2000) who studied a systematic effort to change agency policies and practices, as well as staff attitudes in a network of residential programs. In addition, case studies such as Noble and Gibson's (1994) description of a change effort in a single program, are also instructive.

This study was undertaken to learn more about possible predictive factors that may explain variation in family participation in treatment planning when their children are in out-of-home care. A central question concerns the relative contribution of family and child characteristics, as compared to policies or practices employed by the out-of-home placement. The aim is to identify policy-relevant variables that are amenable to intervention, especially those factors that can be changed within agencies or systems of care.

Method

This analysis was conducted as part of a larger study of family participation in children's mental health services. The Family Participation Survey addressed topics such as educational planning and review, caregiver empowerment, and involvement in decisions about the child's daily life. We hypothesized that:

1. Caregiver participation would vary by family and child characteristics;
2. Caregiver participation would vary by of placement characteristics; and that
3. Placement characteristics would uniquely contribute to differences in participation over and above those of family characteristics.

Sampling

Our cross-sectional study utilized a convenience sample recruited through randomly selected chapters of the Federation of Families for Children's Mental Health and other family organizations, in addition to the Research and Training Center mailing list. Eligible participants were caregivers with long-term responsibility for youth aged 0-20 who received three months or more of treatment for their emotional, behavioral, or mental disorders between September 1, 1996 and August 31, 1998, and were living at home or in an out-of-home placement. Four hundred eighty-nine surveys were returned from 46 states resulting in a usable completion rate of 56.6%. This analysis focuses on a subset of the sample, the responses from 105 caregivers whose children received out-of-home care in one of three settings: residential treatment centers (64.8%), psychiatric hospital/units (21.9%), and group homes (13.3%).

Measures

Participation was measured using the Family Participation Measure (FPM; Friesen & Pullmann, 2001). The FPM is an ordinal scale measure (1 = *Not at all* to 4 = *A lot*) of participation in service and treatment planning for children with emotional or behavioral disorders. Caregivers were asked about participation during their child's most recent out-of-home placement lasting 30 days or more. Items asked the extent to which: (1) they were able to influence planning; (2) their family's needs/circumstances were taken into account; (3) their ideas were valued in planning; (4) they agreed with the plan; (5) staff listened to ideas during planning review; (6) the family's values and culture were taken into account; and (7) staff made changes based on ideas in review. Reliability estimates demonstrated high internal consistency ($\alpha = .95$). Average scale scores were 2.9 (range 1-4, $SD = .90$).

Caregivers were asked if parent-child contact was limited for an initial period of adjustment after placement (57.1% = Yes) and whether subsequent parent-child contact was contingent upon the behavior of the child (59%), the caregivers (12.4%), and/or peers' in the living or treatment unit (16.2%). Respondents were also asked about the number of activities parents were permitted to engage in with their child at the facility (e.g. sharing meals, going to medical/dental appointments). Finally, caregivers were asked about how much they felt encouraged to participate in activities while their child was in out-of-home care. Nineteen percent (19%) responded *Not At All*; 22% *A little*; 36% *Some*; and 23% *A lot*.

Results

Seven male caregivers and 98 female caregivers reported on 76 male and 29 female children. Birthmothers constituted 69.5% of respondents, and adoptive mothers made up 18.1%. Over half of caregivers had a college degree and the median yearly household income was \$48,000 per year. Based on U.S. household income data (U.S Department of Health and Human Services, 1999b; U.S. Census, 1999), 15% of respondents were at or below the poverty threshold, 22% low-income, 41% middle-income, and 23% upper-income. Respondents reported an average household size of 3.4 ($SD = 1.3$) persons. Seventy-nine percent (79%) had legal custody of the child at the time of placement.

Children were 78.1% Caucasian, 8.6% were African-American, with 6.8% multiracial, 2.9% Hispanic, and 1.9% Native American. The average age was 15.8 years (range 3-23, $SD = 3.4$). Ninety percent (90%) of the children had more than one diagnosis ($M = 3.97$, $SD = 2.13$). The most common diagnoses reported were attention deficit hyperactivity disorder (49.5%), bi-polar disorder (42.9%), and oppositional defiant disorder (40%). Youths, on average, received out-of-home care 1.55

times during the two-year study period for an average of 13.7 months per occasion. Sixty-seven percent (67%) of youths had just one out-of-home placement. In addition to general demographic information describing caregiver and child, we asked questions about the age at which the child first experienced difficulties ($M = 3$ years, $SD = 3.77$) and first received mental health services ($M = 6$ years, $SD = 3.74$). We also assigned a severity rating to each child based on the number of diagnoses reported and the number of years the child had been experiencing difficulties ($M = 13.6$, $SD = 4.9$).

A bivariate analysis of the relationship between the FPM and independent variables is shown in Table 1. Interestingly, several family and placement characteristics hypothesized to be related to participation were not so related (i.e., severity, income category, initial limits on parent-child contact, contingencies, and distance to placement). This may be an artifact of homogeneity in the caregiver sample (e.g. race, sex). Nevertheless, four of the variables that were nonsignificant at the bivariate level (severity, income category, initial contact limited, and contingencies) were included in the multivariate analysis because they have been reported on in previous studies of family participation.

A hierarchical multiple regression analysis was performed using SPSS version 10.0. The model was significant, explaining 36% of the variance (see Table 2). Two family characteristics were found to be predictive of participation—family income and marital status. One placement characteristic—activities permitted—was moderately so, while the most significant predictor by far was the perception of caregivers that the placement actually encouraged them to participate in their child’s service and treatment planning.

Table 1
Bivariate Analysis of FPM
and Independent Variables

	<i>Participation</i>
Education	-.128
Income	.013
Household Income Category	-.068
Custody Status	.208*
Distance to Treatment	.008
Severity Rating	-.057
Income category	-.077
Marital Status	.260**
Initial Contact Limited	-.026
Contingency	-.131
Activities Permitted	.360**
Encouragement to Participate	.571**

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

Table 2
Hierarchical Multiple Regression Analysis
of Family and Placement Characteristics

	<i>Model 1</i>		<i>Model 2</i>		<i>Model 3</i>		<i>Model 4</i>		<i>Model 5</i>	
	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>	β	<i>p</i>
Severity Rating	-.01	.583	-.006	.738	-.0001	.990	-.008	.628	-.0002	.991
Custody Status			.458	.049	.408	.070	.353	.104	.305	.117
Household Income Category					-.209	.039	-.242	.014	-.190	.031
Marital Status					.603	.003	.430	.033	.370	.039
Activities Permitted							.08	.003	.002	.503
Contingencies							-.406	.040	-.345	.051
Initial Contact Limited							.246	.198	.177	.301
Encouragement to Participate									.410	<.001

$F=7.573$; $df=(1, 86)$; $Adj. R^2=.359$; $p<.001$

Discussion

Our study supports previous findings demonstrating the relationship between caregiver and child characteristics and participation. In addition, we found that when caregiver characteristics are statistically controlled for, participation varied with reported differences in placement characteristics such as contingencies for parent-child contact and perceived encouragement to participate. This research also supports the idea that out-of-home service provision should include opportunities for caregivers' meaningful involvement in their child's treatment and encourage caregivers to utilize those opportunities to participate (e.g. scheduling meetings at times convenient for caregivers). Further research is needed to understand the mechanisms by which agency policies and procedures impact caregiver participation and to understand their impact on outcomes for children.

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Parent Satisfaction with Mental Health Services: Relationship to Outcomes

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Introduction

With concerns about inadequate services and the emergence of new care delivery models, there has been a need to assure that children with mental health problems and their families receive appropriate services (Boyd, 1994; Junek & Thompson, 1999; Knitzer, 1993; Megivern, Halm & Jones, 1992; Plante, Couchman & Diaz, 1995). One component used to assess service adequacy has been assessment of parent satisfaction. Concerns have existed, however, about methodological and theoretical problems in parent satisfaction measurement. Concerns include lack of psychometric support for many parent satisfaction instruments, highly positive responses with limited variability, response bias caused by non-respondents and social desirability, and use of global versus specific items that result in only finding that parents were generally happy, but not gaining specific, useful information for service improvement (Gerkenmeyer, 1999; Young, Nicholson & Davis, 1995). With these identified problems, the perceived value of measuring parent satisfaction has decreased among researchers and service providers.

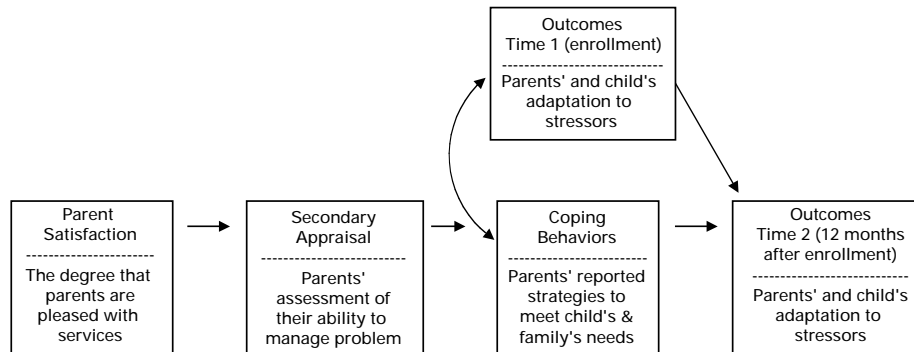
To address these methodological concerns, Gerkenmeyer and colleagues developed and tested a parent satisfaction scale that had adequate support for validity and reliability, provided specific versus global information, and could be used across studies and settings (Gerkenmeyer, McBride, Finke & Austin, 1996). To address the need for theoretical frameworks to better understand the underlying determinants of parent satisfaction, Gerkenmeyer and colleagues conducted a study with parents of students receiving special education for mental health problems; exploring the relationship of parent satisfaction to other variables such as demographics, attributions about their child's illness, caregiver strain, and parents' ratings of parent and staff interactions (Gerkenmeyer, McBride, Feaster & Austin; 1997). Utilizing information gained from this study, a consumer satisfaction model was developed and tested.

Data, from another study with parents of children with serious mental health problems being served by one of five treatment programs in a mid-western state, were used to test the consumer satisfaction model (Gerkenmeyer, 1999). Structural equation modeling indicated a good fit between relationships proposed in the model and data with some revisions. Although this study focused on variables influencing parent satisfaction; the variable, pessimism, emerged as being influenced by parent satisfaction. When parents were more satisfied, they were less pessimistic about the changeability of their child's mental health problems and about services' impact on maintaining improvement in the future. This finding lent support for this study's research question: Does parent satisfaction influence outcomes?

Gotlieb and colleagues (1994) tested and found support for a model where met expectations and met desires influenced satisfaction; and satisfaction influenced behavioral intentions to engage with services. They described their model as similar to Lazarus' general framework of appraisal where appraisal (the extent that desires and expectations were met) led to an emotional response (satisfaction), that, in turn, led to coping. The Satisfaction-Outcomes Relationship Model (SORM) was adapted from Gotlieb, et al.'s model for use in this study (see Figure 1). In SORM, parent satisfaction (the degree that parents are pleased with services) was proposed to influence secondary appraisal (parents' assessment of their ability to act on their own or their child's behalf to increase control over their child's and family's mental health needs). Secondary appraisal was proposed to influence coping behavior (strategies parents use for problem management to meet their child's and family's mental health needs). Coping behavior was proposed to influence outcomes (parents' and child's adaptations to stressors; Lerman & Glanz, 1997).

Parent satisfaction may be more than a desired outcome. It may also influence other outcomes. There are limited and contradictory findings about the direct relationship of parent satisfaction with other outcomes (Rey, Plapp & Simpson, 1999).

Figure 1
The Satisfaction-Outcomes Relationship Model



Adapted from: Gotlieb, Grewal & Brown (1994), and Lerman & Glanz (1997).

Purpose. The purpose of this study was to systematically investigate the relationship of parent satisfaction with mental health services for children to other outcome variables by testing the Satisfaction-Outcomes Relationship Model. It may be that parent satisfaction has an indirect relationship to other outcomes by influencing intermediate outcomes such as parents' appraisal of their ability to cope with their child's mental health problems.

Data Analysis. Descriptive statistics were used to describe the sample. Pearson's correlation coefficients were used to summarize inter-relationships among study variables (see Table 1). Data reduction was done on the Family Empowerment Scale (FES) (Koren, DeChillo & Friesen, 1992) and the Family Satisfaction Questionnaire (FSQ) (Rouse, McCabe & Toprac; 1996) using exploratory factor analysis (see Table 2 and 3 for salient factor loadings). Structural Equation Modeling (SEM) using AMOS 4.0 was used to estimate and test the model. A model generating approach was used with SEM in which a variety of revisions of the model and a variety of combinations of available data were used in an effort to obtain a good fit between the model and data without compromising the conceptual meaning of the model (Joreskog, 1993).

Methodology

Design. Existing data from Phase I evaluation of the Center for Mental Health Services' Comprehensive Community Mental Health Services for Children and their Families Initiative were utilized after obtaining Institutional Review Board approval. The evaluation included 22 sites funded by competitive program grants. There were 44,640 children and their parents or caregivers participating in this longitudinal, repeated measures design with data collection at intake and every six months, thereafter, up to 24 months. Specific site identifiers were removed from the data.

Sample. After data cleaning to assure that all instruments needed for this study were completed, 1284 participants remained. The children's average age was 11 years and 67% were males. The majority, 68%, were Caucasian. Of 1245 reporting, 1061 of the children were living at home. About 52% of household incomes were less than \$15,000 per year.

Instruments. Upon initial review, it appeared that items within the instruments used in the Phase I evaluation would potentially provide adequate operationalization of SORM's conceptual variables (see Figure 2). Factor analysis of the FES and FSQ provided factors that appeared to represent the concepts well (see Table 2 and 3). Each of these factors had acceptable internal consistency reliability except for the FES factor, Informed ($\alpha = .62$; see Table 2 and 3).

Table 1
Satisfaction-Outcomes Relationship Model Correlations

Construct	Collected	Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15		
Family Empowerment Scale	Appraisal	6 m	1. Parent Satisfaction	--															
		6 m	2. Dealing with service	-.322**	--														
		6m	3. Child Focus	-.265**	.602**	--													
		6 m	4. Informed	-.127**	.621**	.575**	--												
	Coping	6 m	5. Assertive	-.131**	.575**	.470**	.534**	--											
		6 m	6. Advocacy	-.128**	.625**	.474**	.497**	.462**	--										
		6 m	7. Coping Factor Score	-.233**	.695**	.606**	.609**	.623**	.548**	--									
		6 m	8. FES Item 27	-.178**	.527**	.435**	.469**	.467**	.437**	.786**	--								
Outcomes	12 m	9. Total CAFAS Score	.177**	-.051	-.104**	-.011	.036	-.017	-.045	-.038	--								
	12 m	10. CBCL T-score: Internal	.091**	-.091**	-.175**	-.078**	-.067*	-.024	-.081**	-.017	.336**	--							
	12 m	11. CBCL T-score: External	.148**	-.080**	-.186**	-.062*	-.036	-.047	-.074**	-.024	.461**	.618**	--						
Pretest	Admission	12. Total CAFAS Score	.111**	-.099**	-.133**	-.065*	-.020	-.061*	-.080**	-.036	.440**	.218**	.275**	--					
		13. CBCL T-score: Internal	.065*	-.059*	-.148**	-.033	-.029	-.008	-.050	.012	.164**	.573**	.329**	.306**	--				
		14. CBCL T-score: External	.111**	-.059*	-.200	-.049	-.015	-.072**	-.073**	-.007	.302**	.315**	.583**	.437**	.541**	--			
Demo		15. Age	.119**	-.039	-.137**	-.030	-.051	-.055*	-.067*	-.097**	.124**	.053	-.019	.142**	.078**	.002	--		

***p* < .01 **p* < .05

Table 2
Family Empowerment Scale: Salient Factor Loadings

	<i>Factor Loadings</i>					
	<i>I Coping</i>	<i>II Dealing with Services</i>	<i>III Child Focused</i>	<i>IV Advocacy</i>	<i>V Assertive</i>	<i>VI Informed</i>
<i>Internal Consistency Reliability (Alpha)</i>	.83	.85	.82	.84	.74	.62
I make efforts to learn new ways to help my child grow and develop.	0.71					
When necessary, I take the initiative in looking for services for my child and family.	0.67					
When I need help with problems in my family, I am able to ask for help from others.	0.63					
When dealing with my child, I focus on the good things as well as the problems.	0.56					
I make sure I stay in regular contact with professionals who are providing services to my child.	0.48					
When faced with a problem involving my child, I decide what to do and then do it.	0.41					
I have a good understanding of the service system that my child is involved in.		0.65				
I understand how the service system for children is organized.		0.65				
I know the steps to take when I am concerned my child is receiving poor services.		0.63				
I am able to work with agencies and professionals to decide what services my child needs.		0.57				
I know what the rights of parent and children are under the special education laws.		0.51				
I am able to get information to help me better understand my child.		0.50				
I am able to make good decisions about what services my child needs.		0.44				
When problems arise with my child, I handle them pretty well.			0.76			
I feel confident in my ability to help my child grow and develop.			0.71			
I believe I can solve problems with my child when they happen.			0.69			
I know what to do when problems arise with my child.			0.64			
I feel I am a good parent.			0.57			
I tell people in agencies and government how services for child can be improved.				0.75		
I help other families get the services they need.				0.66		
I have ideas about the ideal services system for children.				0.65		
I know how to get agency administrators or legislators to listen to me.				0.63		
I feel that my knowledge and experience as a parent can be used to improve services for children and families.				0.62		
I get in touch with my legislators when important bills or issues concerning children are pending.				0.60		
I feel I can have a part in improving services for children in my community.				0.53		
I believe that other parents and I can have an influence on services on children.				0.51		
My opinion is just as important as professionals' opinions in deciding what services my child needs.					0.66	
I tell professionals what I think about services being provided to my child.					0.56	
I make sure that professionals understand my opinions about what services my child need.					0.51	
I have a good understanding of my child disorder.						0.51
I know what services my child needs.						0.47
Professionals should ask me what services I want for my child.						0.47

Table 3
Family Satisfaction Questionnaire: Salient Factor Loadings

<i>Variables Measured</i>	<i>Factor Loadings</i>	
	<i>I</i> <i>Parent Satisfaction</i>	<i>II</i> <i>Quality of Services</i>
<i>Internal Consistency Reliability (Alpha)</i>	.70	.82
Did you get the help you wanted?	0.74	
Have the services helped you with your life?	0.71	
Did you like the help you were getting?	0.68	
How satisfied have you been with your child's progress in the past 6 months?	0.44	
If you were to seek services again for your child, would you use these services again?	0.41	
How often do the people who are helping your child listen to you?		0.74
How often are you asked for your ideas and opinions concerning your child treatment?		0.71
How much would you agree with: I feel involved in my child treatment program?		0.70
How often do you have a choice in deciding what services your child receives?		0.65
How much do you agree with: The people who are helping us will stick with us no matter what?		0.64
I think the services my child have received in the last 6 months have been . . . (Excellent, Good, Average, Poor, Terrible)		0.58
When your child has a personal issue, that is troubling, how often do you feel as though your child will have someone to talk to?		0.51

Figure 2
Conceptual and Operational Definitions of Concepts with Instruments

<i>Parent Satisfaction</i>	<i>Secondary Appraisal</i>	<i>Coping Behavior</i>	<i>Outcomes</i>
CONCEPTUAL DEFINITIONS			
The degree that parents are pleased with mental health services. (Gerkenmeyer, 1999)	Parents' assessment of their ability to act on their own or their child's behalf to achieve increased control over their child's and family's mental health needs. (Lerman & Glanz, 1997)	Strategies parents use for problem management to meet their child's and family's mental health needs. (Lerman & Glanz, 1997)	Parents' and child's adaptations to stressors. (Lerman & Glanz, 1997).
OPERATIONAL DEFINITIONS: PRIMARY INSTRUMENTS			
Family Satisfaction Questionnaire (FSQ) (Rouse, McCabe, & Toprac, 1996)	Knowledge & Attitude Subscales of Family Empowerment Scale (FES) (Koren, DeChillo, & Friesen, 1992)	Parents' self-report of behaviors from FES. (Koren, DeChillo, & Friesen, 1992)	Child & Adolescent Functional Assessment Scale (CAFAS) Child Behavior Checklist (CBCL) Caregiver (Achenback, 1991)
DATA UTILIZATION POINTS			
Six months after enrollment	Six months after enrollment	Six months after enrollment	Time 1. At enrollment Time 2. 12 months after enrollment

Adapted from: Gotlieb, Grewal & Brown (1994), and Lerman & Glanz (1997).

Results

The model in Figure 3 was selected because it had the strongest goodness of fit with the data, was relatively parsimonious and retained meaningful associations conceptually. As can be seen on Table 1, some factors within existing scales tended to be highly correlated. This became problematic when attempting to use them to operationalize concepts, such as the factors used in Appraisal and the Coping factor (all derived from the FES). It was for this reason that the inclusion of Coping in the model did not work well and it ended up being removed.

Similar problems existed between the Parent Satisfaction factor from the FSQ being highly correlated with the Dealing with Services factor and the Total CAFAS score at 12 months (Outcomes). This necessitated arrows being drawn between Parent Satisfaction and these variables. A direct relationship between Parent Satisfaction and Outcomes is indicated by the arrow connecting them. The fit between the model and data was much less supported, however, without inclusion of Appraisal. Additionally, the Total CAFAS score at 12 months was highly correlated with the internalizing and externalizing CBCL T-scores. This resulted in use of the Total CAFAS, alone, to represent Pretest and Outcomes for a better model fit; versus in combination with the CBCL T-scores.

Although the use of Appraisal was necessary to obtain strong measures of model fit, Appraisal had the weakest standardized regression weights and lowest critical ratios as can be seen on Table 4. With this limitation in mind, however, the fit indexes were strong for the SEM model. The probability for Chi-square was 1.00 with anything greater than .05 indicating support for the model. The minimum value of discrepancy divided by degrees of freedom (CMIN/DF) was .15 with anything less than 2 representing an acceptable fit. The Root Mean Square Error of Approximation (RMSEA) was .000 with anything less than .05 representing a good model fit. PCLOSE (p-value) was 1.000 with values greater than .90 representing a good model fit.

Figure 3
Relationship of Parent Satisfaction to Outcomes:
Structural Equation Model with Standardized Regression Weights

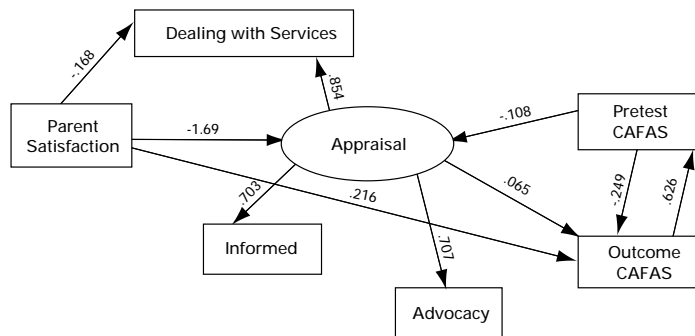


Table 4
AMOS: Standardized Regression Weights and Critical Ratios
in Structural Equation Model (SORM)

Path	Standardized Regression Weight	Critical Ratio
Parent Satisfaction ----->Appraisal	-.169	-4.915
Parent Satisfaction ----->Outcome (CAFAS)	.216	5.189
Appraisal ----->Dealing with Services	.854	21.937
Appraisal ----->Informed	.703	
Appraisal ----->Advocacy	.707	22.421
Parent Satisfaction ----->Dealing with Services	-.168	-7.692
Outcome (CAFAS) ----->Pretest (CAFAS)	.626	4.328
Appraisal ----->Outcome (CAFAS)	.065	1.415
Pretest (CAFAS) ----->Appraisal (CAFAS)	-.108	-2.732
Pretest (CAFAS) ----->Outcome (CAFAS)	-.249	-1.153

Discussion

Support is present for an indirect relationship of Parent Satisfaction with Outcomes. Because of the model generating approach used to analyze the SORM, however, there is a need to retest this model with another data set. Operationalization of variables was limited to an existing data set that was not generated with the intent of testing this model. Operational definitions of the Coping and Appraisal variables need to be strengthened.

When interpreting these results, it is important to focus on the primary goal of mental health services for children, to promote the well-being of children and their families. If continued evidence demonstrates that parent satisfaction is related to outcomes, then efforts to increase parent satisfaction with services would be indicated. To assume that parents have an intractable proneness to dissatisfaction would be non-productive in improving parent satisfaction or promoting the well-being of the child and family. Peplau (1952) described how the service provider and client (in this case, the parent) often begin their relationship with somewhat disparate goals, but that with time and communication, these goals should become increasingly mutual. Both the parent and service provider influence and learn from each other.

Parent satisfaction in previous model testing was shown to be influenced by parents' met expectations, needs and desires. After previous experiences where desires, needs and positive expectations were not met, more effort on the part of providers to regain or achieve a more trusting and mutual therapeutic alliance with parents may be required. Additional research is needed to further examine both what the underlying determinants of parent satisfaction are and if, indeed, parent satisfaction is related to other outcomes. The existing data used for this study had outcomes that measured clinical improvement of the child. Future studies need to also explore if parent satisfaction with mental health services influences the quality of life of the parent, child and family irrespective of clinical improvement in the child.

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Child and Family Predictors of Service Use in Two Service Systems: Role of Caregiver Strain

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Purpose and Background

Better understanding of the child and family factors that influence children's mental health service utilization patterns could inform program planners of potential areas for intervention beyond formal mental health services. Although a great deal of research has focused on determining *whether* mental health services will be used, little research has been directed at *how* children use those services and what factors predict service use patterns. The factors studied as potential predictors of service patterns have largely been limited to client need and socio-demographic characteristics.

The current study examines how mental health services are used by children over time. Obviously, children's clinical characteristics such as diagnosis, symptoms, and functioning should influence how they will use services. Less obvious, perhaps, are the caregiver and family variables that could potentially influence service use. In general, the role of the family in children's mental health service has received increased attention over the past decade and there is now widespread recognition that the importance of families in mental health services has long been overlooked.

The impact of family-focused service delivery on the care and outcomes of individual children, and on the system as a whole, has not yet been thoroughly examined (Koroloff, & Friesen, 1997). In a preliminary effort to address this gap, the current study investigates the role of caregiver and family variables, along with child demographic and clinical factors, on children's mental health utilization patterns. The influence of the strain associated with caring for a child with behavioral or emotional problems is of special interest in this study.

Findings from several studies have indicated that caregiver strain can be a powerful predictor of service utilization (e.g., Brannan, 1996; Farmer, Burns, Angold, & Costello, 1997; Foster, Saunders & Summerfelt, 1996; Lambert, Brannan, Heflinger, Breda, & Bickman, 1998). However, three of those studies used the same sample. In general, reports of elevated caregiver strain were found to be associated with children's use of any services, of inpatient hospitalization, and extended use of intermediate outpatient services (e.g., day treatment, in-home services). Lower caregiver strain was found to be associated with use of traditional outpatient therapy alone.

Method

The current study builds on previous research by investigating how caregiver strain predicts service utilization patterns in two samples of children who were Medicaid beneficiaries in two southern states, Tennessee and Mississippi. The children in Tennessee received services under a managed care Medicaid system, while the children in Mississippi received services through a traditional Medicaid fee-for-service system. The data used in this study were collected as part of a SAMHSA-funded study of the impact of managed care on vulnerable populations. This study was guided by a conceptual model that integrated two prominent models: the Behavior Model of Health Service Use (Aday & Andersen, 1981), and the Double ABCX model of family stress and coping (McCubbin, & Patterson, 1982).

Sample

Data were provided by the caregivers of 666 children with emotional and behavioral challenges who were Medicaid recipients in Tennessee and Mississippi. The children in the samples ranged in age from 4 to 17 years, with a mean age of 11.5 years old. Sixty-nine percent of the children were boys. The caregivers were primarily biological parents (73%) or other relatives such as grandparents

or aunts (18%), and were predominantly female (96%). The caregivers ranged in age from their twenties to their sixties, with nearly half (48%) being in the 30 to 39 year old age range. Most of the caregivers had at least completed high school (79%). The median per capita income for these Medicaid families was approximately \$300 per month. All children in the study had Medicaid coverage for mental and physical health problems, and approximately half of the caregivers also had Medicaid coverage themselves. Samples from the two systems were very similar in terms of their demographic profiles, with one exception: 67% of the families in the Mississippi fee-for-service sample were African-American compared to 21% of the Tennessee managed care sample.

Measures

The variables used to predict service use in this study included caregiver strain, caregiver depression, caregiver education, family functioning, child symptoms, and child psychosocial functioning. Demographic characteristics of the child (i.e., age, race, and gender) and family (i.e., per capita income) were also included as control variables.

The two broad band scores (i.e., externalizing and internalizing problems) of the Child Behavior Checklist (CBCL; Achenbach, 1991) were used to describe child emotional and behavioral symptoms. Three CBCL narrow band scores (i.e., aggression, attention, and anxiety/depression) were also used. To measure social functioning, the global score of the Columbia Impairment Scale (CIS; Glied, Hoven, Garrett, & Moore, 1997) was used. Caregiver depression was measured with the Center for Epidemiological Studies – Depression scale (CES-D; Radloff, 1977). The Caregiver Strain Questionnaire (CGSQ; Brannan, Heflinger, & Bickman, 1997) measured three dimensions of caregiver strain. The objective strain score was a measure of the daily “hassles and consequences” of caring for a child with SED, such as interruption of personal time, work or family routines, or disruption of social activities. Subjective internalized strain is a measure of being “worried and tired.” Subjective externalized strain reports the level of “anger, embarrassment, and resentment” the caregiver feels in relation to the child’s problems.

Several service-use constructs were used as the dependent variables including: type of services used (i.e., traditional outpatient services, intermediate outpatient services, support services, and residential/inpatient treatment), amount of services used, and continuity of care (i.e., breaks in care of 30 days or more). These data were extracted from the Medicaid data sets in two states.

Samples from the two systems were very similar in their scores for child clinical status, caregiver strain, and caregiver depression. However, the children in the fee-for-service system utilized substantially more mental health services. Table 1 summarizes these differences.

Table 1
Comparison of Service Use between the Fee-for-Service and the Managed Care Medicaid Samples

	<i>Managed Care Tennessee</i>		<i>Fee-for-Service Mississippi</i>	
General Service Use				
Proportion who used any service		75%		88%
Average number of encounters		35		117
Types of Services Used	<i>% Who Used Service</i>	<i>Mean # of Services Used</i>	<i>% Who Used Service</i>	<i>Mean # of Services Used</i>
Support services	31%	23	60%	36
Traditional outpatient	73%	19	87%	34
Intermediate outpatient	8%	9	28%	178
Residential/inpatient	17%	74	17%	97

Analysis and Results

The primary goal of this study was to discern what child and family variables predicted service use patterns in the 12 months after the family entered the study. Of particular interest was the role of caregiver strain. In addition, separate analyses were conducted to examine the predictors of service use in the Medicaid managed care system, and in the traditional fee-for-service Medicaid system. Findings from the separate analyses were then compared to identify similarities and differences.

Logistic regression was used to examine what child and family variables were associated with the use of the types of services described above. Logistic regression was also used to discern what variables were related to breaks in care of 30 days or more. To explore what variables predicted the number of services used by children, standard linear regression was used.

Best fitting models and the variables that predicted service use patterns in both systems are summarized in Table 2. Relationships were considered statistically significant at $p < .05$.

In general, the selected variables predicted service use in the managed care system better than in the fee-for-service system (compare the χ^2 and R^2 estimates). It is also noteworthy that different sets of variables predicted service use in the two service systems. In both systems, child clinical variables were important predictors of most service use patterns. Although caregiver strain predicted at least some service use patterns in both systems, it was a more powerful predictor in the managed care system. It is likely that including provider and other system variables in the analysis would improve the explanatory power of the models, especially for the Mississippi fee-for-service system.

Table 2
Summary of Findings

Service Use Pattern	Managed Care Medicaid Tennessee	Fee-for-Service Medicaid Mississippi
Use of Support Services	($\chi^2=51.6, p < .0001$) Subj. externalized strain (+) ^c Child externalizing problems (+) ^a Child aggressive symptoms (-) ^a	($\chi^2=25.2, p < .05$) Child externalizing problems (+) ^c Race (+White) ^c
Use of Traditional Outpatient Services	($\chi^2=69.3, p < .0001$) Caregiver educ < high school (+) ^c Gender (+Males) ^a Race (-White) ^a	($\chi^2=25.2, p < .05$) Child psychosocial functioning (+) ^b
Use of Intermediate Outpatient Service Use (e.g., day Treatment)	($\chi^2=35.5, p < .001$) Objective strain (+) ^b Subj. externalized strain (+) ^c	($\chi^2=37.2, p < .001$) Subj. internalized strain (+) ^b Caregiver educ < high school (+) ^c Race (+White)
Use of Residential Treatment Center or Inpatient Hosp	($\chi^2=44.5, p < .0001$) Objective strain (+) ^c Child externalizing problems (+) ^c Child aggressive symptoms (-) ^c	($\chi^2=79.8, p < .0001$) Subj. internalized strain (+) ^b Caregiver depression (-) ^a Child externalizing problems (+) ^b Child aggressive symptoms (-) ^b Child psychosocial functioning (+) ^c Child's age (+) ^a
Amount of Services Used	($R^2=.13, p < .0001$) Objective strain (+) ^b Child externalizing problems (+) ^c	($R^2=.07, p < .05$) Child externalizing problems (+) ^b
Continuity of Care	NS	NS

^a $p < .001$, ^b $p < .01$, ^c $p < .05$

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Topical Discussion Overview: Family-Centered Systems of Care: The Challenge of Parental Mental Illness

**Judith Katz-Leavy
Joanne Nicholson
Beth Hinden
Lisa Lambert**

Introduction

Child systems of care explicitly emphasize the central and critical roles of family support and interagency collaboration in effectively serving children with Serious Emotional Disturbance (SED). Systems of care founded upon Child and Adolescent Service System Program (CASSP) principles and values (Stroul & Friedman, 1986) aspire to be family centered and collaborative across the child serving agencies. New data, however, indicate that these values and principles may have to be even more broadly conceived.

Results from the National Evaluation of the Comprehensive Community Mental Health Services for Children and their Families Program (CCMHS; Macro International, 1998), combine with the literature on child risk and parental mental illness to suggest that there is substantial overlap among families in which a child has a SED, and families in which a parent has a mental illness. However, CASSP-based systems of care for children with SED and their families were not designed to address parental mental illness. To the contrary, commitment to a family-friendly, strengths-based model, and a genuine desire to eradicate the malignant tradition of parent “shame and blame” may have made consideration of parent mental illness anathema. Thus, despite best intentions, systems of care as currently conceived and implemented, may not be family-centered or interagency “enough.”

In addition, documentation of the experiences of families in systems of care and families in which a parent has a mental illness, suggest that there is substantial overlap in the needs of these two populations for family-centered, interagency, and coordinated service systems. Specifically, there is a need for integration of adult and child systems so that each can inform the other. This topical discussion considered available data in an effort to highlight important implications for family-centered policy and practice integrating the child and adult mental health systems.

Method

Existing data from the National Evaluation of CCMHS and from the National Comorbidity Study (NCS; Kessler, 1994) were reviewed, and considered with respect to mental health services policy from the family and professional perspective.

Results

Child Data

Decades of research on mental illness clearly indicate that children who have parents with a mental illness are at significantly greater risk for development of serious mental health problems (U.S. Department of Health and Human Services, 1999; Oyserman, Mowbray, Meares, & Firminger, 2000). Evaluation data from CCMHS (Macro International, 1998) reveal that families served by systems of care across the United States evidence high rates of parental psychiatric hospitalization (20%), mental illness (40%), and substance abuse (60%). Indeed, family history of mental illness with or without substance abuse represents the third most prevalent risk factor assessed. (History of substance abuse and history of family violence, both likely to be correlated with family mental illness, showed higher rates). In addition, the presence of family risk factors such as history of parental mental illness is related to the presence of child risk factors such as hospitalization, suicidality, and substance abuse, and to child functioning. The impact appears to be cumulative, such that children who live in families with three or more risk factors show higher symptom levels, and greater functional impairment (Macro International, 1998). Thus, systems of care appear to be serving large

numbers of families that are grappling with both children and adolescents having SED, and parental mental illness; this overlap increases risk for poor child outcomes.

The CCMHS evaluation also assessed services available within systems of care across six sites that had completed the program (i.e., were no longer receiving funding). The evaluation listed services that may have included direct services for parents, including family therapy, family preservation, in-home services, family support/advocacy, respite, and wraparound services. Although detailed, qualitative data were not available, none of the services appeared designed to address parental mental illness or its potential impact on the family. It seems fair to speculate, therefore, that a substantial subgroup of families are experiencing a high degree of unmet need.

Adult Data

Adults with mental illness appear to evidence fertility rates similar to those of the general population (Oyserman et al., 2000). Until recently, however, there were no reliable estimates of the number of the adults with mental illness bearing or raising children. Recent analyses of data from the National Comorbidity Study (NCS; Kessler, 1994) indicate that approximately 45% of the women and 30% of the men in the United States have a lifetime prevalence of at least one psychiatric diagnosis. Approximately two-thirds of these women, and more than half of these men are parents (Nicholson, Larkin, Simon, & Banks, 2001). Thus, among adults with mental illness, parenthood is more likely than not. Indeed, data from the NCS indicate that adults with mental illness are actually slightly more likely to have had children than adults without a history of mental illness (Nicholson et al., 2001). As noted above, children in these families are at greater risk for emotional and behavioral disorders. Thus, consistent with the National Evaluation data on a specialized sample (children with SED), epidemiological data reveal that there are a great number of families likely to be coping with parental mental illness and serious child mental health problems.

Adult mental health systems are no better equipped than child systems to address the multiple needs of families in which a parent has a mental illness and a child has a serious emotional disturbance. A recent survey of state mental health agencies (SMHAs) revealed that many SMHAs do not formally assess parenting status of adult consumers, and few have explicit policies and/or procedures to address parenting or child needs (Biebel & Nicholson, 2001). A parallel survey of provider agencies in the U.S. revealed that there were relatively few programs for parents with mental illness. Interviews with administrators, staff, and participants of existing programs indicated that the needs of families far outstripped resources (Hinden, Biebel, Nicholson, Henry, & Stier, 2001); and that there were multiple barriers to creating and implementing effective services for this population.

Specifically, parents with mental illness are confronted with severe social stigma. Adults with mental illness are not identified in their role as parents in the public sector, and are therefore not provided opportunities to exercise control over, or choice in service planning for themselves as parents, or for their children. Traditional services are not strengths-based or family-centered. Parenting services are most often found in the child welfare system, and are accessible to parents only after children are determined to be at risk, or victims of abuse or neglect (Nicholson, Fisher, & Dion, 1993). Mental health services are provided within an adult system to address adult mental health issues only. Parenting needs and/or family issues are generally considered to be outside the purview of adult providers. Finally, services are fragmented or duplicated, due to mandates and funding streams focusing on either individual adult or child clients, or lack of coordination and collaboration among systems, agencies, or providers (Blanch, Nicholson, & Purcel, 1994).

Family Perspective & Policy Implications

Parents with mental illness attend support groups and contact parent advocates within family advocacy organizations nationwide. They are initially seeking services for their children with emotional disturbance and additionally attempt to access family based services that will accommodate

their own needs as well as those of their children. Child serving systems primarily focus on the child as “identified client” and assume that all parents have the same set of skills, strengths, and abilities that home- and community-based services require. Parents with mental illness often have additional needs that must be addressed if their children are to have optimum outcomes. In addition, service providers who treat children with emotional disturbance are often unacquainted with adult mental health issues and appropriate services. Categorical structures and funding streams create further barriers. These same barriers do not appear to exist for parents with physical disabilities. If a parent needed physical accommodations in order to parent, child mental health systems would see that those accommodations were provided. Services needed by a parent with mental illness to care for his/her child are just as essential.

We need to shift to a model where the family is the “identified client,” and where organizational structures and funding streams reflect this. CASSP principles emphasize collaboration. This principle is usually applied to collaboration between child serving systems, but needs to be expanded to include adult and child serving systems that support the strengths of families.

Conclusion

The literature on child systems of care, and on parental mental illness, clearly illustrate that there is overlap between the families that comprise these groups, and the issues with which they must cope. Categorical adult and child systems create a bevy of “unmet needs” that impact functioning of both parents and children. The concept of interagency collaboration so eloquently articulated by CASSP (Stroul & Friedman, 1986), needs to be expanded so that families may be fully supported according to their needs. The implications for policy and practice are obviously far-reaching, and will challenge existing paradigms.

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Grandparents Raising Their Grandchildren in Rural Communities

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Introduction

This research is part of a larger project established in a southeastern state to assist rural grandparents who are raising their grandchildren. The project is funded through the Division of Family & Children's Services under the Promoting Healthy and Stable Families Initiative. The overall goal is to provide support to kinship care families to increase safety and permanency for children. Specifically, Project Healthy Grandparents® targets grandparent caregivers and their grandchildren and is based upon a case management model that works to empower grandparents within their caregiving roles (see Whitley, White, Kelley, & Yorker, 1999). Besides case management, this model includes nursing assessment, legal education, and a support group as interventions to assist grandparents with child-raising tasks and managing their own emotional and physical needs.

Methodology

The project started in October 1998 and families were recruited through a variety of strategies. Newspaper stories were run in the local county paper, and program announcements were made through schools, social service agencies, and churches. Grandparents were eligible if that had responsibility for raising one or more grandchildren in parent-absent households.

Several measures were included in the data collection. The assessment instruments were administered during initial contacts with the family and were completed by the primary caregiving grandparent. Demographics included items about the grandparents, grandchildren, and household characteristics. In addition, information about the caregiving relationship was recorded, such as length and reasons for co-residence.

The instruments, which addressed the grandparents' appraisal of their caregiving competence and stress, included the Brief Symptom Inventory (BSI; Derogatis, 1993); the Family Empowerment Scale (FES; Koren, DeChillo, & Friesen, 1992), and the Parental Locus of Control (PLOC; Campis, Lyman, & Prentice-Dunn, 1986).

Supports and resources available to the family were measured using the Family Resource Scale (FRS; Dunst & Leet, 1987) and the Family Support Scale (FSS; Dunst & Trivette, 1989). In order to represent the structure in the families involved in the project, the terms "grandparent" or "grandchild" were substituted for the terms "parent" or "child" in several of the instruments.

Results

Data were gathered from grandparents who lived in rural/semi-rural areas ($n = 22$). There were no statistically significant demographic differences between grandparents by county. The average age of the grandparents was 58.9 ($SD = 7.4$) years. There was more than a 20-year difference in age between the youngest grandparent, 46 years, and the oldest grandparent, 71 years. The sample was overwhelmingly Caucasian (68.2%, $n = 15$; African American 31.8%, $n = 7$), and was largely female (95.5%, $n = 21$). The families were economically poor, with ninety-five percent ($n = 21$) having incomes equal to or less than \$25,000. Half of the grandparents had more than one grandchild in the home.

Demographic and statistical data were gathered on the oldest child in the home. Almost 60% ($n = 13$) of the grandchildren were male, and nine were female (40.9%). The average age of the grandchildren was 11.76 ($SD = 3.6$) years, with ages from 3 to 18 years. The median grade level of the grandchildren was 5th grade, with a range from preschool to the 11th grade.

Reasons for living with the grandparents related to both health and mental health problems of the children's parents. An equal number of grandchildren were placed with their grandparent as a result of either abuse and neglect (23%), or parental death (23%). Addiction problems of the parents were listed as reasons for placement in six of the families (28%). Three of the grandparents could not cite any particular reason why the grandchild lived with them.

The Child Behavior Checklist (CBCL; Hodges & Wong, 1996) was administered to the oldest grandchild in the household in order to assess the degree of difficulty in the grandparents' child rearing role. In general, the majority of the oldest grandchildren, especially the boys, scored in the borderline clinical ranges on the individual externalizing and internalizing scales. No grandchildren scored in the borderline or clinical range total score.

Three instruments were selected to assess functioning of the grandparents. The Brief Symptom Inventory (BSI) was administered to the primary grandparent caregiver. Overall, mean scores on all nine subscales were low, indicating that few symptoms were reported by primary grandparents. Additionally the mean Global Severity Index (GSI) score, which is the total score of the BSI, was 3.86, indicating very little tendency to report psychiatric symptoms.

The Family Empowerment Scale (FES) measured the degree to which grandparents perceived feelings of empowerment within their family and community. Mean scores ($M = 142.6$, $SD = 20.0$) on the total FES indicated high levels of feelings of empowerment. Mean scores on these subscales (family: $M = 53.8$, $SD = 5.0$; service system: $M = 53.8$, $SD = 7.9$) reflected high levels of feelings of empowerment in these areas. The mean for the community/political subscale ($M = 35$, $SD = 8.8$) while still high, indicated a lower feeling of empowerment in this arena. The Family Resource Scale (FRS) measured the adequacy of resources that grandparents perceived were available. The FRS revealed that these families had minimum resources available. The mean score for all families was 105.81 ($SD = 21.5$), with a range of 74 to 155. The level of support available was assessed with the Family Support Scale (FSS). In general, the grandparents reported low levels of support including assistance provided by members of their family.

Pearson's correlations were run to determine the relationship between several demographic variables and scores on the BSI, FES and FRS. There was a moderate and statistically significant relationship between the age of the grandchild and the FRS ($r = -.55$, $p \leq .008$, $N = 22$), and the family subscale of the FES ($r = -.47$, $p \leq .027$, $N = 22$). The negative coefficient indicated that grandparents who were raising older grandchildren reported less resources and lower levels of empowerment.

Significant correlations were also found between grandparent age and certain measures. There was a moderate and statistically significant relationship between grandparent age and total FES score ($r = -.48$, $p = .024$, $N = 22$), and between grandparent age and the family subscale of the FES ($r = -.61$, $p = .003$, $N = 22$). Again, negative scores indicate that younger grandparents reported higher degrees of empowerment.

Finally, correlations were run between grandparent functioning and support/resource variables. A strong, statistically significant correlation was found between the FRS and PLOC ($r = -.73$, $p \leq .001$, $N = 22$). This result indicates that grandparents who had high levels of perceived resources also reported a higher locus of control in the relationship with the grandchildren. Scores on the BSI anxiety dimension were strongly, statistically correlated with the PLOC scores ($r = .66$, $p \leq .001$, $N = 22$). This relationship indicates that grandparents who had greater locus of control reported lower levels of anxiety.

Regression analysis was utilized to further understand the relationship between scores on the BSI and the FEQ, FRS, FSS scales. These scales explained over half of the variance in the BSI Interpersonal Sensitivity subscale ($R^2 = .56$, $F = 6.30$, $p = .002$). The FRS negatively contributed to 84% of the variance ($R^2 = -.84$, $F = -4.47$, $p = .001$). The FEQ positively contributed to 68% of the

variance ($R^2 = .68$, $F = 2.70$, $p = .016$). Specifically, those Grandparent-headed families that perceived a greater degree of resources were not as plagued by self-doubt, inferiority, and interpersonal relationship problems. It follows that families that demonstrate difficulty on the BSI Interpersonal Sensitivity subscale feel less empowered.

Discussion

In spite of the small sample size under analysis, this research adds to the understanding of grandparent caregiving by focusing on families that live in rural areas. In many ways, grandparents in this research report experiences that are similar to their counterparts who live in urban areas. Most were raising their grandchild because of the health/mental health problems, addictions, and abusive/negligent actions of parents toward their children.

Particular experiences of these grandparents appear to pose potential threats to their functioning and well-being. It is interesting that scores on all dimensions of the BSI were low and that scores on the FES were high overall. These results seem to indicate that these grandparents were able to manage the role of care provider without undue distress and disturbance. On the PLOC, however, grandparents indicated that they perceived themselves as having low levels of control in certain dimensions of their child-rearing role. Correlations between the PLOC and demographics suggest that grandparents who were raising older grandchildren and those who had fewer resources had the lowest sense of control in the grandparent-grandchild relationship.

These grandparents had low levels of support and resources. For example, the economic status of the families was disturbingly low. Only one family reported an income above \$25,000 and some had incomes of about \$10,000 per year. Few were able to access additional resources in either their communities or support from families. Living in a rural area can add complexity to these issues. Poverty is a very real problem with these families and one that can exacerbate other situations. Transportation was also a major concern for virtually all of the families in the project.

Based upon their appraisal of competence as a caregiver, many grandparents struggle with the dynamics of raising their grandchildren. As indicated by CBCL scores, many of the grandchildren (especially grandsons) exhibited challenging behaviors. School districts, which can provide support programs such as mentoring or tutoring, were lacking in these areas. In addition, some grandparents struggled with the transitional difficulties that their grandchildren encountered as these children adjusted to a new geographical area.

In summary, many of the issues that face grandparents in large cities also are found in grandparent-headed families in rural areas. This research identified some salient issues for grandparents who live in communities that have few resources and sources of support. Grandparents in these rural family situations appear to have the most stress and fewest resources to support them in their caregiving roles.

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