

*Family Involvement
& Perspectives*



Chapter 3

Chapter 3: Family Involvement & Perspectives

Enrichment and Stress in Families of Children with Serious Emotional Disorders

Introduction

Only during the last decade has research attention been given to the experiences of families whose children have serious emotional, behavioral, or mental disorders. Before then most family-oriented research focused either on possible parental contributions to the child's emotional problems, or on developing and testing interventions aimed at changing parents' or family functioning (Friesen & Koroloff, 1990). Work in other disability fields (e.g., Singer, Powers, & Olson, 1996) and a small but growing literature within children's mental health (Friesen & Huff, 1996; Heflinger & Nixon, 1996) reflect an interest in the well-being of the entire family. Services for children and families have also been expanded to include family support strategies as well as traditional therapeutic services.

Here we present findings from a study that examined the effects on families, both positive and negative, of dealing with the variety of demands and opportunities associated with caring for a child with an emotional disability. This study was based on data from a larger evaluation of the Oregon Partners Project (OPP), one of eight projects funded by the Robert Wood Johnson Foundation's Mental Health Services Program for Children and Youth (MHSPY) (Cross & Saxe, 1997).

This summary is based in part on the paper by Yatchmenoff, D. K., Koren, P. E., Friesen, B. J., Gordon, L. J., and Kinney, R. F. (in press), entitled "Enrichment and Stress in Families caring for a Child with a Serious Emotional Disorder," to be published in a forthcoming issue of the Journal of Child and Family Studies.

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The Oregon Partners Project provided community-based services to children 5-18 years old who had serious emotional problems and were living at home or in other community settings. The agencies that came together to plan and pool funds included state and county mental health and child welfare agencies, the state Medicaid office, and two school districts. Children and their families were provided intensive case management, interagency planning that included family participation, and flexible funding to fill in service gaps. Family impact was assumed to result from the family's total situation (child's needs, responses from family and friends, services and supports, public reaction, etc.).

A previous effort to measure family impact (Friesen, 1989) asked family members about the extent to which various aspects of their lives were made better, made worse, or remained the same as a result of living with and caring for a child with a serious emotional disorder. In contrast with that approach, the current investigation allowed for the possibility that specific areas of family life could be both positively and negatively affected. This perspective is reflected in the words of one parent in the study:

The situation has caused a great deal of stress as well as enrichment between my child and me...The stress is caused by anger and frustration at each other and the caregivers, and the enrichment has come about by working together to get the help he needs, and mutual respect.

Methods

Data for the study were provided by 214 primary caregivers of children with serious emotional disorders who participated in the OPP evaluation. The children ranged in age from 5 to 18 years, with an average age of about 12. Boys outnumbered girls (71%), and the sample was largely Caucasian (72%)

with smaller numbers of African American (16%) and Native American (8%) children. Most of the children (86%) scored in the clinical or borderline-clinical range on the Total Behavior Problem score of the Child Behavior Checklist (Achenbach, 1991), and commonly had been diagnosed with Attention Deficit Hyperactivity Disorder (41%), emotional disorders (30%), and/or learning disabilities (25%).

Respondents were mostly women (88%). About half were employed outside the home and nearly that many had some college education. Incomes were relatively low, averaging less than \$20,000 annually. More than half of the respondents (63%) reported they had someone to share parenting with them. Data about child and family characteristics, enrichment and stress, social and personal support, family empowerment and key service characteristics were gathered through interviews.

The Effects of the Situation questionnaire measured both positive and negative caregiver experiences. Positive impact was conceptualized as enrichment, the sense on the part of the respondent that her/his life was made better by the situation. Negative impact was conceptualized as stress, an internal sense of difficulty or distress. The 17 items in the questionnaire clustered conceptually into personal and emotional issues (emotional well being, view of self, physical health); social relationships (with life partner, with other children in the home, with friends or extended family); and practical matters (keeping up the home, family finances, time for day-to-day activities). An additional open-ended question elicited information not already covered.

For each of the 17 items, caregivers rated the amount of stress they experienced, on a scale from one (*caused no stress or limitations in this part of my life*) to four (*caused a lot of stress or limitations in this part of my life*) and the amount of enrichment experienced, also on a scale from one (*did not make this part of my life better*) to four (*made this part of my life a lot better*).

Enrichment and Stress

These dual ratings provided an opportunity to look at areas in which caregivers reported the greatest stress and the greatest enrichment, and to consider the possibility that stress and enrichment might occur together.

Other measures included a subscale from the Family Empowerment Scale (Koren, DeChillo and Friesen, 1992) which examines empowerment within the family. Personal and social support were assessed with three subscales of the Family Crisis Oriented Personal Evaluation Scale (McCubbin, Olson and Larsen, 1991): Support from Friends and Neighbors, Support from Extended Family, and Spiritual Support. Three aspects of services were also considered. The Service Coordination Scale (DeChillo and Lebow, 1992) assessed the degree to which providers were working together on behalf of the child and family. Complexity of Services was measured by the total number of formal services received by the family within a six-month period. Finally, Family Participation assessed caregiver involvement in the planning process for their children.

Results

Families reported considerable stress, with mean ratings of 3.0, indicating “some stress,” in the areas of emotional well-being and outlook on life, personal health, relationships between children in the home, time for social activities, sense of order and structure in life, relationship with partner, and view of self as a parent. Somewhat less stress (mean ratings of about 2.0) was reported in areas of religious or spiritual life, relationships with friends, and involvement in organizations or groups. Families experienced less enrichment than stress, with highest average ratings of about 2.0, indicating “a little” enrichment in areas such as relationships with other children in the home, view of self as a parent, religious or spiritual life, sense of order and structure in life, and relationship with partner.

There was virtually no enrichment reported in areas like family finances, time for social activities or hobbies, job and health. Individual item means appear in Table 1.

In order to examine the relationship between stress and enrichment, Pearson product-moment correlations were calculated for individual stress and enrichment item pairs. While some negative relationships were found between stress and enrichment, the associations were only moderate, with the strongest correlations of between $-.20$ and $-.29$ (see Table 1). In areas such as relationship with partner, relationships between children in the home, time for social activities, and keeping up the home, greater stress was modestly associated with less enrichment. In a number of areas, such as involvement in groups, religious or spiritual life, and relationships with friends, there was no link at all between stress and enrichment, suggesting that positive and negative impacts on families are independent of one another.

In order to examine the overall experiences of stress and enrichment, composite measures were created from the individual items, excluding those that were not applicable to all respondents (such as job, relationship with partner, and items pertaining to other children in the home). The overall scores on stress and enrichment were examined in relation to child characteristics, material resources, informal personal and social supports, empowerment, and selected service characteristics.

The severity of the child’s disorder, as measured by the Total Problem Behavior Score on the CBCL and by Duration (the number of months since the child’s disorder was identified), was linked with stress ($r = .54, p < .001$, and $r = .22, p < .01$, respectively) but was not associated with enrichment. Empowerment was the only variable in the study to be linked with both enrichment and stress, with more empowered families reporting more enrichment and

less stress ($r = .25, p < .001$, and $r = -.31, p < .001$). Support from Extended Family was modestly linked with lower stress ($r = -.18, p < .01$), while Support from Friends and Neighbors and Spiritual Support were associated with enrichment ($r = .21, p < .01$, for both). Finally, Service Coordination was negatively associated with stress ($r = -.29, p < .001$), indicating that families who reported more coordinated services also reported less stress. Bivariate results are summarized in Table 2.

In order to examine the joint contribution of these variables to our understanding of enrichment and stress, a final set of analyses were conducted using least-squares multiple regression procedures, with enrichment and stress analyzed separately. The two measures of severity, Total Problem Behavior Score and Duration, were entered first in each analysis to examine and control for their effects before looking at the influence of other variables. Following this procedure, variables found to be associated with either stress or enrichment were allowed to enter stepwise. Tables 3 and 4 present a summary of the final models.

For stress, the severity indicators jointly accounted for approximately 28% of the variance ($p < .001$). Empowerment and Service Coordination also each made a small but significant contribution to the model, with higher empowerment and greater service

the positive or negative effect of involvement with service providers and professionals, the enrichment experienced in learning or gaining knowledge from the situation, and family members' feelings of embarrassment, guilt or shame.

The voices of family members themselves speak to each of these summarized findings from the qualitative data. Multiple quotations were used as illustrations in the presentation itself; representative

Table 1
Stress and Enrichment Means and Correlations ($n = 214$)¹

Item	Stress		Enrichment		<i>r</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Emotional well being/outlook on life	3.2	0.9	1.7	0.9	-.22**
Health	3.2	1.0	1.4	0.8	-.12
Relationships between children ¹	3.1	1.0	1.7	0.9	-.27***
Social activities or hobbies	3.0	1.0	1.4	0.7	-.25***
Sense of order or structure in your life	3.0	1.0	1.8	0.8	-.14
Relationship with your partner ¹	3.0	1.1	1.8	1.1	-.29**
View of yourself as a parent	3.0	1.0	2.0	1.1	-.20**
Job ¹	2.9	1.1	1.4	0.8	-.19
Family social activities	2.8	1.0	1.7	0.9	-.22**
Keeping your home up	2.8	1.1	1.5	0.8	-.25***
Family finances	2.7	1.2	1.3	0.7	-.15
Relationships with other children ¹	2.6	1.1	2.0	1.0	-.18
Time for day-to-day activities	2.6	1.1	1.5	0.8	-.20**
Relationships with extended family	2.4	1.1	1.7	1.0	-.17
Involvement in organizations/groups	2.3	1.1	1.6	0.9	-.03
Relationships with friends	2.3	1.1	1.8	0.9	-.08
Religious or spiritual life	2.0	1.1	1.8	1.0	.05

Note. Ratings were made on four point scales (for stress, 1 = no stress or limitations in this part of respondent's life, while 4 = a lot; for enrichment, 1 = did not make this part of respondent's life better, while 4 = a lot better).

¹Sample sizes vary on items that were not applicable to all respondents.

** $p < .01$ *** $p < .001$

Enrichment and Stress

coordination associated with less stress. The final Multiple R of .59 indicated that 34% of the variance in stress was accounted for by the model. With enrichment as the dependent variable, the measures of severity, as anticipated, did not account for significant variance. Spiritual Support and Empowerment each made a small but significant contribution to the model, with a total Multiple R of .36, indicating that approximately 13% of the variance could be explained by these variables together.

Qualitative Findings

More than half (65%) responded to the question “Are there other ways you have been affected by the situation with your child?” Analysis of family members’ comments not only confirmed key findings but also pointed toward other life areas not directly addressed by the rated questions.

Content was first appraised as *negative, positive or mixed*. The proportion of positive to negative responses (62% to 27%) mirrored the quantitative findings of substantially greater stress over enrichment. The mixed responses (11%) also support the finding of simultaneous stress and enrichment.

Comments related to each item in the questionnaire were found, which also corroborated the quantitative results. Family members reported significant stress, particularly in the area of emotional well-being and outlook on life, but also in their view of themselves as parents, their relationships with extended family, and their sense of order and structure in their lives. Emergent themes included the stressful effects of the child’s behavior,

Table 2
Correlations of Enrichment and Stress with Family, Child, and Service System Variables ($n = 214$)

Enrichment	
Empowerment	.25***
Support from Friends and Neighbors	.21**
Spiritual/Religious Support	.21**
Stress	
Total Problem Behavior	.54***
Empowerment	-.31***
Service Coordination ¹	-.29***
Duration of Disorder	.22**
Support from Extended Family	-.18**

¹Families with two or more services, $n = 194$.
** $p < .01$ *** $p < .001$

Table 3
Regression of Stress on Total Behavior Problems, Duration, Service Coordination, and Empowerment ($n = 194$)

Variable	Multiple R	ΔR^2	F for Δ	β	t for β
Duration of Disorder ¹				.10	1.69
Total Problem Behaviors ¹	.53	.28	35.23***	.42	6.64***
Empowerment ²	.57	.04	12.41***	-.18	-2.93**
Service Coordination ²	.59	.02	6.09**	-.15	-2.47*

Note. Multiple $R^2 = .34$; Adjusted $R^2 = .33$; $F(4,189) = 24.71, p < .001$

¹Forward entry as a block.

²Stepwise entry.

* $p < .05$ ** $p < .01$ *** $p < .001$

Table 4
Regression of Stress on Total Problem Behaviors, Duration, Spiritual Support and Empowerment ($n = 194$)

Variable	Multiple R	ΔR^2	F for Δ	β	t for β
Duration ¹				-.11	-1.62
Total Behavior Problems ¹	.17	.03	2.93	-.06	-.82
Spiritual Support ²	.30	.06	13.17***	.22	3.21**
Empowerment ²	.36	.03	7.38**	.19	2.72**

Note. Multiple $R^2 = .13$; Adjusted $R^2 = .11$; $F(4,189) = 6.86, p < .001$

¹Forward entry as a block.

²Stepwise entry.

** $p < .01$ *** $p < .001$

examples are included here. Regarding general stress, one family member reported:

...you feel isolated. You feel inadequate as parents, like you missed something along the way. A lot of times, friends and neighbors will feel it's your fault for the way your child is.

On the other hand, another family member found enrichment in the situation with her child:

I have a much better understanding of diversity than I ever had before and I'm glad for that. The reading and contacts I've made about mental illness and especially about ADHD has made a difference in how I relate to others at work and in general.

Effects on relationships and emotional well-being and the effect of involvement with services are spoken to by the following comment:

It puts a strain on the whole family, wondering where to turn and who to go to. Until you finally get the help you need, you get really frustrated...Then you finally get help and it's like a big lift off your shoulders...you know there's a light at the end of the tunnel.

Finally, one grandmother expressed her thoughts in this way:

Overall, I'm glad he's with me and I'm learning more and more, being educated, and I'm grateful for the opportunity to make a difference in his life and am hopeful that his life will turn out better than it would have otherwise. I am blessed. Him being with me has made my life more enjoyable although more stressful.

References

- Achenbach, T. M. (1991). *Manual for the Child Behavior Checklist/4-18 and 1991 Profile*. Burlington, VT: University of Vermont Department of Psychiatry.
- Cross, T. P. & Saxe, L. (1997). Many hands make mental health systems of care a reality: Lessons from the Mental Health Services Program for Youth (pp. 45-72). In C. T. Nixon & D. A. Northrop (Eds.), *Children's mental health services: Research, policy and evaluation*. Thousand Oaks, CA: Sage.
- DeChillo, N. & Lebow, W. (1992). *Help when it's needed: Community mental health crisis services for children and youth*. Portland, OR: Regional Research Institute for Human Services, Portland State University.
- Friesen, B. J. (1989). *Survey of parents whose children have serious emotional disorders: Report of a national study*. Portland, OR: Portland State University, Research and Training Center on Family Support and Children's Mental Health.
- Friesen, B. J. & Huff, B. (1996). Family perspectives on systems of care (pp. 41-67). In Stroul, B. (Ed.), *Children's mental health: Creating systems of care in a changing society*. Baltimore: Paul H. Brookes.
- Friesen, B. J. & Koroloff, N. M. (1990). Family-centered services: Implications for mental health administration and research. *Journal of Mental Health Administration*, 17, 13-25.
- Heflinger, C. A., & Nixon, C. T. (Eds.). (1996). *Families and the mental health system for children and adolescents*. Thousand Oaks, CA: Sage Publications.
- Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology*, 37(4), 305-321.
- McCubbin, H. I., Olson, D. H., & Larsen, A. S. (1991). F-COPES: Family Crisis Oriented Personal Evaluation Scales. In H. I. McCubbin & A. I. Thompson (Eds.), *Family assessment inventories for research and practice* (2nd ed., pp. 210-216). Madison, WI: University of Wisconsin-Madison.
- Singer, G. H. S., Powers, L. E., & Olson, A. L. (1996). *Redefining family support: Innovations in public-private partnerships*. Baltimore: Paul H. Brookes.

Understanding Families in the Public Mental Health System: A Study in Diversity

Introduction

Families of children with emotional disorders report that they want a system of care that includes them in decision making, is respectful, and is supportive to both them and their children (Friesen, 1989). However, relatively little is known about the needs, burdens, or child and family functioning as described by caregivers whose children participate in urban public mental health systems (Webb, Hicks, Leaf, Merrick, Hammel, & Sakwa, 1995). Much of the literature that examines caregiver burden has focused on adult populations of persons with chronic mental illness (Jones, Roth, & Jones, 1995) or children with developmental disabilities (Friedrich, 1979). More recently, the needs of grandparents raising children whose parents are chemically dependent have also been studied (Roe, Minkler, & Barnwell, 1994).

Families served by the public mental health system are more likely to be impoverished than the larger cohort of families of children with emotional disturbance (McLeod & Shanahan, 1993). Poverty is possibly the strongest predictor of stress among caregivers of children with emotional disturbance (Baldwin, Brown, & Milan, 1995). Consequently, mental health professionals must be informed about the resources and stressors confronting families served by the public mental health system in order to assist this at-risk group. The purpose of the study reported here was to examine the demographic characteristics,

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This research was funded by a grant from HHS-Center for Mental Health Services, Grant Number SM47950.

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needs, burdens, and child/family functioning of a random sample of families of children with emotional disturbance participating in Philadelphia’s public mental health system.

Method

Sample Selection

Families were randomly selected to participate in the study if they were receiving outpatient services that exceeded the average number of contacts from Philadelphia’s public mental health system. Other inclusion criteria included:

- child was 9 to 11 years of age;
- family received services from another public system in addition to mental health in the past year;
- child lived in same family unit for the past year;
- child scored at the 90th percentile total behavior problems;
- child received DSM-III-R diagnosis;
- child scored ≤ 65 on the CGAS.

Primary caregivers and children who met the inclusion criteria and provided informed consent (or assent for the child), were interviewed face-to-face, usually in the family home. Interviews were conducted by a research assistant who was trained in the use of the questionnaire and families received \$15 in appreciation for their time.

Description of the Sample

The sample consisted of 122 primary caregivers of children with serious emotional disturbance who were 9 to 11 years of age. Almost half of the caregivers were African American biological parents ($n = 59$), and a quarter were either African American grandparents ($n = 33$) or White biological parents ($n = 30$). As shown in Table 1, there were significant differences in age among the groups, with grandparents, not surprisingly, being older than biological parents. Grandparents were also significantly more likely to be married or have been married than either group of biological parents. More than half of the African American parents had never been married as compared to a third of the White parents, although this difference did not reach significance. No significant differences were found among the groups in education or income.

Table 1
Description of the Sample

Characteristic	White Parents <i>n</i> = 30	African American Parents <i>n</i> = 59	African American Grandparents <i>n</i> = 33
Age			
<i>M</i>	34.5	33.1	55.8*
<i>SD</i>	6.2	6.0	7.2
Yearly Income			
<i>M</i>	\$15,463	\$14,645	\$16,131
<i>SD</i>	\$10,210	\$ 7,656	\$ 6,806
Education			
<i>M</i>	12.1	12.1	11.5
<i>SD</i>	1.5	1.5	1.8
Marital Status			
Ever married	67%	42%	93%*
Never married	33%	58%	7%

* $p < .05$

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Measures

Child Measures

The Child Behavior Checklist, parent form (Achenbach & Edelbrock, 1983) was used to measure social competencies of children ages 4 to 16.

The Matson Evaluation of Social Skills for Youngsters (Matson, Rotatori & Helsel, 1983), self-report version, was used to measure social skills.

The Children's Depression Inventory, a 27-item self-rated symptom inventory, was used to assess psychomotor, cognitive, and affective dimensions of depression (Kovacs, 1981).

The State-Trait Anxiety Inventory for Children, a child self-report measure consisting of two 20-item scales, was used as a measure of anxiety. One scale assesses situationally specific anxiety and the other assesses anxiety as a relatively stable characteristic of the child (Spielberger, 1973).

Family Measures

The informal social support for primary caregivers was measured by the Carolina Parent Support Scale (Bristol, 1983). The scale measures the availability and helpfulness of immediate and extended family, friends, neighbors, and other parents of children with special needs.

Family burden was measured by Stein and Riessman's (1980) Impact on Family. This 25-item instrument examines the economic social, familial, and emotional impact of caring for a child with special needs.

The McMaster Family Assessment Device (Epstein, 1983) was used to measure seven dimensions of family functioning: problem solving, communication, family roles, affective responsiveness, affective involvement, behavior control, and overall functioning.

A comprehensive needs assessment also was conducted. Caregivers were asked to indicate, from a list of 41 services and resources, if they felt they needed the particular service. A brief description accompanied each service so that caregivers were familiarized with the scope and purpose of the service.

Analysis

Chi-square tests were performed for all categorical data and ANOVAs were conducted for continuous variables. All analyses were conducted using the SPSS software package.

Results

Family Needs

When primary caregivers were asked about the services they needed to assist them in raising a child with special needs, there were some significant differences by type of caregiver. Overall, African American parents were more likely to report that they needed assistance than either African American grandparents or White parents. As shown in Table 2, they more often indicated that they needed help with: transportation to access services, counseling for themselves, income assistance (i.e., finding additional sources of income), and counseling to help keep their kids from using drugs. White parents were significantly different from the other two groups of caregivers in that they more often reported that they needed help in the area of marital or partner therapy. When asked if they needed to borrow money in the past six months to help cover expenses, almost half (47%) of African American grandparents, 37% of African American parents and a little less than a quarter (24%) of the White parents reported that they had borrowed money, although the differences were not statistically significant.

Identification of the Problem

In terms of who first discovered that the child had problems, over half (53%) of African American grandparents reported that they discovered the problem on their own, 34% of African American parents, and 40% of White parents discovered the problem themselves. The mean age of the child when his or her problem was first discovered was 5 years and this did not vary by caregiver group. Although African American grandparents tended to discover the problem on their own, White parents (88%) and African American parents (76%) more frequently took the first steps towards seeking help for their children than did grandparents (67%). However, none of the differences between the groups reached statistical significance.

Child and Family Measures

The data indicate that there were no significant differences between the three groups on any of the child or family measures, except for the emotional burden subscale of the Impact on Family Scale. African American grandparents reported significantly greater emotional burden than White parents. Interestingly, significantly more children

who were being cared for by African American grandparents were taking psychiatric medications. Ninety percent of children cared for by their grandparents were prescribed psychotropic medication compared to 73% of children cared for by their African American parents and 58% of children living with their White parents.

Discussion

The findings from this random sample of families who were participating in Philadelphia’s public mental health program and receiving services that exceeded the average number of service contacts for families demonstrates the diverse needs of this population. Results suggest that mental health providers must be prepared to address both the needs of grandparent caregivers and the issues confronted by children who are separated from their parents. In addition, professionals must be culturally competent in providing services to both African American and White parents.

While there was diversity in the sample by age and race, there was one important characteristic that all of the families shared, poverty. Lack of financial resources has been shown to correlate with stress among caregivers of children with emotional disturbance (McLeod & Shanahan, 1993). Consequently, mental health providers who work with families in the public system are challenged to identify concrete resources for families, as well as assist them in coping with and managing their child’s disability.

The findings of this study suggested that African American parents were more likely to need assistance with concrete needs

Table 2
Percentage Indicating Service Need by Type of Primary Caregiver

Service	% White Parents <i>n</i> = 30	% African American Parents <i>n</i> = 59	% African American Grandparents <i>n</i> = 33
Transportation	49	78*	67
Counseling for Parent	79	64	50
Support Group for Parent	79	86*	63
Marital/Partner Therapy	42	31	13
Drug Prevention for Child	12	41*	27
Income Assistance	46	73*	63

**p* < .05

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such as housing and other basic needs than either African American grandparents or White parents. However, African American grandparents more frequently reported that they needed to borrow money to help cover expenses. White parents generally wanted help with counseling for themselves and/or their partner. African American parents most frequently identified the need for support groups.

In terms of burden, grandparents reported greater levels of emotional stress, which is not a surprising finding. What is interesting, however, is that children being cared for by their grandparents were significantly more likely to be taking psychotropic medication. This difference was not explained by child diagnosis or functioning. It may be that physicians were prescribing medications in response to their perception of the grandparent's emotional burden. This is an issue that deserves further exploration.

In summary, the results of this study begin to identify issues and experiences that are common and unique to different family types in the care of their children with emotional disorders.

References

- Achenbach, T. N. & Edelbrock, C. (1983). *Manual for the child behavior checklist and revised child behavior profile*. Burlington, VT: Thomas M. Achenbach.
- Baldwin, K., Brown, R. T., & Milan, N. A. (1995). Predictors of stress in caregivers of attention deficit hyperactivity disorder children. *The American Journal of Family Therapy*, 23, (2), 149-159.
- Bristol, N. N. (1983). *Carolina Parent Support Scale*. Unpublished manuscript, University of North Carolina at Chapel Hill, The Frank Porter Graham Child Development Center.
- Cook, J. A., Lefley, H. P., Pickett, S. A., & Cohier, B. J. (1994). Age and family burden among parents of offspring with severe mental illness. *American Journal of Orthopsychiatry*, 64, 435-447.
- Epstein, N. B., Baldwin, L. M., & Bishop, D. S. (1983). The McMaster Family Assessment Device. *Journal of Marital and Family Therapy*, 9(2), 171-180.
- Friedrich, W. N. (1979). Predictors of the coping behavior of mothers of handicapped children. *Journal of Consulting and Clinical Psychology*, 19, (337-346).
- Friesen, B. J. (1989). *Survey of parents whose children have serious emotional disorders: Report on a national study*. Portland State University, Research and Training Center of Family Support and Children's Mental Health.
- Greenley, J. R. & Robitschek, C. G. (1991). Evaluation of a comprehensive program for youth with severe emotional disorders: An analysis of family experiences and satisfaction. *American Journal of Orthopsychiatry*, 61, 291-297.
- Horwitz, A. V. & Reinhard, S. C. (1995). Ethnic differences in caregiving duties and burdens among parents and siblings of persons with severe mental illnesses. *Journal of Health and Social Behavior*, 36, (2), 138-150.

- Jones, S. L., Roth, D., & Jones, P. K. (1995). Effect of demographic and behavioral variables on burden of caregivers of chronic mentally ill persons. *Psychiatric Services*, 46, (2) 141-145.
- Kovacs, N. (1983). Ratings scale to assess depression in school-aged children. *Acta Paedopsychiatry*, 46, 305-315.
- Matson, J. L., Rotatori, A. & Hensel, W. J. (1983). Development of a ratings scale to measure social skills in children: The Matson Evaluation of Social Skills with Youngsters (MESSY). *Behavior Research and Therapy*, 21, 335-340.
- McLeod, J. D. & Shanahan, N. J. (1993). Poverty, parenting, and children's mental health. *American Sociological Review*, 58, 351-366.
- Roe K., Minkler, M., & Barnwell, R. S. (1994). The assumption of caregiving: Grandmothers raising children of the crack cocaine epidemic. *Qualitative Health Research*, 4, (3), 281- 303.
- Spielberger, C. (1973). *Preliminary test manual for the State-Trait Anxiety Inventory for Children*. Palo Alto, CA: Consulting Psychologist Press.
- Stein, R. E. & Riessman, C. K. (1980). The development of and impact on family scale: Preliminary findings. *Medical Care*, 18, 465-472.
- Webb, N. B., Hicks, R. A., Leaf, P. J., Nerrick, T., Hammel, G. J., & Sakwa, D. (1995). Parental perspectives on an urban child mental health system: Service needs and barriers to care. In C. Liberton, K. Kutash, & R. Friedman (Eds.), *The 7th Annual Research Conference Proceedings. A System of Care for Children's Mental Health: Expanding the Research Base* (February 28 to March 2, 1994) (pp 209-211). Tampa, FL: University of South Florida, Florida Mental Health Institute, Research and Training Center for Children's Mental Health.

Theoretical and Methodological Foundations of the Family Experience Study

Introduction

This summary describes the concept and application of a case study methodology to the assessment of systems of care quality and effectiveness using an example from the children's mental health area. The summary describes the developmental sequence followed in the construction of a case study protocol beginning with the expression of its theoretical and philosophical foundations, elaboration of broad guiding questions, structuring of the research protocol's content and items, and analytical approaches. We propose that this "recipe" or sequence of events can be utilized in the development of any system assessment instrument. Furthermore, we suggest that the instrument generated in this fashion can also be used as a quality improvement self-assessment tool, and can help lay the foundations for a remediation and technical assistance plan.

The Family Experience Study (FES) is one of the components of the Evaluation of the Annie E. Casey Foundation's Mental Health Initiative for Urban Children. The FES is conducted by a multidisciplinary evaluation team from the Louis de la Parte Florida Mental Health Institute, University of South Florida.

Theoretical and Philosophical Foundations

Carol Weiss proposes that program evaluation should be grounded in the theories of change that guide program development (1995:66). In making this statement she also assumes that social programs are in fact based on explicit or implicit theories about cause and effect. She further suggests that evaluators should

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“construct methods of data collection and analysis to track the unfolding of [theoretical] assumptions. The aim is to examine the extent to which theories hold.”

In designing a method to assess the quality of a children’s mental health system of care developed as a result of a grant from the Annie E. Casey Foundation to four low income urban communities (Boston, Houston, Miami, & Richmond), we adopted this proposition, and began by making the program’s theory of change explicit. The Foundation grounded its Initiative on the proposition by Lisabeth Schorr that “Well developed, neighborhood driven systems of care, which are based on formal and informal structures, increase the likelihood that the needs of families and their children will be effectively met” (1988). In other words, positive outcomes for children and families were linked to certain characteristics of the system of care (e.g., being neighborhood driven, incorporating formal and informal structures). The higher the quality of the program, the more likely that outcomes would be positive.

Stroul and Friedman (1986) had already spelled out six quality principles of an effective system of care for children with severe emotional disturbance which the Foundation also incorporated into its guiding documents. The six principles are as follows:

Family centered/focused: Services are dictated by the needs of the child and family, are based on the family’s strengths, and are provided in a manner which maximizes opportunities for involvement and self-determination in planning and delivery.

Individualized: Services are designed in accordance to the unique needs and potentials of each child and family, and are guided by an individualized plan.

Community-Based: Services are provided in the community, in the least restrictive environment possible, and are accessible and available to residents.

Integrated and Coordinated: Services respond to an inter-related array of problems, are delivered through linkages between public and private providers.

Culturally Competent: Services which value diversity, acknowledge and work with the underlying cultural dynamics of the community and family, and adapt to meet the needs of culturally and ethnically diverse groups within the community.

Early Intervention/Prevention: Services aimed at reducing the prevalence and severity of problems faced by families through effective early identification and intervention.

Beyond using the theoretical base linking program characteristics to client outcomes, we approached the development of the case study protocol from a client-centered perspective. In our design, the quality of the system is evaluated through the experience of consumers using the system. This philosophical position is captured in the name of our instrument, *The Family Experience Study*. Through this instrument, we sought to determine whether consumers experienced services as “culturally competent,” or “individualized,” or “family centered” by asking them to describe actual exchanges and interactions with representatives of the system of care (e.g., case managers and providers), and to rate the effectiveness of services provided to them in terms of impact on the child and family.

This approach is different from client satisfaction measures traditionally used as proxies for reflecting service quality. We believe that asking a client to express satisfaction or dissatisfaction with services often places them in a position to make a judgment that can be influenced by many factors, including fear of retaliation if the assessment is negative, desire to please the provider, or “averaging out” numerous positive and negative interactions into a single rating. Instead, we chose to seek answers about the quality

Theoretical and Methodological Foundations of the Family Experience Study

of the system of care from an organized interview process that allowed participants to describe first, and rank later. For example, rather than developing a list of mental health and related social services and asking consumer interviewees to check the ones they had used, the protocol included a needs assessment in which the primary caregiver was asked to list all family needs, and then rank them according to how they impacted their family. Similarly, rather than asking the family's case manager to identify the family's providers, primary caregivers were asked to list all individuals who were involved in a helping relation with the family around the needs of a target child. The interviewees listed both formal and informal helpers and then ranked them according to how important these people were to them as sources of support. All individuals identified in this fashion are interviewed as part of the study.

Protocol Development

After the program's theory of change and philosophical approach to the research were articulated, the process of protocol development began. From the broader set of principles, a list of more focused questions was derived:

1. What are the perceived/identified needs of the children and families, and how are they determined?
2. What services have they received?
3. What are the experiences of the children and families while they are in the system?
4. What was the family's involvement in the development of the service plan?
5. Are there mechanisms for service coordination among the providers working with the family?
6. Where are the services located and how are these services accessed?
7. What are the family's most important sources of formal support?

8. What are the family's most important sources of informal support?
9. How do formal and informal supports interact?
10. How satisfied are the children/families with the system's response to their needs?
11. How and to what degree have the children/families' quality of life changed over time?

Since the main focus of the FES is on the consumer's experience of services, the methodology chosen to gather data was structured interviews with key individuals who make up the service network around a child of interest (i.e., a child who is involved with the system of care under study). These individuals include the primary caregiver, child, lead casemanager, one or more providers, and one or more informal sources of support (e.g., relatives, friends, neighbors). Thus, the final step in the development of the protocol involved the generation of specific items to address each of the principles and help answer the focused questions in each of the interviews (e.g., primary caregiver interview, child interview, provider interview, etc.). Protocol items include a combination of open-ended and close-ended questions. Frequency, satisfaction and improvement scales are used to rate perceptions across the protocol. The main topics addressed in the interview items include: the process of development of the child/family support plan and the child/family's involvement in that process; relationship of the child/family with case managers and providers; type, frequency and accessibility of services received; involvement of the child/family's sources of informal support; and perceptions of satisfaction and effectiveness.

In addition to the interviews, case records were reviewed to substantiate and supplement the information obtained from the interviewees, and specifically, to examine the service/treatment plan documentation.

Analysis

The analysis of the FES is a two-fold process. The first step employs the judgment of expert case reviewers who, after completing each case study, answer a set of summative questions and produce a rating for each of the principles addressed by the study. The means of the ratings for each principle across all cases reviewed constitutes the final measure of quality of the system of care. The second step is to examine the responses to the interview protocol items concerned with each principle (these have been previously coded by principle). This analysis looks for correspondence between actual responses and reviewer judgments. During this process, reviewers compare responses across interviews and summarize trends across cases.

In order to assure the inter-rater reliability, a set of steps have been followed. First, before going into the field the interviewers (and raters) agree on the criteria that will guide the rating of the principles of the system of care. The criteria includes (a) agreement on the meaning of each summative question for each principle, and (b) agreement on what does each rating represents. Secondly, after the interviewers rate each one of the principles for their respective cases, the group meets and checks the reliability of each rating. As a result of these group sessions, ratings may be altered to meet the consensual decision.

The FES as a Self-Assessment Tool

One of the goals of developing the FES protocol was to provide timely feedback to the developers of the system of care under study to allow them to improve quality and staff performance and therefore, improve the likelihood of positive outcomes for children. This was accomplished by building a preliminary debriefing session with the main system of care stakeholders into the data collection site visit.

Process. After their daily case review (each reviewer conducts two to three case studies during a site visit), reviewers meet to discuss their cases and preliminary impressions on the quality of services provided to the target child and family. After all cases studies are completed, reviewers meet again to

identify trends and commonalties across cases. The discussion is organized around each principle, which the reviewers address based on what they have learned in the field. The reviewer's team leader summarizes the preliminary findings and leads a discussion around strengths of the system of care and opportunities for improvement. Finally the review team makes suggestions as to how the system could be improved and where additional technical assistance may be needed. On the final day of the visit this information is shared with service providers, consumers, and any other stakeholders involved in service delivery. Following the site visit, a full report is prepared using the analytical approach previously described

Another goal of the FES was to make study procedures available for programmers to independently evaluate the quality of their services as an ongoing monitoring tool for service improvement. This was accomplished by developing a Training Manual which accompanies the protocol and covers the various aspects of the study's implementation (i.e., case selection, screening and interview scheduling, interviewing techniques, field work considerations, etc.). A complementary piece is being developed on the training of interviewers, inter-rater reliability checks, and data analysis approaches.

References

- Schorr, L. B. (1988). *Within Our Reach: Breaking the Cycle of Disadvantage*. With Daniel Schorr. New York: Doubleday.
- Stroul, B.A., & Friedman, R. (1986). *A System of Care for Severely Emotionally Disturbed Children and Youth*. CASSP Technical Assistance Center. Georgetown University Child Development Center. Washington, D.C.
- Weiss, C. (1995). Nothing as Practical as Good Theory-Based Evaluation for Comprehensive Community Initiatives for Children and Families. In J. P. Connell, A. C. Kubisch, L. B. Schorr and C. H. Weiss (Eds.), *New Approaches to Evaluating Community Initiatives: Concepts, Methods, and Contexts* (pp. 65-92). Washington, D.C.: The Aspen Institute.

Family Satisfaction with Level of Cultural Competence in Systems of Care: Development of a Cultural Competence Scale

Introduction

Ideal systems of care for children have been conceptualized as having a full continuum of care where services are (a) tailored to meet the individual needs of children and their families are involved in decisions regarding service delivery; (b) provided in the least restrictive environment, and (c) delivered by culturally competent service providers. Cultural competence of a system of care can be defined as a set of congruent behaviors, attitudes, practices, and policies that come together in a system and enable that system to work effectively in cross-cultural situations (Isaacs-Shockley, Cross, Bazron, Dennis, & Benjamin, 1996). Culturally competent systems of care are characterized by (a) placing a high value on cultural diversity; b) having an understanding of the relationship between culture and definitions of normal and dysfunctional behavior; and c) adapting the service delivery system to meet the needs of culturally diverse children and their families (Pumariiega, 1996).

The technology to assess the development of cultural competence within a system of care is newly emerging. Instruments to evaluate the culturally competent behaviors, attitudes, and practices of service providers from the consumer perspective are almost nonexistent. A recent review of 14 instruments designed to evaluate dimensions of cultural competence noted that most of the instruments have not yet established reliability or validity (Roizner, 1996). In addition, the majority were designed to use

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administrators or service providers as informants. Very few directly assessed ethnically and culturally diverse consumers' perceptions of the cultural competence of organizations nor their satisfaction with this aspect of services. Measuring change at the organizational level is a necessary first step in helping service systems become increasingly more culturally competent. However, only the consumer can inform us whether having a more culturally competent staff makes a difference in their satisfaction with services.

Traditional consumer satisfaction surveys can be modified to include items that address issues relevant to the concept of cultural competence. For example, the following general types of survey questions can address the more specific content identified in parentheses:

- ***Did consumers get the services they needed?*** (Was there an absence of discriminatory practices in the provision of services?)
- ***Were services appropriate?*** (Was the determination of need for services based on culturally unbiased diagnostic instruments and assessments?)
- ***Did consumers seek help when they needed it?*** (Were geographic, linguistic and other barriers restricting access eliminated?)
- ***Did consumers get the kind of help they wanted?*** (Were services adapted to differences in family structure, expectations, preferences, and world views?)

If systems of care are rated in the affirmative on the dimension above, then consumers should report that they felt respected, welcomed, and that their experiences were understood, regardless of their cultural or ethnic background. As a result, families should report feelings of satisfaction related to this aspect of the system of care. Using these principles as guidelines for item development, the Cultural Competence Scale (CCS) was designed to assess family satisfaction with the level of cultural competence in systems of care. This paper will report on the initial steps taken to design the CCS.

Method

Participants

The 26 parents of youth with serious emotional disturbance participated in this study. The youth were receiving services from two projects funded by the Center for Mental Health Services (CMHS) Comprehensive Community Mental Health Services Program for Children and Adolescents with Serious Emotional Disturbance. The two projects were the FRIENDS Initiative of the Mott Haven community of the South Bronx and the ACCESS project in Alexandria, VA. The parents selected for inclusion in this study had children whom were scheduled for a six month follow-up evaluation during the data collection period. This sample of youth was described as being 69% female with a mean age of 14 years. The ethnic composition of the youth was 54% African American, 35% Hispanic and 11% White. Of the Hispanic group, 36% identified themselves as Puerto Rican, 9% Mexican and 54% other (primarily Central American countries).

Item Selection and Procedures

In designing the items for the CCS efforts were made to address some of the problems typically found with satisfaction measures, such as vulnerability to social desirability response bias and lack of differentiation among dimensions of satisfaction (Young, Nicholson, & Davis, 1995). Other investigators have found that consumer reports of cultural competence of services can be confounded with the consumer's overall feelings towards the service provider. Therefore, our goal was to develop a set of items that would assess cultural competence independently of the consumer's relationship with their service provider. To evaluate the success of the cultural competence items in achieving this goal, the authors decided to include items that would directly measure satisfaction with the therapeutic relationship. Only items that could be demonstrated to measure something different from overall feelings towards the service provider would be included in the final scale.

Cultural Competence Scale

Initial brainstorming by the authors resulted in 26 items that measured both the cultural competence issues identified above and the positive aspects of the therapeutic relationship. Since the new items would be collected as part of a national evaluation of projects funded by CMHS that included the Family Empowerment Scale (Koren, DeChillo & Friesen, 1992) and the Family Satisfaction Questionnaire (MACRO International, 1995), items were eliminated that appeared to duplicate items in either of those instruments.

The remaining 20 items were subjected to a field trial in two sites to evaluate the clarity and face validity of the items. At each site four staff and two parents of youth receiving services reviewed the items. Their feedback resulted in considerable re-wording of the items to reduce the amount of professional jargon. In addition, three of the original items were eliminated as being too confusing and three new items were added to directly address issues of concern to the families. The final 20-item instrument was included in the ongoing evaluation of services provided in the FRIENDS Initiative and the ACCESS project.

Items were scored on a 5 - point Likert-type scale ranging from 1= *very dissatisfied* to 5= *very satisfied* on items measuring satisfaction with the cultural sensitivity of services. Items assessing the parent's perceptions of the service provider were scored on a 5 - point Likert-type scale ranging from 1= *no, definitely not* to 5= *yes, definitely*. All items were scored in the positive direction where higher scores indicate higher levels of satisfaction.

Data for this study were collected over a period of three weeks. Project staff met with the parents in their homes to complete the instruments required by the national CMHS evaluation. The items being reported here were included at the end of the Family Satisfaction Questionnaire.

Analysis

Correlation techniques were used to examine the relationships between the 20 items and to identify items that appeared to measure the constructs of cultural competence and therapeutic relationship. Once the two subscales were identified, the relationship between subscale scores was calculated using a Pearson product moment correlation.

Results

Pearson correlation's among the 20 items ranged from $-.38$ to $.81$. Several items showed low correlation's with all other items. Using $.50$ as a cut off for inclusion in subsequent analyses resulted in a few items that correlated with each other but not with any other items (e.g., availability of services in the participant's primary language). Therefore, in order to identify subscales, a correlation coefficient of $.60$ with at least one other item served as a criteria for inclusion of that item in further analysis. Table 1 shows the correlation coefficients for the 11 items that met this criteria. Cronbach's alpha for the 11 items was $.79$.

By grouping items with high inter-item correlation's and conducting a content analysis, the 11 items were divided into two groups. Means and standard deviations for each of the items are presented by group in Table 2. Each group of items showed adequate internal reliability. Cronbach's alpha was $.85$ and $.74$ for Group 1 and Group 2, respectively. Finally, a mean score was calculated for all items in each group, or subscale. The low Pearson correlation of $.09$ between the mean subscale scores indicates that the subscales were, in fact, independent.

Discussion

The results indicate that the Cultural Competence Scale (CCS) shows some promise as a reliable, internally consistent instrument to measure family satisfaction with the level of cultural competence in systems of care. Six items measure the consumer's satisfaction with the service system's ability to understand cultural beliefs and values, life experiences within his/her own community, as well as the availability of services that are culturally sensitive. Moreover, these items are measuring a different construct from the service provider's ability to be respectful and accepting.

Further use of the CCS in protocols evaluating systems of care for youth with serious emotional difficulties will be required before the design of this instrument is finalized; two problems with this study limit the usefulness of the CCS in its present form. First, the sample size was inadequate for sophisticated analyses. Second, several of the items had low variance because respondents showed a strong endorsement of the item. For example, all respondents reported that they would "definitely" recommend their service provider to a friend in need of similar services. Therefore, these items will likely be eliminated from the final version of the instrument due to their inability to differentiate respondents with lower levels of satisfaction. The next step in developing the CCS will focus on obtaining a sufficient sample to conduct a factor analysis and to evaluate its relationship to the items in the Family Satisfaction Questionnaire and the Family Empowerment Scale.

References

- Isaacs-Shockley, M., Cross, T., Bazron, B. J., Dennis, K. & Benjamin, M. P. (1996). Framework for a culturally competent system of care. In B. A. Stroul (Ed.), *Children's mental health: Creating systems of care in a changing society* (pp. 23-39). Baltimore, MD: Paul H. Brookes Publishing Co.
- Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology*, 37, 305-321.
- MACRO International, Inc. (1995). Evaluation of the comprehensive mental health services program for children with severe emotional disturbances. Atlanta, Georgia: Author.
- Pumariega, A. J. (1996). Culturally competent evaluation of outcomes in systems of care for children's mental health. *TABrief*, 2, 1- 5.

Table 1
Pearson Inter-item Correlations (*N* = 26)

	Q2	Q3	Q4	Q6	Q10	Q13	Q14	Q15	Q16	Q17	Q20
Q2											
Q3	.78										
Q4	.70	.70									
Q6	.78	.54	.69								
Q10	.19	.03	.10	.14							
Q13	.24	.20	.21	.07	.70						
Q14	.22	.26	.10	.11	.66	.81					
Q15	.19	.06	-.03	-.01	.13	.24	.17				
Q16	.08	.31	.20	-.19	-.02	.11	-.23	.38			
Q17	.60	.63	.60	.34	-.11	.03	-.16	.37	.72		
Q20	.25	.04	-.02	.	.09	.17	.	.70	.50	.53	

Cultural Competence Scale

Roizner, M. (1996). *A practical guide for the assessment of cultural competence in children's mental health organizations*. Boston, MA: Judge Baker Children's Center.

Young, S. C., Nicholson, J., & Davis, M. (1995). An overview of issues in research on consumer satisfaction with child and adolescent mental health services. *Journal of Child and Family Studies*, 4, 219-238.

Table 2
Means and Standard Deviations of Correlated Items

		<i>M</i>	<i>(SD)</i>
Group 1			
Q2	understand how children are raised	4.09	.90
Q3	respect for the religious beliefs of your family	4.13	.81
Q4	sensitivity toward your family's beliefs about mental health	3.87	1.06
Q6	availability of services that teach child about positive aspects of culture of origin	3.96	1.02
Q16	understanding of customs and values shared by community	4.26	.75
Q17	understanding of what life is like in community	4.09	1.00
Group 2			
Q10	service provider's belief in ability to care for children with mental health needs	4.39	.84
Q13	service provider listens and understands situation	4.56	.73
Q14	service provider respects family's values	4.65	.88
Q15	service provider friendly and warm	4.96	.21
Q20	would recommend service provider to a friend	5.00	.00

The Parent Involvement Project: Analysis of Parent Focus Groups

Introduction

This summary reports on the data analysis from the Parent Involvement Project (PIP) focus groups conducted by the Florida Center for Parent Involvement located in the Department of Child and Family Studies, Louis de la Parte Florida Mental Health Institute (FMHI), University of South Florida, in Tampa, Florida, and the Florida Children's Forum in Tallahassee, Florida. The Florida Center for Parent Involvement (Florida Center) acts as a dissemination center to provide information, technical assistance, and consultation to the 25 Florida Child Care Resource and Referral Centers, school systems, Head Start programs, Even Start programs and other family support agencies in an effort to expand parent participation in the education of their children. The Center's goals are to assist parents to better understand their children's educational needs, enhance their communication with school personnel, and become full partners with the schools and community in the educational and social development of their children.

In 1996, the Florida Center in collaboration with the Florida Children's Forum conducted eight focus groups throughout Florida as the principle method for obtaining parental input on their needs and preferences for resources and informational support. The data gathered from the focus groups provided information that will be used to guide the selection of topics for

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resource materials and the development of informational formats appropriate for reaching Florida parents.

The Focus Groups and Data Collection

Data from five of the eight groups were found to be complete and are reported on in this paper. The focus groups were asked seven open-ended questions that dealt with areas of interest to the Florida Center staff. The questions were in the areas of 1) the greatest challenges faced by parents, 2) their child’s level of school readiness, 3) the differences in parent involvement in preschools and public schools, 4) the violence faced by children, and 5) the best information formats for distribution of resources to parents. A focus group moderator asked the questions and facilitated the parents’ conversations. The moderator’s job was to keep the group participants focused on the questions and help draw each person into the conversation. Each focus group took about 1.5 to 2 hours. A recorder took notes and ran an audio tape during the group. A written verbatim transcription was made from the tape recordings and the recorder’s notes.

The focus groups were composed of specifically selected groups of parents that matched a range of socioeconomic characteristics of interest to the Center staff (i.e., income levels, mothers and fathers, race/ethnicity, and geographic location). To take part in a group each parent had to have at least one child attending a pre-school program, and at least one child enrolled in public school. Most of the preschoolers were in Head-Start or a supported day care setting. Table 1 lists the focus groups and shows that a total of 43 parents took part in the five focus groups.

Data Analysis

The Florida Center staff sorted data taken from the transcripts, compared and contrasted the different parent groups’ conversations, and developed general categories of topics and issues. The general categories of issues important to the focus group parents reflect cross-case (i.e., group) clustering of topics and issues. Although each group emphasized different individual issues, there was much overlap in the five groups’ issues. For instance, all the groups expressed concern about the attitudes of public schools and teachers, and agreed that Head Start and

**Table 1
The Five Focus Groups**

Focus Group	Date	Number of...		Number of...			Average Number	Average Age
		Moms	Dads	Black	Hispanic	White	Children	Children
Tampa Moms	Mar 26	9	0	8	1	0	3.30	6.39
Tallahassee Parents	Apr 15	12	1	12	0	1	2.07	6.36
St. Pete Fathers	Apr 20	0	8	6	0	2	2.75	6.43
Dover Moms	Apr 26	7	0	1	5	1	3.00	8.28
Ormand Beach Parents	Aug 15	5	1	0	0	6	2.66	6.43
Total		33	10	27	6	10	Mean = 2.69	Mean = 6.74

Parent Involvement Project

other supported pre-schools were more positive and helpful toward parents. Categories were also developed for the issues expressed by individual groups, and noted as unique to the respective group. An example of an issue unique to a single group, is the communication barriers non-English speaking parents (Dover Moms) confront when dealing with teachers who only speak English. All issues discussed by the parent groups were analyzed and placed in major categories in an effort to provide the Florida Center with the full range of issues important to a variety of parent groups. The next step in the analysis of the parent focus groups is to add data from several more focus groups that met in 1997. The added groups should provide a further opportunity to examine the validity of the general categories and specific parent issues.

Findings

Analysis found that the parents' discussions fell into four main areas of concern to them, 1) the schools, 2) their children, 3) being a parent, and 4) the best information formats. Table 2 shows examples of specific parent issues listed under each of the four main topic areas or categories. The data from the focus groups are extensive and can not be fully described in this paper. The parents concerns with their children's transition from preschool to school is presented as an example of the data provided by the focus groups.

Transition from Preschool to School. The focus group parents had many concerns about their children's transition from pre-school to kindergarten and to first grade. Many were concerned about the different or added demands the first grade teachers placed on the children. Parents talked about the different attitudes of the schools and the less personal atmosphere in the public school classes. They were also concerned about the first grade teachers expectation in areas such as timeliness,

Table 2
Examples of Specific Parent Issues
for Each Topic Area

- 1) The Schools
 - Transition from Preschool to School
 - Strategies for Successful Transition
 - Parent Communication with Teachers
 - Children's Academic Readiness
 - Children's Behavior Problems
- 2) Their Children
 - Well-Being of Children
 - Uniqueness of Each Child
 - Communication with Children
 - Teaching Children Life Values
- 3) Being a Parent
 - Power and Control Issues
 - Lack of Response from the Other Parent
 - Parental Stress
 - Time Concerns
- 4) The Best Information Formats
 - TV and Radio Shows, and Advertisements
 - Videos for Both Parents and Children
 - Calendars with Needed Information
 - Home Visits by Staff
 - Meetings in Schools and Churches
 - Information in Different Languages

discipline, and academic issues. For instance, a Tampa mom talked about her son's first day in first grade, "... he came home, 'mommy, (he said) I want to go back to kindergarten.' And I said why, and he said because 'in kindergarten we take naps, we play.' In first grade he had to sit down in the chair, work, and it was time set aside for everything, and he's day just didn't go freely...the transition that they have to make sometimes they are not ready for it because they are used to stopping, they are used to the teacher hugging on them and sitting them in their laps and all this in pre-K and Head Start and kindergarten. And when they get to first grade that's not there."

This issue is closely related to the second area of concern for parents, which was good strategies for preparing their child for transition into kindergarten or first grade. One Tampa mother

explained that at her daughter's school, "the teachers give you a list of things that can help your child at home, and gives you packets on how to get your child ready for kindergarten or (first grade)." The parents in this group all agreed that a list would be very helpful in preparing their children for the transition to the next grade, and that most schools did not provide this type of information. The Tampa group also suggested that the schools hold an open house before school starts, or hold a workshop for the parents, and that the schools should always involve the parents. The Dover mothers discussed that if a child attended a pre-school program then the beginning of kindergarten or first grade is much easier for both the child and the parent. A mother in this group explained, "For some parents that need to have their kids in pre-K or some other kind of day care, the kid (is ready) for what they have to face; not being around their parent, and know[ing] that at certain times the parent will be there to get them. But if they start all of a sudden, put into an environment they are not used to, eventually it (is) going to cause some kind of conflict, some kind of complication because they will realize that you are not there and they are used to seeing you and they are around strange people, so they have to adjust to that. Some kids don't adjust because they always (were) at home."

Summary

The use of the focus groups allowed the Florida Center staff to gather specific types of information based on the parents' expressed needs and concerns. Although parents were asked questions about their greatest challenges, their children's school readiness, parent involvement, violence faced by children, and information formats, the parents actual conversations were much broader in scope. Analysis of the group discussions showed that the parents' issues fell into four general categories with a clustering of related topics within each category. The only topic asked by the moderator that was not expanded on and considerably changed by the parents was the topic of the best information formats. The goal of the analysis was to categorize the types of information parents want. The cross-case comparisons strengthened the analysis and gave more assurance that the categories developed from the data were broad based. The information from the focus groups will be used to develop the Center's resource catalog and to help develop appropriate formats for distributing information to Florida parents.

Gathering Information from Families – Enriching the System of Care

Introduction

To maximize accountability of public resources, the Continuum of Care for Emotionally Disturbed Children (COC) in South Carolina is developing a set of outcome measures. Parents were invited to participate in this process in two ways; through Family Forums (focus groups) and a Family Feedback Survey. Parents provided information about appropriate goals for their child. They also commented about the need to improve existing services, the need for more attention to the dynamics of the family, and the need for development of additional specialized services for their children.

Methods

Participants/Sites

Parents of twenty-two clients attended the Family Forums, representing 12% of the COC's client population. Based on statistical analysis, the families attending were representative of all COC families on such measures as client age, diagnosis, and length of time in the COC. Children of parents who attended the Family Forums were slightly younger than those of parents who did not attend the Forums. The COC sponsored seven Family Forums. All parents received letters inviting them to a local Family Forum. Regional staff along with at least two representatives from the state office attended each Forum. At each Forum a facilitator used open-ended questions to generate discussion. Comments were recorded.

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For the Family Feedback Survey, pre-survey letters were sent to all parents informing them of the Family Feedback Survey. All parents were mailed survey packets that included a cover letter, a survey, and a drawing ticket. The drawing ticket was used to track which parents responded and as a raffle ticket for a gift certificate. A second survey packet was sent following the original deadline to parents who did not respond to the first mailing. Forty-seven percent of the custodial parents returned their surveys.

All data was collected between August and October of 1996.

Measurement/Instruments

The Family Feedback Survey and facilitator questions used in Family Forums were designed to be specific to the COC population, addressing such issues as overall satisfaction, satisfaction with the service coordinator and treatment providers and perceived child progress toward stated goals. Questions for the Family Feedback Survey were selected from a pool of questions, narrowed by senior staff. Questions were then checked for readability and rewritten until the survey read at the 9th grade level.

Statistical Analysis

The Family Forum data and data gathered from the open-ended questions of the Family Feedback Survey were treated as qualitative data gathered using an exploratory research design; therefore, no statistical analyses were made. Quantitative data collected from the Family Feedback Survey was analyzed using EpiInfo 6.0, an epidemiological analysis program designed for the Centers for Disease Control and Prevention. Univariate and frequency analyses were performed. Chronbach's Alpha was calculated to determine internal consistency.

Results

Family Forum

Several themes emerged from the Family Forums. A synopsis of the parents' comments are presented:

Long-Term Client Outcomes. Parents stated the desire for their children to learn appropriate living and coping skills, enabling them to live independently as adults and maintain connections with their families' of origin.

Life Skills Development (Vocational, Social, Coping). Parents stated the need for early, strengths-based, vocational training. Parents stated the need for children to learn social skills, communication skills, impulse control, and how to handle money responsibly. Parents stated the need for children to learn coping skills such as anger control and taking responsibility for their behaviors.

Improving the System of Care—General Issues. From public agencies, parents expressed expectations that agencies provide a complete array of services to children diagnosed as severely emotionally disturbed and develop services for children with dual diagnoses of mental retardation and severe emotional disturbance.

From the public education system, parents expressed the need for appropriate local academic services with staff trained in behavioral management techniques. Parents expressed the need for children to be served in the least restrictive educational setting and for special attention to be given to the educational needs of children in residential care.

Parents expressed the need for more services addressing the individualized needs of children. Parents want services that address the child's outward behavior as well as underlying issues such as anger and depression. Services requested included: day treatment services, intensive therapy for

Gathering Information from Families

children who have been sexually abused, and recreational activities for children who remain at home. Overwhelmingly, parents requested enforcement of high standards on all purchased residential and wrap services through adequate monitoring and the refusal to use programs that do not meet services standards or therapeutic goals for children.

Improving the System of Care—Residential Services. Parents had two overarching expectations of residential providers. First, parents expect services to be safe, individualized, age appropriate, strengths-based, and therapeutically appropriate. Second, parents expect to be included in treatment decisions involving their child.

Services for Family Members. Parents stated that the entire family has the need for a safe place to express and work through their feelings related to experiences with their child who has been diagnosed as severely emotionally disturbed. In addition, parents requested educational information related to their child's diagnoses and medication, behavior modification techniques, and case management skills.

Role of the COC. Parents expect case managers to provide necessary information about the child's progress, serve as a link to other providers, and to help with problem solving. Parents look to case managers to help them feel empowered when working with service providers and help them maintain their role as parents if the child enters residential care. Parents look to case managers to provide accurate information about service providers so parents can make informed decisions.

Early Intervention and Prevention. Parents requested increased interagency communication, focused at developing earlier intervention services to avoid problems escalating to crisis points, leading to hospitalizations or involvement with the juvenile justice system.

Family Feedback Survey

The results show that, overall, families were satisfied with the services provided by the COC. Their satisfaction can be seen in three ways. For the questions using a Likert-type scale (1=*low*, 4=*high*), the mean response was about 3.5. The percentage of responses indicate that about 85% of respondents were either "satisfied" or "very satisfied." A third indicator of satisfaction was the question which asked for a letter grade on the COC's performance; 82% gave the COC an "A" or "B."

Other items of note:

- 96.2% of respondents stated that they were "very involved" or "fairly involved" in helping to make treatment decisions for their child.
- 85.9% felt that their child's treatment needs are met "yes, completely" or "most needs are met."
- 92.4% felt that the present case manager understands the special needs of their child "very well" or "fairly well."
- 77% of the respondents were the child's mother.

The survey also included open-ended questions. When asked what improvements they would like to see in their child by the time he or she leaves the COC, family members responded in a variety of ways (see Table 1).

Table 2 shows the responses of family members when asked what they would like for the COC to do for or with their families.

Discussion

Analysis of the data from the Family Forums and Family Feedback Surveys found several themes:

- The System of Care still needs some development, especially in the area of specialized services to meet the needs of children in rural areas or with dual diagnoses.
- Families want their children to have the ability to work and love.
- Families want public agencies to focus on earlier detection and earlier intervention.
- Public agencies' services need to become more family centered.
- Families could benefit from training in case management skills.

The Family Feedback Survey, which had a response rate of 47%, noted that about 85% of respondents were satisfied with the COC's operations. The COC plans to collect information from families annually to ensure that services are congruent with their needs. Information gathered from families can be used to highlight areas of strength for an organization and system of care as well as provide direction for improving the system of care.

Table 1
Improvements Parents Said They Would Like to See in Their Child by the Time He or She Leaves the COC

Responses:	#	%
Educational attainment	41	53.2
Control over emotions	35	44.2
Not hurting others	25	32.5
Developing social skills	24	29.9
Accepting responsibility	12	15.6
Learning self-control	9	11.7
Getting a part time job	7	9.1
Learning to follow directions	5	6.5
Maintaining a positive role model	2	2.6
Receiving sex offender counseling	1	1.3
did not respond to this question	17	22.1

Table 2
Family Member Responses When Asked What They Would Like for the COC To Do For or With Families

Responses:	#	%
Family Counseling	17	22.1
Nothing more than what is currently provided	12	15.6
Support group for parents	10	13.0
Services to ease transition of the client back into the home	8	9.1
To have the child home	5	6.5
Placement closer to home	3	3.9
Removal of the child from the home	2	2.6
Daycare for other children	1	1.3
did not respond to this question	26	33.8

Expectations of Parents and Providers: Insoluble Differences or Potential Solutions?

Introduction

As a result of the recent shift in public policy from institutional care to community-based services, it has been recognized that changes need to be made within the delivery of mental health services in three areas: service system development, components of a system of care, and the role of families within the system and in the care of their children (Lourie & Katz-Leavy, 1991). With current trends encouraging partnership between parents and providers (Stroul & Friedman, 1986), it is necessary to develop mechanisms for opening up lines of communication. It is essential that parents and providers develop some understanding of each other's needs, expectations and limitations and find common ground on which to work together effectively. While some research has been done to identify families' needs and experiences with service systems (Friesen, 1990; Tannen, 1996; Tarico, Low, Trupin, & Forsyth-Stevens, 1989), it appears that little research has been conducted with regard to each group's perception of what it needs from the other, as well as what each group feels are barriers to working together effectively.

The degree to which each group understands the other directly impacts the perception of partnership. It is important for the two groups to develop a better understanding of each other's perceptions so that they may come together, speak the same language and work in partnership toward a common goal: That is, to improve service delivery to children with serious emotional disturbance and their families.

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The purpose of the study was twofold. The first goal was to gather relevant information with regard to needs, expectations, limitations and successes from the two groups of stakeholders. Secondly, the information collected was to be used to develop training for parents and providers, both together and separately. The goal of the training is to educate each group with regard to the other's issues, as well as to openly explore ways to get past some of the barriers that impede working together effectively.

Throughout this summary, the term "provider," as opposed to "professional" was used to refer to those who provide service. It was felt to be more respectful to parents and what they bring to the process, than if the word "professional" was used (which implies by default that parents are "non-professionals" regarding either the needs of their children or what they extend to the partnership with providers).

Method

A qualitative approach was chosen in an effort to leave the two groups of stakeholders free to define the universe of issues regarding their needs, perceptions of the other's needs, barriers, and successes. Focus groups were selected as the best approach to enable a diverse group of parents and providers, separately, to engage in an open discussion with regard to these issues, as identified by group participants.

Letters soliciting participation in the focus groups were mailed to providers ($N=125$) and parents ($N=134$), whose names appear on the mailing list of a county level peer support and advocacy organization for parents caring for children with serious emotional disturbance. Separate focus groups were arranged for parents and providers. Following the standard protocol for focus groups (Beck, Trombetta, & Share, 1986 and

Krueger, 1988), the groups were brief in duration (90-120 minutes) and informal.

Three focus groups, with a total of 23 participants, were created. Two focus groups were created for parents ($n=12$), one held during the day and one in the evening to accommodate parents' schedules and to maximize participation. The parents participating in the focus groups represented various family structures (such as single parent, adoptive parent, grandparent, etc.), and were diverse in their ethnic background and from different residence types (suburban, rural, urban). Additionally, the number of service systems in which the families were involved ranged from 1 to 5, with a mean of 3 systems.

One focus group was created for providers ($n=11$) and was held during normal working hours. Providers represented both direct service providers ($n=5$) and administrators ($n=6$) from various county ($n=3$) and not-for-profit ($n=8$) agencies providing a wide variety of services. All services being received by families were represented by a provider who participated in the provider focus group.

Each of the focus groups was facilitated by the same three people: an individual trained at the doctoral level in evaluation research, a parent of a child with a serious emotional disturbance, and a provider who worked with children and families from the county. All participants were given a copy of the questions they were to discuss. Questions asked during the focus groups included: What do you need from providers (parents)? What do you think providers (parents) need from you? What are the barriers to working effectively with providers (parents)? What works? With the consent of the group participants, sessions were audiotaped and verbatim transcripts were compiled. To ensure objectivity, the transcripts were reviewed and themes constructed individually by the parent and

Expectations of Parents and Providers

provider who helped facilitate the groups. Each statement in the transcripts was linked to a theme. The themes and statements were then compared and discussed between the parent and provider and a final set of themes was agreed upon. The final group of themes were then compared and contrasted between the two groups and paradoxes were identified.

Results

During the focus groups, it was noted that there was near universal agreement between parents participating. Providers, on the other hand, were more likely to disagree with each other on issues that were discussed.

Parent and provider groups identified many similar themes with regard to the needs of parents and the needs of providers (see Table 1 and 2). Themes developed for both groups indicated that parents and providers identified a need to trust, respect and be honest with one another. Less agreement between the two groups was present for the themes relating to barriers to working effectively together. Themes identified relating to barriers for providers included issues relating to service systems; while themes identified for parents

included issues related to being accepted by the provider (see Table 3). Themes related to what works for families differed by parent and provider groups (see Table 4). For example, provider group themes related to service systems issues; whereas, parent group themes related more to relationship issues. Thus, it seems that parents focus more on the therapeutic relationship as an important aspect of treatment, while providers appear to focus more on issues related to service systems. Future directions include developing a survey to collect quantitative data to ensure the veracity of the themes and to prioritize them.

Discussion

Overall, parents and providers seem to have some understanding with regard to each others needs. However, some needs were identified by one group and not the other which may have a negative impact when the two groups work together. Parents expressed a need for concrete ideas, for rules to be bent to meet their needs, and for experienced and knowledgeable workers. Providers identified the need to develop partnerships, connections, open communication and acceptance from families. Parents appeared to hold a double standard for

Table 1
Provider Needs as Identified
by Parents and Providers

Providers	Both	Parents
Partnership	Honesty	Willingness to try new things
Acceptance	Trust	
	Respect	
	Involvement	
	Openness	
	Information	

Table 2
Parent Needs as Identified
by Parents and Providers

Parents	Both	Providers
Concrete ideas to try	Honesty	Information
Bend rules/ no red tape	Trust	Openness
Experience/ knowledge	Respect	Advocacy
	Partnership	Concrete needs met
	Strength-based	
	To be heard	
	Acceptance	
	Accessibility	
	Options	

Table 3
Barriers as Identified
by Parents and Providers

Parents	Both	Providers
Lack of experience/education	Blame/labeling	Provider's own issues
Culture/ethnicity	Bureaucracy	Lack of interagency coordination
	Distrust	Concrete needs not met
	Parent not part of process/coercion	Time limitations
	Dishonesty	Giving up on families

Table 4
What Works as Identified
by Parents and Providers

Parents	Both	Providers
Family focused/child centered	Partnership	Respect
Encouragement	Flexibility	Flexible service system
Accessibility		Increased accountability
Being heard		
Qualities of successful provider		
Acceptance of problem		

partnership and acceptance as a need of their own, but not as need of providers. This difference may result from the parents' perception that, even though they report needing to be treated as equals, the provider has all the power in the relationship. This perception may have important implications for parents' comfort in advocating for services they feel their child and family may need, and the approaches necessary to empower them to do so.

While there was much agreement with respect to the needs of parents and providers, differences exist with regard to identifying barriers and what works for families. For example, providers identified more bureaucratic issues, while parents identified relationship issues with regard to barriers and success. Additionally, parents and providers had few areas of agreement on what works for families.

Upon comparing and contrasting the responses of the two groups, some interesting paradoxes arise. One paradox deals with the issue of trust. Both parents and providers agree trust is a major issue, yet parents appear to have learned it is unwise to trust providers as a result of the provider's actions (e.g., blaming, labeling), while providers may at

times find it difficult to trust parents due to their own unresolved issues and beliefs (e.g., the parent as a probable cause or negative influence on the child's well-being). A second paradox involves service system issues. The service systems that are designed to help families in need, many times only serve to hurt them as a result of the bureaucracy that is involved. Providers are often bound by rules and regulations that prevent them from providing what the family may need. A third paradox relates to expectations parents and providers hold. Parents often expect providers to have the answers to their problems or concrete suggestions for them to try, while providers often feel they should have the answers, but are at a loss as to what to do in certain situations. As a result of this frustration, providers may label the family as resistant to treatment.

Implications for Training

The issues, with regard to developing an understanding of what is needed by each group, what works for families, and the paradoxes, have important implications for training. By opening up the lines of communication between the two groups of stakeholders, it is possible to develop strategies to

Expectations of Parents and Providers

better understand each other and methods to decrease and/or eliminate the existing barriers preventing true partnership.

Training activities can provide information to providers about what families say works for them. Communities can develop empowerment training for families, and address ways to eliminate barriers that prevent parents and families from getting what they need. Training may occur for each group separately or for both groups of stakeholders. For example, parents may benefit from training addressing advocacy skills and ways in which they can take more responsibility in the treatment process of their child; whereas, it may be helpful to develop forums in which parents and providers can work together to begin to brainstorm solutions to address some of the barriers that prevent families from getting needed services.

References

- Beck, L. C., Trombetta, W. L. & Share, S. (1986). Using focus group session before decisions are made. *North Carolina Medical Journal*, 47, 73-74.
- Friesen, B. J. (1990). Parents whose children have serious emotional disorders: Their expectations and experiences with professional services. Paper presented at Research Institute: Foundations for Success: A Blueprint for the Future. Cincinnati, Ohio.
- Krueger, R. A. (1988). *Focus groups: A practical guide for applied research*. Beverly Hills, California: Sage.
- Lourie, I. S. & Katz-Leavy, J. (1991). New directions for mental health services for families and children. *Families in Society: The Journal of Contemporary Human Services*, 277-285.
- Stroul, B. & Friedman, R. (1986). *A system of care for severely emotionally disturbed children and youth*. Washington, D.C.: Georgetown University Child Development Center.
- Tannen, N. (1996). *Families at the center of the development of the system of care*. Washington, D.C.: National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center.
- Tarico, U. S.; Low, B. P.; Trupin, E. & Forsyth-Stevens, A. (1989). Children's mental health services: A parent perspective. *Community Mental Health Journal*, 25 (4), 313-326.

An Evaluation of the Impact of a Family Partnership Team on a System of Care and the Families it Serves

Introduction

The San Mateo County Family Partnership Team (FPT) is a new and essential unit of the County Children and Youth System of Care and exists for the purpose of developing and strengthening full partnership between service providers and families. The overarching mission of the FPT is to ensure that families have access to meaningful involvement at all levels of the System of Care (SOC) including policy decisions as well as individual service planning for their children. An evaluation protocol has been developed and implemented to assess the impact of the FPT on the families they serve and the system of care in which they work. This summary presents a description of the evaluation design and preliminary data.

Background

The FPT serves families of children and youth in the SOC who have serious emotional and behavioral disorders and are at risk of out-of-home placement. During 1995-1996, the first year of the FPT, approximately 80 families were served by the team, which includes the full-time FPT Coordinator and three part-time (20-26 hours per week) family members.

The San Mateo County FPT is funded by the federal Center for Mental Health Services' Comprehensive Community Mental Health Services Program for Children with Serious Emotional Disturbances and is in its second year of implementation. While

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in many counties family involvement activities are contracted out to organizations outside the county structure, in San Mateo the family members responsible for spearheading this aspect of the SOC were hired directly by the San Mateo County Mental Health Division and work under the direction of the Coordinator of the FPT, a county employee. These team members' functions include outreach services provided directly to families; however "inreach" services, such as consultation and training to the workers and management of the total SOC, are equally important.

As part of their outreach work, team members work with individual families. They educate them about the system and how to communicate effectively with service providers, often accompanying them to meetings with mental health, juvenile justice, school, and human services personnel. They offer parent-to-parent support, and they work with families and staff to support and reinforce care and treatment plans. As part of their "inreach" function, the FPT seeks to include families in those levels of the SOC previously dominated by professionals with little or no family participation. Some arenas, such as multidisciplinary case review and planning committees and other agency and interagency activities where planning and decision making for the child take place, have traditionally been the exclusive domain of the professionals. The FPT works to ensure that families are included and invited to participate at all levels, including policy planning and implementation.

FPT Evaluation

As the FPT approached the end of their first year of operations, it became clear that the project would need to be able to demonstrate its impact to a variety of stakeholders in order to ensure sustainability once federal grant funding ceased. In discussions among the FPT, management, and evaluators, the following four types of information needs were identified:

1. ***Descriptive information.*** What services does the FPT provide to families? How many families are served? What types of families are likely to be referred to the team? Who refers families to the team?
2. ***Impact on families.*** Are families satisfied with their interactions with the FPT? Do they feel that these interactions have changed their family lives or have helped them in their interactions with the system?
3. ***Impact on system.*** Do county staff understand the role of the FPT? Are they satisfied with their interactions? Are attitudes and practices of service providers and managers in the SOC changing? How much has interaction with the FPT contributed to these changes?
4. ***Client outcomes, service utilization and costs.*** Does FPT involvement with families affect client outcomes, service utilization, or costs?

A four-pronged evaluation protocol was developed and is currently being implemented to address these questions.

Development of Tracking System

At the end of the first year, the FPT had no effective system in place to track their efforts. While individual team members had lists of families' names and phone numbers, no database was available with crucial information such as source and time of referral, amount of time spent with families in a given time period, types of services provided, and demographic information. Such information is crucial in providing

Family Partnership Team

an accounting of how the FPT spends its time and is necessary for analyses evaluating the effects of different types and amounts of services on client outcomes. The FPT developed forms to be completed monthly, tracking the number of hours spent with each family in different types of activities. In order to track time spent in “inreach” activities, a separate form was developed to track time spent at policy and planning meetings in the SOC. Finally, referral sources were tracked, providing important information about which elements of the SOC were using FPT services and identifying the routes by which families come to the FPT. One immediate impact of this new tracking system was the discovery that the majority of referrals to the FPT came not from individual service providers, but from the “Case Assistance Committee,” a multiagency body designed to aid families with specific and unique challenges and service providers involved with those families. A decision was made to increase outreach to SOC staff in order to educate them about the FPT and when a referral might be appropriate.

Assessment of Impact on Families

Of particular interest to the FPT were fellow parents’ perspectives on their interactions with the FPT. After reviewing a number of instruments, the FPT selected the *Parent Satisfaction Survey*, developed by Jo Ann Garner-McGraw (1990) for this purpose. This 16-point instrument is brief, but it assesses not only parents’ satisfaction with services, but also their perspectives on how the services have influenced their lives. Unlike many satisfaction questionnaires, which tend to generate universally positive results (Attkisson & Greenfield, 1996; Waxman, 1996), this questionnaire provided useful diagnostic information. The questionnaire was sent out to 46 families, 18 of which returned a completed questionnaire. Preliminary results show that while the majority of parents agreed with statements such as, “The staff listen and respond to my questions and concerns”

(94.1%) and “Because of my participation in this program, I know more about community services that can help my child and family” (75.1%), most disagreed with statements, such as, “Because of my participation with this program, I have more friends or family members helping me with my child” (31%) or “Because of my participation with this program, I have gotten support from other parents like me” (40%). These findings confirmed the need for the team to redouble their efforts to build a family network to support families, and will serve as a baseline against which to compare responses in the future as the family network develops.

Assessment of Impact on System

The FPT is working to effect radical changes in the system from the inside. A third component of the evaluation was to begin to assess the impact of the team on county workers as the system shifts over to a model of serving families as allies and partners. The transition is not without its difficulties and provides a fascinating case study in system change. In order to begin to track this process of change, a questionnaire was developed and distributed to service providers and managers throughout the SOC, assessing (a) number and types of interaction with the FPT, including whether they have made referrals to the team; (b) their satisfaction with their interactions with the FPT; (c) their understanding of the role of the FPT and their support for the FPT; and (d) their beliefs about the role of families in the system. The questionnaire was widely distributed throughout the SOC and 96 responses were received. Staff were asked to respond to whichever questions they felt they had enough knowledge or experience to answer. Table 1 indicates the percentage of respondents that expressed an opinion for each statement, along with the percentage agreeing with each statement.

Table 1
Staff Opinions of Role of Families and FPT in SOC
(N= 96)

	% responding to item	% of total N expressing agreement with statement
I have a clear understanding of the role of the FPT.	99.0	60.4
I am comfortable w/ the role of the FPT in collaborating with staff to meet families' needs.	92.7	67.7
I believe the role of the FPT needs to be changed.	71.9	20.8
I believe the FPT is a crucial component of the SOC.	82.3	62.5
I believe the FPT should be expanded.	84.0	42.8
I believe that serious confidentiality issues arise when the FPT becomes involved with a family.	70.8	33.4
I have concerns about the use of the term "family partnership" to refer to the relationship between staff and families.	89.6	14.6
I believe that parents and caregivers' input is crucial for determining how to meet their children's needs.	96.9	94.8
While I agree with the notion of families as partners in theory, it is difficult to incorporate into practice.	92.7	48.0
I believe that, because parents and caregivers lack professional training, they are often less equipped to make good judgments about the services their children need.	96.9	30.2
I believe that in the SMC SOC, staff generally view families as partners.	89.6	64.6
I believe that families should be incorporated into every level of decision-making in the SOC, including policy decisions and decisions about their own children's care.	90.6	54.1
The FPT was helpful in meeting the families' needs.	65.6	69.9*
The FPT worked effectively with myself and other staff.	64.6	77.4*
The FPT was able to accomplish things that others could not have accomplished.	60.4	51.7*
The FPT had an important impact on the client's functioning and service utilization.	57.3	60.0*
	Percent responding	Percent Interacting
How frequently have you interacted with the FPT to meet the needs of specific families.	96.9	70.8
How frequently have you interacted w/ FPT in their role as advocates for families at the system level.	96.9	65.7
How many families have you (or a member of your staff) referred to the FPT?	62 referred	34 not referred
How likely to refer in the future.	90.6 % responding	64.6 % likely to refer

* Percentage out of those responding to the question.

Family Partnership Team

The initial findings indicate that about two-thirds of staff responding had some understanding of the role of the FPT and were convinced that it is a crucial component of the SOC. 70.8% of respondents had worked with the FPT to meet the needs of specific families, and out of those, most were satisfied with the FPT's work. Over two-thirds (69.9%) felt the FPT was helpful in meeting the families' needs, and 77.4% felt the FPT had worked effectively with other staff; 64.6% of respondents indicated that they were likely to refer families to the FPT in the future.

How did staff view the role of families in the system? While 94.8% of respondents believed that parents' and caregivers' input is crucial in determining how to meet children's needs, only 54.1% agreed that families should be incorporated into every level of decision-making in the SOC. The findings from this first administration of the questionnaire provide a snapshot of the role of families and the FPT in the SOC at this point in time. These results will also serve as a baseline against which to compare staff responses in the future as the transition to incorporating families as full partners in the SOC proceeds.

Cost and Service Utilization

Finally, for the managers making funding decisions, it was crucial to be able to demonstrate the impact of FPT services on "bottom line" variables such as cost and service utilization. In order to assess the impact of receiving FPT services on these variables, families who were referred to the FPT upon completion of a six-week intensive in-home intervention program are being compared with those who completed the program but were not referred to the team. Similarly, families referred to the FPT after a psychiatric hospitalization are being compared with those who had a hospitalization but were not referred. Costs and service utilization over six months, including psychiatric emergency service visits, hospitalization days, group home days, non-

public school placements, and overall cost of services per month are being compared. Findings from this study should be available later this year.

Discussion

This evaluation is providing a detailed account of the implementation of one model of family involvement in a System of Care; the protocols show promise for tracking the activities of the FPT, their impact on the families in the SOC, and changes in the SOC resulting from their work. In the future, findings from this evaluation can provide other SOCs with guidance regarding the benefits and pitfalls of such an approach. Ongoing evaluation of family involvement efforts has important implications, not only for identifying barriers and opportunities for program implementation, but for ensuring community support and funding for these initiatives.

References

- Attkisson, C. C. & Greenfield, T. K., (1996). The Client Satisfaction Questionnaire (CSQ) Scale and the Service Satisfaction Scale-30 (SSS-30). In L. I. Sederer & B. Dickey (Eds.), *Outcomes Assessment in Clinical Practice*. Baltimore: Williams & Wilkins.
- Garner-McGraw, J. (1993). Family characteristics related to respite care effects and satisfaction. (Unpublished dissertation, University of North Carolina, Chapel Hill)
- Waxman, H. M., (1996). Using outcomes assessment for quality improvement. In L. I. Sederer & B. Dickey (Eds.), *Outcomes Assessment in Clinical Practice*. Baltimore: Williams & Wilkins.

