

Chapter Six

Family Involvement and Perspectives

Symposium

Unearthing the “Why’s” of Quantitative Outcomes through Qualitative Analysis

Symposium Introduction

Katherine Lazear

Approaches to examining family perspectives about mental health services have been largely cross-sectional and quantitative, relying heavily on the use of standardized instruments and rating scales of consumer satisfaction. While these studies have been effective in identifying the strengths and deficits of services, qualitative analysis offers an opportunity to examine how and why those effects occur. The challenge of qualitative research has often been to provide the large numbers of study participants more easily available in quantitative studies. However, as qualitative approaches to data collection increase, an examination of similar studies can result in strengthening and supporting individual findings. Regardless of the program investigated or geographic region, studies using qualitative approaches to data collection to investigate parent and caregiver views of mental health service delivery for children are reporting very similar findings.

This presentation will focus on three qualitative studies examining families’ experiences of mental health policy and service delivery, and will demonstrate how mixed methods research can provide comprehensive policy and service evaluation. These studies include: The Supplemental Security Income Family Impact Study; The Child and Family Experience of the Mental Health System; and Parent Impressions of a County’s Mental Health Service Delivery System for Children. The power of the qualitative methodology captures the complexities of life changes and provides context to family experiences, such as where they live, how they feel about their circumstances, the reasons for decisions made, and co-occurring events.

The Supplemental Security Income Family Impact Study

Katherine Lazear, Sharon Lardieri, Ricardo Contreras, Robert Friedman, Joko Sengova, & Janice Worthington

Introduction

Family participation in mental health services, once limited to the roles of patient or client, has expanded to include a wide range of roles including planning, decision-making, and evaluation (Osher, deFur, Nava, Spencer, & Toth-Daniels, 1999). While the inclusion of family perspectives in system reform efforts through their participation in decisions that govern policy and design services at a system level is crucial, it is a different and equally important challenge to build understanding about how family members experience the results of policy and service delivery.

Building understanding about family experiences with service delivery offers a valuable opportunity to evaluate the ways in which service-related policies impact families at the level of practice. Three areas of feedback from parents on their experiences with mental health services emerge from the literature: (a) feedback from parents about individual professionals, (b) feedback on the types and levels of services they receive, and (c) feedback on the agencies from which the services are received (Dinnebeil & Rule, 1994). It is important to integrate these family perspectives, such as unmet needs and barriers to effective interventions, into the design and provision of services if those services are to be effectively used by families (Tarico, Low, Trupin, Forsythe, & Stephens, 1989).

Chair

Katherine Lazear

Discussant

Trina W. Osher

Authors

Katherine Lazear et al.

Tommy Burrus et al.

Ringeisen et al.

There are demonstrated benefits to integrating the experiences of families into the processes of policy planning, development, and implementation. These include: (a) an increased potential for developing service-related policies that are consistent with the needs and wishes of families, (b) an improved ability on the part of service systems to respond to the increasing number of parents who are asking to actively participate in decisions affecting the care of their children, and (c) an increased responsiveness of service providers to the core values and guiding principles of systems of care, including the need for services to be child-centered and family focused, with the needs and opinions of the child and family determining the types and mixes of services (Pires, 2003; Stroul & Friedman, 1994).

This study captures the perceptions and experiences of families as they experience a change in a major policy—the Supplemental Security Income (SSI) program—and how they identify issues and make decisions about the kinds of care and supports available to them and that they find useful. The qualitative approach used 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 with private choices (Elmore, 1980).

More than 263,000 children of the one million children on the SSI rolls in 1996 were identified as being potentially affected by the SSI revised eligibility criteria. Based on 1998 data from the Bazelon Center for Mental Health Law, about 58% of children whose cases were reviewed were continued in the program. Forty-two percent of children had their benefits terminated (based on their first level of appeal). Data compiled by the Social Security Administration (SSA) indicated that most of the children who ended up losing disability benefits (after one or more appeals)—78,600 of the 95,180—had “mental disorders.” This represented about 83% of all the cases that were found ineligible. What were the experiences of these families, and how did the policy change impact their lives?

Neither qualitative nor quantitative research alone can provide comprehensive policy evaluation (Jacobs, 2003). However, this study is designed to complement some of the more cross-sectional quantitative research on the impact of the SSI changes by using qualitative methodologies to study a sample of families over time and in depth. Such an approach goes beyond looking at aggregate numbers and seeks to provide an understanding of the policy change in more human terms.

Methodology

In order to deepen understanding of the impact that changes in the SSI regulations had on children and families, the study utilized a qualitative, multi-site, longitudinal approach. The study followed 40 families over a 22-month period, through a combination of in-person and telephone interviews every three months. The families participating in the study came from rural Kansas, New York City and west central Florida. All had received a letter from the SSA notifying them that their child’s eligibility for benefits was being reviewed. In addition, a series of focus groups was held in the three communities to gain additional perspectives on the impact of the SSI changes.

Timelines were created during the data collection process to review, over time, the experiences of the families. If necessary, the timelines were updated and revised after each interview by the study team member and then reviewed for accuracy with the family member during the final interview.

The study analysis was completed using a data transformation approach. Data transformation is an analysis process that allows for the representation of the point of view of interviewees through a systematic procedure. Information is transformed, step-by-step, from raw data into interpretive descriptions. The process controls the level of interpretation, follows a traceable pattern and increases the level of reliability of the qualitative data (Contreras, Lazear & Boterf, 2001).

Throughout the course of the study, at least three parents of children with a serious emotional or behavioral disturbance and experiencing an SSI review for their children were members of the research team. Two additional parents from each of the three sites were also hired as part of the research team that conducted interviews and recruited other parents in their locales.

Findings/Conclusions

The study identified six major categories of findings: (a) children and families impacted by the change, (b) loss of cash benefits (c) negative family outcomes, (d) loss of medical insurance, (e) parent action, and (f) SSI review process, as discussed below.

Who are the children and families impacted by the change? These were children with severe emotional and behavioral disorders and the change in eligibility and loss did not change their need for services. During the course of the study, primary caregivers clarified their health status and that of their immediate family. Often, not just one child, but adults and siblings had major physical or mental health problems. These were families experiencing consistently high stress with co-occurring negative events and challenging existing circumstances.

Loss of cash benefits. Families reported that the SSI cash benefit represented an average of 41% of the families’ total income and was important as a stable source of income. Families typically used the SSI cash benefit as part of the household income to meet basic needs, pay bills, and cover expenses.

Negative family outcomes. Although the worst fears of child and family advocates—that children would be placed outside their homes—was realized for only one of these families during the study period, there was an increase in turbulence and crisis that lead to negative outcomes and changes in the families’ quality of life. Continuity of health care was disrupted for many families and families experienced a loss of ability to provide “normalizing” supports, such as recreational opportunities, including sports and school activities.

Loss of medical insurance. While a few families that lost benefits reported some positive outcomes, those families that retained the benefits reported having greater peace of mind, primarily due to the assurance that their children had medical coverage. The main reason most families appealed was the potential loss of Medicaid. Health care coverage was tenuous for many families in the study, and many parents were without health insurance or health care coverage of any kind.

Parent action. Parents were not passive in their response to the loss of SSI. They made numerous key decisions weighing costs and benefits, including how to respond to the review and denial of benefits, whether they should seek help, and where to find it. Informal and formal helpers were major sources of support; however, support from some informal and formal sources was inconsistent.

SSI review process. Families found the SSI review process difficult and confusing. Experience with the state and local SSA offices generally proved problematic for parents, requiring a lot of “waiting and wondering,” thereby contributing to increased levels of stress. The SSI review/appeal process was lengthy, with outcomes that extended beyond the review period. One mother waited a full year to have a hearing on her first appeal after experiencing delays caused by the SSA and her attorney.

In conclusion, the SSI Family Impact Study complements more quantitatively designed studies through its in-depth focus on a limited number of families, which adds a “human face” to other studies examining the impact of this legislation. Such a methodology helps policy-makers, advocates, and researchers look beyond the numbers to enhance their understanding of the impact of policy changes.

References

- Contreras, R., Lazear, K. J., & Boterf, E. (2001, March). *Building the family experience into policy research*. Paper presented at the National Association of State Mental Health Program Directors, Washington, DC.
- Dinnebil, D. A. & Rule, S. (1994). Variables that influence collaboration between parents and service coordinators. *Journal of Early Intervention, 18*, 349-361.
- Elmore, R. E. (1980). Backward mapping: Implementation research and policy decisions. *Political Science Quarterly, 94*, 601-616.

- Jacobs, E. (2003). Mixed methods and moving to opportunity. *The Evaluation Exchange*, 9(3), 14-15. Cambridge, MA: Harvard Family Research Project. Harvard Graduate School of Education. Available at: <http://www.gse.harvard.edu/hfrp/content/eval/issue23/fall2003.pdf>
- Osher, T. W., deFur, E., Nava, C., Spencer, S., & Toth-Daniels, D. (1999). New roles for families in systems of care. In *System of care: Promising practices in children's mental health, 1998 Series, Vol. 1*. Washington, DC: Center for Effective Collaboration and Practice, American Institutes of Research.
- Pires, S. A. (2003). *Building systems of care: A primer*. Washington, DC: National Technical Assistance Center for Children's Mental Health, Center for Child Health and Mental Health Policy, Georgetown University Child Development Center.
- Stroul, B. A., & Friedman, R. M., (1994). *A system of care for children and youth with serious emotional disturbances (Revised edition)*. Washington, DC: National Technical Assistance Center for Child Mental Health, Georgetown University Child Development Center.
- Tarico, V. S., Low, B. P., Trupin, E., & Forsythe, S. A. (1998). Children's mental health services: A parent perspective. *Community Mental Health Journal*, 25, 313-326.

The Child and Family Experience of the Mental Health System Study

Tommy Burrus, Janice Worthington, Katherine Lazear, Sharon Lardieri, Maridelys Detres & Robert Friedman

Introduction

Community studies of emotional disorders in children indicate that while many children are in need of services, only a small percentage of those in need actually receive services. Estimates suggest that about 80% of children and adolescents with mental illness fail to receive treatment (Jensen, 2003), and only 25- 40% of children with serious emotional disturbances receive services within a 12-month period (Burns et al., 1997; Leaf et al., 1996). Research also shows that there is at least a two-year gap between the time parents identify a problem, and the time they seek or receive help for their children and adolescents with serious emotional disturbances (Bussing, Zima, Gary, & Garvin, 2003; Lardieri, Greenbaum, & Pugh, 1996).

In addition, data on participation in treatment suggests a high rate of leaving services before treatment is completed. Estimates for outpatient treatment, for example, are that 40-60% of clients terminate prematurely (Kazdin, Holland, & Crowley, 1997). This premature termination can be devastating to children and families. Most studies examining this phenomenon have been quantitative, focusing exclusively on demographic, socio-economic and diagnostic correlates of dropping out from treatment, and surveys of consumer satisfaction (Harris-Kojetin, Fowler, Brown, Schnaier, & Sweeney, 1999).

This study seeks to understand the decisions made by children and their families with regard to both help-seeking behavior and treatment continuation. One of the current major challenges faced by the the children's mental health field is to demonstrate, at a minimum, that children and families in need of treatment can be identified and retained in services. This is especially the case for families from low socio-economic communities, and families that might be less likely to seek mental health treatment for cultural reasons (Angold, et al., 2002). While there are several encouraging studies about participation in treatment (Koroloff, Elliott, Koren, & Friesen, 1996; Santisteban, et al., 1996), there is still significant work remaining to address this challenge.

Similarly, there is major effort in the field to identify empirically supported treatments (Chambless & Holland, 1998; Kazdin & Weiss, 1998; Lonigan, Elbert, & Johnson, 1998; Weisz & Hawley, 1998). One of the issues within this literature concerns how to reconcile the individualized and relationship-oriented components of treatment with the more standardized and manualized components (Arnold et al., 1997; Friedman, 1997; Kaslow & Thompson, 1998), and with caregiver perception of services and

their children’s mental health outcomes (Brunk, Innes, & Koch, 2002). The traditional approach to identifying effective treatments is to provide treatments to randomly assigned groups of individuals (or families) and to measure their responses with standardized outcome measures (Chambless & Holland, 1998; Lonigan, et al., 1998). As useful as this approach is, it is believed that research can be strengthened and complemented through qualitative information from the perspectives of those families who have a child with a disability, and with individuals who receive treatment (Fox, Vaughn, Wyatte, & Dunlap, 2002). For example, researchers may believe that particular aspects of their interventions are critical, while the children and families receiving these interventions may be more concerned with perceptions about whether the intervention provider cares about their well being (Unger & Powell, 1992).

This study is designed in the context of findings that show a gap between: (a) a family’s identification of a problem with their child, and (b) help-seeking from child mental health providers, high drop out rates from treatment, and the inadequacy of traditional approaches to establishing treatment effectiveness for capturing the perspectives of children and families receiving services.

Method

This study utilized a qualitative approach to more broadly examine the experiences of families and their children as they sought services and entered and progressed through the mental health system. The study followed 30 families over two years. Twenty-five families, designated as high frequency users, were contacted in-person and by telephone every two weeks for the first two months. Next, these families were contacted by telephone every four weeks for the following two months, and then every three months for the remaining 20 months. The initial contact, and the 12th and 24th month interviews were conducted in person. Five families, designated as low frequency users, were contacted by telephone the 1st, 12th, and 24th month. All interviews were audio taped, transcribed, coded and placed in a database for qualitative analysis. All families participating in the study lived in Hillsborough County, Florida.

Throughout the study (e.g., from design to analysis and dissemination), parents were included as research partners. The investigators had also received guidance and invaluable input from parents, other primary caregivers, and youth through the Family Advisory Committee (which met each year during the study at the Federation of Families for Children’s Mental Health Annual Conference).

Findings and Implications

Based upon the family interviews and an analysis process that moves from quantitative data to data application through contextual findings, several conclusions and implications can be made.

First, the pathway to mental health services is complex and often occurs through agencies other than the mental health system (e.g., schools, courts, and pediatricians) and often through informal networks (e.g., waiting rooms, playgrounds, etc.). There appears to be no defined mental health system through which families can access services. Researchers, clinicians, and administrators in the field of mental health need to do a better job of establishing a mainline system of care, and to reinforce the importance of providing education about mental health services to address stigma and the relationships among cognitive, physical and emotional development.

A related finding suggests that caregivers are frightened and unsure of placing their children on medication and the unintended effects of medication; this implies that there is a continued need to combat stigma and conduct a targeted education campaign related to research and the dissemination of alternatives to medication as well as the utility, risks and safety of medications.

Second, although the literature suggests high drop-out rates or non-compliance with treatment, families do not drop out of services altogether; rather, they leave particular providers for what are reported to be valid reasons. For example: lack of 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; or a parent not feeling respected or believed by the provider. We found that the system in the study community allowed families little or no choice of providers. In the absence of policies that promote choice, policies must support an agency's ability to provide flexible hours and location for services. Also, providers need to pay far greater attention to the reasons families give for wanting to leave services.

Third, many families who obtained services reported they had persistently and aggressively sought these services. For these families, obtaining and continuing in services is often a part- to full-time job for the caregiver. This persistence is often the key determinant for how and whether a service is identified and ultimately used. Related to this finding are the families' reports that their experiences at intake were pivotal to service continuation. Families often reported that they were treated rudely at the first contact with a provider agency, or that their phone calls were not returned.

Fourth, a few families reported receiving support from advocacy groups. These groups were key to families understanding their child's mental health illness and to their feelings of personal support.

Lastly, although health care coverage may eventually become available to these families, many families in the study were in debt from having to pay cash for mental health services and medications over a prolonged period of time. There is a great financial burden on families when they are not insured or underinsured. Even families with good insurance coverage, because of the chronic nature of a serious emotional disturbance, end up with inadequate coverage.

This in-depth study increases our understanding of the processes families go through and the decisions they must make within the context of the services and supports provided in their community. For example, the families contributing to this study described their experiences, not only in terms of ultimate outcomes, but also with respect to quality of life. Many families experienced constant instability because of major financial challenges, tenuous health care coverage, family health issues, and health care disparities—often associated with their children's emotional and behavioral problems. These families persevered in seeking help for their children, displaying enormous strengths in the face of numerous obstacles. The system can build on this natural resiliency in families by providing them with readily accessible and accurate information and accessible services and supports. An increased understanding of families' experiences with the mental health system will ultimately improve the system-building process and its structures.

References

- Angold, A., Erkanli, A., Farmer, E. M. Z., Fairbank, J. A., Burns, B. A., Keeler, G., & Costello, E. J. (2002). Psychiatric disorder, impairment, and service use in rural African American and white youth. *Archives of General Psychiatry*, *59*(10), 893-901.
- Arnold, L. E., Abikoff, H. B., Cantwell, D. P., Conners, C. K., Elliott, G., Greenhill, et al. (1997). National Institute of Mental Health collaborative multimodal treatment study of children with ADHD (the MTA). *Archives of General Psychiatry*, *54*, 865-870.
- Brunk, M., Innes, K., & Koch, J. R. (2002). Caregiver perception of services and children's mental health outcomes: Are they related? In C. Newman, C. Liberton, K. Kutash, & R. M. Friedman (Eds.), *The 15th Annual Research Conference Proceedings, A System of Care for Children's Mental Health: Expanding the Research Base* (pp. 145-152). Tampa, FL: University of South Florida, The Louis de la Parte Florida Mental Health Institute, Research and Training Center for Children's Mental Health.
- Burns, B. J., Costello, E. J., Erkanli, A., Tweed, D. L., Farmer, E. M. Z., & Angold, A. (1997). Insurance coverage and mental health use by adolescents with serious emotional disturbance. *Journal of Child and Family Studies*, *6*, 89-111.
- Bussing, R., Zima, B. T., Gary, F. A., & Garvan, C. W. (2003). Barriers to detection, help-seeking, and service use for children with ADHD symptoms. *The Journal of Behavioral Health Services & Research*, *30*(2), 176-189.

- Chambless, D. L., & Holland, S. D. (1998). Defining empirically supported therapies. *Journal of Consulting and Clinical Psychology, 66*, 7-18.
- Fox, L., Vaughn, B. J., Wyatte, M. L., & Dunlap, G. (2002). “We can’t expect other people to understand”: Family perspectives on problem behavior. *Exceptional Children, 68*(4), 437-450.
- Friedman, R. M. (1997). Services and service delivery systems for children with serious emotional disorders: Issues in assessing effectiveness. In C. T. Nixon & D. A. Northrup (Eds.), *Evaluating mental health services: How do programs for children “work” in the real world?* (pp.16-44). Thousand Oaks, CA: Sage.
- Harris-Kojetin, L., Fowler, F., Brown, J., Schnaier, J., & Sweeney, S. (1999). *Medical Care, 37*, (Suppl.), pp. MS10-MS2.
- Jensen, P. S. (2003, Summer). Setting the record straight: Fact vs. fiction about ADHD. *NAMI Beginnings*, Premiere Issue, 3-7.
- Kaslow, N. J., Thompson, M. P. (1998). Applying the criteria for empirically supported treatment to studies of psychosocial interventions for child and adolescent depression. *Journal of Clinical Child Psychology, 27*, 146-155.
- Kazden, A. E., Holland, L., & Crowley, M. (1997). Family experiences of barriers to treatment and premature termination from child therapy. *Journal of Consulting and Clinical Psychology, 65*, 453-463.
- Kazdin, A. E., & Weisz, J. R. (1998). Identifying and developing empirically supported child and adolescent treatment. *Journal of Consulting and Clinical Psychology, 66*, 19-36.
- Koroloff, N. M., Elloitt, D. J., Koren, P. E., & Friesen, B. J. (1996). Linking low-income families to children’s mental health services: An outcome study. *Journal of Emotional and Behavioral Disorders, 4*, 2-11.
- Lardieri, S., Greenbaum, P. E., & Pugh, A. M. (1996, February). *Parent reports of problem behavior onset among children and adolescents with serious emotional disturbances*. Paper presented at the 9th Annual Research Conference—A System of Care for Children’s Mental Health: Expanding the Research Base, Tampa, FL: University of South Florida, The Louis de la Parte Florida Mental Health Institute, Research and Training Center for Children’s Mental Health.
- Leaf, P. J., Alegria, M., Cohen, P., Goodman, S. H., Horwitz, S. M., Hoven, C. W., Narrow, W. E., Vaden-Kiernan, M., & Regier, D. A. (1996). Mental health service use in the community and schools: Results from the four-county MECA study. *Journal of the American Academy of Child and Adolescent Psychiatry, 35*, 889-897.
- Lonigan, C. J., Elbert, J. C., Johnson, S. B. (1998). Empirically supported psychosocial interventions for children: An overview. *Journal of Clinical Child Psychology, 27*, 138-145.
- Santisteban, D. A., Szapocznik, J., Perez-Vidal, A., Kuartines, W. M., Murray, E. J., & Laperriere, A. (1996). Efficacy of intervention for engaging youth and families into treatment and some variables that may contribute to differential effectiveness. *Journal of Family Psychology, 10*, 35-44.
- Unger, D., & Powell, D. (1992). Families as nurturing systems: An introduction in prevention. *Human Services, 9*(1), 1990.
- Weisz, J. R., & Hawley, K. M. (1998). Finding, evaluating, refining, and applying empirically supported treatments for children and adolescents. *Journal of Clinical Child Psychology, 27*, 206-216.

Parent Impressions of a County Mental Health Service Delivery System for Children

Heather Ringeisen, Robert Friedman & Gail Stearns

Introduction

Treatment underutilization and high dropout rates are two major obstacles to children's mental health service delivery. It is estimated that 70% of children in need of treatment in the United States receive no mental health services (US Congress Office of Technology Assessment, 1991). Furthermore, it is estimated that between 40-60% of families who begin mental health treatment terminate prematurely (Kazdin, 1996). Thus, many children who need services do not get them, and high rates of attrition in those who do pursue treatment further limit care delivery. Research indicates several factors that predict child and adolescent dropout, such as low socioeconomic status, minority group membership, single parent marital status, and high family stress or difficulties (see Armbruster & Fallon, 1994; Wierzbicki & Pekarik, 1993). However, these broad factors shed little light on why families prematurely terminate services or what might be done to make services more engaging. Few studies directly ask parents as to why they did not seek treatment services or why they terminated prematurely.

The issues of service utilization and dropout become particularly important as children's mental health research begins to examine empirically-validated treatments¹. Empirically validated child treatments find their primary support in clinical trials research, which are most often conducted in highly controlled university/medical settings for nonreferred, non-comorbid populations (Lonigan, Elbert, & Johnson, 1998). Within these settings, treatment efficacy can be evaluated without extensive concerns for service system utilization. Furthermore, families who drop out of treatment are often not factored into outcomes analyses. Further, some authors have suggested that clinical trials research provides little guidance for direct clinical practice (e.g., Goldfried & Wolfe, 1996).

In an attempt to increase generalizability, studies examining treatment effectiveness in real world settings are needed to supplement the existing clinical trials. Parents, as consumers, have critical information concerning treatment effectiveness; however, when assessed, they are typically given a Likert-scale treatment satisfaction questionnaire. These questionnaires invariably demonstrate positive results (Lebow, 1982) and tend to assess only treatment satisfaction, as opposed to dissatisfaction. Satisfaction questionnaires typically fail to acquire detailed information from parents about service effectiveness. As researchers continue to examine how to best aid the families of children with emotional or behavioral disorders, it seems to suggest the need for direct consultation with parents about service helpfulness and barriers to treatment (e.g., Coleman & Collins, 1997; Frese, 1996; Garland & Besinger, 1996; Kazdin et al., 1996; Shilts, Rambo, & Hernandez, 1997). The current study uses a focus group methodology to assess parent impressions of their local mental health service delivery system for children.

Method

A two-person facilitator team conducted five focus groups. Participants were recruited through a mailing sent by the local chapter of the Federation for Families (a parent advocacy group for children with mental illness), flyers posted in area community mental health centers, and letters sent home with students identified by the school system as emotionally handicapped (EH) or seriously emotionally disturbed (SED). A total of 42 parents participated in the focus groups. Parents were predominately female (93%) and five of these women were grandmothers. Fifty-nine percent of the parents were Caucasian, followed by 29% African American, and 12% Hispanic.

1 Author Notes: See (1998) Journal of Clinical Child Psychology, 27(2), for more information about empirically-validated treatments.

Findings and Conclusions

Parents reported having used a variety of mental health services in the county (Hillsborough County, Florida) for their children: 64% of their children were in EH or SED classrooms; 85% of families had participated in counseling; 81% had consulted medical practitioners; 38% of children had received residential treatment; and five children had been hospitalized in a psychiatric facility two or more times. On the average, participating parents reported that their child had been first diagnosed with some emotional or behavior problem at six years of age. Parents appeared to have sought early intervention for their children and utilized multiple services across professional domains.

Based upon focus group findings, seven conclusions and recommendations are made to the program administrators. First, school is very important to these parents. School-related topics often dominated focus group discussions; there seemed to be nothing as frustrating, or potentially rewarding, as their child’s education. It seems clear that systems-of-care initiatives cannot effectively serve children with emotional disturbances without a special focus on schools.

Second, parents appreciated accessible, flexible services that included the whole family in treatment, and they did not want to wait months to receive these services. Systems-of-care initiatives need to build upon the services that parents like, by expanding or enhancing the availability of existing programs.

Third, parents wanted correct, relevant information about their child’s problems and appropriate referral sources for them. Parents reported that this information helped to coordinate their child’s care across service providers; referral information should include service eligibility, geographic limitations, and insurance coverage/fee information.

Participant responses also confirmed that several children experience problems, or are initially referred for mental health services, when they enter school. In addition, because many participants’ children had characteristics consistent with Attention-deficit/Hyperactivity Disorder (ADHD), systems-of-care initiatives should work to identify these children and help them get a good start. A child-development center that specializes in ADHD-related child behavior problems for the general public might be helpful.

Fifth, mental health services are expensive for parents, and particularly for children with chronic mental illnesses. Often parents cannot afford insurance, or needed services are not covered by their insurance plan. By increasing the amount of flexible funds, systems-of-care initiatives could help fill in insurance coverage gaps.

Perhaps the clearest finding of this study is that parents are under a great deal of stress and that efforts to alleviate this stress are not going to be simple. Systems-of-care initiatives should consider a broad array of culturally competent service options that might include supervised family recreational activities, specialized before- and after-school care, transportation, summer camps, trained child mentors, or parent-run support groups that include child activities.

Finally, parents often sensed that their child’s care lacked continuity across service delivery systems (e.g., school and out-of-school, residential and community-based) and service professionals. Systems-of-care initiatives should support parent advocates or care coordinators to work collaboratively with families across service delivery systems and treatment professionals.

Findings from the current study also suggest that: (a) personal characteristics among service providers are as important, if not more important, to parents than professional qualifications; (b) factors which may play a role in treatment drop out, treatment underutilization, and/or service system failures include not knowing where to go for help, lack of appropriate consumer information, a lengthy wait list, transportation difficulties, and poor aftercare services; and (c) parents recognize that mental health treatment for their children is a multi-faceted process involving at the very least doctors, schools, and traditional mental health care providers. In addition, it seems important that mental health service research look at the combined efficacy of medical, school, and out-of-school interventions, as well as their coordination. This research could supplement those studies of singular treatment effectiveness and facilitate the multi-intervention model, which parents suggest is helpful.

References

- Armbruster, P., & Fallon, T. (1994). Clinical, sociodemographic, and systems risk factors for attrition in a children's mental health clinic. *American Journal of Orthopsychiatry*, *64*, 577-585.
- Coleman, H., & Collins, D. (1997). The voices of parents: A qualitative study of a family preservation program. *Child and Youth Care Forum*, *26*, 261-278.
- Frese, C. (1996). *Parents and adolescences' experiences in family therapy: A qualitative study*. Unpublished (master's thesis) manuscript. Texas Women's University at Denton.
- Garland, A. F., & Besinger, B. A. (1996). Adolescents' perceptions of outpatient mental health services. *Journal of Child and Family Studies*, *5*, 335-375.
- Goldfried, M. R., & Wolfe, B. E. (1996). Psychotherapy practice and research: Repairing a strained relationship. *American Psychologist*, *51*, 1007-1016.
- Kazdin, A. E. (1996). Dropping out of child therapy: Issues for research and implications for practice. *Clinical Child Psychology and Psychiatry*, *1*, 133-156.
- Kazdin, A. E., Holland, L., & Crowley, M. (1997). Family experience of barriers to treatment and premature termination from child therapy. *Journal of Consulting and Clinical Psychology*, *65*, 453-463.
- Lebow, J. (1982). Consumer satisfaction with mental health treatment. *Psychological Bulletin*, *91*, 244-259.
- Lonigan, C. J., Elbert, J. C., & Johnson, S. B. (1998). Empirically supported psychosocial interventions for children: An overview. *Journal of Clinical Child Psychology*, *27*, 138-145.
- Shilts, L., Rambo, A., & Hernandez, L. (1997). Clients helping therapists find solutions to their therapy. *Contemporary Family Therapy*, *18*, 117-132.
- U.S. Congress, Office of Technology Assessment. (1991). *Adolescent Health* (OTA-H-468). Washington, DC: U.S. Government Printing Office.
- Wierzbicki, M. & Pekarik, G. (1993). A meta-analysis of psychotherapy dropout. *Professional Psychology: Research and Practice*, *24*, 190-195.

Symposium Discussion

Trina W. Osher

The studies presented in this symposium illustrate the power of family voices and the critically important information they provide to not only supplement, but also explain, quantitative findings. Numbers are not enough, and neither are family stories. Both are necessary if we are to learn whatever “truth” is out there about mental health services for children with serious emotional disabilities and their families. Families and formally trained researchers need to team up to find this “truth,” to document it, and to talk about it with policy makers, service providers, families and others involved in providing services and supports to children and their families.

From these studies we see that satisfaction questionnaires typically fail to acquire detailed information from parents about service effectiveness. Direct consultation with parents about service helpfulness and barriers to treatment are suggested. The research suggests that personal characteristics among service providers are as important, if not more important, to parents than professional qualifications. Findings from the SSI Impact Study also suggest that existing policies regarding funding mechanisms should pay for services and supports that families say make them stronger and healthier. Findings reinforce the need for basic services—food, shelter, transportation, employment, medical care—and that without a foundation to support survival, families and their children will not be able to participate in or benefit from mental health treatments, evidence-based or otherwise. Findings from the Family Experience Study show no defined mental health system through which families can access services, and often these families go into debt in order to receive services. In addition, the study found that families’ experiences at intake were pivotal to service continuation. Further, parents reported that support from advocacy groups was key to understanding their child’s mental health problems.

These studies suggest that the mental health services research community should look at the combined efficacy of medical, school, and out-of-school interventions, as well as their coordination efforts to facilitate a multi-intervention treatment model.

CONTRIBUTING AUTHORS

Tommy Burrus, M.A.

Department of Child and Family Studies, Louis de la Parte Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Blvd., Tampa, FL 33612, 813-974-4651, fax: 813-974-7563, e-mail: burrus@fmhi.usf.edu

Ricardo Contreras, M.A.

Department of Child and Family Studies, Louis de la Parte Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Blvd., Tampa, FL 33612, 813-974-4598, fax: 813-974-7563.

Maridelys Detres, M.S.

Healthy Start, 7709 Hinsdale Dr., Tampa, FL 33615, 813 978-8772, e-mail: mdetres@hotmail.com

Robert M. Friedman, Ph.D.

Department of Child and Family Studies, Louis de la Parte Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Blvd., Tampa, FL 33612, 813-974-4640, fax: 813-974-7743, e-mail: rfriedman@fmhi.usf.edu

Sharon Lardieri, M.S.W.

Division of Applied Research & Educational Support, Louis de la Parte Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Blvd., Tampa, FL 33612, 813-974-4612, fax: 813-974-7376, e-mail: lardieri@fmhi.usf.edu

Katherine Lazear, M.A.

Project Director, Department of Child and Family Studies, Louis de la Parte Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Blvd., Tampa, FL 33612, 202-334-2412, fax: 202-333-8217, e-mail: lazear@fmhi.usf.edu

Trina W. Osher, M.A.

Coordinator of Policy and Research, Federation of Families for Children's Mental Health, 1101 King Street, Alexandria, VA 22314, 703-684-7710, e-mail: tosher3@comcast.net

Heather Ringeisen, Ph.D.

Child and Adolescent Services, National Institute of Mental Health, 6001 Executive Blvd., NSC 7146-9631, Bethesda, MD 20892, 301-496-7227, fax: 301-443-4045, e-mail: bringeis@mail.nih.gov

Joko Sengova, M.A.

Department of Child and Family Studies, Louis de la Parte Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Blvd., Tampa, FL 33612, 813-974-4686, fax: 813-974-7563, e-mail: sengova@fmhi.usf.edu

Gail Stearns, M.S.W.

Department of Special Education, University of South Florida, 4202 E. Fowler Avenue, Tampa, FL 33620, e-mail: stearns@usf.edu

Janice Worthington, M.S.

Department of Child and Family Studies, Louis de la Parte Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Blvd., Tampa, FL 33612, 813-974-6135, fax: 813-974-7376.

PEARL: Lessons Learned from Collaboratively Delivering Mental Health Services in Early Childhood Settings

**P Antonio Olmos
Mary Grimmer**

Acknowledgements: This research was partly funded by the Colorado Department of Human Services, Division of Mental Health, and a three-year grant from the U.S. Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation (ASPE).

Introduction

Modeled after the type of interventions that Knitzer (2001) identified as best-practice in a system to support the healthy emotional development of young children, PEARL is an early childhood program delivering mental health services in early learning environments throughout the city of Denver, Colorado and the surrounding county. Our Mission is to increase support to children and their caregivers by: (1) facilitating early identification of children's mental health needs, (2) promoting positive developmental growth, and (3) reducing multi-system involvement.

PEARL work is accomplished by partnering with parents and care providers to model and promote emotional well-being and the development of healthy interpersonal relationships. PEARL goals are: (a) to promote the social and emotional development of children in child care; (b) to build upon and support the competencies of parents and child care providers; (c) to foster positive relationships between child care providers, families and children; and (d) to improve the overall quality of child care.

The PEARL approach. PEARL clinicians are trained in a vast number of promotion, prevention and early intervention techniques including: support and educational opportunities for parents and care providers, consultation and technical assistance for care providers and, assessment and treatment of children and their families. From this menu of techniques, PEARL clinicians deliver services that are truly tailored to the specific needs of children, families and providers. PEARL clinicians are trained to ensure that four key elements identified by Knitzer (2001) drive the service delivery:

- Grounded on developmental knowledge and encourage the development of supports designed to foster healthy relationships among children and those who care for them (i.e., caregivers and childcare providers).
- Help to strengthen the family's ability to meet the child's emotional needs.
- Provided in settings that are more comfortable to children and the people they trust, like Head Start centers, childcare or preschool programs.
- Responsive to the ethnic and cultural strengths and customs of the community where children live.

Method

The data presented includes children tracked for the last three years of service ($N = 202$). However, due to the mobility of our population, some of the analyses have lower numbers ($n = 168$; analyses were also run for children with complete data only, and the direction and significance of the results did not change). Table 1 presents basic demographics for the population. For the Regression Discontinuity analysis, we also collected data from 158 children that served as control group (see below). The time frame for the pre-measure was the first month in the school year (i.e., September-October) and the time frame for the post-measure was always the end of the academic year (i.e., May). Measures used included: (a) the Colorado Client Assessment Record (CCAR; Ellis, Wackwitz, & Foster, 1991); (b) a modified version of the Family Empowerment Scale (Koren, DeChillo, & Friesen, 1992); and (c) the Devereux Early Childhood Assessment (DECA; LeBuffe & Naglieri, 1999).

Table 1
Demographics for the
Children Receiving PEARL Services

Age range	%
Between 1 and 3 years	16.129
Between 3 and 5 years	67.097
Between 5 and 6 years	9.032
Between 6 and 8 years	5.161
8 and older	1.935
Gender	%
Male	60.645
Female	39.355
Race/Ethnicity	%
American Indian	0.645
White non-Hispanic	20.645
African American	29.032
Hispanic	39.355
Multi-racial	10.323
Family income	%
\$0 - \$4,999.99	51.613
\$5,000.00 - \$9,999.00	2.581
\$10,000.00 - \$14,999.00	9.032
\$15,000.00 - \$19,999.00	5.806
\$20,000.00 - \$24,999.00	9.677
More than \$25,000.00	21.290

Results

Risk Factors. As families experience an increase in risk factors, the possibility of their children experiencing psychiatric disorders and other negative outcomes also increases (Rutter, 1979). It has been shown that children with 3+ risk factors are at high risk for negative adolescent/adult outcomes, as well as having more learning difficulties. Through its risk factors interview, PEARL found that about 37.6 % of the PEARL families report 3+ risk factors. Furthermore, using the CCAR and an algorithm developed by Colorado Mental Health Services to identify serious emotional disturbance (SED) in children, over 9% of the PEARL children warranted the SED designation before they received a clinical diagnosis.

Family Empowerment. During the initial evaluation, one of the major objectives reported by center staff and parents was to “help parents know what resources are available and know how to access them” (MHCD, 1999, p. 15). Based on a modified version of the Family Empowerment Scale, families served by PEARL showed significant increases in their pre-post intervention sense of empowerment in several domains (Acting Upon Children’s needs, $t(170) = -2.761, p < 0.05$; Efficacy as Parent, $t(170) = -1.797, p = 0.07$; Overall Empowerment, $t(170) = -2.32, p < 0.05$).

Social-emotional behavior. Major changes in social-emotional behavior have been demonstrated using converging sources of evidence. Using the CCAR, a comparison against a matched sample drawn from the mental health centers in Colorado showed that children receiving PEARL services have better outcomes after one year than children receiving services at mental health centers across the state (Center for Human Investment Policy, 2003). Additionally, using the DECA, it was shown that both parents and teachers see a significant improvement in the children’s Total Protective Factors (TPF; Teachers: $t(173) = -2.32, p < 0.05$; Parents: $t(167) = -2.93, p < 0.01$) and Behavioral Concerns (BC; Teachers: $t(173) = 3.51, p < 0.01$; Parents: $t(64) = 2.88, p < 0.01$). Also, using DECA scores, it was hypothesized that all things being equal, children with higher BC (i.e., more behavioral concerns) are more protected if they also have high a TPF score than if they do not. Therefore, a system that combines BC and TPF was developed. In a comparison from pre- to post-intervention, it was found that for parents, 81.55% of the children improved or stayed the same. For teachers, 85.05% of the children improved or stayed the same (see Table 2).

Table 2
Level of Improvement from PRE to POST Intervention by Rater

Rater	Improvement	No Change	Worsen
Parents	41.67%	39.88%	18.45%
Teachers	34.48%	50.57%	14.94%

Although research designs where clients can be randomly assigned to control and treatment are considered gold standard in research, from an ethical point of view this approach may prevent clients in from receiving a needed treatment that could be even life saving. Due to these concerns, we used a Regression Discontinuity (RD) design (Campbell & Stanley, 1966; Trochim, 1990) with the

teacher's DECA scores rather than random assignment. In an RD design, the severity of the children's social-emotional behavior is measured before and after treatment. Based on severity scores at pre-test, children are assigned to control (low) or treatment (high) groups to ascertain whether a change has occurred in the treatment group in comparison to the control.

Using DECA scores, we assigned children to control ($n = 158$) and treatment ($n = 174$) groups. As shown in Figure 1, for TPF, the regression model was significant, $F(3,328) = 219.172, p < 0.01, R^2 = 0.67$. The group effect was significant, $t(328) = -17.011, p < 0.01$, with the PEARL scores being higher (broken line) than the control (continuous line). Similarly, the Group X Pretest interaction was significant, $t(328) = 15.722, p < 0.01$, with the PEARL children making higher gains in TPF than the control. For BC, the regression model was significant, $F(3,328) = 204.042, p < 0.01, R^2 = 65\%$ (see Figure 2). The group effect was significant, $t(328) = -11.559, p < 0.01$, with the PEARL scores being higher (broken line) than the control (continuous line). The Group X Pretest interaction was also significant, $t(328) = 13.283, p < 0.01$, with the PEARL children showing a decrease in concerns though still being slightly higher than the control.

Figure 1
Regression Discontinuity Design
Total Protective Factors

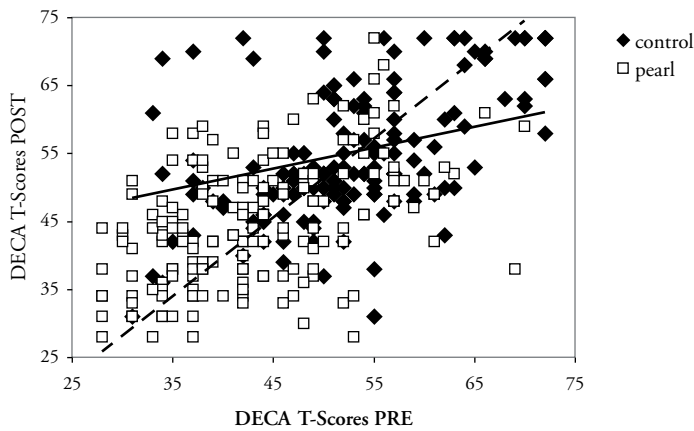
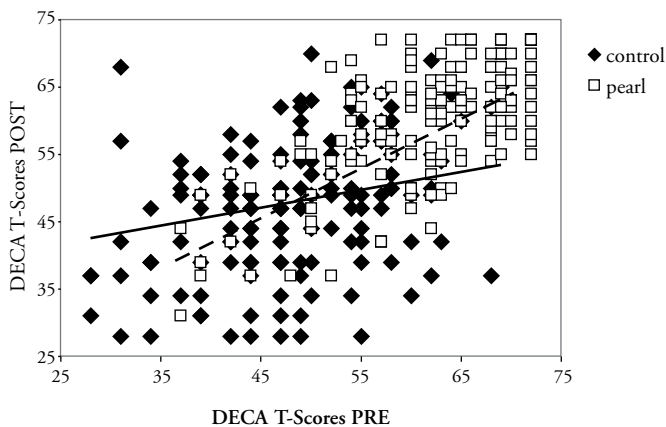


Figure 2
Regression Discontinuity Design
Behavioral Concerns



Impact on Teachers. Based on in-depth interviews and focus groups with teachers and administrators, we found that interaction with PEARL helped providers feel more competent addressing a range of children's social and emotional needs; they also feel less stressed-out, thus reducing burnout and turnover.

Cost-effective services. PEARL has demonstrated that it provides efficient services. A Cost of Failure study conducted in 2001 (Center for Human Investment Policy, 2001) showed that the money spent for one year of PEARL services will pay for itself if: (a) four children avoid the average two-month psychiatric hospitalization, or (b) 11 children avoid one year in special education and 10 children avoid the average six months in foster care, or (c) two children avoid the average two years in detention for delinquency and one family avoids TANF for the average two years.

Discussion/Conclusion

In her seminal paper, Knitzer (2001) concludes that to “improve the social and emotional well-being of children and families by strengthening relationships with caregivers and promoting age-appropriate social and emotional skills (p .9),” the following strategies have to be achieved:

Enhance emotional and behavioral well-being of infants, toddlers and preschoolers to promote early childhood success. According to the CCAR analysis, PEARL's children showed greater improvement compared to children receiving mental health services in other settings. Furthermore, according to parents and teachers using the DECA, children improved in TPF and BC. Finally, compared to an RD-control group, PEARL children showed higher gains in TPF, and a deceleration in BC.

Help parents be more effective nurturers. After PEARL's intervention, parents reported an increased sense of empowerment. This finding may mean that parents had: (a) received better knowledge regarding appropriate developmental expectations for their children, (b) become better able to deal with behavior problems at home, and (c) acquired a greater range of discipline options.

Expand the competencies of non-familial caregivers (like Head-start and Early-Head-Start staff) to prevent and address problems. Care providers reported that PEARL has positively influenced and supported them by providing individually tailored services to address a range of children's social and emotional needs, and by relieving some of the teachers' stress in order to reduce burnout and turnover.

Ensure that the more seriously troubled young children get appropriate help. PEARL has demonstrated its ability to identify (37% with 3+ risk factors) and intervene early with the children more at-risk. Using the algorithm developed by the Colorado Mental Health Services, about 10% of these children were identified as having a serious emotional disturbance before referral.

Lessons Learned

Through our work with PEARL sites, their children and families, we have learned several important lessons: (a) early intervention services delivered on site at childcare and Head-Start centers can foster social, emotional and behavioral improvement for many children; (b) staff and parent child development training and consultation leads to an increase in behavior management knowledge and skills, and increased feelings of empowerment; (c) PEARL services have proven to be most effective at supporting children who are most at-risk; and (d) when early intervention and prevention services are delivered in collaboration with early childhood education and childcare centers, families have easier access and are more likely to respond to treatment resources. In addition, at-risk behaviors are more likely to be identified early when the child is in his or her natural environment.

References

- Campbell, D. T., Stanley, J.C. (1966) *Experimental and quasi-experimental designs for research*. Chicago: Rand McNally & Company.
- Center for Human Investment Policy (2001). *Cost of failure study: Report to Colorado Mental Health Services*. Denver: Graduate School of Public Affairs at the University of Colorado at Denver.
- Center for Human Investment Policy (2002). *Early mental health intervention pilot program for Colorado 2000-2001 report to the legislature*. Denver: Graduate School of Public Affairs at the University of Colorado at Denver.
- Ellis, R. H., Wackwitz, J. H., & Foster, M. (1991) Use of an empirically derived client topology based on level-of-functioning: Twelve years of the CCAR. *Journal of Mental Health Administration*, 18, 88-100.
- Knitzer, J. (2001). *Building services and systems to support the healthy emotional development of young children. An action guide for policymakers*. NY: National Center for Children in Poverty, Columbia University.
- Koren, P. E., DeChillo, N. & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology*, 305-312.
- LeBuffe, P. A., Naglieri, J. A. (1999). *Devereux Early Childhood Assessment Technical Program*. Lewisville, NC: Kaplan Press.
- Mental Health Corporation of Denver (1999). *Twelfth Month Update. Parent Empowerment Alternatives with Resources and Learning (PEARL)*.
- Rutter, M. (1979). Protective factors in children's responses to stress and disadvantage. In J. S. Bruner & A. Garten (Eds.), *Primary prevention of psychopathology* (Vol. 3, pp. 49-74). Hanover, NH: University Press of New England.
- Trochim, W. M. K. (1990). The regression discontinuity design. In: L. Sechrest, E. Perrin, J. Bunker (Eds): *Research methodology: Strengthening causal interpretations of non-experimental data*. AHCPR conference proceedings. Rockville, MD: U.S. Dept. of Health and Human Services, Public Health Service, Agency for Health Care Policy and Research.

CONTRIBUTING AUTHORS

P. Antonio Olmos, Ph.D.

*Co-Principal Investigator, 303-504-6661, fax: 303-757-5245,
e-mail: aolmos@mhcd.com*

Mary Grimmer, L.C.S.W.

*Co-Principal Investigator, 303-504-6522, fax: 303-759-4322,
e-mail: mgrimmer@mhcd.com,*

*Both authors: The Mental Health Corporation of Denver,
4141 E. Dickenson place, Denver, CO 80222*

Symposium

Paying Attention to Parent Mental Illness: Challenges and Opportunities for Systems of Care

Symposium Introduction

Joanne Nicholson

The majority of adults with mental illness are parents and the majority of children with serious emotional disturbance (SED) have a family history of mental illness or substance abuse. The population with overlapping child and parent mental health problems is at risk for poor outcomes and is likely to present unique challenges to policy makers, and providers. Identifying this substantial subgroup therefore, is critical to the development of effective systems of care for children and adults.

This symposium examined the issue of parents with mental illness from several perspectives. First, secondary analyses of data from the National Comorbidity Study, and the National Evaluation of the Comprehensive Community Mental Health Services for Children and Families Program (CCMHS) respectively, revealed the prevalence of parenthood among adults with mental illness, and the prevalence of mental health and substance abuse problems among families of children with SED. Data from the National Evaluation of CCMHS were also analyzed to examine differences on demographic and risk factors between children with SED whose families reported mental health and substance abuse problems, and those who did not.

Second, local and state initiatives to address the issue of parents with mental illness within both the adult and child mental health sectors in the Commonwealth of Massachusetts were presented. Together, the four presentations comprising this symposium emphasized the scope and complexity of the problem, and the need for family-centered services that require a degree of integration across child and adult service sectors that has yet to be achieved.

The Prevalence of Parental Mental Illness: National Data and Implications

Joanne Nicholson

Introduction

United States Census Bureau data indicate that the majority of American women and men are parents. Every year, 22% of the American population is affected by psychiatric disorder. Until recently, there were no national data on the prevalence of parenthood among adults affected by mental illness, or on the prevalence of children affected by parent mental illness. Prevalence data are important for understanding the scope of the problem, accurate assessment of the need for interventions and services, and the development and implementation of appropriate and effective interventions. Prevalence data are also critical for persuading providers, policy makers and administrators of the significance of the issue, and the need for appropriate policy and practice guidelines.

The current study examined prevalence of parent mental illness among participants in the National Comorbidity Study (NCS; Kessler, 1994). Results of this study will be presented and discussed with respect to convergent data on the prevalence of parental mental illness among families participating in children's systems of care developed through the federal Comprehensive Community Mental Health Services for Children and their families Program (CCMHS; Center for Mental Health Services, 1999). Avenues for addressing the needs of this population at the policy and practice level will be highlighted.

Chair

Joanne Nicholson

Discussant

Judy Katz-Leavy

Authors

Joanne Nicholson

Betsy Hinden et al.

Kathleen Biebel

Joan Mikula

The current study presents initial results from a larger study examining distinguishing characteristics, service use, service satisfaction and outcomes for families with overlapping child and parent mental health problems participating in the National Evaluation study of the CCMHS. Current results reflect examination of differences for the study population on demographic characteristics, and risk factors, using secondary analyses of data from the National Evaluation of CCMHS.

Methods

Analyses were conducted using data from the 5,877 respondents aged 15-54 years in the Part II sub-sample of the NCS. Designed to assess the prevalence and correlates of DSM-III-R disorders, this survey was administered from 1990 to 1992 to a nationally representative household sample of non-institutionalized, civilian persons in the 48 contiguous states.

Parenthood was defined as having biological 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 considered non-parents. To reflect the notion that parenthood is a *longitudinal* rather than *cross-sectional* experience (i.e., occurring across years rather than in just one), lifetime prevalence of mental illness was selected for most analyses.

Respondents were classified as having severe and persistent mental illness (SPMI) according to criteria set by Kessler et al. (1996). These criteria included: (a) 12-month prevalence of mania, bipolar disorder or non-affective psychosis (includes schizophrenia, schizoaffective disorder, and other psychotic disorders not accompanied by changes in mood); or (b) lifetime prevalence of mania or psychosis with treatment within the past year; or (c) 12-month prevalence of depression or panic disorder treated with medication and/or hospitalization.

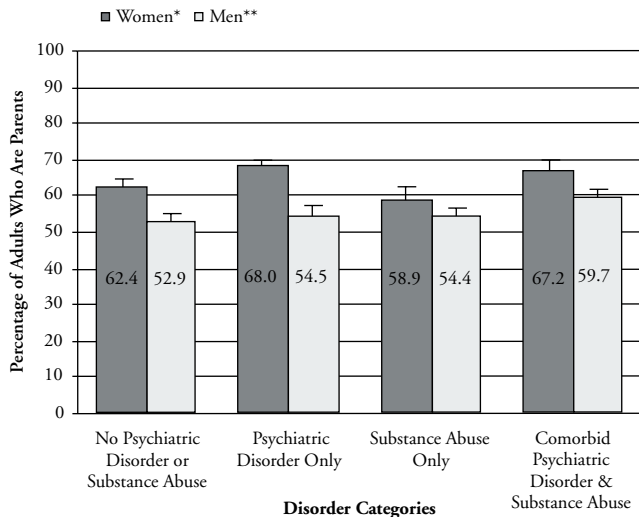
All of the estimates presented here have been weighted, and their associated standard errors have been generated using version 8.0 of the SUDAAN statistical package (Research Triangle Institute, 2001). Comparisons between rates of different groups were made using *t*-tests performed by SUDAAN.

Results

Using the four broad, exclusive and exhaustive categories of (1) no psychiatric disorder or substance abuse, (2) psychiatric disorder only, (3) substance abuse only, and (4) comorbid psychiatric disorder and substance abuse, results indicated that adults with psychiatric disorders or with co-occurring psychiatric disorders and substance abuse were as likely or more likely, to be parents than those who do not meet criteria for psychiatric disorder or substance abuse (see Figure 1). In only one case is the prevalence of parenthood in a disorder category less than the prevalence in the no disorder category, and that is the prevalence of motherhood in the substance abuse only category. Sixty-eight percent of the female respondents with a lifetime prevalence of any psychiatric disorder were mothers, a proportion which was significantly greater ($p < .05$) than the proportion of women with no psychiatric disorder or substance abuse who were mothers. Slightly more than half men (57%) with a lifetime prevalence of any psychiatric disorder were 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.

Similar analyses were performed with the SPMI group, a group often considered to be least likely to have children (Nicholson, Nason, Calabresi & Yando, 1999). Similar to the population with any psychiatric disorder, an equal or greater percentage of adults meeting criteria for SPMI in the previous 12 months were parents than were individuals without psychiatric disorders. As displayed in Figure 2, just over sixty-seven percent (67.2%) of the women with SPMI were mothers; 75.5% of the men with SPMI were fathers. Men with SPMI were significantly more likely to be fathers than men with no psychiatric disorder or substance abuse ($p = .000$). Kessler and colleagues indicated in early reports that nearly 50% of NCS respondents reported at least one lifetime disorder, and close to 30% reported at least one 12-month disorder (Kessler et al., 1994).

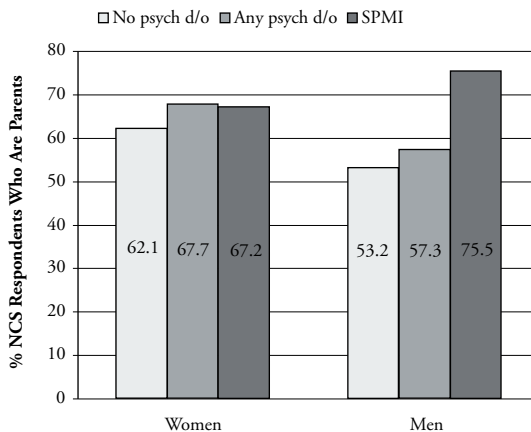
Figure 1
Prevalence of Parenthood Among NCS Respondents



*All standard errors < 3.9

** All standard errors < 3.0

Figure 2
Prevalence of Parenthood Among NCS Respondents



Prevalence for parenthood was also compared across diagnostic categories. As shown in Table 1, prevalence of parenthood was highest for both men and women among respondents who met criteria for diagnosis in the post-traumatic stress disorder category (women 72.8%, men 67.9%), and lowest (women 61.8%, men 55.2 %) among those in the non-affective psychosis category (includes schizophrenia, schizoaffective disorder, and other psychotic disorders not accompanied by changes in mood). About two-thirds of the women who met criteria for an affective diagnosis (includes bipolar disorder type I, major depression, and dysthymia), or an anxiety disorder (includes agoraphobia, panic disorder, generalized anxiety disorder, simple phobias, and social phobia) were parents. A little over half of the men in these disorder categories were parents (58.0% and 56.4%, respectively).

Table 1
Prevalence of Parenthood Among NCS Respondents
Meeting Lifetime Criteria for Psychiatric Disorders

<i>Disorders</i> (<i>UM-CIDI/DSM-III-R</i>)	<i>% of Women in</i> <i>Each Category</i> <i>Who are Mothers</i>	<i>% of Men in</i> <i>Each Category</i> <i>Who are Fathers</i>
	<i>%</i>	<i>%</i>
Affective Disorder	66.8	58.0
Anxiety Disorder	68.2	56.4
Post Traumatic Stress Disorder	72.8	67.9
Nonaffective Psychosis	61.8	55.2

Discussion

The majority of American women and men who meet criteria for mental illness over the course of their lifetime are parents. This is also true for those who meet criteria for severe and persistent mental illness. Clearly, parenthood is a prevalent phenomenon among American adults with mental illness, and a phenomenon with important implications for children, families and the mental health systems and providers that serve them. Families in which a parent has a mental illness are also likely to be families in which a child has an emotional or behavioral problem. Data from the National Evaluation of the Comprehensive Community Mental Health Services for Children and Families Program (CCMHS; Center for Mental Health Services, 1999), a federal initiative to support systems of care for children with the most serious emotional and behavioral disturbances, documents the substantial overlap of families in which a parent has psychiatric condition, and families in which a child has a serious emotional disturbance. Figure 3 reveals that 61 percent of the families receiving children’s services through CCMHSP across the United States have a family member with a history of substance abuse, 45% have a family member with a history of mental illness, and 18% have a parent who has experienced a psychiatric hospitalization.

Thus, families in which a parent has a mental illness are likely to be families that utilize multiple services across both *child and adult* service sectors, a phenomenon with strong implications for research, policy and practice at the global and local level. In particular, the phenomenon of overlapping parent and child mental health problems underscores the need for integration and cross-training across child and parent sectors, as well as across agencies. In addition, the prevalence data presented here in combination with those from CCMHS, clearly indicate the need for increased knowledge and understanding of this sizable subgroup and the development of appropriate and potentially specialized services. 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.

References

- Center for Mental Health Services (1999). Annual report to Congress on the Evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program, 1999, Atlanta, GA: Macro International Inc.
- Kessler, R. C. (1994). The National Comorbidity Survey of the United States. *International Review of Psychiatry*, 6(4), 365-376.

- Kessler, R. C., Berglund, P. A., Zhao, S., Leaf, P. J., Kouzis, A., Bruce, M. L., Friedman, R. M., et al. (1996). The 12-month prevalence and correlates of serious mental illness (SMI). In R. W. Manderscheid and M. J. Henderson (Eds.), *Mental Health United States, 1996*. Rockville: U. S. Department of Health and Human Services, Center for Mental Health Services.
- Kessler, R.C., McGonagle, K.A., Zhao, S., Nelson, C.B., Huges, M., Eshleman, S., Wittchen, H-U., Kendler, K.S. (1994). Lifetime and 12-month prevalence of DSM-III-R psychiatric disorders in the United States. Results from the National Comorbidity Survey. *Archives of General Psychiatry, 51*, 8-19.
- Nicholson, J., Nason, M., Calabresi, A., & Yando, R. (1999). Fathers with severe mental illness: Characteristics and comparisons. *American Journal of Orthopsychiatry, 69*(1), 134-141.
- Research Triangle Institute (2001). *SUDAAN User's Manual, Release 8.0, Vols. I and II*. Research Triangle Park, NC: Research Triangle Institute

Do Family Mental Illness and Substance Abuse Matter? Examination of Data from the National Evaluation of the Systems of Care

Betsy Hinden, Valerie Williams, Bernice Fernandes & Ranilo Laygo

Acknowledgments: This work was produced under contract for the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services (CMHS-contract # 280-02-0101).

Introduction

The majority of adults with mental illness are parents (Nicholson et al., 2004), and the majority of children with the most serious emotional disturbances have a family history of mental illness and/or substance abuse (ORC Macro, 2002a, 2002b). Identification of this subgroup of families in which both children and parents have behavioral health disorders may have important implications for children's systems of care with respect to services, outcomes and evaluation. For example, parent and child psychological functioning is transactional. Parent mental illness is associated with critical deficits in parenting (Goodman & Gotlib, 1999), and child behavioral disorders are associated with increased stress and symptoms for parents (Hammen, Burge, & Adrian, 1991). Families in which both children and parents have behavioral health disorders may therefore be at risk for poor outcomes, and may require a different array of services than families that do not evidence overlapping disorders.

Failure to identify and distinguish this subgroup can also have important implications for research and evaluation. Child interventions that rely heavily on parent participation, such as systems-of-care, may produce different results for families in which a parent has a mental illness. Failure to identify these families, and test for differences in effects, may seriously confound research findings and interpretation.

The current study presents initial results from a larger study examining families with overlapping child and parent mental health problems participating in the Comprehensive Community Mental Health Services for Children and Families Program (CCMHS). Results reported below reflect secondary analyses of data from the National Evaluation (CMHS, 1999) with respect to differences for the study population on demographic characteristics and risk factors.

Methods

Sample. Analyses were conducted using baseline data from the Descriptive Interview Questionnaire (DIQ) from Phases II and III of the National Evaluation of CCMHS. Collected through September 2003, these data included 16,336 children. Because our interest was centered on the question of family mental illness and substance abuse, only data obtained from respondents who were biological parents were included in the analyses ($n=8,782$ children).

Measures and Analysis. Four survey items served as our source of independent variables: (1) Is there a history of mental illness in the child’s biological family; (2) Has one of the child’s biological parents ever had a previous psychiatric hospitalization; (3) Is there a history of substance abuse in child’s biological family; and (4) Has at least one of child’s biological parents ever received treatment for substance abuse? The two items referring to parents were nested within the family-level items (i.e., only respondents

Table 1
Study Sample by Nine Group

Substance Abuse	Mental Illness		
	No/No	Yes/No	Yes/Yes
No/No	2347	992	356
Yes/No	1052	1151	492
Yes/Yes	827	824	741

who answered *yes* to the family level items were asked the follow-up question about treatment at the parent level). All missing data on these items were considered negative responses (*no*) for the purposes of analysis. Using this information, we generated nine groups representing all possible combinations of the four items (see Table 1). The upper left hand cell in Table 1 presents the number of children whose parents answered *no* on both factors (mental illness and substance abuse) at both levels (family level and parent level).

Dependent variables included demographic variables and child and family risk factors. Demographic variables reflected child age, race, and gender, parent education, and household income. Child risk factors included whether the child had ever: been physically abused, sexually abused (or sexually abused others), previously hospitalized, ran away, or attempted suicide. Family risk factors included whether the child’s biological parents were ever convicted of a crime, had a history of domestic violence, or had been convicted of a felony. Because the child and family risk factors were dichotomous variables, parameter estimates could be interpreted as percentages.

Data were analyzed using a General Linear Models (GLM) framework. We used the results of the GLM procedures to check for main effects and interactions at the four-item level.

Results

Demographic Characteristics. Results of the GLM analyses indicated significant group differences on age, race, and parent education. Group differences were non-significant ($\alpha=.05$) for gender and income. History of family mental illness was associated with younger age, Caucasian race, and greater parent education. Family substance abuse was also associated with Caucasian race and higher parent education, and parent treatment for substance abuse was associated with older age.

Risk Factors. Table 2 presents the increase in risk for child and family risk factors associated with the four items reflecting family and parent level mental illness and substance abuse. The base rate is presented as a referent, and reflects the percentage of families endorsing each risk factor in the group of families that did not report a history of mental illness or substance abuse at either the family or parent level. For example, for the group of families that did not report the presence of mental illness or substance abuse at the family or parent level, 8.5% reported that their child had been physically abused. A family history of mental illness was associated a 10.6% increase in risk over and above the base rate for this factor. Similarly, a family history of substance abuse was associated with a statistically significant increase in risk (16.0%) over the base rate for this factor. No additional increase in risk was associated with one of the parents ever having had a psychiatric hospitalization or receiving substance abuse treatment.

Parameter estimates presented in Table 2 represent those that had a statistically significant relationship with the risk factors. Group differences were observed on all risk factors except for *child sexually abusive*. Family history of mental illness was associated with increased risk for child physical abuse, child sexual abuse, child previous psychiatric hospitalization, child suicide attempt, domestic violence and parent felony. Parent psychiatric hospitalization was associated with increased risk for child psychiatric hospitalization, child running away, and child suicide attempt. Family history of substance abuse was related to increased risk for all child and family risk factors except child running away and child sexually abusive. Parent

treatment for substance abuse was associated with increased risk for child running away, child drug abuse, and parent felony. Table 2 indicates that the risk associated with family history of substance abuse is greater for every risk factor except child psychiatric hospitalization, and child drug abuse.

Table 2
Child and Family Risk Factors by Mental Illness (MI) and Substance Abuse (SA) Variables

<i>Child Risk Factor</i>	<i>Base Rate*</i>	<i>History of MI in biological family†</i>	<i>One of biological parents ever had psychiatric hospitalization†</i>	<i>History of SA in biological family†</i>	<i>One of biological parents ever received SA treatment†</i>
Child ever physically abused	8.5%	10.6%		16.0%	
Child ever sexually abused	10.0%	9.7%		13.2%	
Child ever had a previous psychiatric hospitalization	16.3%	7.5%	12.8%	7.3%	
Child ever ran away without hi/her caregiver knowing where he/she was	23.4%		5.2%	11.3%	
Child ever attempted suicide	9.2%	3.5%	6.9%	8.9%	
Child have a history of substance abuse	15.8%			5.8%	6.3%
Child ever been sexually abusive to others	3.4%				
<i>Family Risk Factor</i>					
History of domestic violence in child's biological family (but child was not the direct target of the violence)	20.5%	12.0%		25.3%	
Biological parent convicted of crime	16.0%	5.1%		29.9%	15.6%

*Base rate represents the rate in the group in which respondents answered 'no' to all four survey items.

† All estimates are $p < .05$.

Discussion

Results revealed that both demographic characteristics and risk factors were associated with differences on family and parent mental illness and substance abuse. Specifically, group differences were found for age, race, and parent education. Group differences on risk factors were significant for all risk factors except for *child sexually abusive*. The overall pattern of findings indicated that family level problems were more strongly associated with increased risk than parent level, and that family substance abuse history accounted for the greatest risk on all risks except for child history of psychiatric hospitalization, where history of parent psychiatric hospitalization was associated with the greatest risk; and child history of running away, where parent treatment for substance abuse accounted for the highest risk. The increased risk associated with family substance abuse was particularly noteworthy for domestic violence and parent felony. It is also interesting that interaction effects revealed that the co-occurrence of family mental illness and family substance abuse increased risk to a greater degree that would be expected for child run away history, while it increased risk less than expected for child sexual abuse and parent felony.

Together these findings have important implications at both the systems and family level. Although preliminary, results indicate that families with overlapping child and parent behavioral health disorders are different in meaningful ways from other families participating in systems of care. These differences appear to be relevant to policy and services development, and provider training. In particular, systems of care researchers need to think more broadly about serving "families" and develop mechanisms that allow for integration across child and adult service sectors. Providers need to be trained to work with families as a whole, and to consider parent strengths and needs in the development of family teams, and service plans. In addition, strengths-based provider education about adult mental illness and its relationship to parenting will be critical to effective efforts to serve families in which both children and parents have psychiatric conditions.

References

- Center for Mental Health Services (1999). *Annual report to Congress on the Evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program, 1999*, Atlanta, GA: Macro International Inc.
- Goodman, S. H., & Gotlib, I. H. (1999). Risk for psychopathology in the children of depressed mothers: A developmental model for understanding mechanisms of transmission. *Psychological Review, 106*(3), 458-490.
- Nicholson, J., Biebel, K., Katz-Leavy, J., & Williams, V. (2004). The prevalence of parenthood in adults with mental illness: Implications for state and federal policy makers, programs, and providers. In R. W. Manderscheid & M. J. Henderson (Eds.). *Mental health, United States, 2002*. Rockville: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.
- Hammen, C., Burge, D. & Adrian, C. (1991). Timing of mother and child depression in a longitudinal study of children at risk. *Journal of Consulting and Clinical Psychology, 59*(2), 341-345.
- ORC Macro (2002a, April). Aggregate data profile report: Grant communities funded in 1997 and 1998. Unpublished report.
- ORC Macro (2002b, April). Aggregate data profile report: Grant communities funded in 1999 and 2000. Unpublished report.

Addressing the Service Needs of Parents with Mental Illness: Consensus Building and Services Development at the Local Level

Kathleen Biebel

Introduction

Employment Options, a private, non-profit, psychiatric rehabilitation clubhouse has brought together key stakeholders in the community to build consensus on how best to serve families where a parent has a mental illness, highlighting the Invisible Children's Project (ICP) as an exemplary practice. This summary will describe the background, process and outcomes of the SAMHSA-funded Community Action Grant consensus-building project to date. Data from the evaluation of the project will also be presented.

Methods

The model. ICP, a program of the Mental Health Association in Orange County, New York, was founded on the principles that all parents want to be the best parents they can be, and the act of parenting is a significant and potentially healing role for adults with mental illness. The program's focus is on empowering parents with mental illness by assisting them in the creation of a safe and nurturing environment for their children, and supporting efforts to keep the family unit together. In working with families, ICP embraces the following assumptions: parents with mental illness have strengths, families need and deserve support, parents may require services from multiple systems, and children are usually better off with their parents. However, there may be times when a parent is not the best caregiver for his/her child, enhanced parenting leads to enhanced child development, and dependable, consistent relationships between parents and professionals are therapeutic. ICP provides family-centered, strengths-based intensive family case management service. A recent evaluation (Hinden et al., 2002) of ICP indicated that the program was related to successful outcomes for families.

The local service context. Employment Options provides programs in work readiness, employment, education, housing, parenting skills and other necessary support services for adults with mental illness.

Significant numbers of Employment Options' members are parents. In response to the needs of this segment of their membership, Employment Options developed the Family Project to support parents and address concerns specific to families. The Family Project provides parenting education, limited service coordination and advocacy with other delivery systems, and visitation supports for in-home and clubhouse-based contacts between parents and non-custodial children. Community stakeholders indicate, however, that only a small fraction of families living with parental mental illness are seen in the clubhouse setting. While Employment Options has taken a first step toward providing family supports, they serve a small slice of adults and children living with the challenges of parental mental illness, and have limited capacity to coordinate services.

SAMHSA Community Action Grant. In September 2002, Employment Options was awarded a SAMHSA Community Action Grant to work with community stakeholders to plan for the implementation of ICP in the Massachusetts Metro West area. As part of this process, stakeholders were asked to participate in a process evaluation regarding their experiences with building consensus. An evaluator gathered data from stakeholders in various ways including focus groups and evaluation surveys after all planning meetings. While data were still being analyzed at the time of this writing, initial results reflect both the challenges and successes of the process.

Consensus building. The consensus building process began approximately one year ago. Four phases of the process were identified: (1) Planning and education; (2) Strategic assessment and environmental scan; (3) Modification of ICP model; and (4) Sustainability. Phase I involved planning the project, identifying and engaging key stakeholders, and providing education to stakeholders about families living with parental mental illness and the ICP model. Phase II focused on identifying unmet needs, current services, and barriers in the community for parents with mental illness. Key questions were: (a) what are the unmet needs of families in the Metro West area; (b) what are current services for families, and how are these programs similar or different from ICP; (c) who is the target constituency; (d) what trends contribute to the service environment and; (e) what are the challenges and barriers to adopting the ICP model in the Metro West area? In Phase III, stakeholders developed a modification of the ICP program model based on data gathered in Phase II to best meet the needs of families in the local community. The modified ICP model included all the essential ingredients of the original ICP, plus additional foci on non-custodial parents, supervised visitation, parents not served by the public mental health system, and the legal obstacles confronted by parents with mental illness. The consensus building process is currently in Phase IV, identifying and securing funding to create a modified ICP program and increasing awareness of the issues and concerns of families living with parental mental illness.

Results

Challenges. Evaluation data revealed that stakeholders identified five main challenges of the consensus building process: recruiting stakeholders; systems barriers; stigma; political climate; and the consensus building process itself. Stakeholders felt that critical stakeholders were not engaged effectively in the consensus building process. Specifically, missing stakeholders included adult mental health and school administrators, physicians and other health care providers, and representatives from the faith community. It should be noted that these stakeholders expressed interest in the project, but reported being unable to participate due to time constraints. Systems barriers identified included those related to the lack of awareness of parents with mental illness as an important and prevalent population among public sector systems, providers, and advocates; and the lack of funding and service delivery models for families, rather than "identified clients." Stigma was identified as very problematic in that most systems and providers do not recognize that adults with mental illness are having children, are capable of parenting well, and that children are not necessarily at risk solely based on a parent's mental illness. Attending to these concerns would require a paradigm shift in thinking about adults with mental illness and their role as parent. Stakeholders identified the political climate in Massachusetts as volatile, changing, and unstable with regard to the prioritization and funding of mental health services, which made it difficult to move forward and plan for the implementation of an ICP program. Finally, stakeholders were sometimes

frustrated with the consensus building process itself, feeling that it took too long to make decisions, and that the process was cumbersome and inefficient.

Successes. While there were many challenges, stakeholders were clear that great successes were achieved throughout the year. Successes included: identifying champions; engaging new stakeholders; strengthening relationships with existing partners; being poised to be opportunistic; and, collecting new data. Stakeholders, including representatives from the MA behavioral health care provider, children's mental health, child welfare, advocates, providers, researchers, and family members, became champions for the issues of parents with mental illness and ICP. Stakeholders who had not previously been active regarding families living with parental mental illness were now engaged in the process and partnering in efforts to serve families. New and existing relationships between stakeholders were strengthened as they united around the planning and implementation of the ICP model in their community. As part of the consensus building process, written materials and talking points were created so stakeholders could be opportunistic in promoting the issues of parents with mental illness. Stakeholders were able to speak to the issue in various forums, respond to funding opportunities, and to promote the ICP model. Stakeholders indicated that building the capacity to respond in a timely fashion was critical, since opportunities for interventions often happen quickly. Finally, new data were generated during the consensus building process that shed light on the incidence of families living with mental illness. A survey of child welfare workers in the Metro West area indicated that a significant number of children receiving child welfare services had parents who were receiving mental health services. Gathering these data was important for two reasons. First, the planning team now had incidence data about a previously unknown cohort. Second, the process of collecting the data, which involved a high-level child welfare administrator, allowed her to see first hand the scope of the problem.

Discussion

The significance of the SAMHSA Community Action Grant planning process is four-fold. First, stakeholders have participated in a process of building consensus in order to adapt an exemplary model to the specific needs of a community. Second, the consensus building process has generated interest in and educated stakeholders about the unique concerns and circumstances of families where a parent has a mental illness. Third, the consensus building process has provided a forum for stakeholders to collaborate and share their expertise, knowledge, resources and experiences with families in an effort to develop and implement ICP, identify barriers, and consider adaptations. Finally, successful implementation of the ICP model in Metro West MA will provide family-centered, strengths-based services and supports for parents and families.

References

- Hinden, B., Biebel, K., Nicholson, J., & Mehnert, L. (2002). *The Invisible Children's Project: A family-centered intervention for parents with mental illness*. Rockville, MD: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration.

Parents with Mental Illness: State-level Initiatives in the Child and Adult Systems of Care

Joan Mikula

This summary describes important processes and practices that have supported the history of success of state-level family-support services in Massachusetts, and focuses on two recent initiatives that are making a difference for families in which a parent has a mental illness. Barriers and facilitators to innovation for parents with mental illness are highlighted.

The Department of Mental Health for the Commonwealth of Massachusetts (DMH) has a long history of innovation in mental health services, including efforts to increase family involvement in service planning, and family-support services for families involved in both the adult and child systems. *Family-support services* are defined through program and practice expectations, and include all Department activities that assist families in supporting the growth, recovery and rehabilitation of their affected family member. In providing family support, DMH uses a very inclusive definition of family, which may include parents and guardians, as well as other relatives, and non-related individuals whom the client defines as family and who play a significant role in the client's life.

Case-management is the primary service provided by DMH for qualifying individuals. Family-support is considered to be an integral part of case-management that aspires to be strengths-based and non-judgmental. Family-support is also prioritized in other DMH-delivered and contracted services. Family-support services, whether delivered directly by DMH or through contracted agencies are designed to address family-identified needs for education about mental illness and management of mental illness in the family, support and advocacy in negotiating state systems and provider agencies, access to services, entitlements, and other resources that can reduce the care-giving burden, and linkage with other families coping with similar concerns. For example, DMH provides funding for Parent Partners for families participating in a collaborative project (Collaborative Assessment Project: CAP) with the child welfare system designed to offer assessment, stabilization and an integrated services plan for children with mental health problems who are also at risk for out-of-home placement. Parent partners provide education, support, and advocacy for families entering and learning to negotiate state child-serving systems.

DMH family support services are also available to family members of children, adolescents, and adults with behavioral, emotional or mental health problems, whether or not their family member is a DMH client. DMH funds advocacy groups for both adult and child consumers, and their families. For example, DMH supports at least one parent coordinator position in each of its six catchment areas. Parent coordinators facilitate parent support groups for parents of children with mental health problems. Support groups offer emotional support, provide education about mental health problems and state-of-the-art treatment, teach advocacy strategies, and serve as a self-help venue for parents. For families of adults, DMH supports educational programs provided by the Massachusetts Chapter of the National Alliance of the Mentally Ill (NAMI).

Critical to family-support services, DMH also engages in several activities that provide on-going input from families and other community collaborators (e.g., researchers) with respect to family needs and priorities. DMH Area and Site boards regularly participate in needs' assessments and program planning processes that rely on Statewide Advisory Councils that include family members. There are multiple opportunities during the planning process for family members to have input. Parents and family members are involved in both the design and implementation phases of initiatives.

The need for specialized services and supports for families in which a parent has a mental illness came to light as a result of family input from both the child and adult services sectors. Specifically, researchers with whom DMH has an ongoing collaboration reported that the prevalence of parenthood among adults in the public sector was indeed high; and that the current structure and organization of state services did not well address their needs. In addition, DMH-funded parent support groups for parents of children with serious emotional and behavioral problems revealed that many of the parents were also struggling with mental health problems, and needed services that accommodated these issues.

Strategic Planning Group: Steering Committee for Parents with Mental Illness. Through an on-going and innovative collaboration with the Center for Mental Health Services Research at the University of Massachusetts Medical School (CMHSR), DMH supports and participates in a Strategic Planning Group and Steering Committee for Parents with Mental Illness and their families. The Committee was developed in collaboration with the Parenting Projects at CMHSR, and reflects a family/consumer-centered, multi-discipline approach. The committee includes representatives from DMH, CMHSR, and the DMH-funded Parent Advocacy League (PAL) for parents of children with serious emotional and behavioral problems. Also included in the group are the executive directors from a Clubhouse for adult consumers and a consumer-run resource center, and a legal mental health advocate. DMH administrators, staff, and clients are key stakeholders in identifying the team's agenda, implementing projects, and disseminating findings to the field, consumers and family members.

This committee has been pivotal to raising awareness about the issue of parent mental illness among administrators, providers, and policy-makers, and to the development of two exciting projects. In fall 2003, through the participating adult consumer resource center (The Coles Center), a grant was submitted to support a regional conference on parents with mental illness. This conference was planned for the fall of 2004 with a focus on research, policy, and services issues related to parents with mental illness. The conference targets increasing awareness and information and facilitating effective regional and local collaborations to address both service and policy needs, as well as the overlap of families across service sectors, and the need for service integration.

Collaborative Training Project. The second initiative developed from the Steering Committee on Parents with Mental illness is an important and needed collaboration between DMH, child welfare, and the CMHSR Parenting Projects Team, to train child welfare staff to identify adult mental illness and provide support for adult caregivers with mental illness who are involved with child welfare authorities. This training is a follow-up to a change that DMH made in its eligibility regulations in January 2002 that required DMH to ask adult applicants if they are involved with child welfare, and if so, whether they want short-term DMH services while their application was being considered. If the answer is "yes," DMH will then provide immediate family supports to assure that the children in the home are maintained safely. Inter-agency understanding and cross-training will be critical to the success of this new program.

Symposium Discussion

Discussant: Judith Katz-Leavy

Over the past two decades, there has been growing federal, state, and local interest in reducing service delivery fragmentation for children with multiple problems (including serious emotional disturbances) and in fostering family-centered care. In the 1980s, the Child and Adolescent Service System Program (CASSP) attempted to address this problem in collaboration with the states, and this effort provided the framework for the Center for Mental Health Services' Comprehensive Mental Health Services for Children with Serious Emotional Disturbances and their Families Program initiated in the early 1990s and continuing today. These programs attempted to address the problems of horizontal fragmentation—disconnects and barriers to collaboration across child-serving agencies such as education, child welfare, juvenile justice, public health and behavioral health.

However, less attention has been focused on issues of vertical fragmentation—the sharp and very detrimental split between adult and child services. This too occurs in almost all of the key service systems including behavioral health, public health, welfare, and criminal justice. Adults entering these systems are seldom asked whether they are parents, what provisions have been made for their children, etc. Furthermore, parenting issues and support needs for fulfilling the parenting role are also ignored in treatment and rehabilitation programs. The preceding papers document the scope of this problem and provide some examples of policies undertaken by a few states to address this population as well as small efforts by a few communities to develop programs that meet the needs and build on the strengths of these families. The papers also look at the need for a broader concept of family-centered care.

While acknowledging the strong commitment of the Comprehensive Mental Health Services Program for Children with Serious Emotional Disturbances and their Families to partnering with parents in the development of their own child's service plan, as well as in the areas of program management and governance, the authors note that the program has not actually considered how these services might need to be modified in situations where a parent or other family member has a mental illness and/or substance abuse problem. The data presented in this workshop indicate that this group of families comprises a significant portion of the children and adolescents served in systems of care. Future analyses will look at whether service utilization is different for this group of children and whether child outcomes differ. Implications for a philosophical shift, a service delivery shift, and funding shifts at multiple levels were explored, and the need for further exploration was emphasized.

CONTRIBUTING AUTHORS

Kathleen Biebel, Ph.D.

Center for Mental Health Services Research, Department of Psychiatry, University of Massachusetts Medical School, 55 Lake Avenue North, Worcester, MA 01655-0002, 508-856-8717, fax: 508-856-8700, e-mail: Kathleen.Biebel@umassmed.edu

Bernice Fernandes, B.A.

Center for Mental Health Services Research, Department of Psychiatry, University of Massachusetts Medical School, 55 Lake Avenue North, Worcester, MA 01655-0002, 508-856-6946, fax: 508-856-8700, e-mail: Bernice.Fernandes@umassmed.edu

Betsy Hinden, Ph.D.

Center for Mental Health Services Research, Department of Psychiatry, University of Massachusetts Medical School, 55 Lake Avenue North, Worcester, MA 01655-0002, 508-856-8630 fax: 508-856-8700, e-mail: Betsy.Hinden@umassmed.edu

Judith Katz-Leavy, M.Ed.

Consultant, Child and Family Mental Health, 3053 Porter Street, NW, Washington, DC 20008, 202-362-8298 fax: 202-966-6447, e-mail: Jkatzleavy@aol.com

Ranilo Laygo, Ph.D.

ORC Macro, Applied Research Division, 3 Corporate Square NE, Suite 370, Atlanta, GA 30329, 404-321-3211 fax: 404-321-3688, e-mail: Ranilo.M.Laygo@orcmacro.com

Joan Mikula

Assistant Commissioner, Child & Adolescent Services, Dept Mental Health Central Office, 25 Staniford Street, Boston, MA 02114, 617-626-8086, fax: 617-626-8058, e-mail: Joan.Mikula@dmb.state.ma.us

Joanne Nicholson, Ph.D.

Associate Professor in Psychiatry and Family Medicine, Center for Mental Health Services Research, Department of Psychiatry, University of Massachusetts Medical School, 55 Lake Avenue North, Worcester, MA 01655-0002, 508-856-8712, fax: 508-856-8700, e-mail: Joanne.Nicholson@umassmed.edu

Valerie Williams, M.A., M.S.

Center for Mental Health Services Research, Department of Psychiatry, University of Massachusetts Medical School, 55 Lake Avenue North, Worcester, MA 01655-0002, 508-856-8081, fax: 508-856-8700, e-mail: Valerie.Williams@umassmed.edu

Caregivers' Involvement in Their Children's Health Services

Huey J. Chen

Acknowledgments: The study was found in part of the CMHS grant through the Children's Services Council of Broward County, FL (# 03-4104).

Purpose and Introduction

The purpose of the study was to explore the degree of the family members' involvement in mental health services received by their children with severe emotional disturbance (SED). One of the System of Care's core value and principals (Stroul & Friedman, 1986) is youth focus and family involvement, which is a key factor in promoting desired service outcomes. Understanding the degree of caregivers' involvement in the mental health services received by their children with SED can provide directions in developing strategies and planning for implementing systems of care programs to provide comprehensive, integrated, culturally competent, and individualized services to meet the needs of children with SED and their families.

Broward County of Florida is one of the grantee sites funded by the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration (CMHS) to develop the One Community Partnership program which would incorporate the core values and principles of systems of care to serve children with SED and their families in the community. It provided an opportunity to collect baseline data regarding services and the families' involvement prior to implementing the system of care program.

Method

This cross-sectional descriptive study used a mail survey approach to collect data from 970 caregivers of children with SED who received services from the Connection program, the primary target case management program to serve children with SED in Broward County, Florida. The mail survey packages—including a cover letter explaining purpose of the study and invitation to participate on voluntary basis, questionnaire, and addressed and stamped return envelop—were sent to caregivers after approved by the University of South Florida's Internal Review Board.

The questionnaire included the following measures: (a) the Family Empowerment Scale (FES; Koren, DeChillo, & Friesen, 1992) to assess degree of empowerment among caregivers of children with SED; (b) a subset of questions from the Child Health Questionnaire (CHQ; Landgraf, Abetz, & Ware, 1999), a measure with high reliability for assessment of children's general physical function; and (c) the Pediatric Symptom Checklist to address children's mental health status (PSC; Jellinek, Murphy, & Burns, 1986). Additionally, the questionnaire requested child characteristics including age, gender, race/ethnicity, and schooling, etc.

Analytical Approach. Each Family Empowerment subscale score was transformed to 100 points for analysis purpose. Analysis of variance and *t*-test were used to examine the group differences. Pearson correlation coefficient was used to explore the relationship between family empowerment and children's health conditions.

Results and Discussion

A total of 150 caregivers responded to the mail survey, including caregivers of 66% (*n* = 99) boys, ranging from 6 to 19 years old with a mean age of 13.8 years (*SD* = 3.17). The racial/ethnic distribution was 57.3% non-Hispanic White (*n* = 86), 27.3% non-Hispanic Black (*n* = 41), 9.3% Hispanic (*n* = 14), 4% Native American and other minorities (*n* = 6), and 2% (*n* = 3) unspecified.

Family Empowerment Status. The mean overall scores of family empowerment for three domains of empowerment at different levels were 231.48 ($SD = 36.86$, $N = 149$) at family level; 248.88 ($SD = 30.47$, $N = 149$) for service system; and 213.80 ($SD = 39.92$, $N = 149$) for community/ political empowerment. Caregivers appeared to have a significantly higher level of empowerment for service system but less empowerment for both family and community/political aspects (see Table 1).

Table 1
Levels of Family Empowerment in the
Current System (N=149)

	<i>Family</i>	<i>Service System</i>	<i>Community/ Political</i>
Attitude (<i>SD</i>)	73.77 (15.49)	86.44 (11.12)	75.08 (15.85)
Knowledge (<i>SD</i>)	76.70 (15.02)	76.36 (14.73)	76.51 (15.29)
Behavior (<i>SD</i>)	81.01 (12.00)	86.07 (10.88)	62.21 (17.75)
Overall (<i>SD</i>)	231.48 (36.86)	248.88 (30.47)	213.80 (39.92)

Note. A higher score indicates a higher degree of empowerment.

Empowerment Attitude. The results on the ways of expressing family empowerment indicate that caregivers had a significantly higher level of empowerment attitude toward the service system ($M = 86.44$, $SD = 11.12$) but less empowerment at both family ($M = 73.77$, $SD = 15.49$) and community/political level ($M = 75.08$, $SD = 15.85$). These findings suggest that caregivers felt they were less in control in handling their children's emotional/behavioral problems on a daily basis. Meanwhile, caregivers were also less confident in taking part in influencing the service system through community or political involvement compared to their empowerment attitude toward the service system.

Empowerment Knowledge. Caregivers indicated a significantly higher score in empowerment knowledge compared to their score on empowerment attitude at the family level (76.70 versus 73.70; see Table 1). This finding suggests that caregivers lacked of confidence in dealing with day-to-day issues with their children with SED.

In contrast, caregivers had a significantly lower level of empowerment knowledge score than the empowerment attitude score at the service system level (76.36 versus 84.88). Caregivers appeared to have limited knowledge in how to get involved in the service system, such as what steps to take when they became concerned that their children were receiving poor services; how to make good decisions or work with professionals to decide what services their children needed; or what service system their children were involved in. This difference between knowledge and attitude scores suggests that caregivers could experience helplessness and frustration because they might not know what to do when something needed to be done for their children with SED.

There was no significant difference in caregivers' empowerment knowledge and attitude at the community/political level. Caregivers have limited desire, as well as knowledge, to change the mental health service system for children with SED.

Empowerment Behavior. Though caregivers had expressed lower levels of empowerment attitude and knowledge at the family level, they reported a significantly higher level of empowerment behavior at the family level (see Table 1). It suggested that caregivers not only lacked confidence in dealing day-to-day issues related to their children with SED, they also had limited knowledge in how to deal with those issues. These phenomenon could also result in experiencing frustration and helplessness.

At the service system level, caregivers reported an empowerment behavior score that was compatible with their empowerment attitude toward service system score. However, their empowerment behavior score was significantly higher than the empowerment knowledge score. These findings suggested that caregivers were involved in services received by their children with a limited knowledge about the service system to match with the degree of their involvement in the system, leading to potential inefficient approaches.

In terms of being actively involved in community/political activities to change the service delivery system for children with SED, caregivers were less likely to be involved compared to their involvement either at the family or service system level.

Family Empowerment and Children's Health Status. The general health status was measured with CHQ-24, and emotional/behavioral symptoms were measured with Pediatric Symptom Checklist (PSC). The mean score of CHQ was 68.59 ($SD = 6.22$, $N = 146$) and the mean PSC score was 37.74 ($SD = 12.43$). More than 75% of these children had a PSC score greater than 30, which suggests the child needs further psychiatric evaluation and treatment. There was no significant relationship between degree of family empowerment and children's general health function ($r^2 = .06$, $p < .05$). However, children's emotional and behavioral symptoms were negatively related to their caregivers' involvement at the family level ($r^2 = .322$, $p = .00$). These findings suggest that when children with SED exhibited more emotional/behavioral problems, their caregivers were less likely to be involved, compared to caregivers of children who had fewer emotional/behavioral symptoms.

Family Empowerment and Race/Ethnicity. There were no significant differences in the empowerment attitude among different racial/ethnic groups at both the service system and community/political levels. However, the Non-Hispanic Black caregivers had a higher empowerment attitude score at the family level than caregivers of any other racial/ethnic group. They appeared to feel more confident and in control in handling their children's day-to-day emotional/behavior problems compared to caregivers of non-Hispanic White and Hispanic or other minority children. Caregivers of Hispanic and other minority children also had a significantly lower level of empowerment knowledge related to the service system and community/political levels than caregivers of either White or Black children. No differences were found in empowerment behaviors among different racial/ethnic groups in all three different empowerment levels.

Implications and Future Study

The significantly lower scores for empowerment attitude as compared to both empowerment knowledge and empowerment behaviors at the family level suggests that caregivers lack confidence in dealing with issues related to their children with SED on daily basis, and can benefit from receiving support from providers or other family members. Additionally, a lower score in empowerment knowledge with a higher score on behavior at family level suggests that caregivers may experience difficulty and frustration because they may not have sufficient knowledge to effectively handle issues related to their children with SED. Though further investigation is needed to verify caregivers' experiences, it seems clear they can benefit from health education about how to handle emotional/behavioral problems of their children on daily basis, especially for caregivers of Hispanic and other minority children.

At the service system level, caregivers reported higher empowerment attitude and behavior scores with a significantly lower empowerment knowledge score. These results suggest that caregivers need to learn more about the service system their children are involved in, especially in the case of caregivers from Hispanic and minority groups. Limited knowledge about the service system is an important factor that affects access to care. For minority groups, knowledge not only about existing services, but also about availability of culturally and linguistic competent services can be very important.

The results also indicated that caregivers had a very limited involvement in all three domains at the community/political level. Family voice is important input for developing systems of care that will be youth/family focused to provide comprehensive, individualized service for children with SED and their families; increasing caregivers' empowerment at the community/political level should be a component of systems development

References

- Jellinek, M. S., Murphy, J. M., & Burns, B. J. (1986). Brief psychosocial screening in outpatient pediatric practice. *The Journal of Pediatrics*, *109*, 371-378.
- Koren, P.E., DeChillo, N., & Friesen, B.J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology*, *37*(4), 305-321.
- Landgraf, J. M., Abetz, L., Ware, J. E. (1999). *The CHQ User's Manual*. Second Printing. Boston, MA: Health Act.
- Stroul, B.A. & Friedman, R. M. (1986). *A system of care for children and youth with severe emotional disturbance (Rev. ed.)* Washington, DC: Georgetown University Child Development Center, CASSP Technical Assistance Center.
- Taub, J., Tighe, T. A., & Burchard, J. (2001). The effects of parent empowerment on adjustment for children receiving comprehensive mental health services. *Children's Services: Social Policy, Research, and Practice*, *4*(3), 103-122.

CONTRIBUTING AUTHORS

Huey J. Chen, Ph.D.

Principal Investigator, Department of Mental Health Law and Policy, University of South Florida, Louis de la Parte Florida Mental Health Institute, 13301 Bruce B. Downs Blvd, MHC 2705, Tampa, FL 33712, 813-974-7409, fax: 813-974-9327, e-mail: chen@fmbi.usf.edu

Caregivers of Children In Systems of Care: Economic Outcomes

Anna Krivelyova
Robert Stephens

Introduction

Among the many aspects of family life that can be affected by a child's serious emotional disturbance is caregiver's labor market performance. The demands on caregivers' time make them less likely to enter the labor market, as well as reduce the hours that caregivers can devote to work if they are employed. Caregivers of family members with mental illnesses have been found to work fewer hours (Roberts, 1999). Single mothers of children with chronic illness or disability are less likely to join the labor force (Salkever, 1990). The inability to work because of the special demands required to care for children with mental health problems may be particularly problematic for lower income families, since caregivers often face unusual demands on economic resources, such as high healthcare costs.

The national evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program demonstrated that children served by system-of-care communities showed significant improvement in their clinical outcomes, with caregivers reporting less problematic behaviors exhibited by children (CMHS, 1999; Manteuffel et al., 2002). The question remains whether there are related changes in the employment-related aspects of the caregiver's life. This question is especially relevant since many families of the children enrolled in systems of care are economically disadvantaged.

Methods

Participants. Participants were drawn from youth and families who participated in the national evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program. The study uses data from grant communities funded from 1997 to 2000. Evaluation of these communities showed that more than 47% of children come from families with an annual income of less than \$15,000. The majority of children (71%) served by systems-of-care communities receive Medicaid. The present sample (n varied from 460 to 2,048) included caregivers who were employed at least once over the study's first three six-month data collection waves and who had complete data on all study variables (i.e., household income, Medicaid recipient, service use, service satisfaction, child's CBCL scores at intake).

Measures. Descriptive data collected on children and families included demographics such as household income and Medicaid receipt. The *Child Behavior Checklist* (CBCL; Achenbach, 1991; 118 items, $\alpha > .82$) is a widely used caregiver report measure that assesses children's emotional and behavioral problems. The Family Satisfaction Survey (FSS; Brunk, Santiago, Ewell, & Watts, 1997; 14 items, $\alpha > .88$) assesses satisfaction with services and impact of services received on the ability of family members to work outside the home. Service use is reported by caregivers using the Multi-Sector Service Contacts questionnaire (MSSC; Center for Mental Health Services, 2000).

Analysis. The analysis was performed using Stata statistical software (Stata Corporation, 2001). Univariate group differences in economic outcomes were tested using normally distributed test of proportions (Green, 1990). Multivariate analysis of the effects of services on economic outcomes was performed using logistic regression with Huber-White robust standard errors (Green, 1990).

Results

After the first six months of receiving system of care services, 77.1% of caregivers were employed. After 12 months, 79.3% of caregivers were employed, and after 18 months the proportion of caregivers working outside the home increased to 80.1%. Three samples (interviewed at 6, 12 and 18 months) of caregivers working outside the home were analyzed further to determine what aspects of their work were improved because of the services provided through the systems of care.

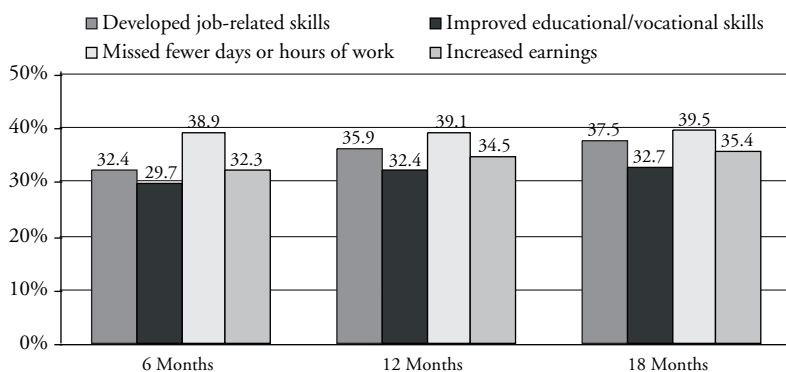
Caregivers reported that services provided by the systems of care helped them increase their earnings; improve job-related, educational and vocational skills; and miss fewer hours and days from work. Figure 1 shows that for each time period 32.4 - 37.5% of caregivers believed that services their children and families received helped them to acquire job-related skills. Improvements in educational and/or vocational skills were reported by 29.7 - 32.7% of employed caregivers. Increases in earnings were reported by 32.3 - 35.4% of employed respondents. The aspect of employment most affected by the services received was the caregiver's ability to miss less time from work; 38.9 - 39.7% of caregivers reported improvements in this area due to the services provided by systems of care.

Caregivers whose family income was less than \$15,000 and caregivers with children receiving Medicaid were more likely to report that services helped them to increase their earnings and improve job-related and educational/vocational skills. Caregivers of children with higher levels of behavioral and emotional problems at intake (as measured by the CBCL Total Problems) were more likely to miss fewer hours or days of work with the help of services provided by systems of care.

Figure 2 present examples of the group differences in the proportions of caregivers reporting at least once during the first 18 months that mental health services provided by the systems of care helped them with various aspects of their working life. Figure 2 shows that among caregivers whose family income was less than \$15,000, 47.2% felt that services their children and families received in systems of care helped them increase their earnings, 47.2% developed job-related skills, and 43.0% report improvements in educational and/or vocational skills as a result of the services the children and families received. The numbers are significantly lower for the group of caregivers with higher family incomes (37.0%, 37.7% and 33.6%, respectively). When differences in the intake clinical characteristics are considered, 50.7% of caregivers with children whose CBCL Total Problems scores fell in the clinical range (score higher than 63) report that services provided by the systems of care helped them miss fewer hours or days of work. The corresponding number for caregivers of children with scores not in the clinical range is 37.8%.

Caregiver's reports on service use were used to examine whether specific types of services provided by systems of care were associated with improvements in the caregivers' job-related outcomes. The MSSC questionnaire assesses the use of the following services: assessment and evaluation, crisis stabilization, family preservation, medication monitoring, group therapy, individual therapy, case management, family therapy, day treatment, therapeutic camp inpatient hospitalization, residential treatment, group home, therapeutic foster care, behavioral aide, independent living, transition, family support, recreation, transportation, respite care and flexible funds. Children and families of caregivers who reported that

Figure 1
Proportion of Caregivers Reporting Improvements



Note: n varied from 605 to 1533. Variation in the sample size is due to the variation in the employment status and availability of data on the variables of interest.

services helped them do their job were significantly more likely to receive medication monitoring, family therapy, family support, and respite care. Figure 3 summarizes the significant service differences that were identified using normally distributed proportion tests. For example, 18.8% of caregivers who reported improvements in the ability to do their job received flexible funds, while among caregivers who didn't report improvements in this area only 7.8% reported receipt of flexible funds. Children and families of caregivers who reported improvements in their job-related skills were more likely to receive family preservation services, individual therapy and family support. Improvements in educational and/or vocational skills were associated with therapeutic foster care, family support and recreation. Caregivers who reported that they missed less work were significantly more likely to report receipt of flexible funds. Increases in earnings were associated with family support and flexible funds.

Figure 2
Proportion of Caregivers Reporting Improvements at Least Once During the First 18 Months by Income

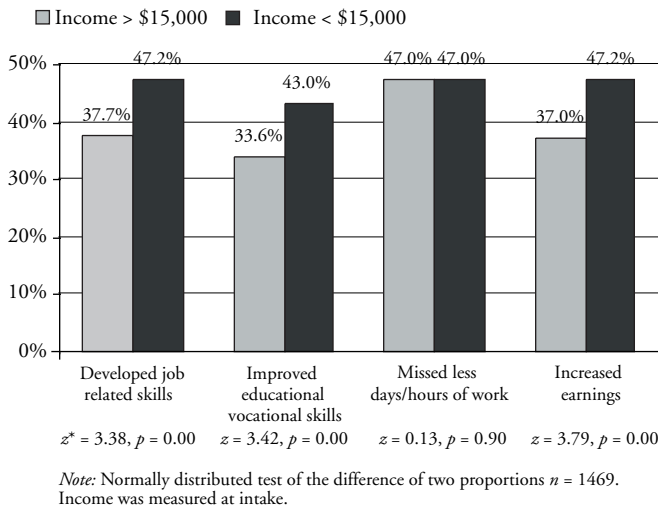
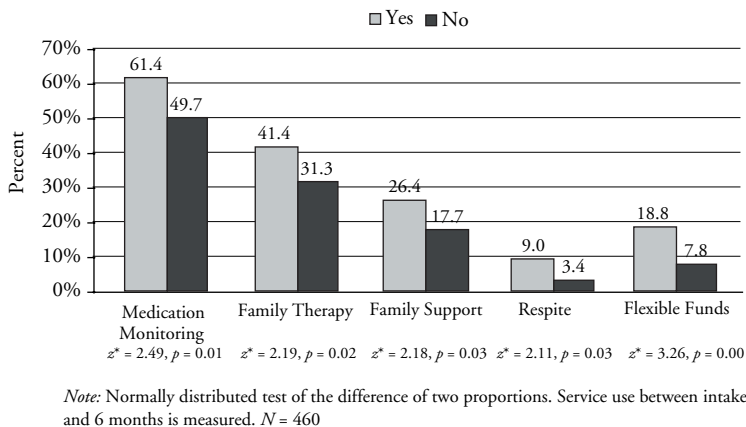


Figure 3
Did services your child and family received help you do your job?



Simple proportion tests suggest that there is a positive association between the use of several traditional and innovative services and improvements in the ability of caregivers to do their job. However, since the observed association may be simply a result of clinical, socioeconomic, or demographic variation in service use, and not the true relationship between receipt of services and improvements, further investigation was conducted using a multivariate technique to control for other factors. Table 1 presents estimates of multivariate logistic regressions modeling improvements in employment-related outcomes. The results suggest that the effects of various services persist even after clinical and socioeconomic factors are included as controls¹.

Table 1
Logistic Regression Estimates

Independent Variables	Dependent variables				
	Improved ability to do your job	Improved job-related skills	Improved edu/ vocational skills	Missed less time of work	Increased money you earned
Medication Monitoring	0.37 (0.07**)				
Individual Therapy		0.44 (0.08)			
Family Preservation		0.85 (0.01)			
Therapeutic Foster Care			1.18 (0.04)		
Family Support	0.30 (0.24)	0.61 (0.01)	0.75 (0.01)		0.69 (0.01)
Recreation			0.40 (0.08)		
Respite	0.96 (0.05)				
Flexible Funds	0.96 (0.01)			0.84 (0.001)	0.71 (0.01)
Income < \$15,000	0.13 (0.57)	0.37 (0.11)	0.47 (0.04)	0.08 (0.70)	0.62 (0.01)
CBCL in the clinical range	-0.16 (0.68)	-0.14 (0.57)	-0.06 (0.79)	0.30 (0.21)	0.08 (0.74)

Note: n = 460; P-values in parentheses. Huber-White robust standard errors are used. Service use between intake and 6 months is measured.

Discussion

The family focused approach to care ensures that systems of care support and assist parents in their role as caregivers. In addition to the improvements in children’s clinical outcomes, the services provided by the systems of care seem to have a secondary benefit: improvements in the various employment-related aspects of the caregiver’s life. Caregivers reported that the mental health services their child and family received helped them develop job-related, educational and vocational skills, and even earn more money. Caregivers observed that the services helped them miss fewer hours and days of work.

The caregivers most likely to be helped by the services are the caregivers whose families are in more challenging situations in terms of economic resources and clinical problems. Observed improvements in economic outcomes are often associated with the receipt of family support and flexible funds—innovative services that are specific to systems of care.

The findings suggest that changes in the economic situation of the caregivers of children served by systems of care should be considered as a relevant outcome. Analysis of the economic outcomes for caregivers allows the examination of the effects of systems of care from a broader socio-economic perspective. The improvements in family economic resources due to the increases in labor participation rates, improvements in skills, and reduced absenteeism can decrease the family’s need for public assistance such as AFDC and Medicaid. Future research needs to examine what particular components of services such as family support and flexible funds are instrumental in improving job-related aspects of caregivers’ lives.

¹The models were also re-estimated with the inclusion of several additional control variables such as age, gender, and other factors. The additional controls were never statistically significant.

References

- Achenbach, T. (1991). *Manual for the Child Behavior Checklist/4-18 and 1991 Profile*. Burlington, VT: University of Vermont Department of Psychiatry.
- Brunk, M., Santiago, R., Ewell, K., & Watts, A. (1997). Family satisfaction with level of cultural competence in systems of care: Development of a cultural competence scale. In C. J. Liberton, K. Kutash, & R. M. Friedman (Eds.), *The 10th Annual Research Conference Proceedings, A System of Care for Children's Mental Health: Expanding the Research Base* (February 23 to February 26, 1997) (pp. 113-118). Tampa, FL: University of South Florida, The Louis de la Parte Florida Mental Health Institute, Research and Training Center for Children's Mental Health.
- Roberts, A. A. (1999). The Labor Market Consequences of Family Illness. *The Journal of Mental Health Policy and Economics*, 2, 183-195
- Center for Mental Health Services. (1999). *Annual report to Congress on the evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program, 1999*. Atlanta, GA: ORC Macro.
- Center for Mental Health Services. (2000). *Annual report to Congress on the evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program, 2000*. Atlanta, GA: ORC Macro.
- Green William, H. (1990). *Econometric Analysis*. New York: Macmillan Publishing Company.
- Manteuffel, B., Stephens, R., & Santiago, R. (2002). Overview of the national evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program and summary of current findings. *Children's Services: Social Policy, Research, and Practice*, 5(1), 3-20.
- Salkever, D. (1990). Determinants of Single Mother's Labor Supply and Earnings. *Research in Human Capital and Development*, 6, 147-181
- Stata Corporation. (2001). *Stata statistical software: Release 7.0*. College Station, TX: Author.

CONTRIBUTING AUTHORS

Anna Krivelyova, M.S.

*Research Associate, Phone: 404-321-3211, fax: 404-321-3688,
e-mail: Anna.Krivelyova@orcmacro.com*

Robert Stephens, Ph.D.

*Technical Director, Phone: 404-321-3211, fax: 404-321-3688,
e-mail: Robert.L.Stephens@orcmacro.com*

*Both authors: ORC Macro International, 3 Corporate Square, NE, suite 370,
Atlanta, GA 30329*

Family Experiences and Satisfaction with Respite Services

Karen A. Friedman

Introduction

Seven core service agencies in the state of Maryland received grants in June, 2000 to develop and implement respite programs for families whose children have emotional disabilities and who are receiving medical assistance. The programs devoted much of their first year to developing outreach to families and providers, and to training respite providers. The first year evaluation employed a qualitative methodology, with information gathered from interviews and focus groups with key stakeholders (including administrators, providers, and families), site visits to each of the programs, and an analysis of available quarterly reports.

The evaluation for the second year was designed to build upon the existing research base by quantitatively measuring families' experiences and satisfaction with respite care services. Information was gathered to determine the existing strengths and weaknesses of the sites offering respite services. In their seminal research on respite care for children with emotional disabilities in Vermont, Bruns and Burchard (2000) reported that caregivers who receive respite services perceived decreased amounts of stress and burden. In addition, these parents preferred respite services to some of the other mental health services their children received. Bruns and Burchard (2000) also found evidence that providing respite care services reduced the number of more costly, out of home placements. The present study provided empirical data to further evaluate these issues.

Methodology

Participants. A questionnaire battery was administered at baseline to 33 family members who were applying for respite services. In order to qualify for the program, their children must have been receiving some kind of mental health service. Follow-up surveys were collected from 23 of the same families in six-month intervals after their children received some form of respite care. These families completed from one to three follow-up surveys. Of the original 33 families responding to the baseline survey, nine did not respond to the follow-up surveys, and one family indicated that they were still waiting to receive some kind of respite care.

Instruments. For the evaluation of respite in Maryland, a survey protocol was developed based upon the Vermont survey (Bruns & Burchard, 2000). First, administrators from each site received a preliminary draft of the survey and were asked to provide feedback from their stakeholders about the survey to the principle investigator. In addition, qualifying family members were also involved in the development of the instruments. The final version of the completed protocol had domains for *caretaker depression*, *burden on the family*, *isolation of the family*, *caretaker's relationship with their partner*, and *family relationships*. Each domain included a 7-item subscale.

Parents also completed the Impact on Family Scale (Stein & Reissman, 1980), which is a 24 question instrument using a 4-point Likert-type scale that addresses areas of family life that caretakers might have to deal with because of their child's difficulties. Finally, caregivers completed the Quarterly Adjustment Indicator Checklist to provide a picture of their child's behaviors and problems.

Procedure. Fifteen packets of the protocol were delivered to six of the seven sites. Included in each packet were instructions, telephone numbers of people to contact for additional information, the consent form, the questionnaires, and self-addressed stamped return envelopes. The protocol was also available on the website of the Maryland Coalition of Families for Children's Mental Health. The evaluator provided instructions to the representatives at each site and answered questions at that time.

Results

Quarterly Adjustment Indicator Checklist

Caregivers were asked to indicate how often in the past three months their child exhibited a variety of problem behaviors. Caregivers most often reported having difficulties with their children stealing, extreme verbal abuse, noncompliance, lack of self-confidence, and poor peer relations. Parents were also concerned about their children being sad and anxious. The total mean score at baseline was 13.6 and after receiving respite was 11.43. While most caregivers indicated more problems prior to the respite period, the difference was not significant, $t(22) = 1.80, p > .05$. Of the 21 items on this inventory, three individual items showed significant changes from baseline to after-respite. After respite, the caregivers indicated there was a reduction in physical aggression, $t(22) = 2.31, p < .05$, less likelihood of the child running away, $t(20) = 2.12, p < .05$, and less life threatening behavior by the child, $t(21) = 2.35, p < .05$.

Impact on Family Scale

The question that received the lowest score on the Impact on Family Scale was, "It is hard to find a reliable person to take care of my child." Other difficulties families reported included having to give up things because of their children's problems, not having time for other family members, feeling like they live on a "roller coaster," and fatigue. Of the 24 questions on the Impact on Family scale, none of the items showed a significant change from baseline to after-respite.

Stress and Burden on the Family

The instrument developed by the stakeholders at the meetings indicated two major areas of stress: (a) caregivers' feelings of guilt, and (b) caregivers' perceptions of not having enough time alone to do things they like. Similarly, caregivers with partners reported that they didn't have enough time together. Respondent results to the subscales for this instrument follow.

Depression. On this 7-item subscale caregivers were asked whether they agreed or disagreed with statements involving depression that they would experience in response to their child's problems. Lower scores indicate greater depression. When all of the items were summed, there were lower scores at baseline ($M = 16.13$) than after respite ($M = 17.82$). However, this difference was not significant, $t(19) = -1.46, p > .05$. Two individual items on the depression scale did show significant changes from baseline to after-respite: After they received respite services, caretakers (a) felt less guilty, or better about themselves, $t(19) = -2.77, p < .05$, and (b) blamed themselves less often when their child did something wrong, $t(22) = -2.13, p < .05$. In general, the scores increased on items within this subscale, indicating less depression and guilt after caregivers received respite services.

Burden. On this subscale caregivers were asked whether they agreed or disagreed with statements involving the burden that they experienced because of their child's problems. Higher scores indicate lower burden. When all of the items were summed there were lower scores at baseline ($M = 12.60$) than after respite ($M = 14.61$). This difference was not significant, $t(19) = -1.15, p < .05$. There were no significant differences on any of the individual items within this subscale.

Isolation. Caregivers were asked whether they agreed or disagreed with statements involving the isolation that they experienced because of their child's problems. Higher scores indicate less isolation. When all of the items were summed there were lower scores at baseline ($M = 16.73$) than after respite ($M = 17.61$); however, this difference was not significant, $t(19) = -0.27, p > .05$. There were no significant changes on any of the isolation items.

Relationship with Partner. On this subscale caregivers were asked whether they agreed or disagreed with statements involving stress on partner relationships because of their child's problems. Higher scores reflect less partner-relationship stress. When all of the items were summed there were lower scores at baseline ($M = 14.19$) than after respite ($M = 15.89$); however, this difference was not significant, $t(11) = -0.75, p > .05$. Of the seven items on this subscale only one showed a significant change: After receiving respite

services respondents felt that they had more interest in sex with their partner, $t(11) = -2.28, p < .05$. This subscale contained a lot of missing data, presumably because there were a number of single caretaker-led households.

Family Relationships. Caregivers were asked whether they agreed or disagreed with statements involving stress on family relationships because of their child's problems. Higher scores indicate lower levels of family relationship stress. When all of the items were summed there were lower scores at baseline ($M = 15.85$) than after respite ($M = 17.04$); however, this difference was not significant, $t(19) = -1.15, p < .05$. There were also no significant differences on any of the individual items within this subscale.

Satisfaction of Respite Recipients

Parents completing the second survey were overwhelmingly positive. A 20-question satisfaction survey was developed on a 4-point Likert scale. Seven of the eight families strongly agreed with almost all of the positive statements. Only one question, "I am satisfied with the number of hours of respite I receive," received two *disagree* responses. Four additional questions each received one *disagree* response. Two of these four questions concerned the type of respite and the flexibility of scheduling of respite care. The other two questions concerned the parent's involvement in the respite process and whether the parent had time to speak with the respite worker before each period of respite care.

References

- Bruns, E. J., & Burchard, J. D. (2000). Impact of respite care services for families with children experiencing emotional and behavioral problems. *Children's Services Social Policy, Research, and Practice*, 3, 39-61.
- Stein, R. E. K., & Riessman, C. K. (1980). *Impact on Family Scale*. Austin, TX: Pro-Ed.

CONTRIBUTING AUTHORS

Karen A. Friedman, Ph.D.

*Research Consultant, Maryland Coalition of Families for Children's Mental Health,
10632 Little Patuxant Pkwy, Columbia, MD 21044, 888-607-3637,
fax: 410-730-8331, email: kfriedman@mdcoalition.org*

Topical Discussion

Evaluating Family Satisfaction with a Managed Care Organization: a Collaborative Effort

**Barbara Zimmerman
Andrea Klein**

Introduction

This session explored the development and results of a satisfaction survey developed to inform a service system on family perceptions. The Managed Care Organization (MCO) Satisfaction Survey was developed by Parents Involved Network Family Satisfaction Team (PIN/FST) in collaboration with Delaware County Office of Behavioral Health (OBH) and its Managed Care Organization. This is the first time a MCO satisfaction survey has been developed by families, and the results of this survey illustrate the level of satisfaction with the services and interactions between MCO and families. Integration of a satisfaction survey providing this level of feedback to service provision can lead to accountability and quality improvement in the public behavioral health care system.

Method

In Delaware County, Pennsylvania, the Office of Behavioral Health contracts with a Managed Care Organization for mental health and substance abuse services. The Pennsylvania Office of Mental Health and Substance Abuse suggested to the county that FST develop a tool to measure family satisfaction with the MCO, as part of developing performance outcome measurements.

FST reviewed other MCO surveys which focused more on the services provided by those who subcontract with the MCO rather than the MCO itself. FST then researched which services the MCO is directly responsible for and examined other interactions families typically have with the MCO. The following categories were developed to describe interactions with MCO: MCO Care managers, MCO Representatives at Interagency Service Planning Team Meeting, MCO Member Services Department, MCO Complaint Process, MCO Denial of Services, MCO Grievance Process, Additional MCO Questions, How Could MCO be More Helpful.

The survey was designed to measure level of satisfaction for each categories through related questions that could be answered by a yes/no response or ranked responses on a 5-point scale (A = *Strongly Agree*, B = *Agree*, C = *Unsure*, D = *Disagree*, E = *Strongly Disagree*, N/A = *Not Applicable*.) Additional open-ended questions and space for comments solicited more detailed opinion of interactions with MCO. The process of developing the survey included ongoing collaboration with the county and the MCO to promote exchange of ideas. For the purposes of this survey, the MCO provided FST with contact information for a sample of its member population including 1,865 families who had children/adolescents receiving mental health services. The county funded the postage for the survey to be mailed to families. The survey included a self-addressed envelope and asked the family to provide postage. All surveys were returned to PIN/FST where the data was compiled.

Of the 1,865 address labels the MCO provided, 151 were discarded because they either were addressed to Children and Youth Services (CYS) or had obvious errors. FST chose not to send surveys to CYS because they would not reach families. Over three months post-mailing, 181 surveys were deemed undeliverable by the Post Office and returned to FST.

Results

The results reported here are based on 108 valid surveys. The study team tabulated responses to yes/no or ranked questions, and compiled narrative responses to open-ended questions. Responses that were recorded incorrectly on the survey instrument were excluded from this analysis, although their content was noted and considered in recommendations.

Level of satisfaction

The percentage of ratings in the A/B range and the percentage of “yes” answers were calculated to derive satisfaction levels. FST determined that any satisfaction level 85% and above would represent family satisfaction, whereas satisfaction levels below 85% indicated areas in which quality improvement should be explored. Table 1 shows the percentage of responses falling into the satisfied category for each item, grouped by category.

Open-ended questions and comments

For the category of “How could your MCO be more helpful,” FST reviewed the 129 responses from question twenty four: “*Please name three (3) ways that MCO could be more helpful.*” Responding families identified two main areas where they felt MCO could be more helpful.

Provide families with information. Families indicated that they would appreciate more information regarding (a) their child’s progress and behaviors, (b) MCO and what they do, and additional options and/or resources.

Improvement in service provision. Responses indicated specific suggestions for improvement, including (a) providing resources outside of MCO services, (b) more convenient provider business hours, (c) additional training for providers, and (d) development and provision of additional services.

Discussion

Results from the survey showed an overall satisfaction level of 60% concerning interactions with the MCO. Based on survey results, the Family Satisfaction Team developed recommendations in each category to promote quality improvement in service delivery. These recommendations encompass systems and organizational issues, as well as service delivery issues. For example, FST recommends that MCO reexamine their system for maintaining accurate member addresses. Currently, MCO obtains addresses through the County Assistance Office. The accuracy of contact information impacts the agency’s ability to disseminate information to families, such as the MCO Handbook, ISPTM surveys and other correspondence. Relatedly, information regarding the MCO’s services and contacts for these services should be easier to access. FST suggested that literature should be easy to locate in waiting rooms, and a tracking system put in place to assure Member Services’ ability to direct members’ calls.

FST developed several recommendations for increasing sensitivity to parental perspectives in training of MCO personnel. Staff responsible for implementing the MCO complaint and grievance process should receive additional training and supervision to ensure a timely and effective response. Feedback on service provision from the satisfaction survey should be incorporated into future training for MCO Care Managers on how to work with families. FST recommended that MCO Representatives at the Interagency Service Planning Team Meetings should receive training on parents’ perspective and have the same representative attend consistently.

The county has directed the MCO to examine current practices in light of survey results and FST recommendations, and to develop a quality improvement plan. FST suggests that a satisfaction assessment process should be included in the plan that solicits suggestions for improvement from families, and gauges their satisfaction on an on-going basis. The FST feels that ongoing collaboration with both the county and MCO will be important to continued improvement in service provision, and is committed to working collaboratively towards reassessing family satisfaction with the MCO in the near future.

Table 1
Percent Responses Rated as “Satisfied” for Survey Items per Category (N = 108)

Survey Items	% at satisfied level
MCO Care Managers	48.0
I know who my child’s Managed Care Organization Care Manager is.	38.8
I feel my child’s Managed Care Organization Care Manager...	
<i>a) is easily accessible.</i>	45.2
<i>b) listens to my questions or concerns.</i>	50.0
<i>c) is knowledgeable about my child.</i>	43.7
<i>d) Knows how the mental health system works.</i>	49.4
<i>e) is courteous.</i>	57.0
<i>f) has treated me with respect.</i>	54.1
<i>g) returns my calls within two business days.</i>	46.0
<i>h) is helpful.</i>	45.3
<i>i) respects our family’s customs, beliefs and culture</i>	48.8
Managed Care Organization Representative at the Interagency Service Planning Team Meeting	80.0
The Managed Care Organization Representative that attended the meeting...	
<i>j) was knowledgeable of my child.</i>	61.9
<i>k) was knowledgeable of the child serving systems.</i>	70.7
<i>l) made appropriate suggestions for my child’s treatment.</i>	73.2
<i>m) listened to my questions or concerns.</i>	85.7
<i>n) treated me with respect.</i>	92.7
<i>o) was courteous.</i>	95.1
<i>p) was helpful.</i>	80.5
<i>q) I knew why the MCO Representative was at the meeting.</i>	87.8
<i>r) was respectful of our family’s customs, beliefs and culture</i>	73.2
Do you feel comfortable discussing treatment options (level of service, medications, etc.) with the MCO at the Interagency Service Planning Team Meetings?	79.5
Managed Care Organization’s Member Service Department	83.0
The Member Service Department agent I spoke to...	
<i>s) answered the call promptly</i>	85.0
<i>t) was able to give me the information I needed</i>	80.5
<i>u) knew whom to direct my call to</i>	82.1
<i>v) listened to my questions or concerns.</i>	85.0
<i>w) was friendly and courteous.</i>	84.6
<i>x) treated me with respect.</i>	90.0
<i>y) was helpful.</i>	72.5
Complaint Process	54.0
Did the Managed Care Organization Representative who took your complaint take the time to understand your complaint?	87.5
Did the Managed Care Organization Representative who took your complaint read your complaint back to you to make sure it was correct?	56.5
Did the Managed Care Organization Representative who took your complaint ask you what you would like done in regards to your complaint?	56.5
Did you receive an answer (resolution) to your complaint within 30 days of filing the complaint?	45.5
Were you satisfied with the resolution?	33.3
Were you informed what to do if you were not satisfied with the resolution to the complaint?	40.0
Denial of Services	29.0
Did you receive a denial letter explaining why the services were denied, and how to file a grievance?	70.0
Did you understand the explanation for the denial of services?	11.1
Were the Date of the letter and the date the denial went into effect 10 days apart?	0
Have you ever filed a Grievance?	
<i>a) Were you satisfied with this first level grievance process?</i>	16.7
<i>b) Were you satisfied with the resolution?</i>	16.7
If you have filed a complaint or grievance, did you feel that you did so without getting a penalty?	44.4
Additional Managed Care Organization Questions	55.0
Are the Services (such as TSS, Mobil Therapist and Behavioral Specialist Consultant), currently authorized being provided in full?	58.7
<i>a) If no, has Managed Care Organization informed you of alternative BHRS providers and/or alternative services that are available?</i>	15.4
Do you feel comfortable discussing treatment options (level of service, medications, etc.) with Managed Care Organization Representatives outside of the Interagency Service Planning Team Meeting (ISPTM) such as your child’s Care Manager or Managed Care Organization Representatives involved in the complaint and grievance process?	78.0
Have you received a DelCare Handbook?	38.0
Have you received an Interagency Service Planning Team Meeting Survey from Parents Involved Network (PIN) after each of your Interagency Service Planning Team Meeting (ISPTMs)?	66.0

CONTRIBUTING AUTHORS

Barbara Zimmerman

Family Satisfaction Team Member, Parents Involved Network, 135 Long Lane, Upper Darby, PA 19082-3116, 610-713-9401 ext. 125, fax: 610-713-9405, e-mail: bzimmerman@mbasp.org

Andrea Klein

Family Satisfaction Team Leader, Parents Involved Network, 135 Long Lane, Upper Darby, PA 19082-3116, 610-713-9401 ext. 104, fax: 610-713-9405, e-mail: aklein@mbasp.org

A Qualitative Analysis of Caregiver Strain in Families of Court-Involved Youth

**James M. Frabutt
Margaret B. Arbuckle
April D. Forsbrey**

Acknowledgement: This project was supported by a grant from the North Carolina Department of Crime and Control and Public Safety, Governor's Crime Commission (180-1-00-FDJ-K-336).

Introduction

If mental health practitioners are to be effective agents of change for court-involved youth and their families, theory-based services and interventions must be grounded in the challenges and concerns facing the caregivers of delinquent youth. Empirical evidence already documents that caring for a child with a serious emotional disturbance can cause strain for all family members (Messer et al., 1997). For example, caregivers of children with emotional disorders report greater feelings of depression, worry, and isolation than do parents in the general population (Messer et al., 1997; Rauktis & Miller, 2002). In addition to predicting service initiation and amount of service usage for children with emotional and behavioral disorders, strain is linked to caregivers' own service use and indicators of physical health (Gallagher & Mechanic, 1996; Pullman, Savage, & Koroloff, 2003).

It remains unclear, however, how caregiver strain is experienced by caregivers of court-adjudicated youth. Moreover, little attention has been paid to extracting detail and description from the lived experience of these caregivers through open-ended, qualitative methods. Therefore, predicated on the notion that effective interventions for youth violence must simultaneously address caregiver needs, the purpose of the current investigation was to examine, through qualitative inquiry, the central demands, responsibilities, difficulties, and challenges in these caregivers' lives.

Methodology

The current study was conducted within the context of a larger action research project, The High Point (NC) Youth Violence Initiative, which was designed to: (a) use qualitative and quantitative methods to examine risk and protective factors among court-adjudicated youth; (b) implement a strength-based, family-centered systems-of-care intervention with court-adjudicated youth; and (c) evaluate and refine the systems-of-care intervention model. The High Point Youth Violence Initiative is overseen by a joint community-university partnership.

Participants were 16 caregivers of court-involved youth (14 female, 2 male; 12 biological parents, one grandparent, one aunt, one uncle, one adoptive stepparent). Ten of the participants had a high school diploma or GED, and the educational level ranged from grade school through some college but no degree. Five of the caregivers reported an annual income of \$10,000-\$14,000, with the range being from less than \$5,000 to \$50,000-\$74,999. Five of the caregivers reported that they had never been married, four were married to the child's father, one divorced, two widowed, and three did not specify. The youth, both boys and girls, ranged in age from 13 to 16 and had been adjudicated on a variety of charges including assault, disorderly conduct, possession of weapon on school property, larceny, and breaking and entering.

University researchers reviewed and summarized for the project partners the literature on youth violence risk and protective factors to form the foundation for the interview protocol. Key questions were developed across thematic areas such as family, school, neighborhood, peer group, and personal strengths and weaknesses. An interview protocol was pilot-tested on two groups of middle school and high school-age youth that were made available by a local pastor on the project team.

Interviewers (five total, two men, three women) were drawn from the High Point community and thus had a common set of experiences with the interviewees. Community interviewers completed two 2-hour training sessions conducted by a PhD-level anthropologist specializing in ethnography. The trainer

was subsequently available to provide a debriefing after initial interviews, serve as a resource for questions that arose from interviewers, and provide ongoing consultation. Once a youth had been adjudicated in the local court office, youth and their caregiver were invited by a system-of-care service coordinator to participate in the project. The purpose and goals of the initiative were presented to the families and formal written consent was obtained from both the youth and caregiver. Interviewers then conducted and tape-recorded a semi-structured interview (often in the family's home) with the youth and caretaker separately (interviews typically lasted about one hour), although only the caregiver data are utilized in the current inquiry.

The interviews were tape recorded, transcribed, and entered into qualitative analysis software (Ethnograph 5.06; Qualis Research Associates). The researchers utilized the constant comparative model (Glaser & Strauss, 1967; Strauss & Corbin, 1990) throughout the analysis. As data were being gathered, the researchers began the process of reviewing available interviews and coding for thematic content (Marshall & Rossman, 1999). Each researcher reviewed and coded the interviews separately, and then converged to determine agreement (reliability). Operational definitions of each theme were constructed and then used to assign themes to subsequent interviews.

Findings

Multiple domains of reference emerged as the caregivers described central challenges in their lives: family, work, neighborhood, personal philosophies, system, child's peer group, and child's school. Although the structure of the interview directed the caregivers to focus on most of the emerging domains, caregivers often shared their perspectives on the system and their personal philosophies without prompting. An especially strong and consistent theme was a certain level of social isolation among the caregivers. In all 16 interviews, the caregivers reported some degree of social isolation or withdrawal.

The caregivers reported an overall lack of social support. Several caregivers reported a belief that they are solely responsible for taking care of their families. A female caregiver spoke about the police in the area, saying, "...but it looks like the police are gonna stop runnin' the streets now, but like, they can't...the only time they can be here like they said, five or six o'clock in the evening, that's only time they step foot in here, in this neighborhood. The rest of the night is up to us."

Eight (44%) caregivers reported some degree of isolation or withdrawal from their neighborhood. A female caregiver instead spoke about her choice to isolate from her neighbors. After being prompted to talk about positive aspects of her neighborhood: "I don't know really, cause I don't really go nowhere but in the house and out the house. I don't interact with people down there and I don't sit down and hold a conversation."

Nine (50%) of the caregivers described negative feelings about, or negative experiences with, their child's school. A large portion of interview text related to the caregivers' belief that the school staff and/or administration were negatively biased toward their child, as reflected when a female caregiver stated, "...that school did not even try to help my child and I resent that school to this day." Another was more straightforward in her assertion, "I believe that the teachers don't like him over there, and they're already, they already got something out for (child). Period." The caregivers' negative feelings for their children's schools translated into low levels of school involvement. Four (22%) reported some level of participation in Parent Teacher Association (PTA) or other positive school activities. Only three (17%) described any intention to become active in the positive aspects of their child's school in the future.

Caregivers described an isolation from family. Several caregivers were dealing with geographical isolation from their families, but most poignant were those who were dealing with emotional isolation from their family members. One female caregiver spoke of differences of opinion that she and her mother share in regard to parenting, "And I think she talks negative to him, as far as, um, she talks negative about me, you know...I need to be doing this, ...So, she, you know...thinks I should be doing more, and I don't know what to do, and that's what my mom thinks."

In some instances, caregivers even seemed to feel isolated from themselves. When asked what they needed to make their situations better or easier to deal with, they were much more likely to answer with either what their child needed to improve, or expressed an inability to identify needs, rather than answering with what they needed.

Some of the caregivers also reported that their primary daily activity is work, leaving little energy for much else. One caregiver in particular stated this struggle very vividly, “I work constantly just to take care of my family. I don’t even get child support from my ex-wife. All I do is work. Um, that’s basically it man, I just work....It’s taken every inch of my body, all my efforts. I don’t have any activities for myself.”

Conclusion

If effective interventions for youth are to be implemented, greater understanding of the lived experience of caregivers of court-involved youth is needed. Likewise, such a level of understanding ultimately lays the groundwork for reducing caregiver strain through advocacy efforts and linkage with appropriate supports and services.

References

- Gallagher, S. K., & Mechanic, D. (1996). Living with the mentally ill: Effects on the health and functioning of other household members. *Social Science and Medicine*, 42(12), 1691-1701.
- Glaser, B., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.
- Marshall, C. & Rossman, G. B. (1999). *Designing qualitative research, 3rd edition*. Thousand Oaks, CA: Sage Publications.
- Messer, S. C., Angold, A., Costello, E. J., Burns, B. J., Framer, E. M., & Patrick, M. K. (1997). The Child and Adolescent Burden Assessment (CABA): Measuring the family impact of emotional and behavioral problems. *International Journal of Methods in Psychiatric Research*, 6, 261-284.
- Pullman, M., Savage, P, & Koroloff, N. (2003). More than money: Do family resources predict caregiver strain. In C. Newman, C. Liberton, K. Kutash, & R. M. Friedman (Eds.), *The 15th Annual Research Conference Proceedings, A System of Care for Children's Mental Health: Expanding the Research Base* (pp. 127-130). Tampa, FL: University of South Florida, The Louis de la Parte Florida Mental Health Institute, Research and Training Center for Children's Mental Health.
- Qualis Research Associates. (1998). *The Ethnograph: Qualitative data analysis software*. Denver, CO: Qualis Research Associates. Available at: <http://www.qualisresearch.com>
- Rauktis, M. B., & Miller, C. (2002). Child strengths and caregiver strain: Is there a relationship? In C. Newman, C. J. Liberton, K. Kutash, & R. M. Friedman (Eds.), *The 14th Annual Research Conference Proceedings, A System of Care for Children's Mental Health: Expanding the Research Base* (pp. 37-41). Tampa, FL: University of South Florida, The Louis de la Parte Florida Mental Health Institute, Research and Training Center for Children's Mental Health.
- Strauss, A. L., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage.

CONTRIBUTING AUTHORS

James M. Frabutt, Ph.D.

Associate Director, 336-334-5826, fax: 336-334-4435, e-mail: jmfrabut@uncg.edu

Margaret B. Arbuckle, Ph.D.

Associate Director, 336-256-1084, fax: 336-334-4435, e-mail: mbarbuck@uncg.edu

April D. Forsbrey, B.A.

Graduate Research Assistant, 336-334-4423, fax: 336-334-4435, e-mail: agforsbr@uncg.edu

All authors: Center for Youth, Family, and Community Partnerships, 41 McNutt Building, University of North Carolina at Greensboro, Greensboro, NC 27402-6170

When Caretakers Refuse to Take Children Home from a Psychiatric Facility

**Philip Friedman
Karen A. Friedman
Jane Walker**

Introduction

There is growing concern about youth with serious mental health problems whose families are unwilling or unable to take them home from a psychiatric hospital. Caregivers may feel their children have not received the necessary treatment or that they may be unable to care for their children at home safely. Some children may remain in the hospital because of the lack of outside treatment programs or more long-term placement in residential treatment centers or foster homes (Blanz & Schmidt, 2000). “Stuck kids” has become a popular term used to refer to children who are ready for discharge from psychiatric hospitals but cannot leave because of insufficient aftercare services (Gutkind, 1993). The problem is compounded when other children in need of acute care are turned away because these youngsters are ‘stuck’ in the hospital facility.

The purpose of this study is to provide empirical data to gain a better understanding of the many factors that may be related to a family’s reluctance to take their children home after they are discharged from a psychiatric hospital. A series of demographic and clinical variables will be analyzed with respect to how they are related to premature discharge becoming an issue for a family. A second focus of this study is to clarify what happens to families and their children when caregivers believe that their children are not ready to be sent home.

Methodology

Sample. The overall sample consisted of 176 families with children hospitalized for mental health reasons within the last two years. An initial survey was collected from each family. Of these 176 children, 38% were female and 62% were male. The average age was 12.8 years ($SD = 3.4$). The majority of the sample children were Caucasian ($n = 90$) with 74 African-American, 2 Hispanic, 1 Native American, and 7 biracial children.

Measure. The primary measure used was the *Listening & Learning From Families Survey*. This 25-question checklist was developed with input from families and staff of the Maryland Coalition of Families for Children’s Mental Health along with indications from the literature and technical assistance from staff at the Research and Training Center for Children’s Mental Health in Tampa, Florida. The checklist of items was tested for reliability and clinical relevance.

This survey provided information on hospital length of stay, type and intensity of services delivered, prescreening living arrangement, placement stability, demographics, and diagnosis. Key items on the survey were whether the caregiver believed that the child was ready to come home at discharge, and what happened when the family voiced these concerns. Survey variables were selected for their clinical relevance, low frequency of missing data, and likely impact on the model based on a priori examination.

Procedure. Approximately 1300 surveys were distributed throughout the state of Maryland in a variety of ways. A staff member from the Mental Hygiene Administration mailed out the bulk of the surveys using names and addresses provided by Maryland Health Partners. Surveys were also given to local coordinating councils, local management boards, departments of social services, and core service agencies throughout the state for distribution. Advertisements were placed in local newspapers and the survey was placed on a web site. The 176 surveys that were returned represent about a 14% return rate.

Completing the Families Survey involved putting a check beside the appropriate responses. If a family had more than one child who was hospitalized due to mental health problems, a separate survey was to be completed for each child. Respondents were paid \$10 for each completed survey.

Included with each survey packet was a consent form asking whether caregivers would be willing to allow an in depth interview by telephone. More than three-quarters of the families signed this consent form. Upon completion of the questionnaire, 48 families who had severe concerns at discharge were given a follow-up telephone interview. Only families who had been threatened with possible charges, been told to relinquish custody for services, or actually lost custody after the hospital discharge were interviewed further, which paid the family an additional \$25.

Results and Discussion

A series of chi-square analyses were computed to determine which demographic variables were related to whether families believed their child was ready or not ready to come home from the hospital after being discharged.

Family type, house type, and race were significant demographic variables differentiating *Ready* and *Not Ready* groups. Couples ($\chi^2(2, N = 165) = 19.1, p < .001$), non-birth parents ($\chi^2(1, N = 163) = 5.46, p < .05$), and white caregivers ($\chi^2(1, N = 154) = 5.56, p < .05$) were most likely to complain about taking their children home. It is possible that when two parents are raising children with complex medical health needs they are less willing to bring their children home without adequate services in place. Couples were also more likely to have more children in the house and were concerned about the resulting disruptions to the family.

Among the non-birth families, a relatively large proportion of adoptive parents were within the Not Ready group. Many adopted children come into families with unexpected baggage. The adoptive parents might be more willing to complain about bringing a child home once they find out how costly and difficult it is to get mental health services.

In spite of numerous hospitalizations a large proportion of families ending up in the Not Ready group reported their child's behavior was progressively deteriorating ($\chi^2(1, N = 165) = 16.75, p < .001$) and that the services they received were not meeting their child's needs ($\chi^2(1, N = 127) = 23.79, p < .01$). These families often felt they were forced to make choices and take time and resources away from their other children because of the child with mental health needs. In addition to financial burdens, families expressed exhaustion, depression and hopelessness for themselves.

In general, the more their involvement with public agencies, the more likely the caregiver felt a child was not ready to leave the hospital. Families demonstrated perseverance; some reported going to five or more agencies seeking assistance. Several families contacted advocacy organizations and elected officials including councilmen, congressmen, senators, and even the governor. Because of the intensive needs of these children and the budget constraints of agencies, responsibility for children with complex mental health needs and multi-agency involvement was often shifted from agency to agency. Shamsie, Sykes, and Hamilton (1994) suggested that the source of the ineffectiveness of psychiatric treatment for youth is the lack of continuity of care from multiple agencies—with little occurrence of follow-up. This would lead one to believe that part of the caregiver's reluctance to take their child home involves an unwillingness to deal with these outside agencies once the child is out of the hospital.

The symptomatology of the child was a major factor in the family's concerns at discharge. As shown in Table 1, most of the symptoms that showed significantly greater percentages within the Not Ready group involved safety issues for the child and others. Families tolerated many years of emotional turbulence in their homes. When families began to fear for the safety of their child, their other children, or even their own personal safety or the safety of others, they reached the breaking point. Many described situations where they were attacked or threatened by their child. Safety in the home, protection of siblings, and keeping the child safe were key reasons families stated their child should not return home even though they risked charges of abandonment for refusing to pick up their child from the hospital.

The frustration most frequently expressed by those not ready to take their children from the hospital was the inability to access residential treatment and other less traditional services such as respite care, mentoring, and intensive in-home support for a child regardless of the severity of the child's illness or the recommendation of the child's treating professionals. Caregivers reported their children waited for months for outpatient therapy or case management. This was reflected in the finding that the Not Ready group was significantly more likely to report that services received after discharge had not met their child's needs. The parents cannot have the children home without appropriate support services, and the community-based services aren't available.

Caregivers reported that when they were not ready to remove their child from the hospital this led to major confrontations with professionals (see Table 2). These included threats that charges would be brought, or that families should relinquish custody for services. During the interviews it was suggested that hospitals had initiated

state investigations that could strip families of custody. Often, parents were so intimidated by hospitals that they took home sick children only to have them re-hospitalized days later.

While there were many significant findings, some speculations about issues surrounding a caregiver's refusal to take a child home have been severely questioned. Caregiver perceptions of premature hospital discharge cut

Table 1
Breakdown of Ready and Not Ready Groups by Significant Symptoms

<i>Disability</i>	<i>Did Exhibit Symptom</i>		<i>Did Not Exhibit Symptom</i>		χ^2
	<i>Not Ready</i>	<i>Ready</i>	<i>Not Ready</i>	<i>Ready</i>	
Drug Abuse	19	9	61	77	5.22*
Threaten Family	65	50	15	36	10.40**
Out of Control	73	69	7	17	4.07*
Stealing	45	27	35	59	10.42**
Abusive	16	4	63	81	9.24**
Animal Cruelty	26	14	53	72	6.20**
Weapons	26	13	53	73	7.22**
Withdrawn	48	38	31	48	4.53*
Paranoid	36	23	43	63	6.35**

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

Table 2
Breakdown of Not Ready and Ready Groups by Response to Discharge Questions

<i>Upon Discharge:</i>	<i>Answered Yes</i>		<i>Answered No</i>		χ^2
	<i>Not Ready</i>	<i>Ready</i>	<i>Not Ready</i>	<i>Ready</i>	
Brought child home from hospital	65	86	13	0	15.57**
Given discharge plan with services	50	74	25	12	8.50**
Refused to pick up child at hospital	7	2	69	84	3.65
Told staff child was not ready	50	7	28	79	56.49**
Told staff can't care for child at home	20	2	55	84	20.12**
Told I could get in home help	29	25	46	59	1.40
Told child needed long term care in RTC	27	6	49	80	20.27**
Told to take child home while awaiting RTC	25	7	53	77	14.35**
Told to leave child while awaiting RTC	5	5	73	81	0.25
Child transferred while awaiting RTC	6	5	72	80	0.21
Told to relinquish custody for services	20	6	58	79	10.48**
Told I could lose my other children	10	1	68	84	8.76**
Told I would be charged with abuse and neglect	20	3	67	82	16.71**
Told I would be charged with abandonment	24	4	53	80	19.50**
Told about voluntary placement	9	2	67	81	5.48*

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

across number of siblings, age of child, gender of child, and whether or not the child had another disability. Hospital related factors such as frequency of hospitalizations and length of hospital stay were not significantly related to whether the caregiver believed the child was ready for discharge. There was no evidence that those who had private insurance either exclusively or together with public insurance were significantly more likely to be in the Not Ready group. Finally, there was no difference between the groups in the proportion of children ending up in a detention center or jail facility.

In conclusion, caregiver's beliefs that their children are not ready to leave the hospital and that they cannot take proper care of them at home are major issues affecting the well being of children and families and straining public agencies, providers and public resources. The issues warrant the highest priority of public policymakers.

References

- Blanz, B.U., & Schmidt, M. H. (2000). Preconditions and outcome of inpatient treatment in child and adolescent psychiatry. *Journal of Child Psychology & Psychiatry & Allied Disciplines*, 41, 703-712.
- Gutkind, L. (1993). *Stuck in time: The tragedy of childhood mental illness*. New York: Holt.
- Shamsie, J., Sykes, C., & Hamilton, H. (1994). Continuity of care for conduct disordered youth. *Canadian Journal of Psychiatry*, 39, 415-420.

CONTRIBUTING AUTHORS

Philip Friedman, Ph.D.

*Professor, Department of Human Development and Psychoeducational Studies,
Howard University, Washington, DC, 20059*

Karen A. Friedman, Ph.D.

*Research Consultant, Maryland Coalition of Families for Children's Mental
Health, 10632 Little Patuxant Pkwy, Columbia, MD 21044, 888-607-3637,
fax: 410-730-8331 email: kfriedman@mdcoalition.org*

Jane Walker, L.C.S.W.

*Executive Director, Maryland Coalition of Families for Children's Mental
Health, 10632 Little Patuxant Pkwy, Columbia, MD 21044, 888-607-3637,
fax: 410-730-8331 email: jwalker@mdcoalition.org*