# Chapter Two

## Family Involvement and Perspectives

# Family Involvement in Evaluation: Evaluator Perspectives

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## Introduction

The last decade has presented new opportunities for families with children with serious emotional disorders to become involved in the evaluation of children's mental health services. Since 1993, system-of-care projects funded by the Center for Mental Health Services' Comprehensive Community Mental Health Services for Children and Their Families Program have been required to involve family members as participants in the evaluation of the projects. As a result of this requirement, family members are working on teams that are evaluating the services their children are receiving.

A number of benefits of involving family members on evaluation and research teams have been identified. Teams have found that family members involved in conducting the research share common experiences with those who are part of the study. These family evaluators are more likely to gain the trust of the research participants and they are more likely to get accurate information from participants. Family evaluators can share their insights with the team in order to verify findings and seek explanations for unexplained results (Osher & Telesford, 1996). In addition, family participation in research improves the usability of instruments, and the information gathered is more relevant to the needs of the families (Friesen & Stephens, 1998). Lastly, dissemination efforts can be enhanced by the involvement of family members. Families can help to design more user-friendly formats for findings, which increase the dissemination of results to a wider range of people, especially other family members (Vander Stoep, Williams, Jones, Green, & Trupin, 1999).

While some researchers and evaluators may recognize the value of working with family evaluators on research and evaluation teams, few have experience working with family members in this capacity. Traditionally, evaluators and researchers have not had experience working closely with people experiencing the issues that are the focus of their research. In the traditional research model, evaluators and researchers were trained to be objective scientists, keeping control of the research process and distancing themselves from the "subjects," i.e., those who were being researched. In this traditional model, the participants make no contribution to the formulation of the research questions (Sohng, 1992). In contrast, the new approach to family-evaluator partnerships in systems of care requires evaluators to collaborate with family members in all aspects of the evaluation of services.

This summary discusses the preliminary findings of an ongoing study being conducted by the Research and Training Center on Family Support and Children's Mental Health. This study focuses on the evaluators who work on evaluation teams with family members whose children have serious emotional disorders. The purpose of the study is to gain understanding of the challenges facing traditional professional evaluators and family evaluators working together, and to identify the most effective strategies that promote collaborative relationships on evaluation teams. The findings will inform future training for both evaluators and family evaluators.

## Method

Evaluators who have worked with family members on evaluation teams were identified through nominations by key informants and snowball sampling. We conducted telephone or face-to-face interviews with open-ended qualitative questions. The preliminary results presented in this paper are based on interviews with 18 professional evaluators from different parts of the U.S. Thirteen evaluators reported that they had Ph.D.s, two were Ph.D. candidates, two held Masters degrees, and one held a Bachelors degree. Fourteen were female and four were male, with a mean age of 41.8 (*SD* = 11.2, ranging from 28-66 years). The average number of years these evaluators reported working in the field of children's mental health was 13.5 years (*SD* = 7.4, ranging from 3-30 years) and 66% said they had some level of experience as a family member or consumer of mental health services.

Study participants answered questions about the roles of family evaluators on the team, their training to work with family evaluators, the challenges they have faced, and the strategies they have used to overcome these challenges. Evaluators were also invited to provide suggestions about the types of information and training strategies that would be helpful to evaluators and researchers working with family members. The interviews were audio-taped and transcribed. The transcripts were analyzed qualitatively using a grounded theory approach (Glaser & Strauss, 1967). A coding scheme was developed and team members coded data independently; next, they compared coded sections of the interviews and negotiated the categorization of the data. Team members then categorized the data according to themes, synthesized these themes, and identified examples to illustrate the themes.

## Results

### Roles

Evaluators reported that family evaluators held a variety of roles on evaluation and research teams. These roles included:

- helping with the development of the project;
- developing instrument and surveys;
- collecting data;
- training other family evaluators;
- participating in decision making;
- assisting with the analysis of the data;
- participating in the interpretation of results;
- presenting data; and
- helping with the dissemination of results.

Evaluators described several benefits of having family members on the evaluation teams. For example, they stated that family involvement makes the project richer, improves data collection efforts, improves the interpretation of the data, and contributes relevancy to presentations. One evaluator stated, "As it turns out, [family evaluator]'s contribution was the single most important piece of [the presentation] being relevant or engaging."

Evaluators reported that they were not specifically trained to work with family evaluators. While a few evaluators said that they had received some training in participatory research, most had been trained as traditional researchers. One participant said, "This is very different from my training….Nothing about family involvement. Even in qualitative research there was an emphasis on objectivity. Nothing about partnering." Some participants reported personal or family experience as consumers of services and others mentioned experiences that had contributed to their openness to working collaboratively with community members.

### Challenges

A number of barriers were identified as challenges by respondents. Several institutional barriers described were:

- hiring policies that are based on academic qualifications, often making it difficult to hire family evaluators who may not have a degree;
- concerns about how family evaluator involvement affects their objectivity;

- difficulties in scheduling meetings to fit family members' schedules;
- status differences between evaluators and family evaluators; and
- the need to pay family evaluators adequate salaries and provide timely reimbursement of expenses.

One evaluator appreciated the life experience that the family evaluator brought to the project and commented that at her place of employment, "Experience as a parent doesn't count. There are pay and equity problems." A host of other barriers were also identified as challenges by evaluators working with family members. These included:

- family evaluators need to acquire technical skills to do the job;
- conflict regarding family evaluator's desire to use preliminary data for advocacy;
- evaluators anticipating stress related to family members' dual roles as advocate and evaluator;
- family members' reluctance to get involved in research and evaluation; and
- failure of the wider community to value family evaluator role on evaluation teams.

One evaluator commented that, "One person who first had the job…[experienced] frustration at seeing the data and not being able to be an advocate… [family evaluators] need to accept a slower pace of change."

### Strategies

Evaluators identified a number of strategies they have used to overcome the above-mentioned challenges. Examples of these strategies were:

- appreciating the strengths of family evaluators;
- working as a team;
- having a flexible working environment;
- providing on-the-job training and other training opportunities;
- promoting a culture of mutual learning; and
- communicating openly, especially about differences in perspectives.

One evaluator commented that it was important to be "open to learning in a bi-directional manner… learning from each other." Evaluators were asked about the kind of training they would find useful in helping them to work with family members on a team. Some evaluators suggested joint trainings with evaluators and family evaluators. Others recommended attending panel discussions where participants discuss working together on evaluation teams and participating in conference calls, where people could share their experiences and offer advice.

Evaluators were asked about effective ways to get information out about working with family members to both family-friendly and non family-friendly audiences interested in evaluation. They suggested presenting at conferences and submitting articles to journals. Participants also commented that posting information on the Internet would be helpful, for example putting a "how-to manual" on the World Wide Web or posting information on listservs. Some evaluators recommended teaching about family-evaluator partnerships in university classes, and a few said that they were already doing this.

## Conclusion

These preliminary findings suggest that family evaluators play a variety of roles on evaluation teams. Participants of this study reported being faced with a number of challenges but they also reported developing strategies to work successfully with family evaluators. The participants suggested that a professional curriculum for evaluators include content on working with family evaluators. In addition, the participants recommended providing opportunities for evaluators and family evaluators to learn from others who have already worked in partnerships.

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# *Barriers and Supports to Family Participation: What Residential Treatment Providers Need to Know*

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## *Introduction*

### *Background and Rationale*

Family participation in children's mental health is a primary principle guiding the implementation of systems of care. Families are increasingly involved in the planning, implementation, and evaluation of services both for their own family and also at the service system level (Friesen & Koroloff, 1990). There is also beginning evidence of the benefits of family participation in systems of care (Koren et al., 1997). In contrast, little information is available about families' experiences with participation in residential treatment and other out-of-home treatment programs or about factors that may hinder or facilitate their participation.

Family participation is conceptualized in a number of ways. Friesen and Stephens (1998) identify six broad role sets for family members: as context; targets for change and recipients to service; partners in the treatment process; service providers; policy makers and advocates; and as researchers and evaluators. Baker, Blacher, and Pfeiffer (1993) define family involvement in residential treatment centers for children with serious emotional disorders as the inclusion of family members in the child's treatment process, particularly visits, telephone contact and participation in decision making. Some researchers describe participation as a multi-dimensional construct, with elements such as family participation in the milieu, shared parenting, formal, shared decision making, and child/family contact (Johnson, 1999).

### *Barriers and Supports to Family Participation*

In focus groups, caregivers of children placed in out-of-home care described institutional barriers and staff attitudes and behaviors that restricted their contact with their children and participation in their children's treatment (Friesen, Kruzich, & Schultze, 1995). Caregivers identified scheduling constraints on visits and meetings, and behavior management practices at facilities as factors that limited parent-child contact. Lack of open and honest communication by staff and failure to implement agency policies were also reported as limiting participation.

Jenson and Whittaker (1987; 1989) identified factors that explain caregivers' limited involvement in children's residential care including: (a) location of treatment facilities in rural or isolated areas; (b) limited roles offered to caregivers; (c) parental attitudes of personal guilt; and (d) problems such as inadequate finances, family disorganization, and legal difficulties. Several studies have also identified residential staff support as essential to increasing family involvement (Baker et al., 1993; Coleman, 1999; Friesen, et al., 1995).

This summary reports barriers and supports to participation identified by a national sample of caregivers whose children received out-of-home care for serious emotional disorders. Specifically we describe parent participation, barriers and supports to participation, and the importance of barriers and supports to participation and satisfaction.

## Methods

### Procedures and Sampling

Eligible participants were parents or other caregivers with primary responsibility for youth aged 0 to 20 who had received three months or more (in-home) or 30 or more continuous days of (out-of-home) treatment for their emotional, behavioral, or mental disorders between September 1, 1996 and August 31, 1998. Data collection occurred in 1999-2000. A total of 117 out of 221 mailed out-of-home questionnaires were returned for a response rate of 56.6%. The focus of this analysis is a subset of the sample, which consisted of 102 caregivers whose children received treatment in one of three settings: residential treatment centers (66.7%), psychiatric hospital/units (20.6%), and group homes (12.7%). Chi-square and *t*-test analyses indicated there were no significant demographic differences among families and children being served in the three settings except for child custody status at time of placement. Because of the similarities across the three groups, they were aggregated for the rest of the analyses.

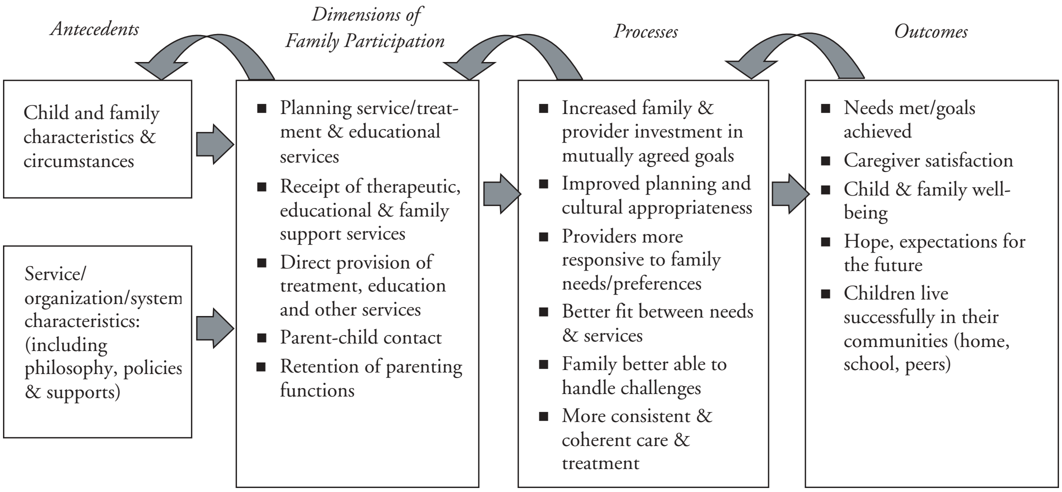
### Measures

Measures of participation were developed based on a conceptual model that delineated five dimensions of family involvement (see Figure 1): (a) planning service/treatment & educational services; (b) receipt of therapeutic, educational, & family support services; (c) direct provision of treatment, education, and other services; (d) parent-child contact; and (e) retention of parenting functions.

Caregivers were asked to indicate from a list the extent of their involvement for each dimension of participation. For example, under *parent-child contact*, family caregivers were asked to indicate how often they spoke with their child by telephone or had visits with the child on-campus, away from campus, and at home. The response choices were *Daily*, *2-6 times per week*, *Weekly*, *2-3 times per month*, *Monthly*, *6-11 times per year*, *1-5 times per year*, and *Never*. The total amount of contact was calculated by converting responses into contact episodes for each type of contact per day and summing them.

Educational planning and service/treatment planning were measured using the Family Participation Measure (FPM; Friesen & Pullmann, 2001). The FPM is an ordinal scale measure (1 = *Not at all*, 2 = *A little*, 3 = *Some*, 4 = *A lot*) of participation in education and treatment planning. Items included questions such as, *To what extent were your ideas valued in planning?* For receipt of services and participation in decision making and daily activities with child, caregivers were asked to indicate their involvement from lists of items. Items were summed and analyzed as index scores for each dimension.

**Figure 1**
**Conceptual Framework: Family Participation in Systems of Care**



## Results

### Description of Sample

Eight male caregivers and 94 female caregivers reported on 74 male and 28 female children. Most of the respondents were birth mothers (68.6%) or adoptive mothers (18.6%). Over half (53%) of caregivers had a college degree and the median yearly household income range was $35,000 - 44,999 per year. Based on U.S. household income data, 32% of respondents had an income of less than 50% of the U.S. median, one half of whom were at or below the federal poverty threshold (Federal Register, 1998; U.S. Census Bureau, 2000). Respondents reported an average household size of 3.4 persons (*SD* = 1.3). Seventy-nine percent had legal custody of the child at the time of placement. The majority of those without legal custody (52%) reported relinquishment of parental rights as a prerequisite of state funding of treatment services.

Eighty percent of the children were White, 9% African-American, 6% Multiracial, 3% Hispanic, and 2% Native American. The average age was 14.1 years (range 6.7 - 20.6, *SD* = 3.1). Nearly ninety percent (89.1%) of the children had more than one diagnosis (*M* = 3.8, *SD* = 2.1). The most common diagnosis reported was attention deficit hyperactivity disorder (49.0%). The average accumulated length of out-of-home placement over a two-year period was 13.8 months (*SD* = 7.6). Most (65.7%) of the children had just one out-of-home placement during the study period.

### Participation, Barriers and Supports

Of the different forms of contact with their children, telephone contact occurred most frequently with 88.2% of caregivers reporting telephone contact once a week or more, while 63%, 33%, and 23.7% reported that visits occurred once a week or more on-campus, off-campus, and at home, respectively. The average educational planning score was 2.77 (*SD* = .91, range 1-4). The average service/treatment planning score was 2.88 (*SD* = .88, range 1-4). Family caregivers reported receiving an average of 1.3 services (*SD* = 1.52, range 0-6), participating in making an average of 3 types of decisions (*SD* = 1.87, range 0-7), and participating in an average of 4.8 types of activities with their child (*SD* = 1.81, range 1-10).

**Table 1**
**Percentage of Family Caregivers who Identified Item as a Barrier to Participation**

| | *Barrier* | | *Most important barrier* | |
|---|---|---|---|---|
| | *N* | *% of total* | *N* | *% of total* |
| **Family Circumstances** | | | | |
| Distance from service providers | 45 | 44.1 | 22 | 21.6 |
| My work schedule | 38 | 37.3 | 10 | 9.8 |
| Cost of transportation | 29 | 28.4 | 3 | 2.9 |
| Lack of access to transportation | 10 | 9.8 | 1 | 1.0 |
| Child care arrangements | 8 | 7.8 | | |
| Cost of child care | 7 | 6.9 | | |
| **Facility Characteristics** | | | | |
| Lack of communication between staff in different program or agencies | 40 | 39.2 | 8 | 7.8 |
| Lack of open communication | 22 | 21.6 | 4 | 3.9 |
| Lack of opportunity or encouragement to participate | 21 | 20.6 | 3 | 2.9 |
| Inflexible visiting and meeting schedules | 19 | 18.6 | 4 | 3.9 |
| Unclear who to contact at program with questions and concerns | 17 | 16.7 | 2 | 2.0 |
| Negative staff attitudes about my family | 11 | 10.8 | 4 | 3.9 |
| Restrictive policies | 10 | 9.8 | 3 | 2.9 |
| Cultural values were not taken in to consideration | 8 | 7.8 | 1 | 1.0 |
| Other | 7 | 6.9 | 2 | 2.0 |
| Blank | | | 35 | 34.3 |

Caregivers were asked to indicate *what things made it difficult* and *all the ways that program staff or caseworkers supported* their participation in their child's care. Distance from service providers was endorsed by the largest percentage of parents, followed by lack of communication between staff in different programs or agencies (see Table 1). Distance to service providers was also endorsed as the greatest difficulty. Table 2 shows that being provided a contact person was endorsed by the largest percentage of parents and ranked among the most important supports. *Being treated with dignity and respect* was also an important support.

Single caregivers reported more barriers ($t = 2.18$, $p < .05$), and caregivers who reported more barriers also reported lower levels of satisfaction ($r = -.56$, $p < .01$). Caregivers of boys reported more supports than caregivers of girls ($t = 2.47$, $p < .05$) and caregivers who reported more supports also reported higher levels of satisfaction with amount of contact ($r = .60$, $p < .01$).

### *Importance of Barriers and Supports*

Bivariate analyses of barriers and supports with participation and parent satisfaction yielded significant results. Family reports of more barriers were associated with: receiving fewer services ($r = -.288$, $p < .01$); having less total contact with their children ($r = -.425$, $p < .01$); involvement in fewer decisions ($r = -.400$, $p < .01$); retaining fewer parenting functions ($r = -.217$, $p < .05$); and lower educational ($r = -.559$, $p < .01$) and service/treatment planning scores ($r = -.651$, $p < .01$). Conversely, family reports of more supports were associated with: receiving more services ($r = .380$, $p < .01$); having more total contact with their children ($r = .249$, $p < .05$); more decision-making ($r = -.464$, $p < .01$); retaining more parenting functions ($r = .302$, $p < .01$), and higher educational ($r = .658$, $p < .01$) and service/treatment planning scores ($r = .767$, $p < .01$).

**Table 2**
**Percentage of Family Caregivers who Identified Item as a Support to Participation**

| | *Support* | | *Most important barrier* | |
|---|---|---|---|---|
| | *N* | *% of total* | *N* | *% of total* |
| **Concrete Supports** | | | | |
| Provided a contact person | 83 | 81.4 | 13 | 12.7 |
| Notified me (us) when something was wrong or if there were health or other concerns with my child | 68 | 66.7 | 15 | 14.7 |
| Offered flexible scheduling for meetings | 63 | 61.8 | 4 | 3.9 |
| Provided information about rights and grievance procedures | 58 | 56.9 | | |
| Provided comfortable and private space for meetings | 58 | 56.9 | | |
| Returned phone calls promptly | 58 | 56.9 | | |
| Added my comments to my child's records | 59 | 57.8 | 2 | 2.0 |
| Supported transitions into or out of the services or programs | 42 | 41.2 | 1 | 1.0 |
| Communicated with all relevant family members | 42 | 41.2 | 4 | 3.9 |
| Helped with transportation costs | 24 | 23.5 | | |
| Helped with telephone costs | 22 | 21.6 | | |
| Assisted with child care costs | 11 | 10.8 | 2 | 2.0 |
| **Interpersonal Supports** | | | | |
| Treated me with dignity and respect | 77 | 75.5 | 5 | 4.9 |
| Made me feel my participation was important | 66 | 64.7 | 11 | 10.8 |
| Made me feel welcome | 63 | 61.8 | 2 | 2.0 |
| Encouraged all relevant family to participate | 49 | 48.0 | 3 | 2.9 |
| Were responsive to my family's cultural values | 33 | 32.4 | 3 | 2.9 |
| Blank | 4 | 3.9 | 3 | 2.9 |
| Left blank, no item selected as most important | | | 34 | 33.3 |

## *Conclusion*

Our findings suggest an important relationship between caregivers' perceptions of barriers and supports and their participation. Administrators and practitioners can use the findings of this study as a guide for enacting polices and practices that facilitate parent involvement. They can also use the list of barriers and supports used in this study to evaluate their current practices. The lists may prove helpful to families making decisions regarding their children's placement in an out-of-home treatment facility.

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# Building the Family Experience into Policy Development, Research and Program Improvement

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## Introduction

It is believed that families directly affected by the impact of policies can provide a critical source of input concerning those policies and their reform. This is particularly the case regarding policies effecting children's mental health services, since the perspective of children and families on mental health and related services is not always the same as the perspective of services providers, administrators, and policy makers (Friedman, 1997; Unger & Powell, 1991). Moreover, including the family perspective has been found to improve the quality and effectiveness of service delivery (Reimers et al., 1995; McNaughton, 1994; Friesen et al., 1992). Increasingly, research is showing the efficacy of meaningful family involvement in mental health service delivery (Pires, 2002).

This paper discusses findings from two studies: (a) the SSI Family Impact Study, which examined the impact of changes in policy on families with children who had been receiving SSI benefits because of a serious emotional disturbance, and who were in jeopardy of losing these benefits, and; (b) the Child and Family Experience of the Mental Health System Study, which more broadly examines the experiences of families and their children as they seek services, enter, and progress through the mental health system.

The findings from each study illustrate the ability of the qualitative approach to gather data that provide a comprehensive view and that accurately reflects the effectiveness of policy and service delivery to provide individualized, family-centered, and culturally competent interventions in child mental health services. Both studies were designed to meet a need for information from family perspectives about the general impact of policy and service delivery, as well as specific aspects of policy and service that are most and least helpful. Findings also provide a clearer picture of the decision-making of families around both help-seeking behavior and treatment continuation. The studies' qualitative approach offers a systematic way of documenting families' experiences, without the limitations of more traditional, standardized, quantitative research methodologies, allowing parents considerable latitude in describing their experiences. Seeking to understand, rather than predict and generalize, this approach explores the family setting and context, and captures the complexities of the experiences and viewpoints of those most affected by policy and implementation—families themselves.

## Methodology

Both projects utilize a longitudinal design employing semi-structured interview techniques framed within a case study protocol. This technique offers a useful tool for gathering information from families, with naturalistic inquiry, about their experiences with service-related policies as well as the services themselves. The case study approach is consistent with the backward mapping approach to policy analysis. Backward mapping begins not at the top of the implementation process but at the point at which administrative actions intersect private choices (Elmore, 1979/80).

### The SSI Family Impact Study

The SSI Family Impact Study followed 40 families whose children were receiving SSI benefits for a serious emotional disability and who had each received a letter from the Social Security Administration giving notice that their children's eligibility for SSI was slated for reevaluation. Between 12 and 15 families from each of three sites (Kansas, Florida, and New York) were contacted over a 22-month period, through a combination of in-person and telephone interviews every three months. During the study, the Kansas site included families who were served by the federally funded Comprehensive Community Mental Health Services for Children and Their Families Program. In addition, the study utilized a series of focus groups with 22 parents to enhance the understanding of how families have been impacted by the legislative changes. Participants were paid for each interview. Throughout the course of the SSI Family Impact Study, parents of children with a serious emotional or behavioral disorder and experiencing an SSI review for their children were members of the research team.

### *The Child and Family Experience of the Mental Health System Study*

The Child and Family Experience of the Mental Health System Study, now in its final data collection phase, has followed 30 families in Hillsborough County, Florida, over a two-years time period. Twenty-five families, designated as high frequency, were contacted in person and by telephone every two weeks the first two months. High frequency families are on a much higher frequency of contact. The low frequency families were interviewed less frequently over the two-year period. This step was taken as a control for the influence that frequent interviewing may have on given responses. Participants were recruited in various ways: fliers were placed in the waiting room of a local community mental health center and pediatrician offices, a research team member attended CHILD FIND activities and approached parents after they met with the CHILD FIND interviewer, and recruitment presentations were given at the local chapter meetings of the Federation of Families for Children's Mental Health. These families were then contacted by telephone every four weeks for the next two months, then every three months for the remaining 20 months. The initial twelfth month and final twenty-fourth month interviews are conducted in-person. Five families, designated low frequency, were scheduled for contact by telephone the first, twelfth and twenty-fourth month.

All interviews were audio taped with the consent of the interviewees; they were transcribed, coded, and placed into a database for qualitative analysis. The study analysis was completed within a data transformation approach, based primarily on qualitative summaries, with a heavy reliance on direct quotations of interviews rather than numerical descriptions of the data that are possible with full content analysis. Information is transformed step-by-step, from raw data into interpretive descriptions. The findings were analyzed with the aid of NVIVO qualitative software. Interviews were audio-taped, transcribed, and then imported into NVIVO and categorized following a coding list based on the study's research questions. Participants were paid for each interview. The Child and Family Experience of the Mental Health System Study has had guidance and invaluable input over the past three years from parents, other primary caregivers, and youth through a Family Advisory Committee.

## *Results*

### *SSI Family Impact Study*

The SSI policy change clearly created a hardship for families who were already fragile in many ways and who had children with serious problems. While it is not possible to document specifically the full impact on the families, the preponderance of evidence from the families suggests that this is truly a group of families who have children with serious problems, in need of supports. And, removing basic economic support and health care coverage adversely affected the families, often followed by a series of crisis and negative events.

Most families in the study did not lose their children to out of home placement—not because the system 'made up for the loss' and wrapped other supports around them—but because these families made heroic efforts to keep their families intact and exhibited enormous resilience and commitment to their children.

The SSI Family Impact Study identified a cascade effect. The loss of income as a result of a policy change in one area of support had a comprehensive, and as described by one participant, "downward spiraling" effect. The loss of income for a family with a child who has a mental illness is complicated and comprehensive in effect, especially with the array of services a family may need. While it is difficult to identify the cause and effect of the "downward spiral," many families' stories aptly illustrate an important sequence of events beginning with the loss of the SSI benefit.

Study findings have implications that are equally applicable to federal, state and local policymakers, evaluators and the family advocacy support movement. These include: the inter-relatedness and importance of services, including natural supports, for low-income families with children who have mental health needs; the importance of an effective process for communicating legislated program changes; the importance of physical and behavioral health care coverage for families with children who have serious emotional or behavioral disability; the importance of a basic minimum income for the well being of families; and, the importance of strategic interventions by policy-makers and front-line practitioners to help families in the decision-making process.

### *Child and Family Experience of the Mental Health System Study*

A central finding from this study is that there appears to be no single defined mental health system through which families can access services. The pathway to services is complex and often runs through avenues other than the mental health system (i.e., schools, courts, and pediatricians) and often through informal networks (i.e., waiting rooms, playgrounds, etc.). Many parents report first seeking out non-mental health services, looking for physiological explanations before pursuing mental health related causes.

Although the literature suggests high rates of non-compliance with treatment, we found that families do not drop out of services altogether, but rather leave particular providers for what are reported to be valid reasons. For example: lack of a "connection" with the provider; problems with accessing transportation; "impossible" times a provider is available for the family to access a service; a parent's perception that the service is not what the child needs; a parent not feeling respected or believed. They do report their experience at intake as being pivotal to service continuation. Too often the families experience being treated rudely at the first contact with a provider agency. Phone calls are not returned, and they do not receive clear information about the purpose of meetings.

Compounding the problem, families reported they found little or no choice of providers. Caregivers also expressed concerns about placing their children on medication. Parents are frightened and unsure of the unintended effects of medication, especially on their younger children. Parents are not comfortable with the current knowledge about, and choices for, medication.

This study found that many families are persistent in seeking services and aggressively seek education about services. Seeking, obtaining, and continuing in services is often a part time to full time job for the caregiver. The ability of a caregiver to independently and aggressively seek services is often the key determinate in how and whether a service is identified and ultimately used. Families also believe that the school plays a key role in legitimizing their children's need for services. They believe there are different norms concerning acceptable child behavior that are evident not only among different families, but also within individual classrooms and schools about what constitutes problem behavior.

Families offered many examples of barriers created by a disconnect between policy and implementation of numerous federal, state and local agency rules and regulations. For example, Hispanic families report the schools do not always provide translators, even though they are required by law to do so. Further, families are told that they have to receive services from a certain provider depending upon their address, when they may actually have some choices available to them. Families are also told that there is a waiting list for services, or that "we just cannot serve the family," even though policy and Medicaid contracts stipulate a "no waiting list" approach to services.

These families also face a long-term financial burden. Although health care coverage may eventually become available to families, many find themselves in debt from having to pay in cash for mental health services and medications for a prolonged period of time. Because of the chronic nature of a serious emotional disturbance, even families with “good insurance coverage” end up with inadequate coverage. Families that must pay with cash are not just paying for the care of the child; they often end up paying a debt-servicing fee, since most have to use credit cards or take out a loan to pay for care.

Families with multiple children–whether all children are in need of services or just one–experience a need for support and services for all members of the family. Families report receiving more and more support from the Federation of Families for Children’s Mental Health, Stand for Children, and other advocacy groups. Families like the information and the support they receive from these groups and often feel that advocacy groups are the only ones who truly understand their experiences.

## Conclusion

The SSI Family Impact Study and the Child and Family Experience of the Mental Health System demonstrate the need for timely, longitudinal, and qualitative research. This is the case, not only because of the long process nature of legislative change and appropriate service attainment, but also because the impact of these changes and difficulties experienced in obtaining services may unfold over a long period of time. An in-depth, comprehensive picture is critical when we see families who are experiencing constant instability or major financial challenges, or being criticized for being poor decision-makers. The effects of their total experience, added to the system’s ineffectiveness for providing accurate information or accessible and appropriate services and supports, sets the family up to fail. Families need to be able to make decisions from a position of strength and to be viewed in that light. What is evident in both studies is that behind most of the children are one or more parents, grandparents, or other caregivers, struggling to keep up their sense of hope and their emotional and physical energy, while consistently searching for solutions to meet the needs of their children.

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# Caregiver Strain and Utilization of Services for Children with Serious Emotional Disturbances

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## Introduction

This study examined the relationship between caregiver strain and service utilization in a sample of children with serious emotional disturbances (SED) served by a systems of care (SOC) initiative across seven sites in North Carolina. SOC is a philosophy of intervention for children with SED which emphasizes community-based services that are culturally competent, child-centered, and family-focused (Stroul & Friedman, 1996). Research on caregiver strain for children with SED who are involved with an SOC has been limited. The Great Smoky Mountain Study of Youth (GSMS) examined caregiver strain and how it affected service utilization, but did not specifically look at children who were involved with an SOC (Angold et al., 1998; Farmer & Burns, 1997). The GSMS did find that children of caregivers who experienced higher levels of strain were more likely to receive services than were caregivers who reported less strain (Angold et al., 1998). A relationship between service utilization and caregiver strain could serve to improve the ability of service providers to promote family participation in children's services, and to decrease treatment dropout. This study predicted a more significant relationship between service utilization and the Objective Strain subscale of the Caregiver Strain Questionnaire (CGSQ; Brannan & Heflinger, 1997) than between service utilization and the Subjective Strain-Externalized and Subjective Strain-Internalized subscales of the CGSQ.

## Method

The sample consisted of 400 male and female children between the ages of 5 to 18 with SED served by a SOC in seven CMHS-funded sites across North Carolina. Data were collected at baseline and every six months over a three-year period as part of the national evaluation being conducted by Macro International, Inc. The data included in the current study were collected at two time periods: six-month follow-up and twelve month follow-up. Measures included the CGSQ, the Descriptive Information Questionnaire (DIQ), and the Multi-Sector Service Contacts (MSSC).

The CGSO consists of an overall measure of Global Strain, and includes subscales for Objective Strain, Subjective Strain-Externalized, and Subjective Strain-Internalized. The Objective Strain subscale derives its score from questions about observable events that disrupt family routines and relationships, social activities, or personal time, or which cause trouble with neighbors and the community. The Subjective Strain-Externalized subscale addresses the amount of negative feelings the caregiver has had toward the child, such as anger, embarrassment, and resentment. The Subjective Strain-Internalized subscale measures the amount of negative feelings the caregiver has experienced because of the child, such as worry, guilt, and fatigue.

## Results

Using a standard multiple regression at six month follow-up and at twelve month follow-up, this study assessed whether there was a more significant relationship between service utilization and the Objective Strain subscale than between service utilization and the Subjective Strain-Externalized and Subjective Strain-Internalized subscales. The dependent variable was service utilization as measured by the MSSC and the independent variables were scores from the Objective Strain subscale, the Subjective

Strain-Externalized subscale, and the Subjective Strain-Internalized subscales of the CGSQ. The Objective Strain subscale was found to be more predictive of service utilization ($\beta = .200$, $p < .05$) than either the Subjective Strain-Internalized ($\beta = .061$, *ns*) or the Subjective Strain-Externalized ($\beta = -.927$, *ns*) subscales at six-month follow-up ($N = 219$). This pattern was repeated at twelve month follow-up ($N = 137$): the Objective Strain subscale was more predictive of service utilization ($\beta = .289$, $p < .05$) than either the Subjective Strain-Internalized ($\beta = -.070$, *ns*) or the Subjective Strain-Externalized ($\beta = -.192$, *ns*) subscales.

## Discussion

It appears from these results that the amount of observable disruption to the caregiver's life is related to service utilization more so than to the amount of negative feelings that the caregiver experiences. In other words, a caregiver may be more motivated to utilize services if his or her daily activities and routines are being disrupted due to the child's emotional and behavioral problems than if they are only experiencing negative feelings related to those emotional and behavioral problems.

These findings are similar to those of the GSMS (Angold et al., 1998), in which caregiver strain was a strong motivator for service utilization. In the presence of caregiver strain, the child's symptoms and functional impairment had little to no effect on whether services were utilized. The measurements used in the current study, as well as in the GSMS, attributed caregiver strain to financial expenses, problems within social relationships, decreased positive feelings concerning the caregiver's ability to cope with the child, and restrictions on personal activities. While the GSMS did not attempt to determine which of these factors contributed the most to service utilization, it did find that restrictions on personal activities was one of the most commonly reported caregiver burdens.

The most important implication for this study may relate to how services are offered to families. By identifying the factors related to service utilization, service providers can take steps to alter the way services are offered to caregivers in order to ensure that those children who need services will receive them. Service providers may be able to identify characteristics related to caregiver strain that cause one caregiver to consistently follow through on services and another to be noncompliant with services. An important area of mental health services that has been at times overlooked is the merging of practice and research. Researchers need to have knowledge about service delivery in order to identify and complete research that can aid in changing the service delivery system in a positive way.

There are some important limitations to this study which affect the generalizability of the findings. First, the data reflected children and their families from North Carolina only. A study using national data would be more representative of the population. Second, no control group was used. Third, the way service utilization was measured did not necessarily reveal how many services the caregiver wanted. Fourth, this study did not control for other aspects of caregiver strain that are not due to the child's emotional and behavioral problems, such as strain resulting from other family members with and without behavior problems, financial level or job status, or the caregiver's own mental health issues. Finally, further research should investigate the direction of this relationship; do increased levels of caregiver strain lead to increased service utilization, or does increased service utilization lead to increased levels of caregiver strain?

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# *Family Impact of Emotional and Behavioral Disorders*

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## *Introduction*

It has long been recognized that the illness of a child can affect the family in multiple ways. Data on the family impact of emotional and behavioral disorders (EBD) in youth are limited, and have focused primarily on factors predicting family impact and the relationship between family impact and service use. For example, Baker & Heller (1996) found that higher externalizing behaviors in pre-school children were associated with greater negative family impact, as well as with lowered self-efficacy in parenting skills. Similarly, in a sample of children ages 7-17 years with Tourette's syndrome, Wilkinson and colleagues (2001) reported that family impact was more pronounced in those children with severe symptoms and comorbid disorders than in those without. Race has also been associated with family impact, with Black families reporting equivalent caregiving duties but less impact on families when compared with Whites (Horwitz & Reinhard, 1995). Farmer and her colleagues (1997) found that adolescents who were 10-15 years of age when they first used mental health services were either longer users of mental health services, or had more severe symptoms or worse functioning and had higher family impact rates than comparison samples. Despite these findings, there has been no research examining initial and post-treatment ratings of family impact in a sample of parents seeking treatment for an adolescent with EBD. This information could be particularly useful for clinicians in developing treatment options that are congruent with family need and monitoring treatment outcomes. This paper investigates the relationship between adolescent emotional and behavioral disorders and the impact of these illnesses on the family.

## *Methods*

### *Participants*

Participants (*N* = 256) were recruited at intake from seven inpatient and outpatient treatment sites to participate in a validation study of the Adolescent Treatment Outcomes Module (ATOM; Robbins et al., 2001). Adolescents ranged in age from 11-18 years; 55% were male. Approximately two thirds (64.8%) were Caucasian; 28% were African American. Half of the families earned less than $20,000 per year.

### *Measures*

Parents were administered the ATOM and the Child Behavior Checklist (CBCL; Achenbach, 1991) at baseline and six-month follow-up to assess symptom severity, functioning and satisfaction. Parents also completed a modified version of a child and adolescent Burden Assessment Scale (BAS; Horwitz & Reinhard, 1995; Reinhard, 1994; Reinhard, Gubman, Horwitz, & Minsky, 1994), which assesses *Objective Burden* (e.g., missing days at work, changing personal plans, cutting down on leisure time), *Subjective Burden* (e.g., worry about child's behavior, feeling guilty) and *Total Burden* on a 0 to 3 point scale, with higher scores representing more impact.

Six items of the Child Health Questionnaire (CHQ; Landgraf, Abetz, & Ware, 1996) family impact scale (Time Limit due to Physical Health, Time Limit due to Emotional Well Being, Limited Family Activities, Interruption of Everyday Family Activities, Worry about Child Physical Health and Worry about Child Emotional Well Being) were also included in the assessment. Scores on the CHQ items were administered and aggregated, with lower scores representing more severe impact. Parental satisfaction with care was assessed at the six-month follow-up using a five-item satisfaction scale, adapted from other widely used measures of patient satisfaction (Lubalin et al., 1995; Larson et al., 1979). Parents completed the baseline ATOM and validation instruments within one week of intake and at the six-month follow-up.

## Results

The BAS and CHQ family impact subscales were correlated ($r = -0.63$, $p < .0001$). Internal consistency was measured for the BAS and CHQ ($\alpha = .76$ and .90, respectively).

The relationship between family impact and demographic and clinical variables at baseline was examined using stepwise linear regression models. Family impact was modeled individually by race, age, gender, and income, using three ATOM functioning scales (Role Performance, Relationships, and Consequences of Behavior); the ATOM symptom severity scale; and CBCL externalizing and internalizing scales. Those variables significant at the .05 level were then used in a stepwise linear regression procedure. CHQ family impact was associated with ATOM symptom severity, higher CBCL internalizing symptoms, impairment in role performance and increased age. BAS family impact was associated with higher scores on CBCL internalizing and externalizing scales and more functional impairment in role performance and relationships. Total variance accounted for in the stepwise regression models for the CHQ and BAS was 40% and 46%, respectively (see Table 1).

Scores on both family impact scales improved significantly at the six-month follow-up. Results of the stepwise regression for the CHQ indicate that improvements in family impact were associated with improvements in ATOM symptom severity and CBCL internalizing and externalizing symptoms. Caucasians were less likely than other participants to report change in family impact. Total variance accounted for was 30%. Change scores on the BAS were associated with improvement in CBCL externalizing symptoms, ATOM relationship functioning and higher parental satisfaction. Total variance accounted for was 28%.

**Table 1**
**Models of Family Impact Entering Demographic and Clinical Variables (Baseline and Change Scores)[a]**

| | *Baseline* | | *Change* | |
|---|---|---|---|---|
| | *Standardized Estimate* | *F-Value* | *Standardized Estimate* | *F-Value* |
| **Burden Assessment Scale (BAS)** | | | | |
| CBCL Internalizing Symptoms | 0.26 | $24.16^{***}$ | – | – |
| CBCL Externalizing Symptoms | 0.20 | $7.96^{**}$ | 0.38 | $36.08^{***}$ |
| ATOM Role Performance | 0.24 | $12.94^{***}$ | – | – |
| ATOM Relationships | 0.21 | $12.73^{***}$ | 0.24 | $15.08^{***}$ |
| Parent Satisfaction | – | – | 0.12 | 3.75 |
| | | $R^2 = 0.46$ | | $R^2 = 0.28$ |
| **Family Impact Child Health Questionnaire (CHQ)** | | | | |
| ATOM Symptom Severity | -0.20 | $5.71^{*}$ | -0.17 | 3.27 |
| CBCL Externalizing Symptoms | – | – | -0.30 | $8.65^{**}$ |
| CBCL Internalizing Symptoms | -0.34 | $23.28^{***}$ | -0.16 | 2.88 |
| ATOM Role Performance | -0.24 | $11.13^{***}$ | – | – |
| Age | -0.12 | $4.09^{*}$ | – | – |
| Race (Non-Caucasian) | 0.11 | 3.41 | -0.13 | 2.87 |
| | | $R^2 = 0.40$ | | $R^2 = 0.30$ |

[a] Variables retained in model if $p < .15$; variables > .15 omitted from table.
$^{*}p<.05$; $^{**}p<.01$; $^{***}p<.001$.

## Discussion

In this sample of 256 parents of adolescents in treatment, baseline severity of symptoms and functional impairment were associated with a higher burden on families, especially for older adolescents. Consistent with prior studies, family impact was higher when adolescents had more severe symptoms and impairment in role functioning. The results also indicate that older adolescents with emotional and behavioral disorders may require more care from parents, perhaps because they have more opportunity to get into trouble, have more serious consequences for their behaviors and/or are able to disrupt the family more significantly than younger adolescents.

In addition, a decrease in family impact over a six-month period was associated with a decline in adolescent symptom severity and improvement in role and relationship functioning. The results also suggest that treatment may alleviate family impact as a result of declining symptoms and improvements in functioning. Future research should compare families with adolescents in various stages of recovery and treatment and identify specific interventions that are most effective in reducing the systemic effects of emotional and behavioral disorders.

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# *How Do Siblings Fare in a Family-Focused System of Care?*

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## *Introduction*

This project examines risk and resilience among siblings of children with severe emotional disturbances (SED), involved in System of Care (SOC) sites in North Carolina. It constitutes an early step in the Sibling Resilience Research Project (SRRP), a longitudinal examination of resilience and adjustment among these siblings, and the child, family, and contextual variables which differentiate siblings who adapt successfully from those who experience problems. Understanding resilience can improve family-centered service delivery and inform preventive intervention strategies (Cowen, 2000; Masten & Coatsworth, 1998). This summary examines early findings, comparing siblings and target SED children across multiple dimensions.

Resilience, effective adaptation in the face of major stress, has been the focus of burgeoning interest (Cicchetti & Garmezy, 1993; Cowen et al., 1992; Luthar, Cicchetti, & Becker, 2000; Masten, 2001; Wyman et al., 1999). This effort has identified multiple protective variables (i.e., child attributes and dispositional qualities, family milieu variables, and extrafamilial factors), apparently functioning to increase the likelihood of healthy outcomes, in studies involving children experiencing varying risk conditions and stressors (e.g., Werner & Smith, 1992). However, little is known about siblings of children with SED, who are at elevated risk because they share many risks with the diagnosed child and are affected by that child's impact on the family, such as increased family turmoil and reduced parental attention (McCammon, Cook, & Kilmer, 2002).

This project evolved from parental questions regarding differences among their children. Furthermore, parents from multiple sites expressed concern about the siblings, fearing they had been overlooked, given the child with SED's needs (McCammon et al., 2002). This project meets an important need for families by exploring sibling adjustment empirically. To date, virtually no systematic research has examined how well these siblings are faring or factors that influence their functioning, a gap that is not consistent with a family focused SOC (Kilmer & Cook, 2002). This paper describes differences among siblings and targets in stress exposure, competencies and adjustment, and examines the role of gender in sibling adjustment.

## *Method*

### *Participants*

Participants were recruited from two rural sites of a statewide SOC initiative. Approximately 400 children are currently served in NC by this system of mental health care. All siblings aged 5-18 were initially assessed, and those aged 5-10 are being followed over time. Families are reimbursed for participating. To date, caregivers from 31 families have provided information on 46 siblings.

### *Procedural Overview and Measures*

While numerous diverse variables are included in the overall study, this paper focuses on the following measures:

***Life Events Checklist*** (LEC; Kilmer, Cowen, Wyman, Work, & Magnus, 1998). Parent-completed measure of stress exposure for siblings and the SOC child. Items reflect: Family Turmoil, Poverty, Family Separation, Illness/Death, and Violence.

***Parent-Child Rating Scale*** (P-CRS; Cowen et al., 1996; Hoyt-Meyers et al., 1995). Parent ratings of both siblings and the target SED child's problem behaviors and competencies on: Negative Peer Social Skills, Positive Peer Social Skills, Assertive Social Skills, Task Orientation, Shy-Anxious/Withdrawn, Frustration Tolerance ($\alpha$ = .72 - .85) (e.g., Cowen et al., 1996; Hoyt-Meyers et al., 1995). Higher scores indicate more positive ratings on a given factor.

***Behavioral and Emotional Rating Scale*** (BERS; Epstein & Sharma, 1998). Strengths-based assessment of children's adjustment on: Interpersonal Strength, Family Involvement, Intrapersonal Strength, School Functioning, and Affective Strength. This measure allows comparisons with target SOC children and examination of specific child competencies potentially related to resilience (Mean $\alpha$ = .84 - 98). Higher scores indicate more positive ratings on a given factor.

***Formal Services Received.*** Assesses services needed and received by the family. Primary caregivers indicate whether the sibling/family have ever needed and received one or more of 14 formal services.

## Results

### Demographics

The sibling population is 60% male and 40% female, and 52% African American, 26% Caucasian, and 19% Bi-racial. Two-thirds of the siblings are younger than the target SOC children. The sample is predominantly poor—53% of siblings live in families with an annual household income of less than $15,000, and 80% live in homes with an annual income of less than $25,000. Caregivers report an average of 5.77 people living in their homes, and an average of 4.08 children.

### Sibling vs. SOC Target Comparisons

Caregivers reported a tendency for target children to experience slightly more stressful life events than their siblings (target $M$ = 14.16, $SD$ = 6.55; sibling $M$ = 11.64, $SD$ = 6.29; $F$(1, 76) = 2.91, $p$ < .10). An analysis of covariance was performed to assess whether children's age influenced the total number of stressful life events reported on the LEC. Analyses did not detect a main effect for age, and covarying this variable did not meaningfully (i.e., significantly) impact the findings. When LEC subscales were examined separately, two (Family Turmoil and Family Separation) showed a tendency for target children to have higher scores than siblings.

When the groups were compared to explore differences in adjustment, siblings evidenced significantly better adjustment than target children on all subscales of the P-CRS (see Table 1). Similarly, on the BERS, siblings demonstrated significantly more strengths than the target children on four of the five subscales and on the total BERS score (see Table 2). Although the mean differences were in the expected direction, there was considerable variability. Child strengths, as measured by the BERS total score, were divided into tertiles based on the total sample of siblings and target children, and each child was placed into low, middle and upper tertiles for the BERS subscales and total score. These scores were then graphed to illustrate the distribution of scores of target children versus siblings. Although the general pattern of scores (see Figure 1 for an example using the BERS total) is consistent with siblings showing higher adjustment than target children, a sizable number of siblings appear to be functioning, in some areas, as poorly as the target siblings classified with SED. Yet, none of the siblings had been designated as SED.

### Sibling Services Needed/Received

According to their caregivers, 70% of the siblings receive one or more of the following services in school: remedial reading, counseling/therapy, tutoring, speech therapy, special education, and medication; 12% receive five or more. However, 24% of the siblings are not receiving needed services in school. Half of the sibling sample receives one or more community service (i.e., drug/alcohol counseling, counseling/therapy, day treatment, foster care, out-of-home placement, psychiatric medication, court-ordered programs); only 14% are not receiving a community-based service that their parent judged as needed.

### Table 1
### Factor Score Comparisons of Target SOC Children and Siblings: P-CRS Subscales

| | *Target (n=30)* | | *Sibling (n=46)* | | | |
|---|---|---|---|---|---|---|
| *Factor* | *M* | *SD* | *M* | *SD* | *F* | |
| | Pillai's Trace MANOVA *F*(6, 69) = 5.53[b] | | | | | |
| Negative Peer Social Skills | 17.27 [†] | 5.62 | 24.04 | 5.96 | 24.57 [b] | S > T |
| Assertive Social Skills | 18.73 | 6.11 | 22.15 | 6.16 | 5.63 [a] | S > T |
| Task Orientation | 15.73 | 6.03 | 20.67 | 6.24 | 11.68 [b] | S > T |
| Shy-Anxious-Withdrawn | 17.37 | 6.31 | 20.72 | 5.76 | 5.70 [a] | S > T |
| Positive Peer Social Skills | 20.77 | 6.34 | 25.80 | 4.40 | 16.74 [b] | S > T |
| Frustration Tolerance | 7.33 | 3.42 | 12.37 | 5.19 | 21.97 [b] | S > T |

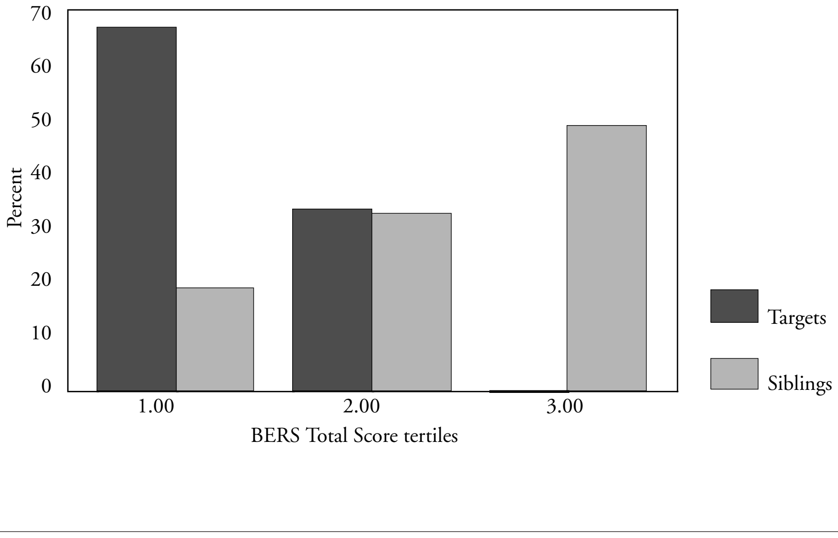
[†] High scores indicate more positive ratings on a given factor.
[a] $p \le .05$; [b] $p \le .01$

### Table 2
### Comparisons of Target SOC Children and Siblings: BERS Subscales

| | *Target (n=18)* | | *Sibling (n=36)* | | | |
|---|---|---|---|---|---|---|
| *Factor* | *M* | *SD* | *M* | *SD* | *F* | |
| | Pillai's Trace MANOVA *F*(6, 69) = 3.41[a] | | | | | |
| Interpersonal Strength | 17.61[†] | 8.67 | 28.68 | 11.72 | 12.72[a] | S > T |
| Family Involvement | 16.94 | 5.67 | 22.32 | 7.04 | 8.00[a] | S > T |
| Intrapersonal Strength | 19.28 | 6.64 | 25.11 | 5.40 | 12.35[a] | S > T |
| School Functioning | 13.61 | 5.18 | 18.18 | 5.97 | 7.78[a] | S > T |
| Affective Strength | 13.67 | 3.90 | 16.03 | 4.99 | 3.11 | |
| BERS Total[††] | 81.11 | 25.67 | 110.34 | 31.11 | 12.00[a] | S > T |

[†] High scores indicate more positive ratings on a given factor. [††] Univariate analysis of variance conducted. [a] $p \le .01$

### Figure 1
### BERS Total Score: Targets vs. Siblings



### Gender Comparisons

To examine differences in risk/stressors experienced by female and male siblings, MANOVA-ANOVA comparisons were conducted on the LEC factors, and an ANOVA was conducted on the LEC total score. Results indicate no significant gender differences on the LEC factors or its total score.

To examine gender differences in adjustment, a MANOVA, followed by appropriate ANOVAs, was conducted on the P-CRS. Caregivers rated female siblings significantly higher than males on two of the P-CRS subscales: Task Orientation (female $M$ = 24.18, $SD$ = 4.75; male $M$ = 18.62, $SD$ = 6.16; $F(6, 39) = 10.23$, $p < .01$) and Frustration Tolerance (female $M$ = 14.65, $SD$ = 4.62; male $M$ = 11.03, $SD$ = 5.11; $F(6, 39) = 5.74$, $p < .05$). Analyses did not detect significant gender differences on the BERS Total Strength Quotient or its standardized scale scores.

## Discussion

Preliminary data suggest that families served by SOCs have experienced significant adversity; caregivers report very high levels of risk. This finding underscores the health and mental health implications of work assessing the needs, strengths, and functioning of the *entire* family, including siblings – researchers have long documented that stress predisposes maladjustment in children (e.g., Johnson, 1986), and that exposure to multiple, chronic risk conditions may increase the probability of such negative effects (e.g., Luthar et al., 2000; Rutter, 1979; Sterling, Cowen, Weissberg, Lotyczewski, & Boike, 1985). Given evidence that children vary considerably in their responses to stress, with some coping and adapting particularly well (Cowen, 1994; Wyman, Sandler, Wolchik, & Nelson, 2000), it is necessary to document the impact of stress, and to identify potential protective factors and processes that shape stress-resilience (e.g., Cicchetti & Garmezy, 1993; Cowen, Wyman, Work, & Parker, 1990). Significantly, a number of the siblings demonstrated fewer strengths and poorer adjustment in several areas, relative to the target children who have been judged to be SED. This implies that families, and the service systems that serve them, need to be sensitive to and responsive to the needs of siblings. Clearly the families are at risk, and while many of the siblings are adjusting better than their SED brothers or sisters, others are showing some signs of maladjustment. The fact that the siblings are largely younger than their system-identified brothers and sisters also has important implications for prevention.

Findings suggesting gender differences (i.e., favoring females) among siblings contrast with results of prior studies. In a study examining the relationships of aggressive children and their siblings (Aguilar, O'Brien, August, Aoun, & Hektner, 2001), dyads with male target children and female siblings were rated as more aggressive, and researchers noted a strong pattern whereby older brother targets and younger sister dyads appeared to be at the highest risk, i.e., more likely marked by aggression, conflict, and negative affectivity. Parallel research involving siblings of physically handicapped children suggests that female siblings generally seem to be more adversely impacted than males (Summers, White, & Summers, 1994; Hannah & Midlarsky, 1985). As the sample grows, exploring potential gender differences will be an ongoing question of interest.

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### *Topical Discussion Overview*

# *Steps Toward Evidence-Based Practices for Parents with Mental Illness and their Families*

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## *From Science to Service and Service to Science: A Two-Way Street*

Discussion of contemporary interventions for parents with mental illness and their families provides an opportunity to explore *science to service* and *service to science* approaches to treatment development, testing, and dissemination. Over the past 20 years, providers, parents with mental illness, adult children, family members, and advocates have responded to the needs of families living with parental mental illness (Nicholson, Biebel, Hinden, Henry, & Stier, 2001). Available programs for parents with mental illness and family members, typically developed in community settings, reflect a range of theoretical orientations, and serve diverse target populations (Hinden, Biebel, Nicholson, Henry, & Stier, 2002).

One group of programs grew out of the recognition among adult mental health providers or policy-makers of the gap in and need for specialized services for pregnant and parenting adults with mental illness. The second group of programs developed among early intervention providers who realized that many “high-risk” families of young children include a parent with mental illness. The passionate commitment of at least one advocate devoted to the “cause” of parents with mental illness was essential, that is, someone who was able to engage sufficient political and economic support to begin and then sustain the program. Funding streams contributed to the definition of the target populations (via eligibility requirements) and program goals (via agency mandates, e.g., child welfare and the goal of family reunification), as well as to program sustainability. These community-based efforts have out-paced the testing of interventions developed in laboratory or academic settings, and remain largely unstudied.

Traditionally, researchers most frequently develop mental health interventions and test them within relatively controlled settings, following the *science to service* path. Intervention scientists have accumulated solid evidence in support of the efficacy of treatments for childhood mental disorders tested in research settings (Kazdin, Bass, Ayers, & Rodgers, 1990; Weisz, Weiss, Han, Granger, & Morton, 1995). When such interventions achieve positive outcomes (e.g., symptom reductions, improvements in child functioning), within such efficacy trials, researchers may perform effectiveness trials that expand to more heterogeneous, or real-world populations and service settings. At this point, fit with a broader population and novel service setting (e.g., school, primary care setting), becomes an issue. In other words, systemic fit is most often considered only after an intervention has been developed and preliminarily tested.

Unfortunately, the therapies tested in efficacy and effectiveness trials are often not the ones typically used in real-world settings (e.g., Weiss, Catron, & Harris, 2000; Weisz, Weiss, & Donenberg, 1992). In order to increase the applicability of efficacious interventions to real-world settings, some have argued for a consideration of real-world population and service setting fit throughout all stages of intervention development and testing. Such a model is proposed within the recently released NIMH report “*Blueprint for change: Research on child and adolescent mental health*.” This model, termed “A Model for Effective Deployment and Translation of Science into Practice,” argues that factors relevant to the eventual deployment of an intervention (e.g., provider attitudes and skills, implementation processes, barriers to intervention adoption), should inform both intervention development and research on intervention testing. Such an approach brings service relevance to scientific development.

Rigorous study is required to move interventions that originate in the community, rather than in the laboratory or academic setting, down the path from *service to science*. There are many research challenges inherent in distinguishing them as evidence-based practices. These include the fact that clients typically are a heterogeneous group, often with multiple problems. The number of clients served may be smaller than required to show statistical effects. Community contexts are complex, and may be resistant to precise description and measurement. Treatments may need to be "deconstructed" to focus on specific elements that can be tested in relation to "dose" and outcomes (Hoagwood, Burns, & Weisz, 2002). Providers may be reluctant to endorse the random assignment of program participants to treatment conditions, particularly if client empowerment and choice are core program values or goals. Traditional research methods and measures may need to be modified or alternatives developed to achieve the preponderance of evidence standard.

Four important steps are recommended to achieve a meaningful and useful test of an intervention developed in the community, critical to moving from service to science. First, evaluation of an existing intervention must relate to a comprehensive program description. This description should focus not only on intervention variables, but also on agency and community contextual variables that are often critical moderators of program effectiveness as well as implementation and sustainability (e.g., size and philosophy of the agency, available service array, and local political climate). Assessment of these factors should rely on the reports of multiple stakeholder informants. Second, the comprehensive program description should define measurable "key ingredients" with respect to program success. These ingredients may be informant specific (e.g., defined only by participants), or may be common across multiple stakeholders. Third, key ingredients should be used to construct a theory of change model (Hernandez, Hodges & Worthington, 2000) that specifies hypothesized relationships between key ingredients, processes and outcomes. Finally, appropriate research measures, methods, and analytic strategies must be identified or developed, and applied to test these models. Strategies can and should be both qualitative and quantitative. These steps support the construction of a rigorous evidence base for interventions originating in the community.

Strategies can be shared between the *science to service* and *service to science* paths of intervention development to overcome barriers encountered in each. Building an evidence base can be a two-way street. Researchers espousing the more traditional path from efficacy to effectiveness to community implementation acknowledge the importance of attending to process and context from the beginning to promote the ultimate use of evidence-based treatments (Gonzales, Ringeisen & Chambers, 2002). While individuals typically engaged in real-world, community-based responses to service and support needs (e.g., advocates, providers, and individuals with mental illness themselves) are not scientists *per se*, they often are experts in the process of spearheading community initiatives and understanding the needs of diverse program participants, and can elaborate relevant and meaningful outcomes. They have much to offer research scientists. Likewise, community-based program developers, providers, and participants may lack the expertise or resources to frame rigorous tests of interventions—manualizing treatments, assessing fidelity, or employing scientifically-sound procedures. They may benefit from partnerships with researchers who are both respectful of their contribution, and knowledgeable regarding research strategies and funding opportunities.

Advocates are the players most likely to be effective in linking science and service in either direction. They "live" at the crossroads of perceived need and accumulated evidence, and understand the suffering caused by delays in science. Advocates embrace both the assumption that individuals with mental illness deserve the best available treatments, and the assumption that individuals with mental illness, family members and community stakeholders can be valuable partners in the intervention development and research processes.

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# An Epidemiologic Perspective on Children of Parents with Mental Illness: Implications for Intervention

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## Introduction

Researchers have suggested multiple sources of risk and resilience for children, and pathways between parental mental illness and child outcomes that involve mediating and moderating influences (Goodman & Gotlib, 1999). The development of evidence-based practices for parents with mental illness is limited by the lack of epidemiological data on the prevalence of parenthood among these adults, the distributions of parental and child characteristics, and the relationships among these variables. Without an adequate understanding of the "scope of the problem," appropriate services and supports for parents with mental illness, and relevant preventive and rehabilitative interventions for their children cannot be developed (Nicholson, Biebel, Hinden, Henry, & Stier, 2001).

Recently, data from the National Comorbidity Survey (NCS), a nationally representative cross-sectional mental health survey, have become available for secondary analyses (e.g., Kessler, 1994). The NCS data are one of the main sources of estimates of treatment need in the United States (U.S. Department of Health and Human Services, 2000) and have been used to address a variety of research questions. This paper provides data regarding the prevalence of and relationships among factors contributing to risk and resilience for children whose parents have mental illness. The implications of these findings for prevention and intervention for children and families will be elaborated.

## Methods

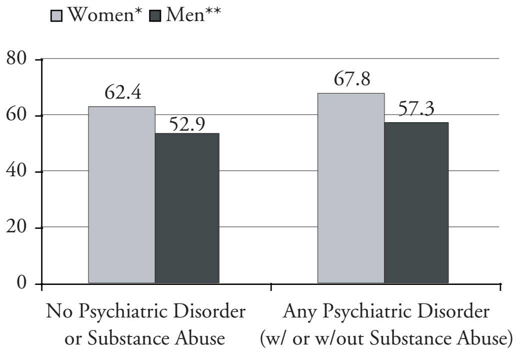
Our analyses used data from the 5,877 respondents aged 15-54 years in the Part II subsample of the NCS. Data were weighted to adjust for non-response, for variation in the probability of selection, and to approximate national population distributions. Respondents were considered parents if they reported having natural-born children. Respondents who reported having only adopted children or only step, foster, or other unrelated children living with them, or who had given birth to a child who subsequently died and had no other children, were classified as non-parents. All of the estimates presented here have been weighted, and their associated standard errors have been generated using version 8.0 of the SUDAAN statistical package (Research Triangle Institute, 2001). Comparisons between rates of different groups were made using *t*-tests performed by SUDAAN.

Lifetime prevalence of mental illness was chosen for most analyses, rather than 12-month prevalence, to reflect the notion that parenthood is a longitudinal rather than cross-sectional experience, occurring across years rather than in just one. It is likely that having a parent with mental illness affects the lives of children at any age, though its impact is likely to differ by the age of the child when the parent becomes ill, as well by the severity and duration of the parent's illness (Oyserman, Mowbray, Meares, & Firminger, 2000; Wickramaratne & Weissman, 1998).

## Results

Adults with psychiatric disorders or with co-occurring psychiatric disorders and substance abuse may be at least as likely, if not more likely, to be parents than those who do not meet criteria for psychiatric disorder or substance abuse (see Figure 1; Nicholson, Biebel, Katz-Leavy, Williams, in press). Of the female respondents with a lifetime prevalence of any psychiatric disorder, 68% are mothers. The difference between this proportion and the proportion of women with no psychiatric disorder or substance abuse who are mothers is statistically significant ($p < .05$). Among men with a lifetime prevalence of any psychiatric disorder, slightly more than half (57%) are fathers. Among NCS respondents who are parents, almost half (47%) of the mothers and almost a third (30%) of the fathers have a lifetime prevalence of psychiatric disorders.

**Figure 1**
**Prevalence of Parenthood Among NCS Respondents**



* All standard errors are < 2.1.
** All standard errors are < 1.9.

The adverse impact of parental mental illness on children has been demonstrated (e.g., Goodman & Gotlib, 1999). Table 1 shows that parents with mental illness tend to have as many children as parents without mental illness and exhibit characteristics that may moderate outcomes for children (Nicholson et al., in press). Moderators include environmental stressors such as minority status, single parenthood, low educational levels, and poverty (Nicholson et al., 2001). Significantly fewer mothers in the *any psychiatric disorder* group report being married/living with a partner in a steady, marriage-like relationship than in the *no psychiatric disorder* group (72% and 81%, respectively). The two groups of NCS fathers do not differ significantly in terms of this characteristic. Fathers in the *any psychiatric disorder* group report significantly fewer years of education than the *no psychiatric disorder* group ($p = .04$). Significantly more mothers in the *any psychiatric disorder* group report household incomes falling below the poverty level than do those in the *no psychiatric disorder* group ($p = .006$).

Age at onset of maternal mental illness may be an important factor related to risk for children. Earlier parental age at onset of depression (prior to 30 years old) is related to poor child outcomes (Warner, Mufson, & Weissman, 1995; Wickramaratne & Weissman, 1998). Age of illness onset and average age at birth of first child vary across diagnostic categories. Mothers with affective disorders and those with nonaffective psychotic disorder are likely to have their first child before illness onset (see Table 2). Illness onset for mothers with anxiety disorders or PTSD is likely to precede birth of their first child.

Figure 2 shows that the majority (62%) of natural children of mothers with psychiatric disorders within 12 months of the interview are less than 18 years of age. Approximately thirty-two percent of all natural children less than 18 years of age ($n = 862$) have a mother with a 12-month prevalence of any psychiatric disorder.

**Table 1**
**Selected Characteristics of NCS Respondents Who Are Parents***

| | *Mothers* | | *Fathers* | |
|---|---|---|---|---|
| *Characteristic* | *No Psychiatric Disorder* | *Any Psychiatric Disorder* | *No Psychiatric Disorder* | *Any Psychiatric Disorder* |
| Mean Age | 37.1 | 36.9 | 38.4 | 38.4 |
| Mean # of Children | 2.2 | 2.3 | 2.2 | 2.3 |
| % Non-White | 27.1 | 24.3 | 23.1 | 17.3 |
| Mean Years of Education | 12.9 | 12.7 | 13.0 | 12.7† |
| % Married/Living w/ Partner | 80.5 | 72.2†† | 83.6 | 81.6 |
| % Below Poverty Level | 10.8 | 16.3†† | 6.6 | 8.6 |

* Categories represent lifetime prevalence.
† Significant difference compared to fathers in the no psychiatric disorder category ($p < .05$).
††Significant difference compared to mothers in the no psychiatric disorder category ($p < .007$).

**Table 2**
**Lifetime Prevalence of Psychiatric Disorders,**
**Average Age of Illness Onset, and Average Age at Birth of First Child**
**Among NCS Respondents Who Are Mothers**

| | *Mothers (n=1,899)* | | |
|---|---|---|---|
| *Disorders* | *% of Mothers* | *Average Age of Illness Onset* | *Average Age at Birth of First Child* |
| Affective Disorders | 25.7 | 25.7 | 21.9 |
| Anxiety Disorders | 32.4 | 15.7 | 21.9 |
| Post Traumatic Stress Disorder | 11.3 | 16.8 | 21.1 |
| Nonaffective Psychotic Disorder | 0.9 | 23.4 | 19.5 |
| Any Psychiatric Disorder* | 46.8 | 17.2 | 21.9 |
| No Psychiatric Disorder** | 53.2 | N/A | 22.8 |

* Excludes substance abuse only and antisocial personality disorder.
** Includes substance abuse only and antisocial personality disorder.

## Discussion

The majority of American women and men who meet criteria for mental illness over the course of their lifetime are parents. While parenthood, per se, is common among these individuals, their experiences and those of their children, may well vary by characteristics of their illnesses. These variations have implications for family interventions and support in terms of timing, point of access/service portal, identified patient, prevention opportunities, and the foci of interventions.

***Implications for Interventions: Mothers with PTSD.*** Almost 70% of NCS mothers with PTSD have their illness onset before the birth of their first child. This finding highlights the importance of accurate diagnosis and effective treatment for women prior to pregnancy and motherhood. It also suggests the benefit of prenatal and postpartum opportunities for prevention and intervention.

***Implications for Interventions: Mothers with Affective Disorders.*** For this group of respondents, the first child is born, on average, 3-4 years prior to mother's illness onset, indicating that pediatricians or day care providers may be first to identify a mother's illness or impact on the child. This sequence suggests opportunities, apart from the mental health arena, for screening/earlier identification and intervention for both mothers and children.

***Implications for Interventions: Mothers with Anxiety Disorders.*** Since illness onset generally precedes the birth of the first child by several years, the earliest identification may come via the woman herself, her family, health care provider, or school. This finding suggests the benefit of strategies for intervention and psycho-education prior to or during pregnancy and of prevention strategies for mother and child postpartum. This finding also underscores the importance of the support of resilience and coping for individuals with these disorders who are considering parenthood and becoming parents, as well as for their offspring.

Overall, our findings point to the complexities in the relationships between illness, individual characteristics and parenting, and only suggest potential impact on adults and children. The NCS data do not allow for complete understanding of these complexities. Data are not intergenerational, i.e., individuals are sampled, not families, limiting our use of family-related variables and our interpretation of findings. While responses of adults are weighted to match national population distributions, information obtained about children has not been similarly statistically manipulated, limiting our ability to make inferences about the characteristics or experiences of the larger population of children living with parental mental illness.

The most simple, and perhaps most powerful conclusion that can be safely drawn from analyses of the NCS data is that parenthood is extremely prevalent among the millions of women and men with mental illness in the United States and, therefore, many more millions of children are potentially affected by parental mental illness at some point in their lives. Data on the prevalence of, and relationships among, factors conveying risk and supporting resilience in children have significant implications for the development of preventive strategies and intervention approaches. These results highlight the need for multiple, coordinated, family-centered services and supports for children and their parents with mental illness.

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# *Building the Evidence Base: Evaluation of the Invisible Children's Project*

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## *Introduction*

Millions of adults in the United States are affected by mental illness. The majority of these adults are, or will become parents (Nicholson, Biebel, Hinden, Henry & Stier, 2001). Children of parents with mental illness are at increased risk for serious emotional and behavioral problems, and expensive out-of-home placements (Oyserman, Mowbray, Meares, & Firminger, 2000). Little is known about effective interventions for these complex families. The Invisible Children's Project (ICP) in Orange County, New York is a nationally recognized program for parents with serious mental illness and their children. ICP provides home-based, family-centered case management, focused on supporting parents and preventing out-of-home placements and custody loss. ICP provides services for many families also involved with child welfare at the greatest risk for custody loss. The ability of ICP to address child safety issues, achieve family preservation, and prevent long-term and costly out-of-home placements has never been formally assessed. The current study describes an evaluation of ICP as it affects families with a history of child welfare involvement. Specifically, the study addressed the hypotheses that: (a) ICP services improve the ability of parents to maintain children in the home; and (b) ICP services prevent costly out-of-home placements.

## *Method*

This study involved case-study methodology, a recognized methodology that allows for qualitative examination of the relationship of processes to outcomes. We use the term "family study" rather than the more traditional term to underscore ICP's approach to clients as people and families rather than cases. Thus, a family study methodology was used to describe program participants and ICP services, define key program ingredients, examine family outcomes, and assess costs over time. Inclusion criteria for families included current enrollment in ICP for at least one year, and a history of child welfare involvement. One hundred percent of eligible families involved with ICP at the time of the study ($N = 8$; 50% of ICP families overall) agreed to participate. Parents, ICP case managers, and child welfare caseworkers from the Department of Social Services (DSS) completed semi-structured interviews to assess child and family characteristics, service and key program ingredients, and family outcomes. Parents also completed a modified version of the Family-Centered Behavior Scale (FCBS; Allen, Petr, & Brown, 1995), and two measures of child adjustment, the Child Behavior Checklist (CBCL; Achenbach, 1991), and the Behavioral and Emotional Rating Scales (BERS; Epstein, 1998). ICP family files were extracted to complement services and outcome data. Data on service costs were collected on DSS service costs for the year prior to ICP enrollment, and for both DSS and ICP costs from the time of enrollment in ICP to the initiation of the study (November 2000).

## *Results*

### *Child and Family Characteristics*

Parents from the 8 participating families ranged in age from 26 to 40 years. Six parents were Caucasian and three were African American. Major Depression was the most frequent diagnosis ($n = 5$), followed by Bipolar Disorder, Schizoaffective Disorder, and Adjustment Disorder (each $n = 1$). Two parents had secondary diagnoses of Borderline Personality Disorder, and one parent had Mental Retardation. Seven parents had histories of substance abuse, and six had histories of suicide attempts.

There were 16 children and two grandchildren currently living with the parents interviewed for this study. Children's ages ranged from two to 14 years. Ten of the children living with their parents had mental health diagnoses of their own, and five had histories of psychiatric hospitalization or residential treatment for emotional and behavioral problems. Among the 18 children currently living in these families, 14 had a history of DSS involvement at the time of referral to ICP. Results on the child adjustment measures were consistent with interview report of clinically significant emotional and behavioral problems.

### Services and Key Program Ingredients

Instrument and interview data revealed that ICP provided strengths-based, family-centered case management. All informants reported that ICP services and approaches were distinct from other providers' approaches with respect to both quality and quantity/comprehensiveness. Scores on the FCBS indicated that program participants reported high levels of family-centered behaviors "almost always," (e.g., felt respected and treated in a strengths-based, culturally competent manner). Parents and providers also defined shared and informant-specific key program ingredients (see Table 1). Five essential and distinguishing components related to improved parent and child outcomes were identified across study informant groups (i.e., parent, DSS caseworker, ICP case manager). These were: (a) high level of availability of ICP case managers; (b) strengths-based, non-judgmental approaches; (c) a trusting relationship; (d) emotional support; and (e) liaison activities between parents and DSS. Informant-specific factors included accountability and reliability of the case manager, concrete assistance made possible by flexible funding, referral and coordination of multiple services, and the mental health expertise of ICP case managers. Parents with mental illness reported that these program ingredients improved their overall functioning and helped them maintain custody of their children. DSS workers echoed parents' testimony. Each DSS worker interviewed for the current study stated unequivocally that the children involved could not have been returned home or maintained in the home without ICP intervention and support.

**Table 1**
**Shared and Non-Shared Key Program Ingredients Across Informants**

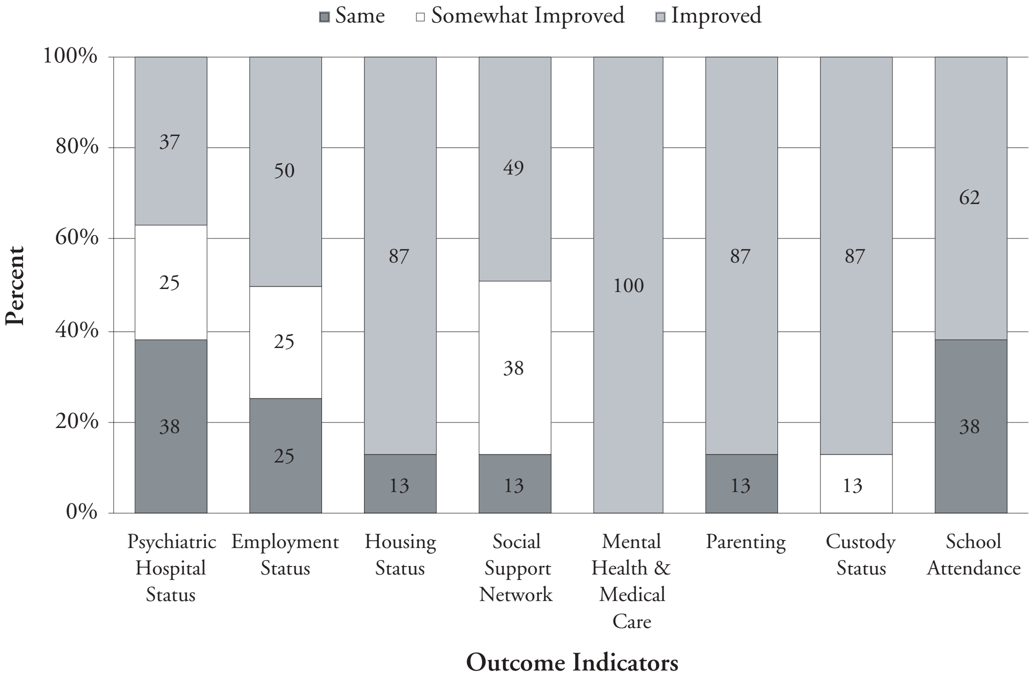
| *Informant* | *Key ingredients of ICP case management** |
|---|---|
| Parent | **Availability of case manager**<br>**Strengths-based, non-judgmental approach**<br>**Trusting relationship**<br>**Emotional Support**<br>**Liaison with DSS**<br>Flexible funds to provide concrete support (e.g. utility bills, furniture, holiday presents) |
| ICP Case Manager | **Availability of case manager**<br>**Strengths-based approach**<br>**Trusting relationship**<br>**Emotional support**<br>**Liaison with DSS**<br>Crisis management<br>Comprehensive services coordination<br>Referral and access to services<br>Role modeling |
| DSS Caseworker | **Availability of case manager**<br>**Strengths-based approach**<br>**Trusting relationship**<br>**Emotional support**<br>**Liaison with DSS**<br>Sharing of critical information about family strengths and risks<br>Mental health expertise and knowledge |

* Bold text reflects ingredients endorsed by entire informant group (i.e., parent, ICP case manager, DSS caseworker).

### Family Outcomes

Study informants agreed that ICP services improved multiple family outcomes, including those prioritized by DSS, such as parenting skills and child safety. Family change over the period of involvement with ICP on eight targeted outcomes is portrayed in Figure 1. As can be seen, the majority of families *improved* or *somewhat improved* on all targeted outcomes, or remained the same over time. None of the families evidenced deterioration on any outcome during the period of ICP involvement.

**Figure 1**
**Family Change for Identified Outcomes**



Specifically, most families evidenced decreased need for hospitalization while involved with ICP. Many showed improved employment and education outcomes, with three parents achieving full-time work status, and several completing vocational training or community college courses. Most families received and maintained housing subsidies, and/or moved to more adequate housing in safer neighborhoods. Social support networks increased, as did access to and appropriate utilization of services. Most importantly perhaps, parents uniformly regained custody of children living in DSS placements, and maintained custody for children at risk for removal. Before ICP involvement, all eight families were actively involved with the child welfare system: Four families had child protective investigations, two families had open child protective cases, and two families had children in foster care. In addition, three families had or previously had children in residential treatment or in psychiatric hospitals. At the time of this study, all children had returned home and were in the custody of their parents. Finally, school attendance improved for children in five families (62%), and child behavior problems decreased for families who had reported problems.

### *Cost of Services*

Only comparable costs across ICP and DSS were assessed. Case management and childcare/respite services comprised the majority of these costs. Overall service costs increased across comparable costs for most families during involvement with ICP. This increase generally reflected the increased cost of intensive case management services provided by ICP, which, according to DSS workers, were absolutely necessary to support the goals of family reunification and preservation. Although overall costs increased, five families (62%) showed decreased DSS costs overtime and decreased DSS costs proportionate to total costs. Additionally, although cost data for the current study did not include DSS costs for foster care and residential treatment, results indicate that these costs decreased for ICP-involved families. Two children were returned home and multiple out-of-home placements were avoided for the remaining families.

## Conclusions

Parents with mental illness and their children who received family-centered case management services through ICP showed improvement across multiple outcomes. This improvement was consistently reported by parents, ICP case managers, and DSS workers. It is noteworthy that DSS workers stated unequivocally that children were returned home, or maintained in the home as a direct result of ICP involvement. While service costs increased for some families, benefits were great. Parent and agency goals were achieved, and more expensive, disruptive, and potentially damaging out-of-home placements, such as hospitalization and residential care or foster care, were avoided.

In summary, these results suggest that family-centered, strengths-based practices distinguished ICP from other services available to parents with mental illness. These practices were highly valued by both consumers and providers that worked with ICP. DSS workers readily acknowledged that ICP involvement allowed DSS to close cases that would otherwise remain open, and to redirect resources to other needy families. Family-centered, strengths-based services proved to be a powerful and precious resource for the parents with mental illness interviewed for the current study, as well as for the child welfare system and providers that worked with them. Future work will include evaluating the policy implications of these findings, and development of evaluation strategies to promote evidenced based interventions for parents with mental illness and their families.

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