

## **Chapter Three**

---

### **Family Voice and Choice**



# **Symposium**

## **Family Driven Approaches to Services, Supports, and Research**

---

### **Symposium Introduction**

Trina Osher

Goal 2 of the President’s New Freedom Commission calls for a transformation to consumer and family mental health systems and services. The Center for Mental Health Services and the Federation of Families for Children’s Mental Health are collaborating to define and conceptualize “family driven.” This process has been informed by an expert panel, open forum discussions, feedback from stakeholders, and a literature review. The three presentations in this symposium informed participants about the need for change, presented and explained the definition of “family driven” and how it was developed, and provided an example of a family driven research project.

The methodology for the first discussion was historical and conceptual. The authors analyzed system of care documents and evaluation data along with data from focus groups, and historical sources. These data were used to describe and analyze how family-agency-professional relationships have been viewed and operationalized in the past, and how these relationships and the organizational cultures and structures which frame these relationships are changing. The summary suggests how family-agency-professional relationships can be conceptualized and operationalized for service delivery and research purposes.

The second summary is descriptive; it presents details about the data gathered to draft an initial definition of family-driven care and the method used to refine and develop consensus among a wide range of individuals. The definition itself, the principles that support it, and the characteristics of family-driven care are also presented.

Third, an example of a family-driven research project conducted with scientific rigor is described. The research focuses on what facilitates the developmental pathway parents and family members follow to achieve the level of self advocacy that is commonly called empowerment. Aspects of the research discussed include the development of the research questions, the design of a randomized trial in a real world setting where family values prevail, strategies for dissemination, and what helped the partnership between families and researchers flourish.

### **Conceptualizing Family-Professional Relationships**

David Osher & Trina Osher

#### **Background**

Service delivery involves a multiplicity of transactions between families, youths, and providers. These transactions are mediated by how participants view each other’s role as well as by the needs, policies, procedures, organizational culture, and resources of providers and the agencies in which they work. The ways in which family-professional relationships are conceptualized help frame service delivery and policy development as well as services research (Hobbes, 1982; Osher, VanAker, Morrison, Gable, Dwyer, et al., 2004). Families can be ignored in children’s mental health, with intra-psycho interventions only focused on the child. Or, families can be viewed as problems that must be changed or overcome in order to improve children’s outcomes. At the same time, families can be treated as the passive receivers of services that are provided by agencies and professionals, usually through professional bureaucracies. Typically professionalized services are limited and determined by agency needs, and evaluated on the basis of agency-defined outcomes. Sometimes families are punished or rewarded based upon their compliance

#### **Chair**

Gary Blau

#### **Authors**

Osher et al.

Blau et al.

Adams et al.

with the demands of agencies and the professionals who the agencies employ (Cloward & Piven, 1974; Sjoberg, Brymer, & Farris, 1966). Alternatively, families and youth can be viewed as allies who can implement and support professionally-driven approaches. Finally, families can be treated as active agents in the development, implementation, and evaluation of interventions (Osher & Osher, 2002).

Traditional children's mental health services ignored families, or blamed them for their children's disorder. These services were provider-driven in that professionals and agencies were viewed as the key force in solving problems. By virtue of their training, professionals were assumed to possess expertise and tools to diagnose problems; to have unique knowledge to prescribe solutions; the precise skills to implement, monitor, and evaluate the prescribed interventions; and the capacity to do all of this in a manner that is consistent with professional ethics and agency procedures. Professionals asked the questions, identified and interpreted the symptoms, dictated the treatment, and evaluated the results. Professionals were expected to employ their professional expertise to fix presenting problems, and in some cases, the clients themselves. Professionals, socialized into this delivery role expected compliance from relatively passive clients, as well as deference from other professionals and paraprofessionals in acknowledgement of their expertise. Similarly, many agencies were organized around a model that viewed the agency as the key source of change. Under this provider-driven paradigm, assessment was deficit oriented and specific to isolated problems. Specific problems were conceptualized as being located in the child or family (Ryan, 1972), and were focused upon and addressed accordingly. Given the resource limitations, the focus on deficits and the need to manage, expectations were low and modest.

### **Family Focused Care**

Systems of care for children's mental health represented an advance on in comparison to the victim-blaming approach that ignored the child's ecology. Systems of care focused on families, not just the individual child, calling for "the needs of the child and family" to dictate "the types and mix of services provided" (Stroul & Friedman, 1986, p. xxiv). Families, under this model, "should be full participants in all aspects of the planning and delivery of services" (Stroul & Friedman, 1986, p. xxiv). This model and the implementation of the Comprehensive Mental Health Services for Children and their Families Program, initiated in 1992, started to transform the relationships between families, professionals, and agencies, and in some cases, youth (Osher, deFur, Nava, Spencer & Toth-Dennis, 1999 ). Systems of care also challenged agency-driven practices which involved resource-driven planning by isolated agencies. They called for individualized service planning and employed flexible funds. Over time the model was elaborated to include culturally competent strength-based approaches, which also affected attitudes toward families. However, as conceptualized in the 1980s and implemented in the 1990s, the system of care model was *family-focused*, not *family-driven*. The language of family focus could promote and support the type of strengths-based family-professional partnerships that were part of good wraparound planning (Kendziora, Bruns, Osher, Pacchiano, & Mejia, 2001). However, the language of family focus could also continue to support more paternalist approaches, which, while focusing on families, and addressing family needs, *wrapped the services* around families and children, and evaluated services based on professional and agency criteria. In fact, practices in many communities still revolve around the needs, expertise, and resources of professionals and agencies.

### **Family Driven Care**

The development of a robust family movement in children's mental health, as well as the more widespread use of strength-based individualized approaches to service planning in the 1990s, stimulated changes in service delivery and agency culture. These changes are consistent with consumer-driven approaches to service delivery in adult education (e.g., Osher & Webb, 1994), family-centered approaches to early intervention (Dunst, 1997), calls for collaboration with families in education (U. S. Department of Education, 1994), community-building approaches (Dunst, Trivette, Starnes, Hamby, & Gordon, 1993), and consumer-directed approaches to health care and disability support (National Council on Disability, 2004).

Where family-driven approaches have flourished, families are viewed and treated as having important and even expert knowledge gained from experience and/or training. Families are expected to contribute to defining the nature of the presenting problems, the various factors contributing to them, and the range of strategies that could effectively resolve these problems. In these settings and communities, service planning and access are truly based on how the needs of a specific child or group of children and their families can best be met. Now families and youth determine what services and supports are “wrapped” and in what manner. For example, the team planning services now consider the family’s schedule, childcare, work responsibilities, and transportation needs in selecting and scheduling specific services from among all the providers in the community.

## Conclusion

The paradigm shift in family role, however, has not been fully addressed in the literature on systems of care. The failure to elaborate the distinctions between being family-focused and family-driven in the system of care literature has led to ambiguous research and policy. For example, professionals can target the passive parent while focusing on the family, or deliver family-focused treatments at a time and place that is convenient to them and their employer. This ambiguity can lead to unfulfilled expectations on the part of families and service providers alike due to confusion of distinct approaches at a rhetorical and a conceptual level. Similarly the failure to compare, contrast, and align conceptualizations of family driven approaches with conceptualizations of family-centered approaches and youth directed approaches may confound systemic change, practice change, and services research at a time when communities are starting to align different systems (e.g., early intervention and mental health) and the consumer youth movement is developing a model of youth directed care.

## References

- Cloward, R. A. & Piven, F. F. (1974). *The politics of turmoil: Essays on poverty, race, and the urban crisis*. New York: Pantheon
- Hobbes, N. (1982). *The troubled & troubling child*. San Francisco: Josey Bass.
- Dunst, C. J. (1997) Conceptual and empirical foundations of family-centered practice. In R. Illback, C. Cobb, & H. Joseph. (Eds.), *Integrated services for children and families: Opportunities for psychological practice*. (pp. 75-91). Washington, DC: American Psychological Association.
- Dunst, C. J., Trivette, C. M., Starnes, A. L., Hamby, D. W. & Gordon, N. (1993). *Building and evaluating family support programs*. Baltimore: Paul Brookes.
- Kendziora, K. T., Bruns, E., Osher, D., Pacchiano, D., & Mejia, B. (2001). *Wraparound: Stories from the field*. Washington, DC: Center for Effective Collaboration and Practice, American Institutes for Research
- National Council on Disability. (2004). *Design for inclusion: Creating a new marketplace*. Washington, DC: Author
- Osher, D., VanAker, R., Morrison, G., Gable, R., Dwyer, K., & Quinn, M., (2004). Warning signs of problems in schools: Ecological perspectives and effective practices for combating school aggression and violence. In M. J. Furlong, G. M. Morrison, D. Cornell, & R. Skiba (Eds.), *Issues in school violence research*. Binghamton, NY: Haworth Press.
- Osher, D. & Webb, L. (1994). *Adult literacy, learning disabilities, and social context: Conceptual foundations for a learner-centered approach*. Washington, DC: U.S. Department of Education.
- Osher, T. W., deFur, E., Nava, C., Spencer, S., & Toth-Dennis, D. (1999). New roles for families in systems of care. *Systems of care: Promising practices in children’s mental health, 1998 series, Volume 1*, (pp. 68-70) Washington, DC: Center for Effective Collaboration and Practice, American Institutes for Research.
- Osher, T. W., & Osher, D. (2002). The paradigm shift to true collaboration with families. *Journal of Child and Family Studies*, 11(1), 47-60.

Ryan, W. F. (1972). *Blaming the victim*. New York: Random House.

Sjoberg, G., Brymer, R. A., & Farris, B., (1966). Bureaucracy and the lower class. *Sociology and Social Research*, 50, 325-337.

Stroul, B. A. & Friedman, R. M. (1986 rev.) *A system of care for children and youth with severe emotional disturbances*. Washington, DC: National Technical Assistance Center for Children's Mental Health.

U.S. Department of Education Office of Special Education and Rehabilitative Services Office of Special Education Programs (September 1, 1994). *National agenda for achieving better results for children and youth with serious emotional disturbance*. Washington, DC. Author

## **Family Driven Care**

**Gary Blau & Trina Osher**

### **Introduction**

To promote the transformation of children's mental health care called for by *Achieving the Promise*, the Center for Mental Health Services commissioned the Federation of Families for Children's Mental Health to develop an operational definition of family driven care. This summary presents the definition, the method used to develop it, and the literature that supports it. The guiding principles of family driven care and the conditions that exist in a family driven care model are also presented.

During the 1990s children's mental health underwent a paradigm shift from provider-driven approaches, which focused on families to family-driven approaches (Osher & Osher, 2002). This paradigm shift moved from viewing families as the passive receivers of services who were expected to carry out professional prescriptions to partners in the development, monitoring, and evaluation of services. The development of the family movement in children's mental health, the roles played by families in systems of care (e.g., Osher, deFur, Nava, Spencer & Toth-Dennis, 1999), calls for family-professional collaboration in the education of children with serious emotional disability (SED; U.S. Department of Education 1994), and the conceptualization of Family Centered Approaches in Early Intervention work (Dunst, 1997) contributed to this paradigm shift. The President's New Freedom Commission recognized this shift when it called for family and consumer driven services. The Center for Mental Health Services continued this process by commissioning an effort to define and conceptualize family-driven care.

Systematically making the transformation to family-driven care is dependent upon having a common understanding of what family-driven care is, the principles that support it, and the conditions that exist in systems, programs, and services that operate in accordance with those principles. From the beginning, we recognized that the definition of family-driven care needed to be acceptable to diverse families, be applicable in a wide variety of settings, and be usable by a widely varied professional, paraprofessional, and volunteer workforce. It also needed to be concise and free of jargon and technical terms.

### **Methodology**

#### **Gathering Data**

There were several methods used to collect information to use in formulating the definition of family driven care. These included a literature review, intensive and in-depth conversations with an expert panel, and interviews with recognized leaders in the family movement. Themes that emerged appear in Table 1.

**Table 1**  
**Themes Identified to Shape Definition of Family-Driven Care**

---

*Valuing Families and Youth*

---

- Voice of families and youth are welcomed, heard, and responded to
- Every family is included
- Systems, programs, and provider hear the ideas, concerns, and needs of families and use these to make decisions and service changes
- Families and youth are in the driver's seat as well as have a voice at the table
- Safety for families and youth to disclose
- True Partnership with Families and Youth
- Genuine respect for families and youth
- Sharing power, resources, authority, control, and responsibility for outcomes
- Partnership is standard operating procedure, default, continual, and routine
- No longer make decisions without families and youth giving input
- Family and youth participation is supported and funded
- Formal credentials get respect but no special privilege
- Comfort and trust zone for families, youth, and professionals
- Family-driven practice is evident in all systems, programs, service teams, and services
- Everyone takes responsibility for transforming systems to be family-driven
- Risk management is a collective responsibility and aims to do what is in the best interest of families and youth
- Procurements, require and treatment approaches incorporate family-driven practice
- Training and Support
- Every one gets initial and ongoing training and support to participate in a family-driven system of care
- Family-driven practice is infused in preservice training in all disciplines
- Cultural Competence
- Family-driven practice and cultural competence are inextricably linked
- The cultures of families and communities provide the overarching framework for operating family-driven system of care

---

### **Field Testing and Revision**

The initial definition was released in June 2004 and widely circulated with a request for feedback. Open forums to gather reaction and comments were held at the Training Institutes conducted by the National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development. Detailed notes were made to record all recommendations. A second draft was released in September 2004. This version was circulated electronically and incorporated into workshops, panel, presentations, and keynote addresses for a wide variety of audiences. The third version (October 2004) made adjustments based on audience reaction to these presentations. It became evident that the concise definition could not stand alone. Therefore, the fourth version incorporated the principles and conditions that exist in family driven care models. Refinements were made in November 2004.

## Results

The definition presented and discussed was the 10<sup>th</sup> version. It is called the working definition because we see it as a living definition that may evolve over time as we gain further insights from its implementation. Family-driven means *families have a decision making role in the care of their own children as well as the policies and procedures governing care for all children in the community, state, and nation*. This includes choosing supports, services, and providers; setting goals; designing and implementing programs; monitoring outcomes; and determining effectiveness of all efforts to promote the mental health of children and youth.

Ten guiding principles that support the definition and implementation of family-driven care were identified. These are:

1. Families and youth are given accurate, understandable, and complete information necessary to make choices for improved planning for individual children and their families.
2. Families and youth embrace the concept of sharing decision-making and responsibility for outcomes with providers.
3. Families and youth are organized to collectively use their knowledge and skills as a force for systems transformation.
4. Families and family-run organizations engage in peer support activities to reduce isolation, gather and disseminate accurate information, and strengthen the family voice.
5. Providers embrace the concept of sharing decision-making authority and responsibility for outcomes with families and youth.
6. Providers take the initiative to change practice from provider-driven to family-driven.
7. Administrators allocate staff, training, support and resources to make family-driven practice work at the point where services and supports are delivered to children, youth, and families.
8. Community attitude change efforts focus on removing barriers and discrimination created by stigma.
9. Communities embrace, value, and celebrate the diverse cultures of their children, youth, and families.
10. Everyone who connects with children, youth, and families continually advance their cultural and linguistic responsiveness as the population served changes.

Six conditions that exist in family-driven care model have been identified. They are:

1. Family and youth experiences, their visions and goals, their perceptions of strengths and needs, and their guidance about what will make them comfortable steer decision making about all aspects of service and system design, operation, and evaluation.
2. Family-run organizations receive resources and funds to support and sustain the infrastructure that is essential to insure an independent family voice in their communities, states, tribes, territories, and the nation.
3. Meetings and service provision happen in culturally and linguistically competent environments where family and youth voices are heard and valued, **everyone** is respected and trusted, and it is safe for everyone to speak honestly.
4. Administrators and staff actively demonstrate their partnerships with all families and youth by sharing power, resources, authority, responsibility, and control with them.
5. Families and youth have access to useful, usable, and understandable information and data, as well as sound professional expertise so they have good information to make decisions.
6. All children, youth, and families have a biological, adoptive, foster, or surrogate family voice advocating on their behalf.



## References

- Dunst, C. J. (1997). Conceptual and empirical foundations of family-centered practice. In R. Illback, C. Cobb, & H. Joseph (Eds.), *Integrated services for children and families: Opportunities for psychological practice* (pp. 75-91). Washington, DC: American Psychological Association.
- Osher, T. W., deFur, E., Nava, C., Spencer, S., & Toth-Dennis, D. (1999). New roles for families in systems of care. *Systems of care: Promising practices in children's mental health, 1998 series, Volume 1*, (pp. 68-70). Washington, DC: Center for Effective Collaboration and Practice, American Institutes for Research.
- Osher, T. W., & Osher, D. (2002). The paradigm shift to true collaboration with families. *Journal of Child and Family Studies, 11*:1, 47-60.
- U.S. Department of Education Office of Special Education and Rehabilitative Services Office of Special Education Programs. (September 1, 1994). *National Agenda for achieving better results for children and youth with serious emotional disturbance*. Washington, DC: Author

## Results Matter: Building an Evidence Base for Family Support

Jane Adams, Corrie Edwards, Sarah Adams, & Kimberly Kendziora

*Inquiries should be addressed to Kimberly Kendziora, Ph.D., Senior Research Analyst, American Institutes for Research, [kkendziora@air.org](mailto:kkendziora@air.org)*

### Introduction

This part of the symposium described the process and content of a collaboration between Keys for Networking, Inc., and the American Institutes for Research to develop an evidence base for family support. The collaboration had four components. The first component conducted the first experimental assessment of the impact of parent-to-parent support on child and family outcomes. The second component examined the implementation of a process for data-driven decision making for parents and their advocacy experiences. A third examined dissemination of a parent support model to diverse state contexts. Last, the collaboration offered an example of rigorous family-driven research.

### Background

For decades, family-run organizations have provided support and advocacy to caregivers of children with mental health, child welfare, special education, or juvenile justice involvement, often at no cost to the families. The interventions provided by these organizations have never been systematically studied; therefore, there is currently no empirical evidence base to support their work. The development of such an evidence base would facilitate progress toward major policy goals for family support organizations, including strengthening their role in systems of care and securing coverage for their services in public and private insurance.

### Keys for Networking

Keys for Networking, Inc. (Keys), a nationally prominent consumer-run family support organization headquartered in Topeka, Kansas, has contracted with the American Institutes for Research (AIR) to assist them in planning a scientifically valid impact evaluation of their work. Keys maintains a comprehensive database that allows for active tracking of the families they serve. Keys knows whom they serve, what callers want, and what interventions are provided. This solid collection of *process* information facilitates the design of an *impact* evaluation.

At the beginning of the collaboration, Keys focused on the impact of Targeted Parent Assistance on parents. Data from their existing records were able to demonstrate that parents who were clients of the agency did indeed move from information-seeking, overwhelmed (level 1) to problem solvers (level 4) to levels of progressively greater advocacy for others.

Additional research questions have emerged as our work has evolved. Here we present these questions and the status of our thinking about them and working on them. The set of questions addressed includes:

- Is Targeted Parent Assistance any more effective at leading to positive family and child outcomes than parent support as usual?
- What is the impact of Targeted Parent Assistance on family outcomes?
- What is the impact of Targeted Parent Assistance on the systems in which children are served and in which parents advocate? (Specifically, how does Targeted Parent Assistance affect child educational outcomes as they pertain to IDEA and the No Child Left Behind Act?)
- How can the process of being evaluated help those delivering Targeted Parent Assistance prepare parents to assume collaborative leadership roles with schools by teaching them to make data-driven decisions for their own child and for classroom and schoolwide improvements
- How can the model of Targeted Parent Assistance be disseminated, transported, and implemented in new states? Specifically, how can results of this work be transferred to state and national parent networks, and school communities to influence approaches to parent support?

## Components of the Research

### The Randomized Trial

The gold standard for knowledge of whether an intervention is effective involves comparing outcomes for participants who receive it with those who do not. The current environment of accountability and differential promotion of practices with demonstrated effectiveness demands that knowledge about parent support be raised to meet this gold standard. Therefore, within a context of a commitment to high-quality service to families, Keys and AIR have proposed testing the proactive Targeted Parent Assistance parent support model against the more reactive support-only models that many parent support organizations use in early stages of development. This effectiveness trial will establish which model produces better parent and child outcomes for which families.

In the Targeted Parent Assistance condition, we will call each family no less often than every 30 days to assess the usability of the recommendations from the last contact, apply interventions for the level at which the parent is currently identified, and then offer interventions that would boost the parent to the next level. In the support-only condition, parents who call Keys will still receive the same high-quality response they would get if they were in the Targeted Parent Assistance condition. The difference is that we will not call them back every 30 days, and we will not specifically recommend training unless they request it. They will be eligible to get whatever services we have available—but they must *ask* for it.

### Promoting Data-Driven Decision Making

In our collaboration, we have been studying how parents' empowerment affects individual child academic outcomes as mediated by parent engagement with educators. We also examine the impact of parental use of Getting to Outcomes (GTO; Chinman et al., 2004), an empowerment process for collaboratively planning, implementing, and evaluating any initiative. In our context, parents use the GTO process to define their own desired school outcomes, access information, evaluate reliable resources, master basic research methodologies, and network with other parents to influence decisions with a collective, reasoned voice.

GTO is a user-friendly process to help community groups navigate the maze of designing prevention and treatment programs. In GTO, the innovative characteristic is an approach that helps users link all the necessary program elements together into a logical and carefully planned coherent whole, thereby increasing the likelihood of achieving desired outcomes and demonstrating accountability to key stakeholders. With increased ownership of the evaluation process, practitioners may better realize the importance of evaluation, understand evaluation methods, and promote capacity among staff and stakeholders. If effective, GTO provides parents with direction on how best to use their time and energy

to support their own child's progress and success. Parental use of GTO can provide teachers, for example, with direction to prioritize the various parent invitations to participate in classroom activities. Further, this component of our research can help school and district decision makers establish effective parent outreach opportunities for families and provide state and national family organizations with direction to allocate very limited and sparse dollars to efforts that provide the most payback for parents and for children.

### **Dissemination and Transportability to Additional Sites**

An increasing research base provides information on how best to diffuse effective innovations to new settings. As a part of our research we collect data on the process of training and implementing Targeted Parent Assistance in at least four additional sites that currently employ the standard support model. To maximize learning, dissemination sites should represent a variety of geographic contexts, including large and small cities, suburbs, rural environments, and frontier environments. We have prepared for transportability in three ways. First, Keys and AIR will deliver an annual workshop at the Federation of Families for Children's Mental Health Conference. The workshop will focus not only on implementing Targeted Parent Assistance, but also on extending the evaluation work to their sites. Second, the executive director and member of the technology and program staff of the dissemination will visit Keys for three days of training in the model and the evaluation. Third, Keys staff who are expert in both Targeted Parent Assistance and management information/data collection will visit dissemination sites to provide additional training and technical assistance.

### **Family-Evaluator Collaboration**

It is worth noting that one reason for the paucity of research in this area is the challenge of conducting research that is consistent with the values of the broader parent support movement (Kagan & Weissbourd, 1994). In a report from a national meeting of leaders in family support evaluation, Diehl (2002) proposed three criteria for meaningful evaluations of family support programs.

1. Families and other stakeholders must be included in the development and implementation of the evaluation framework. We accomplish this goal by establishing a Research and Ethics Council for logic model refinement and data interpretation, employing only family members as data collectors, and involving family members in reporting and presenting findings.

2. Evaluation methods and tools must be appropriate to capture the work of family support initiatives. We accomplish this goal by using several cutting-edge research tools, such as "journey mapping" scores, which capture numerically a highly qualitative concept, and a growth curve approach to data analysis, which allows the data that tell a family's story to unfold gradually over time.

3. Evaluation must be culturally relevant and evaluators must be culturally competent. As we move toward disseminating this model to more racially, ethnically, and linguistically diverse communities, we will pay special attention to composing evaluation staff who reflect the community served. We work toward achieving this goal by continuing to respect individual family cultures in the evaluation through our partnership-based approach to this research.

### **References**

- Chinman, M., Young, A. S., Schell, T., Hassell, J., Mintz, J. (2004). Computer-assisted self-assessment in persons with severe mental illness. *Journal of Clinical Psychiatry*, 65(10), 1343-1351.
- Diehl, C. (2002). *Issues In family support evaluation: Report from a meeting of national thought leaders*. Chicago: Family Support America. Available at: [http://www.frca.org/downloads/Eval\\_monographEAW.pdf](http://www.frca.org/downloads/Eval_monographEAW.pdf)
- Kagan, S. L. & Weissbourd, B. (Eds.). *Putting families first: America's family support movement and the challenge of change*. San Francisco, CA: Jossey-Bass.

---

## **CONTRIBUTING AUTHORS**

---

### **Jane Adams**

*Executive Director, Keys for Networking, Inc. 1301 South Topeka Blvd., Topeka KS 66612, 785-233-8732, e-mail: jadams@keys.org*

### **Sarah Adams**

*Director of Technologies, Keys for Networking, 111301 SW Topeka Boulevard, Topeka, KS 66612*

### **Gary Blau**

*Branch Chief, Child, Adolescent, and Family Branch, Center for Mental Health Service, 1 Choke Cherry Road Room 8-1051, Rockville MD 20857, 240-276-1980, fax: 240-276-1990, e-mail: gary.blau@samhsa.hhs.gov*

### **Corrie Edwards**

*Program Director, Keys for Networking, 111301 SW Topeka Boulevard, Topeka, KS 66612*

### **Kimberly Kendziora**

*Senior Research Analyst, American Institutes for Research, 1000 Thomas Jefferson St. NW, Washington DC 20007-3835, 202-403-5391, fax: 202-403-5001, e-mail: kkendziora@air.org*

### **David Osher**

*Director, Center for Effective Collaboration and Practice, American Institutes for Research, 1000 Thomas Jefferson Street, N.W., Washington DC 20007, 202-403-5373, fax: 202-403-5007, e-mail: dosher@air.org*

### **Trina Osher**

*Coordinator of Policy and Research, Federation of Families for Children's Mental Health, 1101 King Street, Suite 420, Alexandria VA 22314, 703-684-7710 fax: 703-836-1040, e-mail: tosher@ffcmh.org*

## **Topical Discussion**

# **Building Creative Partnerships: Sustaining Family Involvement in Evaluation**

---

Sheila Bell  
Norin Dollard  
Michelle Zadrozny

### **Introduction**

One of the core values in a system of care is that the service system be family centered and family driven. This value charges systems to involve family members in more than just planning for their child's services, but to also enrich the system itself by involving families at all levels. Successful systems of care ensure that families are involved not only at the service delivery level, but also at the administrative levels which involve budgeting, planning, policy making, and evaluation. This summary describes best practices identified by three Substance Abuse and Mental Health Services Administration system of care grantee communities—Austin, Texas, Tampa, Florida, and Pittsburgh, Pennsylvania—for involving families in evaluation processes over a six-year implementation period. Areas discussed below include: family members as evaluation staff, family members on evaluation committees, and providing training and technical assistance opportunities for family involvement in evaluation.

### **Family Members as Evaluation Staff**

Discussions revealed that hiring a family member as an evaluation staff member is a rewarding best practice standard for all systems of care. There are several evaluation positions a family member can fill. In some grantee communities, family members are hired as the data collection staff for the national evaluation. In others, a Family Evaluator position is created to work directly alongside the Evaluation Director. In such instances, it appears important that the person hired is able to act foremost in his/her family capacity, that is, as a family member with the personal expertise as a caretaker of a child with a serious emotional disturbance. Some professional evaluators may also be family members; however, their professional roles may make it difficult to put their family experiences first in their jobs.

There were several challenges described which systems must face in order to hire a family member as a staff person. For example, the hiring entity may require specific credentials or educational requirements that could hinder the hiring of a family member in an evaluation role. In this case, discussants stressed it is important to keep working at changing the system to allow for flexible hiring practices for family members so the family expertise for which they are hired is valued and compensated. The provision of training and support to family members was identified as an essential element to ensure that the family perspective effectively guides the evaluation. Many family members are also advocates for their children and they utilize data and information in this work; if this is written on a resume, their knowledge and experience relevant to evaluation is documented.

Another challenge for families hired as evaluators is working alongside evaluation professionals who may feel threatened by their presence. Most program evaluators have completed extensive college training in the areas of statistics and research. Hiring a family member who may not have a background in this area may make the professional evaluator feel research skills are devalued and may cause tension between staff. This is especially true when family members are involved in more than the data collection phase, such as data interpretation and reporting of results. Just as family members need training and support to fulfill their roles in the evaluation, program evaluators need training and support to understand their own roles as mentors and teachers to family members, the diverse ways in which family members can be involved in evaluation and how they, and the evaluation products, will benefit from that involvement. There should also be clarity about the roles of the program evaluator and the family evaluator. Although the family member may not be running the statistics or choosing a study design, they can still be involved in those activities in meaningful ways that will enhance the evaluation overall. In some instances, rather than being judged on the quality of their work, family members have been dismissed as being unable to be objective in the conduct of the evaluation solely because of their status of *family member*.

There are several benefits to overcoming the challenges discussed above. Family members who take these roles can benefit by having new ways to advocate due to their involvement with collecting and interpreting data. Family members hired can also help to train other family members on the importance of evaluation and can explain to others why research studies are being conducted and how they can participate. Family members as data collectors can add a level of trust to the interview process so that the data collected are more reliable and valid. Finally, family members benefit by changing the system in a role other than as an advocate. Professional evaluators have much to gain by this partnership. They should experience a new appreciation for the data they are collecting, as the family member helps them to see the questions and results from their viewpoints. Professionals also benefit by seeing high retention rates when families collect data or help others to understand the importance of data. Surveys designed by parent-professional partnerships are also better, as family members can monitor the questions for language and content so that respondents will be more likely to answer. In the end, hiring a family member evaluator can be a win-win situation for all parties involved.

### **Family Members on Evaluation Committees**

Another way to involve family members in evaluation is to form an evaluation committee where family members and system partners have the opportunity to come together to evaluate and interpret data. A committee structure can also provide opportunities for staff to form ad hoc or standing subcommittees pertaining to specific evaluation or quality improvement/assurance issues.

One of the activities an evaluation committee can take on is to decide what information is needed to guide decision making processes. This involves prioritizing and monitoring what types of data are collected and how they are collected. The committee provides a good forum for reviewing surveys and focus group questions. The committee also can help to interpret outcomes gathered through the data collection process. Further, a committee can look for ways to improve the quality of services and supports for children and families, based on what the team sees in the collected outcomes. This continuous quality improvement process helps youth and families select those services that are right for them and helps system-of-care staff find services that youth and families want and need. This information can also be used by family committee members to let policy makers and system funders know what is working and what should be funded.

Subcommittees may develop specific projects that support evaluation, such as use of data in social marketing, involving youth in evaluation, presenting data to key audiences, training others about evaluation, creating targeted outcome reports, helping to hire evaluation staff members, and writing proposals to obtain funding for evaluation studies and activities.

There are several challenges to establishing and maintaining an evaluation committee. The first is funding. To ensure the opportunity for family members to attend, childcare and transportation should be provided. Stipends or honorariums should also be offered to family members who sit alongside paid professionals at these meetings since they are there for their family experience expertise. Finally, the offering of refreshments at these meetings can help to “break the ice” among members. However, these items can become costly, especially if the committee meets frequently. Some strategies to meet this challenge could include partnering with a local family organization, soliciting refreshment donations, combining evaluation meetings with an existing committee, having fund raisers, and seeking funding through a grant or foundation.

There are several benefits to establishing and maintaining evaluation committees with family membership. First, the partnerships that form between professionals and family members often cross over into other areas of the system of care beyond the evaluation components. Working with the committee also affords a richer system-of-care evaluation as multiple voices are heard in the process. Committees can

review questions and evaluation reports for content to make them more reader-friendly. They can also help collect data and design studies that will best meet the needs of the population, ensuring a greater chance at successful implementation and the likelihood of participation. Finally, holding an evaluation committee is a learning opportunity for professionals and family members alike. Each party learns something about where the other is coming from, which in turn can help change systems for the better.

### **Providing Training and Technical Assistance Opportunities for Family Involvement in Evaluation**

In order to include family members as key participants, it is crucial that systems of care offer training and technical assistance opportunities for families in evaluation. Many local and national organizations offer these types of trainings. For example, the Federation of Families for Children's Mental Health offers three levels of evaluation training for parents. Supporting families through grantee dollars to participate in this training can help to provide a starter group of family members for an evaluation committee. Systems could also design their own evaluation training and eventually have parents co-train. Another opportunity for family members could include co-presenting at conferences on data and evaluation topics. Evaluation staff also can offer technical assistance to families who need assistance with data for advocacy or for their own evaluation studies.

Again, funding can present a challenge to providing extensive training and technical assistance opportunities. However, many conferences and training events have stipends for family member attendance. The role of trainer can also become a part of professional evaluation staff job descriptions so that this component can continue. Recruiting family members for this type of work can sometimes be challenging (many find data and evaluation to be a somewhat boring topic or irrelevant to what they do). However, the onus is on the trainers to make the topics relevant and interesting to those they want to involve. Data are powerful tools for advocacy and system change. Framed this way, many family members and professionals are likely to want to learn more.

Without a comprehensive and regular training and technical assistance component for family members about evaluation, their involvement may dwindle and even be non-existent. It is critical for professionals to "level the playing field" by ensuring that family members have the information they need to sit as equal partners at the table and participate in evaluation and quality assurance efforts in the system of care.

---

**CONTRIBUTING AUTHORS**

**Sheila Bell, M.A.**

*Evaluation Coordinator, Allegheny County System of Care Initiatives, 304 Wood Street,  
Pittsburgh, PA 15222, 412-350-5760, fax: 412-350-3458,  
e-mail: sbell@dhs.county.allegheny.pa.us*

**Norin Dollard, 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,  
813-974-3761, e-mail: dollard@fmhi.usf.edu*

**Michelle Zadrozny, L.M.S.W.**

*Program Evaluator for Children's Partnership, Austin TX*



# **Youth Involvement in Systems of Care: Youth and Youth Coordinators' Perspectives**

Natalie Henrich  
Phyllis Gyamfi

---

## **Introduction**

Involving youths in their own services is an emerging phenomenon that still faces resistance but is becoming increasingly accepted. Youth report significant benefits associated with their involvement, such as developing positive relationships with adults, learning responsibility and new skills, and feeling positive about themselves and contributing to their community (Linetzky, 2000; Quinn, 1995). But benefits from youth involvement do not accrue only to youth. When youth participate in organizations' activities and decision-making, adults who work with the youth develop improved perceptions of youth and become increasingly engaged in their organizations and communities, and organizations are better able to target programs to youth needs and to use youth as effective spokespersons for fundraising (Zeldin, McDaniel, Topitzes & Calver, 2000).

Recognizing the value of youth involvement, the Substance Abuse and Mental Health Services Administration (SAMHSA) mandated youth involvement in all SAMHSA-funded system-of-care communities that have been awarded grants since FY2002. While the mandate specified that all of these systems of care were required to hire a youth coordinator, the details of the youth coordinators' role and the nature of youth involvement were left vague (Department of Health and Human Services, 2002). Consequently, each system of care is working to determine what youth involvement will mean in its community and how this involvement will be implemented. Although the mandate for youth involvement in systems of care is new, many systems of care that began receiving funding prior to the mandate have engaged youth in different ways and to varying extents.

At this recent convergence of voluntary and mandated youth involvement, the national evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program of the Center for Mental Health Services (CMHS) has included a longitudinal assessment of the status of youth involvement in systems of care. The first stage of this assessment involved focus groups with youth coordinators and youths from across the nation. The findings from these focus groups shed light on (a) how youths are currently engaged in their communities, (b) areas in which youth involvement is absent or minimal, (c) the role of youth coordinators in developing youth involvement, (d) the challenges to youth involvement and strategies for overcoming the challenges, and (e) the benefits to youth from being involved in their systems of care. In addition to increasing awareness about youth involvement in systems of care, the focus group findings will also be used to inform the development of a youth interview that will be administered longitudinally to youths in all federally-funded systems of care as part of the CMHS national evaluation.

## **Method**

Between May and October 2004, focus groups were conducted with youth coordinators and youths from system-of-care communities funded between 1999 and 2003. The two youth coordinator discussions were held at a national system-of-care meeting and a national youth coordinators training conference. A total of 11 youth coordinators representing systems in varying stages of development and diverse geographical areas participated in the discussions. The topics discussed in these focus groups were (1) the role of youth coordinators and youth in their systems of care, (2) the challenges that youth coordinators confront in conducting their work and in trying to get youth involved, and (3) strategies for addressing the challenges.

Of focus groups with youths from system-of-care sites, one was conducted at a national system-of-care conference, and the remaining two youth focus groups were held in system-of-care communities. A total of 22 youths (ages 14-22; 6 White, 16 African American/Black) participated in these focus groups.

Topics covered in the youth discussions were youth groups, and youth involvement in the infrastructure (e.g., governance, conducting of trainings, quality monitoring) and service components of systems of care. Each focus group lasted 1.5 hours and participants were compensated \$50 for their participation (youth coordinators received gift cards and youths received cash). Thematic analyses were conducted using Atlas.ti (Scientific Software Development, 1997).

## Results

Consistent patterns about youth involvement emerged from the youth and youth coordinator focus groups. Both types of respondents identified youth groups as the key mechanism for youth involvement, and it was heavily stressed that these groups need to have a strong social emphasis. Primarily because of issues related to stigma, youth resist joining groups that are about emotional and behavioral problems. However, the youth do appreciate the opportunity to discuss their problems and get emotional support from other youths and staff within a context of coming together to form friendships and participate in fun activities. Stigma was identified as occurring on two levels: (a) the youths do not want to be associated with a group for people with emotional and behavioral problems because of what people outside the system of care will think of them, and (b) some youths do not want to be in a group because they think that people who participate in youth groups have more severe problems and thus they do not identify themselves as being similar to group members.

Youths who are involved in youth groups derive significant benefits from the experience. They value the support they receive from their peers and the staff and the relationships they form in the group. The group also provides a safe place to go and this helps keep the youths out of trouble. As well, youths credit participation in the youth group with helping them develop strategies for coping with their problems.

Other than in youth groups, youth involvement in systems of care is limited. There was little evidence of youths being involved in planning their services, providing feedback on the services they receive, providing trainings or other services, or participating in the decision-making process for their system of care (such as through membership on committees and boards). It appeared that youths were often unaware that they *could* be involved in these activities, although the youth coordinators were aware of the different domains in which youth could participate. In fact, some youth coordinators felt that system-of-care administrators were actively trying to prevent youth coordinators from informing youths about their rights and involvement options because of a general resistance to involve youth. Other barriers to youth involvement include an absence of a true commitment to creating environments in which youths are able, or feel welcome, to participate such as when board meetings are held during school hours or food and transportation are not provided. Youth coordinators report that they are actively working to engage youths in these domains from which they are currently excluded.

Youth coordinators identified several key challenges to youth involvement. Most significant was a lack of support from the system-of-care community and a pervasive “tokenism” mentality. This lack of buy-in for real youth engagement impacts programmatic decisions such as budget allocations for youth involvement, which was often insufficient or unstable. A general lack of support for youth involvement also impacted how youth coordinators are perceived and treated, and many find an unwillingness of system staff to share information about youths and a lack of power to make or implement decisions.

Youths and youth coordinators suggested strategies for increasing youth involvement and addressing societal and system-level barriers to involvement. These strategies include community outreach and education to reduce stigma, creating a social or youth-friendly atmosphere at system-of-care activities in order to increase youth attendance, and clarifying and formalizing the youth mandate so that there is consistency and stability related to youth involvement.

## **Conclusion**

Both the youths and the youth coordinators conveyed similar experiences of youth involvement in systems of care, such as a lack of awareness by youths about the ways in which they could be involved in their communities, the importance of including social activities in youth groups, and an absence of a youth voice in decision-making arenas within systems of care. This consistency is important because two of the three youth focus groups were conducted in system-of-care communities and thus cannot be assumed to be representative of youths from other systems of care. However, the youth coordinator focus groups included youth coordinators from eleven systems of care and thus their experiences are more likely to capture the range of youth involvement across the nation. The congruity between descriptions of youth involvement increases the likelihood that the patterns of youth involvement that emerged from the focus groups may reflect the youth experience in many systems of care. Though it is unlikely that all of the experiences are shared by all of the communities, the findings identify areas that system of care administrators and youth coordinators can review to determine whether the identified shortcomings of youth involvement are present in their communities and take steps to address problem areas. Given the benefits of youth involvement, to both youth and the systems/organizations with which they are involved, finding ways to increasingly and effectively involve youth in their systems may be an important way to improve outcomes for youth in systems of care and enhance the services, infrastructure, and sustainability of these systems.

## **References**

- Linetzky, Mindy. (2000). Youth Development: Putting Theory into Practice. *Focal Point*, 14(2). Available at [www.rtc.pdx.edu](http://www.rtc.pdx.edu)
- Department of Health and Human Services. (2002).. *Guidance for applicants (GFA) No. SM-02-002. Cooperative agreements for the Comprehensive Community Mental Health Services for Children and Their Families Program*. Rockville: Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.
- Quinn, J. (1995). Positive effects of participation in youth organizations. In M. Rutter (Ed.) *Psychosocial disturbances in young people: Challenges for prevention*. London: Cambridge University Press.
- Scientific Software Development. (1997). Atlas.ti Software (Version 4.2) [Computer software]. Berlin, Germany: Author.
- Zeldin, S., McDaniel, A. K., Topitzes, D., & Calver, M., (2000). *Youth in decision-making: A study on the impacts of youth on adults and organizations*. Innovation Center for Community and Youth Development and National 4-H Council. Innovation Center/Tides Center. University of Wisconsin Extension.

---

**CONTRIBUTING AUTHORS**

**Natalie Henrich, Ph.D., M.P.H.**

*Senior Scientist, 404-321-3211 fax: 404-321-3688,  
e-mail: Natalie.J.Henrich@orcmacro.com*

**Phyllis Gyamfi, Ph.D.**

*Senior Scientist, 404-321-3211 fax: 404-321-3688,  
e-mail: Phyllis.Gyamfi@orcmacro.com*

*All Authors: ORC Macro International, 3 Corporate Square, NE, suite 370, Atlanta,  
GA 30329*

# ***The Meaning of Diagnosis: Implications for Clinician-Parent Partnership in Child Mental Health***

Vaishali Patel  
Susan dosReis

---

## **Introduction**

Traditionally children's mental health services research has focused on identifying child and parent characteristics that influence access, utilization, and continuity of care as well as assessing the fragmentation of community-based care (Costello, Pescosolido, Angold, & Burns, 1998; Stroul & Friedman, 1986; Burns, et al., 1995; Farmer, Burns, Phillips, Angold, & Costello, 2003). Far less is known about the mechanisms by which parents navigate the complex, and often uncoordinated, systems to obtain mental health services for their child. This study was undertaken to describe the process by which parents sought services, including their interactions with clinicians, and to describe providers' perspective on the delivery of mental health care to children.

## **Study Design**

Grounded theory informed the research design which consisted of successive iterations of interviewing, inductive analysis of the data, and development of theory grounded in the data (Glaser 1976, 1992; Glaser & Strauss, 1967). This qualitative study incorporated several stages of data collection so that on-going data analysis could inform each subsequent stage. In the first stage, two in-depth interviews were done with a caregiver/parent within one month. This was followed by semi-structured interviews with providers. The final stage consisted of a focus group with parent/caregivers. This study was initially undertaken as part of a qualitative methods course at Johns Hopkins Bloomberg School of Public Health (JHBSPH). All study procedures and materials were reviewed and approved by the Committee on Human Research, which is the Institutional Review Board, at JHBSPH.

Using a purposive sampling strategy, parents with experience seeking mental health care services for their child were sought to participate in the study. Two consumer advocacy organizations recruited eligible parents for the study. The 10 individuals who agreed to join the study were all middle-aged. The majority of participants were female ( $n = 9$ ), served as the parent ( $n = 9$ ), were White ( $n = 9$ ), and were married ( $n = 9$ ). The children whose parents participated in the study were primarily males (75%) aged 6 to 25 years (mean age = 14 years). Bipolar disorder was the most common psychiatric diagnosis reported by parents. Other parent-reported diagnoses included: autism, attention-deficit hyperactivity disorder, attachment disorder, mood, depression, and anxiety disorders.

Child and adolescent mental health clinicians were identified through professional contacts of several members of the research team. The eligibility criterion was that the provider was involved in the administrative or clinical management of child mental health care services. The seven child and adolescent mental health clinicians who were interviewed consisted of three psychiatrists, a mental health hospital administrator (and former clinician), a psychologist, and two school mental health professionals (one clinical social worker and one licensed clinical professional counselor).

## **Data Analysis**

Text from the transcribed interviews and focus group, in addition to field notes were analyzed using the constant comparative method (Glaser 1976, 1992; Glaser & Strauss, 1967). Logic diagrams, data matrices and memos helped us delineate the relationships between the concepts that emerged from initial analyses. Through various iterative steps in the constant comparative analysis, we were able to develop and refine a theoretical construct.

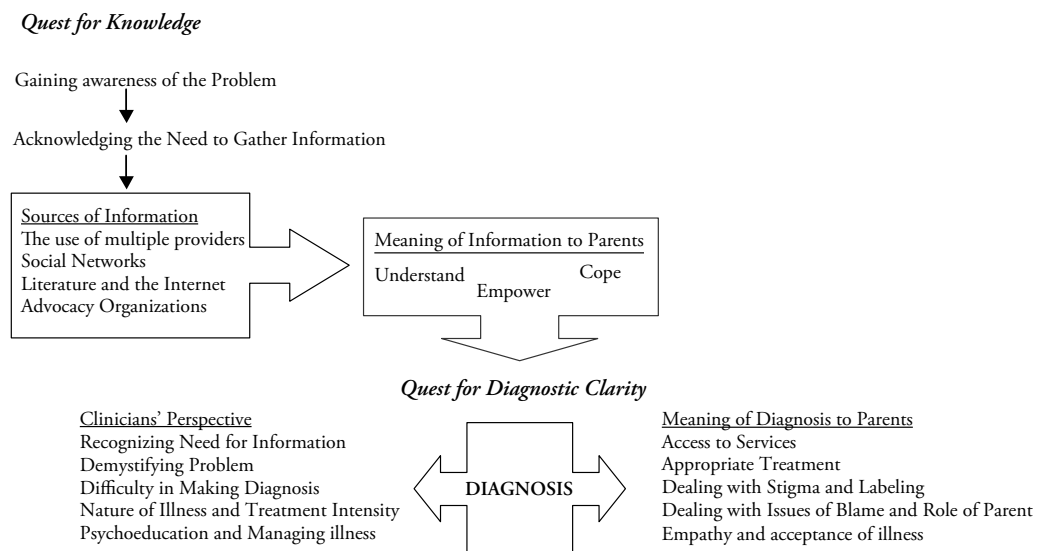
The credibility and quality of our findings were achieved through a triangulation of sources (interviews with both parents and providers), methods triangulation (in-depth interviews and focus group), and the use of member checks (follow-up interviews with parents, and the use of the parent focus group).

## Findings

*“I can’t do anything without knowledge...you know it’s like working in a dark room trying to find a thread in a dark room. No matter how much searching you do you’re not going to be able to help the person who needs help.”*

The process by which parents sought information regarding their child’s mental health was identified as a critical step toward coping with their child’s illness. Parents’ search for information, their *quest for knowledge*, embodied the situations and individual experiences that led parents to recognize their child’s problems and seek mental health services for these problem(s) as well as the various sources of information parents’ used. The ultimate goal of this quest was *diagnostic clarity*, which referred to parents’ need for a “name” for their child’s mental health condition. Figure 1 outlines the process, including the relationship between these two concepts.

**Figure 1**  
**Parents’ of Children with Mental Health Problems Search for Information**



## Quest for Knowledge

*“The early signs were there but no one hands you a book in the beginning when you have a child.”*

Parents uniformly expressed frustration about the delayed recognition of their child’s mental health problems which subsequently postponed accessing needed care.

This delayed awareness, and subsequent impact on obtaining services, was attributed to a number of sources. Pediatricians’ ability to identify and diagnose the problem was questioned by parents. Parents themselves acknowledged uncertainty distinguishing between normal and abnormal behavior, and admitted that they did not fully recognize key signs of developmental delays. A critical incident, cues from other individuals, or their child’s experiences at school/day care often made parents aware of their child’s mental health problem. Finally, parents’ own fears delayed their full awareness of the seriousness of their child’s illness.

Once parents became aware of their child’s mental health problems, some parents expressed a “need to know” about their child’s illness and available services early on, while for others it emerged from their

frustrating experiences accessing mental health care for their child. The search for information was often prompted by requirements that limited access to certain specialized services to children with a particular set of diagnoses. In addition, parents described their frustration with providers knowing or sharing little with them about potential resources, including services that might be available to their children, thus prompting them to seek out the information from other sources.

These alternative resources or strategies parents described included using more than one provider, accessing websites on the Internet, reading both popular and academic books regarding child mental health or experiences raising children with mental health problems, attending seminars and parent support groups provided by consumer advocacy organizations and exchanging information with other parents of children with mental health problems.

### **Consequences of the Quest for Knowledge: Diagnostic Clarity**

*“And things were...not getting any better... But when the knowledge was there — the diagnosis — then that’s when the big guns came out... Up until that point we didn’t have any knowledge. We didn’t know what we were working with. So there wasn’t anything to argue about. And they were not giving us any help... If you needed any help you had to prove it... Prove that you need the help.”*

From the parents’ perspective, this quest for knowledge led to diagnostic clarity, understanding the exact nature of their child’s mental health problems. The consequences of this process for parents were multi-fold: enabling them to better deal with the service system, empowering them to act as advocates on behalf of their child, and helping them and their family better understand and cope with their child’s mental health problems.

Clinicians attached a different meaning to diagnosis. According to clinicians, diagnosis was only one of several different sources of data that they reviewed when making treatment decisions. The importance that clinicians placed upon diagnostic information depended upon the context, including the nature of the illness and the type of treatment prescribed. Because making a diagnosis in children and adolescents is sometimes difficult, diagnosis was more likely to be discussed when a medication was to be prescribed for the child’s illness, and less likely in situations where there was more uncertainty about the illness and treatment. Clinicians reported educating parents about managing their child’s illness rather than communicating a diagnostic label.

### **Implications**

These findings suggest that providers’ and parents’ differing perspectives regarding the utility and value of diagnosis may affect the exchange of information between them about mental illness, potentially contributing to sub-optimal community mental health service use for children. Clinicians can play an important role in providing comprehensive psycho-education or referring parents to programs that educate parents about mental illness. Helping parents discern between developmentally appropriate and problematic behaviors is critical towards identifying children in need of mental health services early. In addition, communicating the nuances of the diagnostic process to parents may be challenging, but it has the potential to encourage parents to be more active partners in the treatment process. The early identification of mental health problems and the importance of information exchange surrounding mental illness should be emphasized in clinical training programs. In addition, this study’s findings suggest the important role that consumer advocacy groups play in educating and empowering families.

## References

- Burns, B. J., Costello, E. J., Angold, A., Tweed, D., Stangl, D., Farmer, E. M., & Erkanli, A. (1995). Children's mental health service use across service sectors. *Health Affairs, 14*, 147-159.
- Costello, E. J., Pescosolido, B. A., Angold, A., & Burns, B. J. (1998). A family network-based model of access to child mental health services. *Research in Community and Mental Health, 9*, 165-190.
- Farmer, E. M., Burns, B. J., Phillips, S. D., Angold, A., & Costello, E. J. (2003). Pathways into and through mental health services for children and adolescents. *Psychiatric Services, 54*(1), 60-6
- Glaser, B. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.
- Glaser, B. (1992). *Basics of grounded theory analysis*. Mill Valley, CA: Sociology Press.
- Glaser, B. & Strauss, A. (1967). *The discovery of grounded theory*. Chicago: Aldine.
- Stroul, B. A. & Friedman, R. M. (1986). *A system of care for children and adolescents with severe emotional disturbances: What are the results?* Washington, DC: CASSP Technical Assistance Center, Georgetown University Child Development Center.
- USDHHS (1999). *Mental health: A report of the Surgeon General*. Rockville, MD: US Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institute of Mental Health.

---

## CONTRIBUTING AUTHORS

### **Vaishali Patel, M.P.H., Ph.D. Candidate**

*Johns Hopkins Bloomberg School of Public Health, Department of Health Policy and Management, 624 N. Broadway, Baltimore, MD 21205, 732-261-8323, e-mail: vapatel@jhsph.edu*

### **Susan dosReis, Ph.D.**

*Division of Child and Adolescent Psychiatry, Johns Hopkins University School of Medicine, CMSC 346, 600 N. Wolfe Street, Baltimore MD 21287, 443-287-4347, fax: 443-287-4346, email: sdosrei1@jhmi.edu*



# **What Caregivers are Saying about Wraparound**

---

**Christina Breault  
Shannon Lewis  
Jennifer Taub**

## **Introduction**

While there has been much literature examining the effects of wraparound services over the past decade, little is known regarding caregivers' thoughts about this service delivery approach. The critical role of caregivers in the wraparound process suggests many research questions including: What is it about wraparound services that meet caregivers' needs? What aspects of wraparound do caregivers feel work best for their child and family? Are there components of wraparound that could be improved? Answers to these questions could be instrumental in keeping providers knowledgeable of families' needs; further, they may give weight to the wraparound services philosophy of how essential it is for families to have "voice and choice" to make the program most effective. Findings could suggest strategies for informing and potentially improving services to children with severe emotional disturbances (SED) and their families.

This summary describes lessons learned from analysis of comments offered by families during an evaluation of a wraparound program in Massachusetts. Four themes derived from data on family perceptions of the wraparound approach can inform future research and program planning.

## **Method**

Coordinated Family Focused Care (CFFC) is a wraparound program for children and youth with SED ages 3-18 in five Massachusetts' communities. Each child and family is assigned a Care Manager, who is a Master's level clinician, and a Family Partner, who has been a primary caregiver for a child with SED. Families work with their Care Manager, Family Partner and other identified supports to form a wraparound team to assess family strengths and needs, to develop a crisis and treatment plan, and to provide support and advocacy for the child and family.

With a grant from the Center for Health Care Strategies, a team from the Center for Mental Health Services Research (CMHSR) at the University of Massachusetts Medical School is conducting an evaluation of the CFFC program. Of the many outcomes being measured treatment fidelity is considered one of the most critical. Although wraparound has become a popular strategy for systems that treat children with serious emotional or behavioral disorders, there is no single set of standards that can be used to implement high quality wraparound.

The Wraparound Fidelity Index (WFI; Bruns, Burchard, Suter, Leverentz-Brady & Force, 2004) is being used by the evaluation team to assess how closely to the model the five CFFC sites are implementing wraparound. The WFI includes caregiver ratings of the philosophical elements of the wraparound process; these elements include:

- Voice and Choice
- Youth and Family Team
- Community-Based Services
- Cultural Competence
- Individualized and Strength-Based Services
- Natural Supports
- Continuation of Care
- Collaboration
- Flexible Resources
- Outcome-Based Services.

The WFI is a structured measure that includes four questions per element on a three point Likert-type scale. Interviews are conducted three months ( $n = 142$ ) and nine months ( $n = 74$ ) after enrollment into services. Participants are paid \$10 for each interview they complete.

In the course of completing the structured WFI interview, interviewers have found that caregivers spontaneously offer additional information. Interviewers are careful to record all of these unsolicited comments. In addition, caregivers are asked three open-ended questions at the end of the interview: (a) What is your favorite thing about the program? (b) What would you change, if you could? And (c) Do you have anything else to say about the team that I haven't touched on?

Responses to these questions, as well as the spontaneous comments offered by caregivers during the interview, were recorded. These data were coded into thematic categories by two raters; an inter-rater reliability of 93% was computed.

## **Results**

Four themes emerged from the analysis of the data: encouragement to participate in treatment planning; support during the wraparound process; focus on child and family strengths; and concerns surrounding discharge.

### **Caregivers were encouraged to participate in the treatment planning process**

Caregivers reported that teams listened to their ideas and didn't make decisions without them. "They listen to everything we have to say even if they don't like it. We're never pushed into anything we don't like." One caregiver stated, "I run the meetings, suggest the changes, and they make it happen."

### **Caregivers felt supported**

Caregivers described receiving generous amounts of concrete and emotional support from CFFC. "They are there to help in every sense of the word." Concrete support, for example providing transportation and helping to navigate complex service systems, was identified as very important to caregivers. "One good thing is they will pick me up if needed and drive me home. They are really good about that stuff [and I need it] because I don't have a car."

Emotional support, such as encouragement, respect, and overall caring about the families was also identified by many caregivers as an important factor in their care. One mother explained, "they don't only help [my child], but they help me." In addition, some caregivers reported receiving help from parent support groups coordinated at some sites—"I go to group every Wednesday. They're there to support me, they are my family...I've learned a lot and I really enjoy the group."

### **Wraparound teams focus on the strengths of children and families**

Caregivers reported that wraparound teams maintained a focus on the strengths of their children and the family, and that identifying and focusing on strengths helped caregivers feel hopeful about the future. "They are constantly reminding me of his strengths," said one parent. Another parent noted that her team tries "to get us to focus on the positive on days when [it feels] there are none." Another caregiver explained, "I used to spend too much time on the negative, but they've changed my ways."

### **Caregivers were concerned about discharge from planning**

Some caregivers expressed concerns about discharge planning; many caregivers wanted the program to continue after their child met graduation goals. One caregiver noted, "We are about to graduate and I feel we aren't ready; we still need the support." Another parent suggested it would be helpful to have "better planning for when we are ready to leave." A number of families stressed the need for better preparation before leaving CFFC services.

## **Conclusion**

Findings from the CMHSR evaluation suggest that in general caregivers feel supported and encouraged by wraparound teams in CFFC, and desire to stay in the program for as long as possible. As one caregiver noted, “This is the first [service plan] I found that works. The only one I have felt comfortable with.”

These results suggest future areas of research regarding the experiences of caregivers with wraparound services. For example, caregivers identified the significance of receiving emotional and concrete support from the CFFC program. Additional research could explore these themes further and ascertain what specific types of emotional and concrete support are most useful to caregivers. Understanding “what works” for caregivers could help wraparound teams to focus on the types of support recognized as most helpful. Future research could also explore caregivers’ concerns about early discharge from the wraparound program to determine as needed supports to families as they transition from wraparound services.

## **Reference**

Bruns, E. J., Burchard, J. D., Suter, J. C., Leverenz-Brady, K., & Force, M. M. (2004). Assessing fidelity to a community-based treatment for youth: The Wraparound Fidelity Index. *Journal of Emotional & Behavioral Disorders*, 12(2), 79-89.

---

**CONTRIBUTING AUTHORS**

---

**Christina Breault, B.S.**

*Research Associate, Center for Mental Health Services Research, UMass Medical School, 55 Lake Ave N. Worcester, MA 01655, 508-856-8713, e-mail: Christina.breault@umassmed.edu*

**Shannon Lewis, B.A.**

*Intern, Clark University, 781-254-1035, e-mail: smlewis@clarku.edu*

**Jennifer Taub, Ph.D.**

*Research Assistant Professor, Center for Mental Health Services Research, UMass Medical School, 55 Lake Ave N., Worcester, MA 01655, 508-856-3522, e-mail: Jennifer.taub@umassmed.edu*

# **What Youth in Foster Care Think about Mental Health Services**

*Acknowledgements: This study was funded by a grant from the National Institute of Mental Health (R01 MH 61404).*

**Bethany Lee  
Michelle Munson  
Marcia Ollie  
Lionel Scott  
J. Curtis McMillen**

## **Introduction**

Concerns about the quality of mental health services have led to increased solicitation of consumer feedback, especially among adult consumers. While there are exceptions (Garland & Besinger, 1996; Shapiro, Welker, & Jacobsen, 1997), there remains a paucity of research that investigates youths' perceptions of the services they receive (Jensen, Hoagwood & Petti, 1996). More commonly, parents or other caregivers are surveyed about their satisfaction with a youth's services (Brannan, Sonnichsen, & Heflinger, 1996; Magura & Moses, 1984; Martin, Petr, & Kapp, 2003). By narrowly defining the consumer as the individual with legal responsibility or insurance coverage, the unique perspectives of youths are lost.

Understanding youths' experiences and their relationships with providers may shed light on underutilization or early termination of services among this age group (Hoagwood, Burns, Kiser, Ringeisen, & Schoenwald, 2003). Additionally, identifying what youths like and dislike about their care has implications for quality improvement efforts in service delivery. In this study, youths were given an opportunity to voice their positive and negative experiences with mental health services, as well as share what they like about specific providers. The purpose of this qualitative study is to identify and describe the concepts youths value in relationships with mental health professionals and the services they receive.

## **Methods**

As part of a larger, longitudinal study assessing the experiences of older youth transitioning from the foster care system (McMillen, Zima, Scott, Ollie, Munson, et al., 2004), 406 youths in the Missouri foster care system were interviewed in person near their seventeenth birthdays (90% of those eligible). Additional data for this study were obtained during an interview six months later, by phone to 371 youths (91% retention). Data collection occurred between December 2001 and May 2003.

The sample was 56% female and over half were youth of color (57%). The sample consisted of youths in varied living situations. Ninety-six percent ( $N = 389$ ) reported a history of using at least one type of mental health service; 73% had received out-patient therapy, 77% had experienced residential treatment, and 42% had received in-patient psychiatric care. Thirty-seven percent were receiving prescribed psychotropic medications at the time of the first interview (McMillen, et al., 2004).

During the first interview, youth were asked to describe "particularly positive" or "particularly negative" experiences with mental health professionals. At the interview six months later, youths currently receiving out-patient therapy were asked what they liked about their therapist, and youths who were receiving residential treatment were asked what they liked about their favorite direct care worker and their residential program therapist or case manager. Answers were transcribed by the interviewers.

Comments from youth were reviewed independently by two reviewers. Through several readings of the responses, empirically observable regularities or patterns could be identified. Each reviewer compiled a list of emerging themes and then the two compared their findings. Similar themes had been identified by each reviewer and the resulting themes were jointly named. After developing coding schemes, two reviewers reread the transcripts and coded 30% of the responses to measure inter-rater reliability. An overall kappa score of .75 was achieved (.71 - .79 for each individual question). Discrepancies were mutually reconciled. The remaining responses were coded by one reviewer. The frequency of each theme's appearance was tabulated to identify the themes most commonly found.

## Results

As stated above, the focus of the first interview was on “particularly positive” or “particularly negative” experiences with mental health professionals. Of the 389 youths who had used mental health services, 144 (37%) described a positive experience with a mental health professional while 101 youths (26%) shared a negative experience. Themes that emerged from the comments are described below.

### Positive Experiences

Youths reported positive experiences that were classified into two broad categories: benefits of mental health services and their relationship with a mental health professional. Frequencies of youth comments by category and theme, based on the number of youths who reported a positive experience, are shown in Table 1.

**Table 1**  
**Youth Comments on Positive Experiences with Mental Health Professionals**  
**(N = 144)**

<i>Theme</i>	<i>N</i>	<i>%</i>
<b>Benefits of Mental Health Services</b>		
Help with personal and emotional issues, coping skills	29	20
Helped me feel better	22	15
General helpfulness	18	13
Promoted behavior change	14	10
Help develop insight/self-awareness	13	9
Catharsis/emotional release	10	7
Advocated to help me get what I needed/wanted	10	7
Help with practical and concrete matters	9	6
Medication management	6	4
<b>Relationship with Mental Health Professional</b>		
Listening/attending	29	20
Engagement	10	7
Consistency/accessibility	7	5
Felt supported	5	3
Empathy/understanding	3	2
Authenticity	2	1
Other personality characteristics	9	6

**Benefits of Mental Health Services.** Youths remarked on several benefits from mental health services, including help with emotional issues and coping skills, experiencing positive behavior change, developing insight, and experiencing a therapeutic catharsis. By choosing to articulate the benefits of care, youths may be indirectly responding to social pressures that challenge their participation.

*“Mr. \_\_\_ helped me cope with my father and brother’s deaths. Pushed me to cope even though I got mad.”*

*“Helped me get my life on track – kept me in school, stopped me from some bad stuff”*

*“One kept me from harming myself.”*

For youths, observable behavior changes offer further evidence of the validation of their participation in mental health care.

**Relationship with mental health professionals.** Youths articulated several desirable characteristics of mental health providers. Major themes within this category included the provider’s listening and attending skills, consistency and support.

*“Every experience with my therapist is positive. She listens and doesn’t see [me] as something to diagnose.”*  
*“She would always come talk to me, even if she didn’t really have time.”*  
*“I can count on him.”*

These central themes suggest that youths appreciate it when providers make time for them.

### Negative Experiences

Youths reported negative experiences that were classified into three categories: treatment concerns, relationship with mental health provider, and unprofessional or questionable behavior. Table 2 displays the frequencies for each category as well as the specific themes shared by youths.

**Table 2**  
**Youth Comments on Negative Experiences with Mental Health Professionals**  
**(N = 101)**

<i>Theme</i>	<i>N</i>	<i>%</i>
<b>Treatment Concerns</b>		
Medication issues	23	23
Ineffective/not helpful	10	10
Coerced/mandated treatment	7	7
Physical restraint	4	4
It made me worse	2	2
<b>Relationship with Mental Health Professional</b>		
Didn’t listen	28	28
Didn’t get along/ didn’t like	10	10
Stigma	5	5
Doesn’t care about me	4	4
Allied with system/guardian	4	4
Unprofessional	29	29

**Treatment concerns.** When sharing negative experiences, several youths commented on the treatment they received. Medication management figured prominently among youths’ negative experiences. Additionally, when youths experienced little change as a result of their mental health care, they perceived these services as ineffective.

*“They try to drill it in my head that I need medicine.”*  
*“Their doctors try to put you on meds that don’t work.”*  
*“They talk, but when I leave, everything is the same as before.”*  
*“They don’t seem to do much.”*

Other themes that emerged in this category include experiencing iatrogenic effects of care, being forced to participate in treatment, and hands-on behavioral interventions (i.e. restraint).

**Relationship with mental health professionals.** Youths also shared negative experiences with a service provider. The detrimental characteristics youths articulated were often the inverse of the previously mentioned sought-after traits. Communication issues with a mental health professional were frequently cited by youths as problematic. Youths expressed feeling ignored and misunderstood.

*“They put words in your mouth.”*  
*“We clashed, so therapy was no good.”*

To improve understanding, one youth offered a practical suggestion.

*“Sometimes psychologists don’t get what you are trying to say. It would be good for psychologists to go back over what you are trying to say just to make sure.”*

Additional difficulties within the therapist-client relationship included feeling stigmatized or feeling the provider was allied with the system or guardian.

**Unprofessional behavior.** Twenty-nine youths cited situations where professionals demonstrated a disregard of the knowledge or ethical standards of their position. These assertions varied from suspected dishonesty to demeaning acts.

*“One therapist told me I was a black male and that I needed to be more masculine and not gay.”*

*“I didn’t like one counselor. She told the staff at the center something that was confidential and I got teased by other patients.”*

*“In order to get me to talk, my therapist would wrap me up in a blanket and my foster mom would sit on me. My therapist would make me sit on her lap like I was a little kid and I was 13.”*

These comments suggest that youths are knowledgeable about the behaviors expected of professionals and are concerned about breaches in judgment.

### **Feedback for specific professionals**

All youths who reported receiving outpatient services from a primary therapist ( $n = 89$ ) or who identified a residential case manager ( $n = 110$ ) or favorite direct care worker ( $n = 113$ ) were asked what they liked about these mental health providers. Since these individuals serve in diverse capacities of service delivery, one might wonder if youth expressed different preferences by provider type. Results suggest that youths appreciate similar characteristics among providers regardless of their role. Youths valued relationship skills, professionalism and helpfulness across provider types. Below are youth comments related to these broad categories with the specific provider referenced after each quotation.

*“I like that she genuinely cares about what is going on.” (Residential case manager)*

*“He’s a great guy, basically a father to me.” (Primary therapist)*

*“He knows what he is talking about.” (Primary therapist)*

*“He treats us with respect and doesn’t lie.” (Direct care worker)*

*“He is helpful when it comes to man-to-man problems. He helps me make better decisions.” (Direct care worker)*

### **Discussion and Conclusions**

Results from this study provide evidence that youth are able to assess their care and have formed opinions about what they like and dislike about their mental health service providers. Consistent with similar work (Garland & Besinger, 1996; Shapiro, et al., 1997; Pickett, Lyons, Polonus, Seymour & Miller, 1995), the broad emergent categories focused on interpersonal aspects of youths’ relationships with providers and the perceived value of the treatment services. However, medication management, a theme not found in earlier studies, featured notably in this sample’s comments. Characteristics unique to this population (McMillen, et al., 2004), as well as growing rates of medication utilization (Warner, Pottick, & Mukherjee, 2004), may explain this emphasis.

In a system of care, youth may interact with several mental health professionals. This study examined what youth like about their primary therapist, residential case manager or therapist, and residential direct care worker. Preferences voiced by youth have implications for staff selection and training.



## References

- Brannan, A. M., Sonnichsen, S. E., & Heflinger, C. A. (1996). Measuring satisfaction with children's mental health services: Validity and reliability of the satisfaction scales. *Evaluation & Program Planning* 19, 131-141.
- Garland, A. E., & Besinger, B. A. (1996). Adolescents' perceptions of outpatient mental health services. *Journal of Child and Family Studies* 5, 355-375.
- Hoagwood, K., Burns, B. J., Kiser, L., Ringeisen, H., & Schoenwald, S. K. (2003). Evidence based practice in child and adolescent mental health services. *Psychiatric Services* 52, 1179-1189.
- Jensen, P. S., Hoagwood, K., & Petti, T. (1996). Outcomes of mental health care for children and adolescents: II. Literature review and application of a comprehensive model. *Journal of the American Academy of Child and Adolescent Psychiatry* 35, 1064-1077.
- Magura S. & Moses, B. S. (1984). Clients as evaluators in child protective services. *Child Welfare* 63, 99-111.
- Martin, J. S., Petr, C. G., & Kapp, S. A. (2003). Consumer satisfaction with children's mental health services. *Child and Adolescent Social Work Journal* 20, 211-226.
- McMillen, J. C., Scott, L. D., Zima, B. T., Ollie, M. T., Munson, M. R., & Spitznagel, E. (2004). Use of mental health services among older youths in foster care. *Psychiatric Services* 55, 811-817.
- Pickett, S. A., Lyons, J. S., Polonus, T., Seymour, T., & Miller, S. I. (1995). Factors predicting patients' satisfaction with managed mental health care. *Psychiatric Services* 46, 722-723.
- Shapiro, J. P., Welker, C. J., & Jacobsen, B. J. (1997). The Youth Client Satisfaction Questionnaire: Development, construct validation and factor structure. *Journal of Child Clinical Psychology* 26, 87-98.
- Warner, L. A., Pottick, K. J., & Mukherjee, A. (2004). Use of psychotropic medications by youths with psychiatric diagnoses in the U.S. mental health system. *Psychiatric Services* 55, 309-311.

---

**CONTRIBUTING AUTHORS**

---

**Bethany R. Lee, M.S.W.**

*314-935-6447, e-mail: brl2@wustl.edu*

**Michelle R. Munson, M.S.W.**

**Marcia T. Ollie, M.S.W.**

**Lionel D. Scott, Ph.D.**

**J. Curtis McMillen, Ph.D.**

*All Authors: George Warren Brown School of Social Work, Washington University in Saint Louis, Campus Box 1186, St. Louis, MO 63130.*

---

*Author Note: Direct inquiries to: Bethany Lee, George Warren Brown School of Social Work, Washington University in Saint Louis, Campus Box 1186, St. Louis, MO 63130.*

# **Using Family Perceptions to Shape the Research and Policy Agenda on Intervention Development**

Jeanne C. Rivard  
Ranilo M. Laygo

## **Introduction**

As the field of children's mental health moves forward to incorporate evidence-based practices into state and local service arrays, it is essential to consider the existing evidence presented by families and children themselves. This was a major conclusion of a meeting of stakeholders in children's mental health in August 2003 that focused on building state and community capacity to implement evidence-based practices (National Association, 2003). Family members, family organizations, state directors of children's mental health services, researchers, and funders advocated for research that focuses on the implementation and effectiveness of services that families value. Meeting participants endorsed an approach to advancing evidence-based practices (EBPs) that gives communities and families responsibility for selecting EBPs that fit with the needs, context, culture, and values of their neighborhoods—and imbeds EBPs in local service arrays within family-driven, quality-improvement oriented systems of care. In an initial effort to respond to this call, an existing data set was utilized to examine family perceptions regarding the extent to which various types of services are used and the extent to which these services actually meet the needs of children and their families.

## **Methods**

A secondary data analysis was conducted using data collected in the Center for Mental Health Services-funded National Evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program (Holden, Friedman, & Santiago, 2001; Manteuffel, Stephens, & Santiago, 2002). Data used in the present analysis were primarily drawn from items of the Multi-Sector Service Contacts (MSSC) instrument, the Family Satisfaction Questionnaire, and the Descriptive Information Questionnaire (National Evaluation Team, 2004). This analysis was not part of the evaluation, but was conducted as a cross-sectional examination of service use at one point in time. The service data analyzed were collected at six months following intake, and were selected because they represented a time period as close to baseline as possible. Demographic and other descriptive information was used from the intake period because the service items of interest inquired about services received during the first six months since intake. Data were analyzed for all children in the longitudinal study for whom the MSSC was first administered in 2002 or 2003 ( $N = 2,167$ ).

## **Results**

Child ages ranged from 0 to 22 years. The mean age was 11.74 years ( $SD = 3.52$ ); the median age was 12 years, and the mode was 14 years. Sixty-seven percent of children were boys and 33% were girls. The following data were reported for the race of the children: White, 60.7%; Black or African American, 27.6%; Hispanic origin, 12.5%; Bi-racial or multiracial, 8.5%; Asian, .7%; American Indian or Alaska native, 5.4%; Native Hawaiian or Other Pacific Islander, .5% and; Other 1.1%. Because individuals may claim more than one racial background, the race variable may add to more than 100%.

The number of problems that children presented with at intake ranged from 0 to 27; the mean was 6.8 ( $SD = 5.5$ ); on the Child Behavior Checklist (CBCL; Achenbach, 1991), 61.4% of children scored in the clinical range of internalizing problems; 76.4% scored in the clinical range of externalizing problems; and 70% of children scored in the clinical range for total problems.

Results showed that 93% of children and families had received services related to any emotional or behavioral problems experienced by the child within the prior six months. During this time period, children received an average of six different services ( $SD = 2.9$ ).

Table 1 shows the proportions of children who received 23 types of services, as well as the average caregiver rating of how well the service met their child and/or family's needs. Services were rated on a Likert-type scale that was rated as follows: 1 = *not at all*; 2 = *somewhat well*; 3 = *moderately well*; 4 = *very well*; 5 = *extremely well*.

**Table 1**  
**Services Received and Ratings of Met Needs**

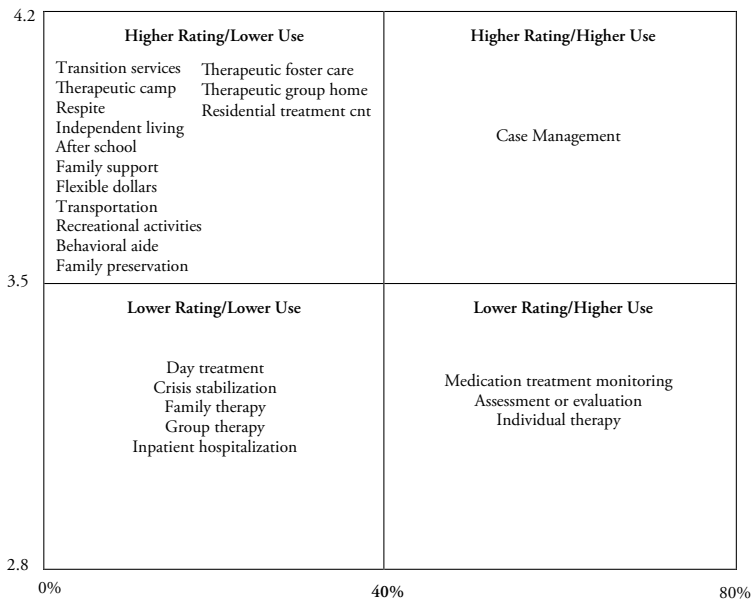
<i>Service Type</i>	<i>Percent that received the service</i>	<i>Mean rating of how well the service met the child/family's needs</i>	<i>SD</i>
Individual therapy	79% ( <i>n</i> = 2,005)	3.35 ( <i>n</i> = 1,492)	1.14
Case management services	76% ( <i>n</i> = 2,006)	3.64 ( <i>n</i> = 1,472)	1.14
Medication treatment-monitoring services	66% ( <i>n</i> = 2,013)	3.47 ( <i>n</i> = 1,281)	1.11
Assessment or evaluation services	63% ( <i>n</i> = 1,992)	3.30 ( <i>n</i> = 1,160)	1.14
Family therapy services	39% ( <i>n</i> = 2,005)	3.42 ( <i>n</i> = 749)	1.16
Group therapy	35% ( <i>n</i> = 1,999)	3.29 ( <i>n</i> = 652)	1.11
Recreational activities	35% ( <i>n</i> = 2,009)	3.80 ( <i>n</i> = 681)	1.04
Caregiver or family support services	30% ( <i>n</i> = 1,991)	3.70 ( <i>n</i> = 545)	1.09
Flexible funds	26% ( <i>n</i> = 1,992)	4.16 ( <i>n</i> = 482)	.96
Transportation services	25% ( <i>n</i> = 1,998)	4.13 ( <i>n</i> = 473)	.93
Crisis stabilization services	20% ( <i>n</i> = 2,003)	3.35 ( <i>n</i> = 379)	1.25
Behavioral therapeutic aide services	19% ( <i>n</i> = 2,009)	3.53 ( <i>n</i> = 370)	1.10
Respite care	17% ( <i>n</i> = 2,007)	3.80 ( <i>n</i> = 320)	1.15
Family preservation services	14% ( <i>n</i> = 1,990)	3.50 ( <i>n</i> = 261)	1.14
After school programs or child care	14% ( <i>n</i> = 1,940)	3.76 ( <i>n</i> = 266)	1.07
Day treatment	13% ( <i>n</i> = 2,009)	3.40 ( <i>n</i> = 257)	1.30
Inpatient hospitalization	10% ( <i>n</i> = 2,010)	3.00 ( <i>n</i> = 190)	1.26
Residential treatment center	10% ( <i>n</i> = 2,009)	3.55 ( <i>n</i> = 182)	1.18
Therapeutic group home	6% ( <i>n</i> = 2,010)	3.54 ( <i>n</i> = 115)	1.10
Therapeutic foster care	6% ( <i>n</i> = 2,009)	3.59 ( <i>n</i> = 109)	1.14
Resid. therapeutic camp or wilderness prog.	4% ( <i>n</i> = 2,008)	3.77 ( <i>n</i> = 74)	1.09
Independent living services	3% ( <i>n</i> = 1,999)	3.60 ( <i>n</i> = 57)	.98
Transition services	2% ( <i>n</i> = 2,000)	3.87 ( <i>n</i> = 52)	1.10

The *n*'s reported in Column 2 of Table 1 indicate the number of caregivers who reported whether or not their child and/or family received the service in question. The numbers shown beside the average ratings in Column 3 are lower because only caregivers who reported receiving the service provided a rating of how well that service met their needs. Both sets of numbers were also affected by missing data (i.e., not applicable, refused, unknown, missing for other reason).

Among the highest used services were individual therapy (79%), case management (76%), medication-treatment monitoring (66%), and assessment/evaluation services (63%). While 79% of families reported having used individual therapy in the prior six months, this service was among the lowest rated in terms of meeting the needs of children and families. The highest rated services were supportive-type services including flexible funds, transportation services, transition services, recreational activities, and respite care. While slightly over a third of families received recreational activities, fewer families received flexible funds (26%), transportation (25%), transition (2%), and respite care (17%) services.

Figure 1 displays a summary of the results of a scatterplot of the same two variables reported above: "proportion of services received" (X axis, with proportions ranging from 0 to 80%) by "ratings of the extent to which the services met the child's needs" (Y axis, with mean ratings of 2.8 to 4.2). Dividing the plot into four even quadrants graphically shows that most of the supportive-type services fall into the "higher rating/lower use" quadrant, along with residential services.

**Figure 1**  
**Display of Services Received by Ratings of Met Needs**



To explore these findings further, a logistic regression analysis was conducted to examine factors associated with families’ satisfaction with their child’s progress in the prior six months. The Family Satisfaction Questionnaire was used to obtain this dependent variable, which covered the same time period as the services data. For this analysis, the ordinal-level variable, families’ satisfaction with their child’s progress in the prior six months, was dichotomized where responses rated as *very dissatisfied*, *dissatisfied*, and *neutral* were scored as 0; and responses rated as *satisfied* and *very satisfied* were scored as 1.

Child age, number of problems, CBCL internalizing and externalizing scores, overall satisfaction with services, and number of services used were entered into the equation along with “met needs” ratings of the three treatment services that were used most by families (i.e., individual therapy, case management, and medication-treatment monitoring). With 655 cases included in the analysis, significant positive associations were found between families’ satisfaction with their child’s progress in the prior six months and the following three variables: greater overall satisfaction with services ( $p < .001$ ), higher “met needs” ratings on medication-treatment monitoring ( $p < .001$ ), and higher “met needs” ratings on individual therapy ( $p < .001$ ). Families were less likely to perceive progress when their child’s externalizing scores were higher ( $p < .001$ ; see Table 2).

**Table 2**  
**Factors Associated with Satisfaction in Progress at Six Months**

	<i>B</i>	<i>P</i>	<i>Exp(B)</i>
Age	-.02	.61	.98
Number of problems	.01	.63	1.10
Internalizing raw score	.00	.76	1.00
Externalizing raw score	-.06	.00	.94
Overall satisfaction with services	.74	.00	2.09
Medication treatment monitoring	.43	.00	1.54
Individual therapy	.40	.00	1.49
Case management	-.13	.23	.88
Number services received	-.05	.21	.95
Constant	-2.26	.00	.11

**Conclusion**

In discussing family perspectives on evidence-based practices, Flynn (2005) noted that some of the areas of highest interest to families included: family engagement, family education, caregiver support, and promoting independence and emancipation for adolescents. A major finding of the cross-sectional analysis presented here was that families generally rated these types of supportive-type services higher in meeting their needs than more traditional clinical services; but small proportions of families reported

receiving these types of support services. The lower proportions of children and families receiving supportive services may simply reflect the lower availability of these types of services. The higher ratings of these same services might indicate that it is somewhat easier to meet support needs than treatment needs. However, it is important to document that families report that these types of supportive services do meet their needs, and to use this additional evidence as validation for further research, policy, and program development in this area.

That residential services also fell into the same quadrant as support services (i.e., higher rating/lower use) shows that families perceive that residential services meet their needs, and probably reflects the trend in children's mental health to place fewer children in reducing out-of-home care. It is important to note here that the source of service data analyzed were families participating in system of care communities where program goals often focus on preventing or reducing out-of-home care.

Although some of the traditional treatment services were rated lower in meeting needs, results of the logistic regression analysis showed that when families perceived that more progress was made by their children, they also rated individual therapy and medication-treatment monitoring as better meeting their child's needs. This might suggest that more effective treatment services yielded better outcomes. The data set that was used in the present analysis inquired about generic types of services that children and families used. It is not known which of these services might have been evidence-based. However, studies that compare the use of traditional treatment services with evidence-based interventions, such as those being undertaken by the National Evaluation Team of the Comprehensive Community Mental Health Services for Children and Their Families Program, will begin to document the differential effects on community levels.

## References

- Achenbach, T.M. (1991). *Manual for the Child Behavior Checklist/4-18 and 1991 Profile*. Burlington, VT: University Associates in Psychiatry.
- Flynn, L. (2005). Family perspectives on evidence-based practice. *Child and Adolescent Psychiatric Clinics of North America*, 14, 217-224.
- Holden, E. W., Friedman, R., & Santiago, R. S. (2001). Special issue: The national evaluation of the comprehensive community mental health services for children and their families program. *Journal of Emotional and Behavioral Disorders*, 9, 1-80.
- Manteuffel, B., Stephens, R. L., & 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.
- National Association of State Mental Health Program Directors Research Institute (NRI). (2003). *Report of the conference: Evidence-based practices in children's mental health: Building capacities for implementation and research*. Alexandria, VA: Author.
- National Evaluation Team at ORC Macro. (2004). *CMHS National Evaluation: Data profile report: Appendix*. Atlanta, GA: ORC Macro.

---

## CONTRIBUTING AUTHORS

### Jeanne C. Rivard, Ph.D.

NASMHDP Research Institute, 66 Canal Center Plaza, Suite 302, Alexandria, VA 22314,  
703-739-9333, ext. 146, e-mail: jeanne.rivard@nri-inc.org

### Ranilo M. Laygo, Ph.D.

ORC Macro, 3 Corporate Square NE, Suite 370, Atlanta, GA 30329, 404-321-3211,  
e-mail: ranilo.m.laygo@orcmacro.com

# **The Relationship Between Family Empowerment and Youth Mental Health Outcomes**

Jennifer Maness  
Susan McCammon  
Thomas Durham  
Erik Everhart  
David Dossler, Jr.

---

*Acknowledgements: We appreciate the work of Dr. Maria Fernandez of the NC Department of Health and Human Services, Division of Mental Health, Developmental Disabilities, and Substance Abuse in making this data set available to the researchers.*

## **Introduction**

While some researchers have begun to analyze predictors and correlates of family empowerment, few have examined the effects of family empowerment on youth mental health outcomes. Those researchers who have investigated the effects of family empowerment on youth outcomes have found mixed results (Bickman, Heflinger, Northrup, Sonnichsen, & Schilling; 1998; Cunningham, Henggeler, Brondino, & Pickrel, 1999; Resendez, Quist, & Matshazi, 2000; Taube, Tighe, & Burchard, 2001). We were interested in studying whether, for youth and their families enrolled in the PEN-PAL Project, family empowerment would increase over time, and whether family empowerment and youth outcomes would be inversely related.

## **Program and Participant Characteristics**

### **PEN-PAL Description**

The Pitt-Edgecombe Nash-Public Academic Liaison (PEN-PAL) Project was established in 1994 as a partnership among state and local child-serving agencies, community groups, parent advocacy groups, and East Carolina University to build a system of care for children and adolescents with special needs and their families in Pitt, Edgecombe, and Nash Counties of North Carolina. The Project was initiated and administered by the Child and Family Services Section of the North Carolina Division of Mental Health, Developmental Disabilities, Substance Abuse Services, and received federal funding from the Center for Mental Health Services (CMHS/SAMHSA; CMHS, n.d.). Children served were 6 to 18 years old; had serious behavioral, emotional, or mental problems; showed impairment in school, family, and/or social function; were separated or at risk of separation from their families; and needed help from more than one agency to meet their unique needs.

## **Method**

It was hypothesized that (a) participation in the PEN-PAL Project would increase scores on the Family Empowerment Scale (FES; Koren, DeChillo, & Friesen, 1992), particularly on the Family and Service System subscales, over time; (b) the FES, particularly the Family and Service System subscales, would be negatively correlated with the total score on the Child and Adolescent Functional Assessment Scale (CAFAS); and (c) the FES, particularly the Family and Service System subscales, would be negatively correlated with the Total Problem, Internalizing, and Externalizing *T*-scores on both the Child Behavior Checklist (CBCL; Achenbach, 1991a) and the Youth Self Report (YSR; Achenbach, 1991b).

The CAFAS is a clinician rating scale used to assess child functioning, with higher scores reflecting greater problems. Scores may range from 0-150, with scores of 70-80 or above generally reflecting significant functional impairment. CBCL and YSR scores are reported as *T* scores (Mean of 50, *SD* of 10). Higher scores reflect greater problems on the behavior scales; lower scores reflect greater problems on the social scales. The FES Family and Service System subscales range from 12 to 60, and the Community subscale from 10 to 50, yielding a total FES score of 34 to 170, with higher scores indicating relatively more empowerment in each respective area.

Data were collected through interviews with caregivers and by completion of questionnaires by caseworkers on intake records. Interviews were completed within 30 days of the child's entry into services. All data for the study were archival, having been obtained at the time the child entered the system with follow-up scheduled at six months, 12 months, and annually after that.

**Participants.** Participants were youth ages 6-17 and their families. Youth had serious emotional disturbance, impaired family, school, and/or social functioning and were separated or at risk of being separated from their families. These youth were in need of services from multiple agencies. Over half of the sample was male (65%), and over half of the sample was Black (66%), followed by White (33%). Eighty-three percent of families made < \$25,000 annually, and 61% made < \$15,000 annually.

## Results

At the time of intake, enrolled clients showed a high level of adjustment difficulty (mean CAFAS score was 80.9, mean CBCL Total Problems score was 70.4). CAFAS scores, however, showed a wide range of scores (CAFAS standard deviation was 36) with a number of clients having CAFAS scores between 0 and 20, suggesting no impairment or very minimal impairment in functioning. Of the adolescent clients who completed a self-rating using the Youth Self-Report, mean Total Problem scores, internalizing scores, and externalizing scores were fully within the average range, suggesting a tendency to minimize the report of problems (see Table 1).

**Table 1**  
FES, CAFAS, CBCL, and YSR Scores at Intake, Six Months, and at One Year

	<i>Intake</i> <i>n = 206</i>		<i>6 Months</i> <i>n = 77</i>		<i>1 year</i> <i>n = 25</i>	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
FES Total	133.2	22.6	135.6	23.5	131.7	26.4
Family	49.2	7.9	49.4	8.4	48.3	10.5
Service Sys	51.0	7.0	51.2	8.1	50.6	9.4
Community	33.2	9.8	34.9	9.2	33.1	10.2
CAFAS	80.9	36.4	74.2	33.1	70.5	32.7
CBCL						
Total	70.4	9.8	67.4	10.6	65.0	9.8
Internalizing	65.0	10.3	62.4	10.0	58.4	11.0
Externalizing	69.1	11.2	66.9	12.0	65.8	10.5
YSR						
Total	59.1	14.0	58.2	4.4	51.8	13.3
Internalizing	55.8	12.9	53.1	12.2	49.1	14.3
Externalizing	61.1	29.6	58.3	12.0	53.3	13.8

*Notes.*

Possible FES Total Scores range from 34 to 170. Possible FES Family and Service System subscale scores range from 12 to 60. Possible FES Community subscale scores range from 10 to 50. CAFAS scores range from 0 to 150. CBCL and YSR scores are T-scores. At Intake, 6 months, and 12 months, the *ns* for each scale were as follows: CAFAS (246, 142, 94), CBCL (230, 117, 68), YSR (113, 59, 39).

Change scores were computed for CBCL and FES scores and CAFAS groupings (minimal or no improvement, mild, moderate, and severe impairment). CBCL change scores were grouped into those who improved, remained the same, or declined.



Using the Reliable Change Index score criteria of 1.96 to indicate meaningful change (Jacobson, Roberts, Berns, & McGlinchey, 1999), 21.3% of participants still receiving services at one year showed significant reduction in CBCL Total Problems Score, with 17.6% showing improvement in CBCL Internalizing Scores and 18.5% showing improvement in CBCL Externalizing Scores. The greatest improvement was found in those children rated in the severe range on the CAFAS at intake (30.8%). Based on CBCL scores, approximately 5% of children were rated as worse after one year of treatment with approximately 75% showing no significant change.

Family Empowerment Scores (FES) tended to be high on intake (mean of 133 out of a maximum possible score of 170). These scores showed no improvement over time (see Table 1). At intake, Total FES, Family FES, and Service System FES scores showed small but statistically significant correlations with CBCL Internalizing scores. The more troubled the child was rated by the parent, the less empowered the parent felt. At one year, FES scores showed consistent high negative correlations with CBCL Total, Internalizing, and Externalizing scores. The more problems the child was having, the less empowered the parent felt (see Table 2).

**Table 2**  
**Correlations of CBCL with FES Scores on Intake and at One Year**

	<i>Total</i>	<i>Family</i>	<i>Service</i>	<i>Community</i>
<b>FES at Intake</b>				
CBCL Total	-.12	-.14	-.09	-.10
CBCL Int	-.15*	-.18*	-.15*	-.11
CBCL Ext	-.11	-.10	-.07	-.13
<b>FES at One Year</b>				
CBCL Total	-.60*	-.56*	-.33	-.68**
CBCL Int	-.71**	-.73**	-.43	-.68**
CBCL Ext	-.52*	-.52*	-.23	-.60**

## **Discussion**

The PEN-PAL program did not lead to improvements in most children's behavior or in parents' sense of empowerment in dealing with their troubled children or in dealing with the mental health care system. However, this project was one of the early CMHS initiatives, begun in 1993. Parents who rated their children as having the most problems tended to experience the lowest levels of empowerment in dealing with the situation.

The lack of change in empowerment may be a function of the empowerment scores at intake being high compared to those of other programs (e.g., Cunningham et al., 1999). It is interesting that empowerment ratings are high given the high levels of poverty of the families; many were struggling to meet basic needs. Examination of the salience and relevance of the FES content to the families' lives would be informative.

The high variance of the CAFAS scores also raises some questions about the reliability of the data, as it was unclear how well the interviewers were trained on that instrument. Other problems with the data set involved high frequency of missing data, low sample sizes, and significant attrition across the participants.

## References

- Achenbach, T. (1991a). *Manual for the Child Behavior Checklist/4-18 and 1991 profile*. Burlington, VT: University of Vermont Department of Psychiatry.
- Achenbach, T. (1991b). *Manual for the Youth Self-Report and 1991 profile*. Burlington, VT: University of Vermont Department of Psychiatry.
- Bickman, L., Heflinger, C., Northrup, D., Sonnichsen, S., & Schilling, S. (1998). Long term outcomes to family caregiver empowerment. *Journal of Child and Family Studies, 7*, 269-282.
- Center for Mental Health Services. (n.d.). *The PEN-PAL project: A system of care* [Brochure]. Raleigh, NC.
- Cunningham, P., Henggeler, S., Brondino, M., & Pickrel, S. (1999). Testing underlying assumptions of the family empowerment perspective. *Journal of Child and Family Studies, 8*, 437-449.
- Hodges, K., & Wong, M. (1996). Psychometric characteristics of a multidimensional measure to assess impairment: The Child and Adolescent Functional Assessment Scale. *Journal of Child and Family Studies, 5*, 445-467.
- Jacobson, N., Roberts, L., Berns, S., & McGlinchey, J. (1999). Methods for defining and determining the clinical significance of treatment effects: Description, application, and alternatives. *Journal of Consulting and Clinical Psychology, 59*, 12-19.
- Koren, P., DeChillo, N., & Friesen, B. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology, 37*, 305-321.
- Resendez, M., Quist, R., & Matshazi, D. (2000). A longitudinal analysis of family empowerment and client outcomes. *Journal of Child and Family Studies, 9*, 449-460.
- Taube, J., Tighe, T., & Burchard, J. (2001). The effects of family empowerment on adjustment for children receiving comprehensive mental health services. *Children's Services: Social Policy, Research, and Practice, 4*(3), 103-122.

---

## CONTRIBUTING AUTHORS

### Jennifer Maness, M.A.

3108 Henslowe Drive, Raleigh, NC 27603, e-mail: Jcm3108@aol.com

### Susan McCammon, Ph.D.\*

Department of Psychology, East Carolina University, Greenville, NC 27858, 252-328-6357, fax: 252-328-6283, e-mail: mccammons@mail.ecu.edu

### Thomas Durham, Ph.D.

Department of Psychology, East Carolina University, Greenville, NC 27858, 252-328-6118, fax: 252-328-6283, e-mail: durhamt@mail.ecu.edu

### Erik Everhart, Ph.D.

Department of Psychology, East Carolina University, Greenville, NC 27858, 252-328-4138, fax: 252-328-6283, e-mail: everharte@mail.ecu.edu

### David Dosser, Jr., Ph.D.

Marriage and Family Therapy Program, School of Human Ecology, East Carolina University, Greenville, NC 27858, 252-328-4513, fax: 252-328-5418, e-mail: dosserd@mail.ecu.edu

---

\*Contact for correspondence

# **Family Empowerment as a Mediator between System of Care and Changes in Child Functioning: Identifying an Important Mechanism of Change**

Kelly N. Graves

Terri L. Shelton

---

## **Introduction**

The emerging trend toward positive psychology and resiliency shifts the conceptual focus from a deficit-based view to a more family-centered system of service delivery for children's mental health (Akos, 2001; Dunst, Boyd, Trivette, & Hamby, 2002). One innovative model of service delivery lies within the family-centered systems of care philosophy (Stroul & Friedman, 1986; 1996). The systems of care philosophy views families as fully capable of making informed choices given that professionals provide the additional support and resources needed to empower families and to foster the development of new skills to create long-term change. The present longitudinal study examines how the family-centered element of the system of care philosophy relates to changes in children's problem behaviors over a one-year period as well as how family-centered care influences levels of family empowerment.

Previous research has documented the link between perceived adherence to the system-of-care philosophy with both positive child outcomes and satisfaction with services (Graves, 2005). However, there continues to be a lack of information regarding the specific *mechanisms* of change. That is, what is it about delivering services consistent with the system-of-care philosophy that leads to better outcomes? The present study begins to address this question by investigating family empowerment as a possible mechanism of change.

Based upon previous research and theory (e.g., Dunst et al., 2002; Graves, 2005; Stroul & Friedman, 1996; Taub, Tighe, & Burchard, 2001), it was hypothesized that:

1. children's problem behaviors would decrease over a one-year period while levels of family empowerment would increase
2. greater perceived adherence to the family-centered element of the system of care philosophy would be linked to greater change in child functioning
3. greater levels of family empowerment would be linked to greater change in child functioning, and
4. family empowerment would mediate the relationship between family-centered care and change in child functioning.

## **Method**

### **Participants**

Participants were 117 children with severe emotional disturbance and their families who were enrolled in a North Carolina system-of-care program. Of those 117 families, five families declined to participate in the evaluation and 14 families dropped out of the longitudinal program evaluation within the first year (12% attrition). Data were not available for the variables of interest in 19 families. Thus, the final sample for the present study included 79 families. The mean age of the children was 12.05 ( $SD = 2.53$ ). Seventy-four percent of children were male. Fifty-five percent of caregivers identified themselves as African American, with 36% White, and 9% Hispanic or Other.

### **Procedures**

Children were referred to their local community mental health program from a variety of sources, including caregivers, child-serving agencies, and schools. Consent forms for treatment and for participation in the evaluation process were signed by the primary caregiver (or legal guardian if different from the caregiver) and the child, if age 11 or older. At baseline (Time 1; T1) and one year later (Time 2; T2), trained evaluators conducted in-home interviews lasting approximately two hours for caregivers and one hour for children. All instruments were read to both children and their caregivers to minimize possible error due to differential reading abilities. Families received \$25 for T1 interviews and \$30 for T2 interviews; children received gift certificates donated from local fast food restaurants at both T1 and T2.

## Measures

**Descriptive Information Questionnaire (DIQ; Center for Mental Health Services [CMHS], 1997).** The DIQ is a 37-item caregiver-reported questionnaire that was completed at T1. The measure describes child and family characteristics such as age, race, ethnicity, risk factors, and family structure.

**Adherence to System of Care Philosophy.** Caregivers reported on the degree to which their services were delivered consistent with a family-centered approach at T2 using the Wraparound Fidelity Index 2.0 (WFI; Burchard, 2001). Two subscales from that scale were chosen that are specifically related to family-centered care: Parent Voice/Choice and Cultural Competence. Each subscale contains four items that assessed the degree to which services were family-centered, with scores ranging from 0 = *no*, to 1 = *sometimes*, and 2 = *yes*. A total score was created by summing all of the items into a total family-centered care score, with higher scores indicating greater adherence to a family-centered approach. Internal consistency (Cronbach's alpha) for the composite score was .79.

**Child Functioning.** Caregiver-report child functioning was obtained at both T1 and T2 using the Child Behavior Checklist (CBCL; Achenbach, 1991). The present study utilizes T-scores from the total problem behavior index.

**Family Empowerment.** Caregiver-reported family empowerment was obtained at both T1 and T2 using the Family Empowerment Scale (FES; Koren, DeChillo, & Friesen, 1992). The FES consists of 34 items rated on a 5-point Likert-type scale from 1 = *not true at all*, to 5 = *very true*. A composite score of family empowerment was created by averaging the 34 items separately at T1 and T2. Internal consistency (Cronbach's alpha) was .90 at T1 and .95 at T2.

## Results

Descriptive analyses for all independent and dependent variables are presented in Table 1. Consistent with hypothesis one, paired samples *t*-tests indicated that there were significant improvements in child total problem behaviors from T1 to T2,  $t(78) = 4.79, p < .001$ , as well as a marginally significant change in levels of family empowerment from T1 to T2,  $t(78) = 1.51, p < .10$ . However, in order to examine what variables were associated with change more directly, additional analyses were conducted.

To test hypotheses two through four, a series of hierarchical regression analyses were conducted. In the first analysis, perceived level of family-centered care was entered as a predictor of T2 children's problem behavior (controlling for T1 problem behavior). That analysis indicated that higher levels of family-centered care predicted lower levels of T2 problem behavior,  $t(78) = -2.12, p < .05, \beta = .27$ , even after controlling for pre-treatment levels of behavioral challenges. In the second analysis, family empowerment at T2 was entered as a predictor of T2 children's problem behavior (controlling for both T1 empowerment and problem behavior). That analysis indicated that higher levels

**Table 1**  
Summary of Hierarchical Regression Analyses  
to Predict T2 Total Problem Behaviors

Variable	B	SE	$\beta$
<b>Regression One</b>			
Step 1			
Total Problem Behaviors at T1	.71	.15	.63***
Step 2			
Family-centered Care	-1.77	.84	-.27*
<b>Regression Two</b>			
Step 1			
Family Empowerment at T1	.30	2.09	.02
Total Problem Behaviors at T1	.72	.14	.56***
Step 2			
Family Empowerment at T2	-6.28	1.85	-.37***
<b>Regression Three</b>			
Step 1			
Family Empowerment at T1	.30	2.09	.02
Total Problem Behaviors at T1	.72	.14	.56***
Step 2			
Family Empowerment at T2	-6.28	1.85	-.37***
Step 3			
Family-centered Care	-1.18	.82	-1.9

\* $p < .05$ . \*\*\* $p < .001$ .

of family empowerment predicted lower levels of problem behavior,  $t(78) = -3.39, p < .001, \beta = -.37$ . In the third analysis, T1 indicators were entered in the first step (problem behavior and family empowerment), T2 family empowerment was entered in the second step, and perceived adherence to family-centered care was entered in the third step. That analysis indicated that family empowerment continued to predict lower levels of children's problem behavior, but the link between perceived adherence to family-centered care dropped out, indicating that family empowerment is a mediator between family-centered care and changes in child functioning. The series of regressions conducted to address hypotheses two through four are reported in Table 1.

## **Discussion**

The purpose of the present study was to begin to investigate specific mechanisms of change for children who receive system of care based services. Specifically, we examined how the family-centered care element of the system of care philosophy relates to changes in children's problems over a one-year period as well as how family-centered care influences levels of family empowerment. Findings indicate that when examined separately, both family-centered care and family empowerment predicted decreases in children's problem behavior over a one-year period. However, once the variance accounted for by change in family empowerment was parceled out, family-centered care no longer directly predicted decreases in children's problem behaviors. Thus, our findings suggest that family empowerment is a mediator between family-centered care and changes in child functioning and appears to be one mechanism of change for children who receive system of care-based services.

The findings of this study indicate that family empowerment is an important factor in children's outcomes, suggesting that additional resources and services should be directed toward enhancing the empowerment of parents. Because the system of care philosophy appears to have some impact through family empowerment, there is a need to focus on those professional activities that lead specifically to increases in family empowerment such as involving families more in treatment planning. The current findings also advocate for the continued movement toward including parents as partners in the coordination, planning, and implementing of services for children, and for viewing parents not as part of the problem, but as the central resource for the child (Lourie & Katz-Leavy, 1986; Stroul, 1996).

## References

- Achenbach, T. M. (1991). *Child Behavior Checklist for Ages 4-18*. Burlington: University of Vermont, Department of Psychology.
- Akos, P. (2001). Creating developmental opportunity: Systemic and proactive intervention for elementary school counselors. In D. S. Sandhu (Ed.), *Elementary school counseling in the new millennium* (pp. 91-102). Alexandria, VA: American Counseling Association.
- Burchard, J. D. (2001). *Wraparound Fidelity Index 2.1*. Burlington, VT: University of Vermont, Department of Psychology.
- Center for Mental Health Services. (1997). *The Descriptive Information Questionnaire*. Unpublished measure.
- Dunst, C., Boyd, K., Trivette, C. M., & Hamby, D. W. (2002). Family-oriented program models and professional helping practices. *Family Relations, 51*, 221-239.
- Graves, K. N. (2005). The links among perceived adherence to the system of care philosophy, consumer satisfaction, and improvements in child functioning. *Journal of Child and Family Studies, 14*, 403-415.
- Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology, 37*, 305-321.
- Lourie, I., & Katz-Leavy, J. (1986). Severely emotionally disturbed children and adolescents. In W. Menninger (Ed.), *The chronically mentally ill* (pp. 159-186). Washington, DC: American Psychiatric Association.
- Stroul, B. A., & Friedman, R. (1986). *A system of care for children and youth with severe emotional disturbances* (Rev. Ed.). Washington, DC: Georgetown University Child Development Center, CASSP Technical Assistance Center.
- Stroul, B. A., & Friedman, R. (1996). The system of care concept and philosophy. In B. Stroul (Ed.), *Children's Mental Health: Creating Systems of Care in a Changing Society*. Baltimore, MD: Brookes.
- 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*, 103-112.

---

## CONTRIBUTING AUTHORS

**Kelly N. Graves, M.A.**

E-mail: [knrogers@uncg.edu](mailto:knrogers@uncg.edu)

**Terri L. Shelton, Ph.D.**

E-mail: [tlshelto@uncg.edu](mailto:tlshelto@uncg.edu)

All Authors: Center for Youth, Family, and Community Partnerships, University of North Carolina at Greensboro, Foundation Place, 330 S. Greene St., #200, Greensboro, NC 27401

# **Depression among Primary Caregivers of Children with Mental Health Needs**

*Acknowledgements: Research funded by Indiana University School of Nursing Center on Enhancing Quality of Life in Chronic Illness (National Institute of Health), Association for Advancement of Psychiatric/Mental Health Research and Practice, and Indiana Family and Social Services Administration.*

**Janis E. Gerkenmeyer  
Eric L. Scott  
Erika LeBaron  
Brenda Costello-Wells  
Kim Walton**

## **Introduction**

Distress experienced by children with mental health needs and their families has created a health crisis in our country associated with many unmet service needs (U.S. Public Health Service, 2000). Primary caregivers, henceforth referred to as parents, have faced tremendous challenges in caring for these children, yet we know very little about parental well-being (Crowley & Kazdin, 1998). Preliminary findings from a larger, unpublished study found high levels of depression among parents. The purpose of this study was to examine variables associated with parents' depression, including variables that mediated, moderated, or predicted depression. Information about factors associated with parents' depression can help guide interventions to improve their well-being.

In a previous study, Dunn and colleagues (2001) found that mothers of children with autism were the most seriously affected family members, with one-third exhibiting symptoms of depression. Further, Mash and Johnston (1983) found that parents' depression, self blame, and social isolation were directly associated with their child's hyperactivity, distractibility and degree of bother.

## **Methods**

A cross-sectional design was used with a convenience sample of 100 parents of a child between 2 to 19 years old, receiving community mental health services in one Midwestern state, and living at home during parents' enrollment in the study and for at least 20 of the past 24 months. Participants included biological, adoptive and foster parents, relatives and guardians. Parents were recruited from community mental health agencies. Institutional Review Board approval was obtained.

## **Sample**

Average age of participants was 37.8 years ( $SD = 8.2$ ); and 44% were married, 28% divorced, 14% single, 9% living with partner, and 5% separated. Participants were predominantly female (98%), including 84% biological mothers, 7% grandmothers, and 5% adoptive mothers. Most participants were Caucasian (85%) with 12% African American and 2% Native American. Participants were employed full-time (24%), part-time (16%), homemakers (30%), unemployed (15%), and other (15%). Average annual household income ranged from \$20,000 to \$29,999 (Median = \$10,000 to \$19,999).

Most (66%) children were males. Average child's age was 10 years ( $SD = 3.9$ ). Most children were Caucasian (76%) with 14% African American, and 2% Native American. The average length of mental health problems was 5.38 years ( $SD = 3.5$ ). Seriousness of the child's problem was rated by parents as 4.05 on a 5-point scale with 5 being *very serious*.

## **Instruments**

The Child Behavior Checklist (CBCL; Achenbach, 1991) internalizing and externalizing raw scores were used to measure antecedent variables considered a stressor for parents. In the initial model, mediators and moderators included parents' optimism, perceived stigma, social support, empowerment, personal control, and home helper. The model was adapted to also examine mediating and moderating effects of variables previously considered outcomes including subjective and objective distress, family satisfaction, and role disruption. The Parents Attribution Scale (PAS; Gerkenmeyer, 1999) had 21

items with a 5-point scale anchored by two opposite statements. Factor analysis of the PAS with varimax rotation resulted in five factors including Stigma (alpha = .89), Threat (alpha = .80), Services Helped (optimism, alpha = .69), Can Change (alpha = .68), and Blames Me (alpha = .61).

Social Support was measured by the 40-item Inventory of Socially Supportive Behaviors (ISSB; Barrera, Sandler & Ramsay, 1981). Factor analysis with varimax rotation resulted in three factors including Advice (alpha = .94), Comfort (alpha = .93), and Tangible (alpha = .82). Home Helper was measured by one item rating how much help was received from someone living with the caregiver. Empowerment was measured by the 34-item Family Empowerment Scale (FES; Koren, DeChillo & Friesen, 1992) on a 5-point Likert scale from 1 = *never*, to 5 = *very often*. Factor analysis with varimax rotation resulted in three factors including Services (alpha = .93), Community (alpha = .91), and Family (alpha = .90). Personal control was measured by the 7-item Pearlin Mastery Scale (PMS; Pearlin & Schooler, 1978) on a 4-point Likert scale from 0 = *strongly agree*, to 3 = *strongly disagree* (alpha = .75).

Distress was measured by the 19-item Parent Experiences Scale (PES), adapted by this author from Reinhard's Burden Assessment Scale (Gerkenmeyer, 1999; Reinhard, 1994). Factor analysis resulted in two factors, Subjective (alpha = .89) and Objective Distress (alpha = .81). Role functioning, measured by the 6-item SF-36 Health Survey-Adapted, used a 5-point Likert scale from 1 = *not at all*, to 5 = *a great deal*. Adapted by the author from the SF-36 (Ware & Sherbourne, 1992), it assessed disruption of parents' work and social activities (alpha = .89). Family Functioning, measured by the 5-item Family APGAR (Smilkstein, 1978), refers to how satisfied parents were with family functioning (alpha = .92).

Depression was measured on the 20-item Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977). Symptoms of depression were measured on a 4-point Likert scale from 3 = *most of the time*, to 0 = *rarely*, with a possible range of 0 to 60 (alpha = .93). A score of 22 or higher indicated a possible major depression. A score of 16 to 21 indicated a possible mild to moderate depression.

## Data Analysis

Bivariate correlations between and among the CBCL internalizing and externalizing scores, mediating/moderating variables, and depression using Pearson correlations were obtained. The mediating and moderating effects of variables on depression were examined using the regression methods of Baron and Kenney (1986). Each regression model included either the internalizing or externalizing CBCL score. The relationship of each potential mediator/moderator variable to depression was examined separately.

## Findings

High levels of depression were found ( $M = 19.87$ ). Of the 100 parents, 38% had a score of 22 or greater and 56% a score of 16 or greater. Depression was found to be highly correlated with many variables (see Table 1). When examining the mediating effects of these variables, only personal control and role disruption were found to mediate the association of the CBCL internalizing score and depression (see Table 2). The family factor of the Family Empowerment Scale and subjective distress were found to moderate the association of the CBCL internalizing score with depression. Subjective distress was found to also moderate the association of the CBCL externalizing score with depression.

When conducting Step-wise regression to identify predictors of depression, only participants whose child scored 60 or greater on the CBCL Internalizing or Externalizing T-score were included in two separate analyses ( $n = 84$  for each). Variables correlated with depression at  $p < .001$  were entered into the Step-wise regression including personal control, family functioning, role disruption, FES family factor, blame, subjective distress, and objective distress. For internalizing, the predictive model was role disruption ( $\beta = .79, p < .001$ ), personal control ( $\beta = -7.34, p < .001$ ), and family functioning ( $\beta = -.56, p < .001; R^2 = .53, p = .001$ ). For externalizing, the model included personal control ( $\beta = -7.05, p < .01$ ), family functioning ( $\beta = -.65, p < .001$ ) and role disruption ( $\beta = .70, p < .001; R^2 = .50, p = .001$ ).



**Table 1**  
**Correlations**

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Income	—														
2. CBCL Internal	-.062	—													
3. CBCL External	-.170	.584***	—												
4. FES Family	.096	-.226*	-.313**	—											
5. ISSB Comfort	.075	-.153	-.065	.168	—										
6. Stigma (PAS)	.037	.335***	.410***	.284**	.235*	—									
7. Threat (PAS)	.053	.364***	.391***	.450***	.094	.474***	—								
8. Home Helper	.330***	-.083	-.097	.085	.153	.138	.002	—							
9. Blame (PAS)	.186	.345***	.349***	.352***	.283*	.470***	.242*	.234	—						
10. Personal Control	.159	.399***	.375**	.394***	.244**	.392***	.337***	.081	.392***	—					
11. Role Disruption	-.023	.408***	.391***	-.246**	-.180	.497***	-.294**	-.255**	.461***	.497***	—				
12. Subjective Distress	-.001	.476***	.501***	.540***	-.096	.581***	.592***	-.077	.481***	.514***	.575***	—			
13. Objective Distress	.012	.431***	.436***	-.273**	-.120	.493***	.453***	-.237*	.405***	.386***	.614***	.625***	—		
14. Family Function	.270**	-.286**	-.212*	.454***	.509***	.290**	.362***	.259**	.324***	.341***	-.267**	-.361***	-.243*	—	
15. Depression	-.311**	.358***	.391***	.328***	-.276**	-.265**	-.250**	-.245**	.471***	.576***	.519***	.413***	.332***	-.497***	—

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

**Table 2**  
**Mediators and Moderators of Depression Among Primary Caregivers of Children with Mental Health Needs**

<i>Antecedent Variable</i>	<i>Mediator</i>	<i>Level of Significance of Mediator to Outcome</i>	<i>Decreased Level of Significance of Antecedent to Outcome</i>	<i>Moderator</i>	<i>Significance of Interaction of Antecedent and Moderator</i>	<i>Outcome Variable</i>
CBCL Internalizing	Personal Control	$p < .0001$	$p < .089$			Depression (CES-D)
	Role Disruption	$p < .0001$	$p < .116$			Depression
				FES Family	$p < .043$	Depression
				Subjective Distress	$p < .008$	Depression
CBCL Externalizing				Subjective Distress	$p < .033$	Depression

## Discussion

It was evident from these findings that there was a high prevalence of depression among parents caring for children with mental health needs receiving community-based care, with 56% having a score on the CES-D indicating that they might have mild to major depression and 38% that might have major depression.

Many of the study variables were significantly correlated with depression. Upon further analysis, it was discovered that a couple of these variables had a mediating effect upon the relationship of internalizing disorders with depression, including personal control and role disruption, thereby providing potential target areas for future interventions. Moderators included family-focused empowerment and subjective distress for internalizing CBCL scores' relationship with depression, and subjective distress for externalizing CBCL scores. Information about moderators of depression provides clues about risk factors for depression. For example, a parent with a high level of subjective distress would be at greater risk for depression. Predictors of depression were similar for internalizing and externalizing CBCL scores and included the two identified mediators of depression for internalizing disorders, personal control and role disruption, along with family functioning.

With such high levels of depression, there is a need to routinely assess these caregivers for depression. With increased reliance on families to care for children with mental health needs at home with ever rising levels of acuity, resources and services are needed to support parents' efforts so that they will be able to experience positive outcomes for their child, family, and themselves.

Research is needed to further examine factors associated with depression for these caregivers. Intervention research is also needed that is targeted at preventing or diminishing parents' depression. Findings from this study support focusing on interventions to increase parents' sense of personal control and to decrease role disruption as potential approaches to decrease parents' depression.

## References

- Achenbach, T.M. (1991). *Manual for the Child Behavior Checklist/4-18 and 1991 Profile*. Burlington, VT: University of Vermont, Department of Psychiatry.
- Baron, R. M., & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical consideration. *Journal of Personality and Social Psychology*, *5*, 1173-1182.
- Barrera, M., Sandler, I. N., & Ramsay, T. B. (1981). Preliminary development of a scale of social support: Studies on college students. *American Journal of Community Psychology*, *9*(4), 435-447.
- Crowley, M. J., & Kazdin, A. E. (1998). Child psychosocial functioning and parent quality of life among clinically referred children. *Journal of Child and Family Studies*, *7*(2), 233-251.
- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, *37*(1), 39-52.
- Gerkenmeyer, J. (1999). *Examining parent satisfaction with services for children and adolescents with mental health problems*. Dissertation, Indiana University.
- Koren, P. E., DeChillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology*, *34*(4), 305-321.
- Mash, E. J., & Johnston, C. (1983). Parental perceptions of child behavior problems, parenting self-esteem, and mothers' reported stress in younger and older hyperactive and normal children. *Journal of Consulting and Clinical Psychology*, *51*(1), 86-99.
- Pearlin, L. I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior*, *22*, 337-356.
- Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, *1*, 385-401.
- Reinhard, S. C. (1994). Living with mental illness: Effects of professional support and personal control on caregiver burden. *Research in Nursing and Health*, *17*(2), 79-88.
- Smilkstein, G. (1978). The family APGAR: A proposal for a family function test and its use by physicians. *Journal of Family Practice*, *6*(6), 1231-1239.
- U.S. Public Health Service. (2000). *Report of the Surgeon General's Conference on Children's Mental Health: A National Agenda*. Washington, DC: U.S. Government Printing Office.
- Ware, J. E., & Sherbourne, C. D. (1992). The MOS 36-item short form health survey (SF-36). *Medical Care*, *30*(6), 473-481.

---

**CONTRIBUTING AUTHORS**

**Janis E. Gerkenmeyer, Ph.D., R.N., APRN.BC**

*Principal Investigator, Indiana University School of Nursing, 1111 Middle Drive, NU403, Indianapolis, IN, 46202, 317-278-4896, fax: 317-278-1378, e-mail: jgerkens@iupui.edu*

**Eric L. Scott, Ph.D.**

*Co-Investigator, Indiana University School of Medicine, 702 Barnhill Drive, Room 4300, Indianapolis, IN, 46202, 317-274-8162, fax: 317-278-0609, e-mail: erlscott@iupui.edu*

**Erika LeBaron, M.S.N., R.N.**

*Co-Investigator, Midtown Community Mental Health Center, 1505 Hillcot Lane, Indianapolis, IN, 46231, 317-941-5010, e-mail: elmsn@cs.com*

**Brenda Costello-Wells, M.S.N., R.N., APRN.BC**

*Co-Investigator, BehaviorCorp, 54 North 9th Street, Noblesville, IN, 46060, 317-587-0535, e-mail: gbrwells@hotmail.com*

**Kim Walton, MSN, RN, APRN.BC**

*Co-Investigator, Community Health Network, 7150 Clearvista Drive, Indianapolis, IN, 46256, 317-621-5928, e-mail: Kwalton@community.com*

# **Symposium**

## **The Ecology of Maternal Depression: Addressing a Silent Epidemic**

---

### **Symposium Introduction**

Larke Nahme Huang

This symposium takes a developmental, ecological approach to understanding the impact of maternal depression in low-income urban communities. Research indicates an increasing prevalence of maternal depression in these communities—particularly among women of color—yet there is a limited understanding of the impact on their children and a lack of systematic intervention for this under-identified condition in traditionally under-served populations. This symposium highlights the impact of maternal depression on critical developmental tasks of young children and adolescents and how culturally diverse groups of women view depression, describe the impact on their children, and seek help. The studies are a combination of quantitative, secondary analyses of larger datasets and a qualitative focus group study of women from community-based organizations. In combination, these studies support an approach for understanding maternal depression in a family and community context and provide a foundation for developing a “family system of care.”

#### **Chair**

Larke Nahme Huang

#### **Authors**

Elizabeth Spier et al.

Bridget Goosby

Katherine Lazear

#### **Discussant**

Mareasa Isaacs

### **Pathways Between Maternal Depression and Early Child Language Development in Low-income Families**

Elizabeth Spier, Catherine Tamis-LeMonda, Barbara Alexander Pan, & Meredith Rowe

*This study is based on data collected for the national Early Head Start Research and Evaluation study. We wish to acknowledge the national Early Head Start contractors (Mathematica Policy Research and Columbia University); the funding agencies (Administration on Children, Youth and Families, National Institute of Child Health and Human Development, Office of the Assistant Secretary for Planning and Evaluation in DHHS, and the Ford Foundation); the local research universities participating in the Early Head Start Research Consortium; program directors from the participating Early Head Start programs; and all of the families who so generously took part in this project.*

#### **Introduction**

Three findings motivated this study. First, mothers living in poverty are at increased risk for depression relative to non-impooverished mothers (Petterson & Albers, 2001). Second, maternal productive vocabulary is positively related to children’s lexical development (Pan, Rowe, Singer, & Snow, in press). And third, depressed mothers speak less to their toddlers than non-depressed mothers. In turn, their children are at increased risk for delays in language development (Murray, Kempton, Woolgar & Hooper, 1993).

The following study was undertaken to examine the relationships between maternal depression, early maternal vocabulary use, and children’s later lexical development in low-income families. It was hypothesized that: (a) maternal depression would be associated with reduced maternal productive vocabulary, (b) maternal depression would be negatively associated with the size of children’s productive and receptive vocabularies, and (c) maternal depression would have a significant impact on children’s lexical development due to reduced early maternal vocabulary use.

#### **Method**

**Sample.** Participants were 116 mother-child pairs from low-income homes in the northeastern United States, with 66 families (56.9%) coming from an urban site and 50 (43.1%) from a rural site. All had applied for Early Head Start services when their children were less than one year of age. Mothers ranged in age from 14 to 43 years at the time of their child’s birth ( $M = 23$  years, 1 month,  $SD = 7$  years 5 months). Almost half of the urban mothers ( $n = 29$ , 43.9%) and four (8.0%) of the rural mothers had given birth prior to age eighteen. Forty-six (39.7%) of the mothers identified themselves as White,

non-Latino; 43 (37.1%) as Black, non-Latino; 24 (20.7%) as Latino, and; three (2.6%) as mixed or other ethnicity. All of the White, non-Latino mothers were from the rural site. At the time of their child's second birthday, 49 (42.2%) mothers had not completed high school, 34 (29.3%) had a high school diploma or equivalency degree, and 33 (28.4%) had some education beyond high school. Sixty-three (54.3%) children were boys, and most ( $n = 69$ , of all children; 59.5%) were a first born or only child.

**Measures.** Mother-child dyads participated in assessments when children were 14 (Time 1) and 36 (Time 2) months of age. Mothers completed the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977) at Time 1. Mother-child dyads were videotaped in 10-minute, semi-structured play sessions at both assessments. Mothers were given a book and age-appropriate toys, and instructed to interact with their children as they normally would. CHILDES (MacWhinney, 2000) facilitated transcription and lexical analysis of videotaped interactions. The *FREQ* program in CHILDES measured maternal word-types (number of vocabulary words spoken) from the transcripts. The *VOCD* program was used to assess children's productive vocabularies at Time 2. The *VOCD* program yields a score (*D*-value) representing the diversity of vocabulary in a speech sample (McKee, Malvern & Richards, 2000). Children's receptive vocabularies were assessed at Time 2 with the Peabody Picture Vocabulary Test III (PPVT-III; Dunn & Dunn, 1997).

## Results

At Time 1, maternal CES-D scores ranged from 0 to 49, with a mean of 12.95 ( $SD = 9.93$ ). More than a third of the mothers ( $n = 40$ , 34.5%) received CES-D scores in the depressed range. Maternal CES-D scores did not vary based on any demographic variables under consideration (maternal age, maternal education, ethnicity, urban/rural, child gender, and child's birth order). During the Time 1 videotaped sessions, mothers used a mean 127.33 word-types ( $SD = 45.92$ , range 23 to 221). Maternal age was positively associated with maternal word-types,  $r = .28$ ,  $p < .01$ . Number of maternal word-types was unrelated to any other demographic variables, once maternal age was taken into consideration.

At Time 2, children's *D*-values ranged from 7.63 to 70.90 ( $M = 38.35$ ,  $SD = 12.51$ ), and were unrelated to demographic characteristics. Children's PPVT-III scores ranged from 40 to 123 ( $M = 84.23$ ,  $SD = 17.06$ ). Overall, children's PPVT-III scores fell well below age norms, and nearly half of the sample (40.0%,  $n = 46$ ) scored below the tenth percentile. Maternal age was positively correlated with children's PPVT-III scores,  $r = .29$ ,  $p < .01$ . Children's PPVT-III scores were unrelated to any other demographics, once maternal age was taken into consideration.

The higher a mother's CES-D score, the fewer word-types she used with her child,  $r = .29$ ,  $p < .01$ . Non-depressed mothers used a mean 135.51 word-types ( $SD = 44.71$ ) and depressed mothers used a mean 112.40, ( $SD = 44.84$ ),  $t(111) = 2.63$ ,  $p < .05$ . Maternal vocabulary use at Time 1 was positively associated with children's expressive vocabularies and PPVT-III scores at Time 2, with  $r = .45$ ,  $p < .001$  and  $r = .24$ ,  $p < .05$ , respectively. There was a moderate correlation between children's expressive and receptive vocabularies,  $r = .27$ ,  $p < .01$ .

The higher a mother's CES-D score at Time 1, the lower her child's expressive and receptive vocabularies at Time 2,  $r = -.28$ ,  $p < .01$  and  $r = -.23$ ,  $p < .05$ , respectively. When mothers scored in the depressed range at Time 1, their children had PPVT-III scores at Time 2 that were nearly two standard deviations below established norms ( $M = 76.59$ ,  $SD = 18.85$ ), compared with scores at the low end of normal limits for children of non-depressed mothers ( $M = 88.14$ ,  $SD = 14.71$ ).

Finally, hierarchical multiple regression analyses were used to examine the relative prediction of Time 1 maternal depression and maternal vocabulary to children's Time 2 expressive and receptive vocabularies. To predict children's *D*-values, maternal CES-D scores were entered into the equation as Step 1, and maternal word-types as Step 2. The resulting model was significant,  $F(2, 106) = 5.10$ ,  $p < .01$ , with  $R^2 = .05$ ,  $p < .05$  for Step 1;  $\Delta R^2 = .03$ ,  $p < .05$  for Step 2. To predict children's PPVT-III scores, maternal age was entered into the equation as Step 1, maternal CES-D score as Step 2, and maternal word-types as Step 3. The resulting model was significant,  $F(3, 111) = 13.20$ ,  $p < .001$ , with  $R^2 = .10$ ,  $p < .01$  for Step 1;  $\Delta R^2 = .08$ ,  $p < .01$  for Step 2; and  $\Delta R^2 = .10$ ,  $p < .001$  for Step 3.

## Discussion

Despite living in a low-income environment, nearly two-thirds of the mothers in this sample did not show evidence of depression, and their children's receptive vocabularies were developing within normal limits. However, more than one-third of the mothers showed evidence of depression. Levels of maternal depression did not differ based on mother's age, education, ethnic background, whether the family lived in an urban or rural environment, or based on the child's gender or birth order. These findings suggest that maternal depression may be pervasive across low-income families, rather than being confined to a sub-population.

All three hypotheses were supported. Maternal depression was associated with reduced maternal vocabulary, with depressed mothers' averaging 23 fewer vocabulary words than non-depressed mothers in just ten minutes of play. Maternal depression at child age 14 months was negatively associated with the size of children's productive and receptive vocabularies at age 36 months. The regression analyses did provide evidence that maternal depression had a significant impact on children's lexical development due to reduced early maternal vocabulary use. However, maternal depression did seem to have an impact on child vocabulary development beyond maternal vocabulary. Consistent with other research, we found that older mothers used more vocabulary with their children than younger mothers, and their children displayed better receptive vocabularies. We did not find a relationship between maternal age and maternal depression, so there appears to be some other reason for this influence of maternal age. Further research is needed to gain a better understanding of how maternal age and maternal depression influence children's lexical development.

Children from low-income homes are at increased risk for poor early lexical development relative to their better-off peers (Hart & Risley, 1995). Past research has shown that in low-income families, children's early productive vocabularies are good predictors of their academic progress in elementary school (Walker, Greenwood, Hart, & Carta, 1994). Our results suggest that it is important to consider maternal mental health when attempting to support children's lexical development in this at-risk population.

## References

- Dunn, L. M., & Dunn, L. M. (1997). *Peabody Picture Vocabulary Test – III*. Circle Pines, MN: American Guidance Service.
- Hart, B., & Risley, T. R. (1995). *Meaningful differences in the everyday experience of young American children*. Baltimore: Paul H. Brooks.
- MacWhinney, B. (2000). *The CHILDES project: Tools for analyzing talk* (3rd ed.). Mahwah, NJ: Lawrence Erlbaum Associates.
- McKee, G., Malvern, D. & Richards, B. (2000). Measuring vocabulary diversity using dedicated software. *Literary and Linguistic Computing*, 15, 223-227.
- Murray, L., Kempton, C., Woolgar, M., & Hooper, R. (1993). Depressed mothers' speech to their infants and its relation to infant gender and cognitive development. *Journal of Child Psychology and Psychiatry*, 34, 1083-1101.
- Pan, B. A., Rowe, M. L., Singer, J., & Snow, C. E. (in press). Maternal correlates of toddler vocabulary production in low-income families. *Child Development*.
- Petterson, S. M. & Albers, A. B. (2001). Effects of poverty and maternal depression on early child development. *Child Development*, 72, 1794-1813.
- Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385-401.
- Walker, D., Greenwood, C. R., Hart, B., (1994). Prediction of school outcomes based on early language production and socioeconomic factors. *Child Development*, 65, 606-621.

## **The Influence of Maternal Well-Being on Low-Income Adolescents' Emotional and Behavioral Outcomes**

Bridget Goosby

### **Introduction**

At present, approximately 35% of children under the age of 18 live in poverty (US Census Bureau, 2003). Poverty's detrimental effects are a problem for children at all ages, yet early adolescence (ages 10 to 14 years old) remains an age group that has been somewhat neglected by sociological researchers. Evidence suggests that environmental factors following early childhood have a significant impact on outcomes in adolescence as well as in the transition to adulthood (Feinstein & Brynner, 2004). This study explores the effect of poverty duration on adolescents' internalized and externalized behavioral problems.

Adolescents who experience poverty tend to have increased levels of drug and alcohol use at earlier ages, early initiation into sexual activity, increased mental health problems, and lower levels of academic achievement. Although adolescents spend much of their time in the company of their peers, families still play an important role in their lives. Maternal behavior and mental health are affected by economic hardship, which in turn may lead to reduced adolescent well-being. These factors must be taken into account when seeking to understand how poverty affects adolescent outcomes.

The purpose of this study is to examine the pathways through which poverty impacts adolescent depression, anxiety, and social withdrawal. In addition, this study also explores the mediational influence of maternal psychological well-being on the relationship between poverty duration and their adolescent children's outcomes. The following questions guided the study:

- Do maternal depression and mastery mediate the impact of poverty on adolescent outcomes and do these outcomes vary by race?
- Does maternal mental health buffer or exacerbate youth socioemotional outcomes?

### **Methods**

**Sample.** The sample comes from the National Longitudinal Survey of Youth (NLSY). The sample includes 854 African American and Caucasian children ages 10-14 at the time of their assessment in 1998. Maternal background and assessments were compiled into a data set separate from child assessment files. The Center for Human Resource Research (CHRR) includes mother and child identification in each data set in order to provide the ability to merge the data sets together. Because this study measures both child and maternal background characteristics, the NLSY79 data files were merged with the NLSY Children and Young Adult Files by matched mother and child identification codes.

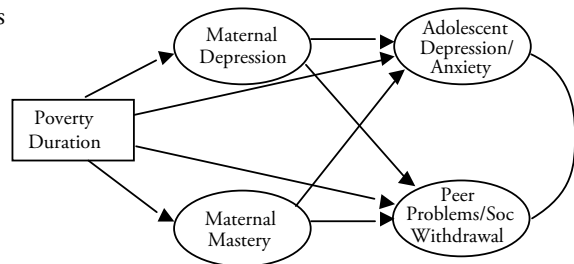
**Measures.** The dependent variables measured were two subscales from Zill and Petersen (1986) measuring (a) depression and anxiety, and (b) peer problems and social withdrawal. The depression and anxiety construct was comprised of six items, tested for model fit; it was found that these measures together demonstrated a strong model fit (CFI = .993, TLI = .993 and RMSEA = .042) using Confirmatory Factor Analysis. Peer Problems and Social Withdrawal also included six items that assessed child social interaction and found that the model fit was acceptable for this factor (CFI = .983, TLI = .977 and RMSEA = .065).

Latent measures include The Center for Epidemiologic Studies Depression Scale (CES-D) developed by Radloff (1977) to measure depressive symptoms. The CES-D demonstrated a strong model fit (CFI = .994, TLI = .990 and RMSEA = .022). The second measure, Maternal Mastery, was measured using the items created by Pearlin and Schooler (1978); the instrument measures the extent to which the mother feels she has control over events in her life. These items also demonstrated a good model fit (CFI = .975, TLI = .957 and RMSEA = .036). The independent variables included were poverty duration, measured by averaging the number of years the adolescent spends in poverty, maternal background characteristics, race, and sex.



**Analysis.** Figure 1 illustrates the conceptual path model reported in the Structural Equation Modeling (SEM) analyses. The models estimate the relationship between the dependent latent variables, depression and anxiety and peer problems and social withdrawal, on mother's depression and mastery, the duration of time spent in poverty, and child's and mother's background characteristics. Total, direct, and indirect effects were estimated in both sets of models. It should be noted that there is an average of 1.4 children per mother, indicating nesting within families. In order to account for the non-independence of observations due to clustering, all previous and subsequent SEM analyses adjust standard errors and estimates of model fit using robust estimators (Muthén & Muthén 2004; these analyses use the *Mplus* v3.x type = complex analysis). The variances of all latent variables in the models are fixed to 1 so that coefficients represent the expected standard deviation difference in the outcome for a one-unit change in the independent variable, and so that regressions among latent variables are fully standardized (i.e., effect-sizes).

**Figure 1**  
**Conceptual Path Model**



## Results

Increased poverty duration has a very strong positive correlation with both adolescent peer problems/withdrawal and depression/anxiety. These relationships are no longer statistically significant and the coefficients decline dramatically in magnitude with the introduction of maternal depression and mastery. Mother's increase in depression increases adolescent depression/anxiety and peer problems/withdrawal. Mothers with low levels of mastery increase adolescent depression/anxiety and peer problems/withdrawal. The effects remain true in the full models where maternal background characteristics and behavior are introduced into the model.

The analyses set out to estimate the effects of poverty duration, maternal depression and mastery on adolescent outcomes. The models supported the hypotheses that maternal depression and mastery for both dependent outcomes increase depression/anxiety and peer problems/social withdrawal scores for adolescents. Within this model, the pathway through which poverty impacts adolescent outcomes is mostly explained by maternal psychological resources. These findings suggest that mothers either act as buffers for their children or exacerbate the effect of poverty on their children through their own mental and emotional well-being.

An additional step assessed what the strongest predictors of maternal depression and mastery are in the model. The model estimates the effects of poverty duration and other maternal characteristics on mother's psychological outcomes. The models show evidence that poverty duration is the strongest predictor of maternal depression and mastery. The longer mothers spend in poverty, the higher their scores on depression measures and the lower their score on mastery. Even after adjusting for all other maternal characteristics, poverty duration retained a strong association—the strongest in the model. The only other significant predictor of maternal depression was mother's AFQT scores. Mothers who scored higher on the AFQT scores have lower levels of depression. In contrast, for maternal mastery (in addition to the significant effect of poverty duration on maternal mastery), being African American increased mother's sense of mastery. In addition, there was a positive correlation between mother's age at the birth of her first child.

## Discussion

Poverty's direct effect on behavioral problems is consistent with previous studies that tested the effects of persistent poverty on later outcomes of children and adolescents. These studies found that children who were persistently poor scored higher on internalizing problems such as depression and anxiety (Bolger, Patterson, Thompson, & Kupersmidt, 1995). In addition, maternal mental health consistently helps to explain the effects of poverty on both White and African American adolescents, replicating the findings of McLeod and Nonnemaker (2000). Interestingly, the findings of that study demonstrate that the affect of maternal psychological resources on adolescent outcomes are not explained by maternal background characteristics or the level of emotional support she provides for her children. The emotional support variable does explain a small portion of effect of maternal depression and mastery. This is consistent with findings that mothers who are in good mental health engage in adaptive coping behaviors that buffer their children from the detrimental effects of economic hardship (Pearlin & Schooler, 1978; Taylor & Roberts, 1995). Also, in exploring the strongest predictors of maternal depressive symptoms and mastery, it was found that increased poverty duration increased depressive symptoms and decreased mother's feelings of mastery.

Overall, the findings indicate that persistent poverty has deleterious effects on adolescent socioemotional problems. Adolescents who engage in problematic behavior, in addition to being in poverty, generally do not have the access to structural resources available to buffer these problems. As a result, increased behavioral problems have more dire consequences for their later outcomes, including employment opportunities, school completion, and family formation. This study also demonstrates that maternal psychological resources play an important role in the lives of adolescents. The analyses also suggest that with improved mental health, mothers can serve as a buffer to the strains and stressors associated with poverty. By increasing access to mental health resources for poor mothers, creating more effective treatments, and providing information, youth well-being among children with low-income mothers could improve. Further, by alleviating economic strain for families in poverty there can be changes in the economic and psychological well-being of families and youth.

## References

- Bolger, K. E., Patterson, C. J., Thompson, W. W., & Kupersmidt, J.B.. (1995). Psychosocial adjustment among children experiencing persistent and intermittent family economic hardship. *Child Development* 66, 1107-1129.
- Feinstein, L & Brynner, J. (2004). The importance of cognitive development in middle childhood for adulthood socioeconomic status, mental health, and problem behavior. *Child Development*, 75, 1329-1339.
- McLeod, J. D. & Nonnemaker, J. M. (2000). Poverty and child emotional and behavioral problems: Racial and ethnic differences in process and effects. *Journal of Health and Social Behavior* 41, 137-161.
- Muthén, L. K. & Muthén, B. O. (2004). Mplus user's guide. Third Edition. Los Angeles, CA: Muthén & Muthén 2004.
- Pearlin, L. I. & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior* 19, 2-21.
- Radloff, L. S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Journal of Applied Psychological Measures*, 1(3), 385-401.
- Taylor, R. D. & Roberts, D. (1995). Kinship support and maternal and adolescent well-being in economically disadvantaged African American families. *Child Development* 66, 1585-1597.
- Zill, N. & Petersen, J. L. (1986). *Behavioral Problems Index*. Washington, DC: Child Trends, Inc.

## **Lessons from a Maternal Depression Focus Group**

Katherine Lazear

### **Introduction**

Maternal depression is a very costly and common mental health condition, affecting almost 10% of the U.S. population in a given year (NIMH, 2003). The effects of maternal depression on families can be debilitating and the effects on young children are devastating, with research studies suggesting that maternal depression increases behavior and learning problems, and predisposes these children to behavioral and affective disorders far greater than those raised in families where mothers are not depressed (Weissman & Olfson, 1995).

Although depression is a major public health problem, placing caregivers and children at risk, very few women receive treatment. Those who do receive treatment often do not receive quality care. Screening, prevention, and treatment efforts aimed at maternal depression would appear imperative. And, although we know that maternal depression is highly prevalent and under-treated in many communities of color, we do not know enough about effective, culturally appropriate ways to outreach to and engage mothers and their families in treatment or how to effectively screen and treat them for depression.

This summary provides an overview of the findings of a maternal depression focus group project and the implications these findings may have on outreach and engagement activities to families in communities with diverse racial and ethnic populations. The study was implemented to gain a better understanding of:

- how culturally and racially diverse populations across the country view depression and its impact on children
- where families, their neighbors and friends turn for help
- approaches or strategies that might be helpful, and
- how families talk about depression.

### **Participants**

The community-based organizations participating in the study were part of the Annie E. Casey Foundation community health project sites. Eighteen organizations representing racial and ethnic diversity—Cambodian, Mexican, Laotian, Samoli, Haitian, Latina, African-American, Sudanese, El Salvadorian, Central American, Vietnamese, Liberian, Congan, Burundian, Rwandan, Senegalese, and Tongonese—facilitated focus groups in the primary language of the 130 participants who were mothers of children newborn through age nine. Participants ranged in age from 17 to 66 years of age. Some had been in the U.S. for as little as one year, while others had lived in the U.S. all of their lives.

Regarding the process of bringing these women to focus groups, other women from similar cultural, racial, or ethnic backgrounds facilitated the groups. In virtually all cases, child care, transportation, food, and a monetary stipend (or equivalent) were provided. Many women were recruited through providers or agencies with whom they already were involved, such as a health clinic. Others were recruited through flyers, letters and phone calls, and others through word of mouth and contacts from other women.

## **Results**

### **Talking About Depression**

Across all focus groups, women recognized and identified the symptoms of depression, such as feelings of sadness and crying, changes in appetite and weight, changes in sleep patterns, difficulty concentrating, avoidance of social interactions, and use of drugs or alcohol. Across virtually all focus groups, women were initially reticent to talk about or admit to experiencing depression. In virtually all

groups, however, the focus group process created opportunity and support for women, leading eventually to rich discussions about depression. When the women in these focus groups felt comfortable discussing depression, they identified it almost without exception as a major issue in their communities.

Across all focus groups, women recognized the link between emotional and physical well being, identifying stress, for example, as a factor that can cause or exacerbate physical health problems. In general, most women reported that they experienced depression more after their second pregnancies than their first, particularly if the pregnancy was unplanned or if the pregnancies were close together. Many women described what could be called a “continuum of depression,” with some problems being manageable by talking to friends or taking steps on one’s own, and others being so serious that professional help was needed.

### **Factors Contributing to Depression**

Many women described financial pressures, physical health problems, racism, sexism, language barriers, and genes as contributing factors for depression. Regardless of cultural group, women who are immigrants to the United States, particularly from war-torn, economically depressed countries, view the U.S. as providing greater opportunities and services but also view the U.S. as enormously stressful because of constant pressures to find employment, make money, resolve immigration status, learn the language, find transportation and housing, etc. Also, many of these women have left children and support systems, such as family and friends, behind in their native countries, which they report creates powerful feelings of sadness and isolation. Many of the women who are immigrants to the U.S. described feeling overwhelmed by the complexities of American life and its emphasis on money and work.

Language barriers, financial pressures, transportation, leaving family behind, isolation, racism, feeling a loss of control and having to be dependent on others—all of these were themes struck by these women as associated with depression. Many women identified domestic violence and a lack of emotional and practical support from fathers as major factors in maternal depression. In some cases, women associated use of drugs and alcohol as contributors to fathers’ lack of support and to domestic violence. Across many of the focus groups, women indicated that the way their respective cultures view and treat women (as “responsible for doing everything,” as subservient to men, as the stoic who should not have her own needs and concerns) creates stress for them, particularly because there is a perception that the status of women in the U.S. is or should be different.

### **Barriers to Seeking Help**

Across all focus groups, women indicated that stigma and a fear of being labeled “crazy” were barriers to talking about and seeking help for depression. Trust in family, friends, and providers seemed to be the single biggest factor in whether women felt comfortable talking about or seeking help for depression. With many women, because of stigma and cultural attitudes and beliefs, acknowledging depression was associated with a sense of shame. A number of women identified lack of health insurance as a major barrier to seeking help, particularly early intervention or preventive care. Many women reported that the attitudes of providers, whether they are respectful, supportive and non-discriminatory, makes a huge difference in women’s willingness and ability to access services.

### **Seeking Help**

Across virtually all focus groups, women who discussed seeking help or support for depression turned first to natural helpers (family members, friends, pastors), then to primary health care providers (health clinics and doctors), with only a few women turning to the formal mental health system or to mental health professionals. Across virtually all focus groups, women felt distrustful toward using medications for depression or other emotional problems either for themselves or for their children, and there is a perception that mental health professionals will be “quick to medicate” if approached for help.

### **Impact on Children**

Across all focus groups, women recognized and identified similar impacts of maternal depression on children, such as children “acting out,” or trying to please, or feeling responsible for their mothers’ sadness, or withdrawing. Across all focus groups, with few exceptions, women reported that the physical health of their children is good. With few exceptions, women across all focus groups recognized the importance of, and had a strong commitment to, school involvement to ensure that their children do well in school. However, also without exception, women with limited English felt disrespected and dismissed by teachers with whom they could not communicate, and language was identified as a huge barrier to school involvement. In general, (except for non-English-speaking women as noted), women reported good relations with teachers and often with primary health care providers.

### **Recommendations to Help**

Across all focus groups, women identified similar steps that could be taken to help with depression, including better access to basic supports, such as jobs, housing, and child care, opportunities to talk with other women, and access to supportive professionals in non traditional ways, such as on the telephone or in-home. Across all focus groups, women felt that simply having the opportunity to talk about depression and other life issues in a safe environment with other women who share common life experiences was helpful.

### **Implications**

Based on the findings from the study, the future work of the mental health field in addressing maternal depression will need to focus on developing trusting relationships; providing opportunities for safe discussion and disseminating accurate information; and providing services and supports that are respectful of the family and proven to be effective. The mental health discussion of a communication strategy needs to be grounded in the experiences of the community (e.g., separation experiences and isolation; stigma; and, women’s changing roles), rather than on a pharmaceutical model. The mental health sector needs to partner with public and private physical health care providers, schools and the community’s natural resources. Last, formal service providers need to work with community’s natural helpers to reach out to and engage in treatment families who have historically been distrustful of the system, or are very unfamiliar with U.S. systems.

## **Symposium Discussion**

### **Mareasa Isaacs**

These studies and findings present many challenges and raise interesting and complex questions. If the data on the prevalence of maternal depression in low-income women and women of color are so well-known, as well as the impact of maternal depression on their children, why has this not been recognized as a critical public health issue? How can we elevate the knowledge of these findings without creating another set of circumstances of “blaming the victim”? Knowing that depression has such a critical impact across generations in the same family, why do we continue to focus on individual interventions when we do provide treatment, rather than on family-focused interventions? How can we begin to distinguish the “natural” depression of being poor and living in financially stressed situations with the more clinical aspects of depression? Both need to be addressed, but interventions might be markedly different.

Finally, among low-income women and women of color, depression appears to be a cluster of conditions that co-occur: depression, trauma, anxiety, substance abuse, domestic violence. These co-occurring conditions often mean that these women are not participants in clinical trials for depression. How can we begin to address depression, regardless of the initial presenting condition that might bring these women and their children to our attention? How can we create a continuum of care that is culturally appropriate for the vast number of women who suffer, often in silence, from a treatable disease? These and other questions must be answered and addressed through our social policies.

---

## **CONTRIBUTING AUTHORS**

### **Bridget Goosby, Ph.D.**

*Program for Research on Black Americans, Institute for Social Research, University of Michigan, 426 Thompson St., Ann Arbor, MI 48106, 202-641-4625, e-mail: bgoosby@umich.edu*

### **Larke Nahme Huang, Ph.D.**

*Managing Research Scientist, American Institutes for Research, 1000 Thomas Jefferson St. NW, Washington, D.C. 20007, 202-403-5180, fax: 202-403-5007, e-mail: LHuang@air.org*

### **Mareasa Isaacs, Ph.D.**

*Associate Professor, Howard University School of Social Work, 601 Howard Place NW, Washington, D.C. 20059, 202-805-4727, e-mail: misaacs5548@comcast.net*

### **Katherine Lazear, M.A.**

*Coordinator, Human Services, University of South Florida, Tampa, FL, Partner, Human Service Collaborative, Washington, D.C., 813-974-6135, e-mail: Klazear56@aol.com*

### **Barbara Alexander Pan, Ph.D.**

*Professor, Harvard Graduate School of Education, Larsen 320, Cambridge, MA 02138, 617-496-0313, e-mail: Barbara\_Pan@harvard.edu*

### **Meredith Rowe, Ph.D.**

*Postdoctoral Fellow, University of Chicago, 5801 South Ellis Avenue, Chicago, IL 60637, 773-702-1234, e-mail: Rowemer@uchicago.edu*

### **Elizabeth Spier, Ph.D.**

*Research Analyst, American Institutes for Research, 1000 Thomas Jefferson St. NW, Washington, D.C. 20007, 202-403-5000, fax: 202-403-5001, e-mail: Espier@air.org*

### **Catherine Tamis-LeMonda, Ph.D.**

*Professor, New York University, 239 Greene Street, New York, NY 10003, 212-493-5399,*

# **Making Time for Parents: Comments on the American Time Use Survey**

Jane Timmons-Mitchell  
Christina Kloker Young  
Patricia Ashford

---

## **Introduction**

In September, 2004, the American Time Use Survey (US Department of Labor, 2004) results were released. The Survey is the first of its kind sponsored by the Bureau of Labor Statistics and conducted by the U.S. Census Bureau. Previous surveys gathered information on activity related to work activities but the present survey used daily journaling to determine what Americans do with their time each day, both in and out of the workplace. The survey estimates are derived from interviews with approximately 21,000 people who described what they did during one 24-hour time period from 4 a.m. on the day before the interview until 4 a.m. on the day of the interview. Activities described were grouped into categories for analysis. Many categories of behavior related to parenting are included in the survey. Other major headings include: work, sleep, sports and leisure, household activities, eating and drinking, attending school, and shopping.

## **Results**

On average, respondents slept about 8.6 hours; spent 5.1 hours doing leisure and sports activities; worked for 3.7 hours; spent 1.8 hours doing household activities (including parenting); and spent 4.8 hours in a combination of eating and drinking, attending school, and shopping.

*Work.* People who were employed worked an average of 7.6 hours on the days they worked. People worked longer on weekdays, and more people worked on weekdays than on weekends. People who worked on weekends were often those who held multiple jobs or were self-employed. Men worked an average of about an hour longer each day than did women. Many people worked at home; self-employed workers were more likely to do some of their work at home.

*Household.* Both women and men performed household chores, including cleaning, cooking, lawn work, and financial management, but more women (84%) performed these tasks than men (53%), and spent more time in these activities than men (2.8 hours compared with 2.1 hours).

*Childcare or parenting activities.* The grouping overall is for children age 17 and younger. A second analysis divides children into two age groups: under 6, and 6 through 17. During an average day, women spent about 1.7 hours engaged in childcare as a primary activity, and men spent about 0.8 hours. More time was spent caring for children under 6 than for children and youth ages 6 to 17. In the 6 to 17 year age range, women averaged about an hour per day in childcare activities and men spent about a half hour. Categories of caregiving included: physical care; education-related activities; reading to/with children; talking to/with children; playing/doing hobbies with children; looking after children; attending children's events; and travel related to the care of children.

*Sports and leisure activities.* Ninety-six percent of respondents age 15 and over said they engaged in some activity such as watching TV, socializing or exercising. Men spent more time doing leisure activities than women (5.4 hours compared to 4.8 hours). Women and men with children participated in fewer sports and leisure activities than did other adults, but they still participated in an average of about 4.5 hours of sports and leisure activities daily. The American Time Use Survey concludes with an invitation to researchers to request the data set for additional analyses.

## Discussion

When survey results were presented as a poster at the *18<sup>th</sup> Annual Research Conference: A System of Care for Children's Mental Health—Expanding the Research Base* (March 2005), 31 people attending the conference chose to comment on the results of the survey. Of these, 7 reported not being surprised by the findings. The majority ( $n = 24$ ) who commented found the results surprising. One of the people surprised by the results commented that the survey addresses a great need, while another said that it has great implications for research in children's mental health. Three people were surprised by the small amount of time parents spend interacting with adolescents. Two people said they thought the findings are "scary." Two people remarked that they had not slept eight hours in years.

Given the amount of time spent overall on parenting activities, it is hypothesized that the amount of time spent parenting adolescents would be quite small indeed. Yet research (Institute of Medicine, 1999) suggests that, instead of spending less time involved with adolescents, parents should spend more time monitoring and supervising them than they do at any other period of childhood except perhaps early infancy. One of the people who commented on results at the conference echoed this sentiment, saying that, "The job is not done when a child becomes 13."

How can we influence policy? There a need for a primary prevention effort to change societal expectations for parents. Primary prevention efforts that are underway to address adolescent substance use, teen pregnancy and sexual behavior focus on parenting to address the target behaviors of youth. Linking youth behavior to parental behavior could be a logical extension, but a necessary precursor to that extension is to value spending time with adolescents. If the majority of households in America do not have this value, it may be important to work on instilling it. One of the people who commented asked, "Where are the values?"

Service providers may assume that parents are willing to spend time addressing the needs of their children. If parents have the expectation that they do not need to spend time with their adolescents, these expectations may clash. Two people commented that, as providers, we "need to re-think what people have time for." Parents and advocates observed:

- In order to address the needs of youth affected with mental health challenges, parents must be available to devote time to the effort;
- It may not be helpful to suggest that parents increase the amount of time they spend with youth if parents are not inclined to do so;
- It may be that parents have the expectation that someone else should have primary responsibility for youth (i.e., schools are responsible for educating; courts and justice facilities are responsible for disciplining);
- One contributor to the expectation that others should be responsible for youth is the practice of blaming parents and disempowering them. One participant cautioned, "The danger is blaming parents, but they may need to work to survive."

Recommendations for future studies from those who commented included: (a) break the 6 to 17 year age range into 6-10, 10-13 and 14-17 years to allow for comparisons among elementary, middle school and high school age students and their families; (b) compare parenting of special needs and non-special needs youth; (c) conduct a longitudinal analysis; and (d) look at youth in Title I and non-Title I schools; and keep in mind that the child care tax credit cuts off at age 12.

Overall, if parents want to become more involved, we must be ready to offer effective tools and to work in partnership with parents on behalf of their youth.



## **References**

Institute of Medicine, Commission of Behavioral and Social Sciences and Education (2004). *Risks and Opportunities: Synthesis of Studies on Adolescence*, Washington, D.C.: National Academy of Sciences.

U.S. Department of Labor. (2004). *American Time Use Survey*. <http://www.bls.gov/tus/home.htm>

---

**CONTRIBUTING AUTHORS**

---

**Jane Timmons-Mitchell, Ph.D.**

*Case Western Reserve University School of Medicine and Center for Innovative Practices, 2995 E. Overlook Road, Cleveland Heights, OH 44118-2435, 216-321-7890, fax: 216-397-1607, email: jtmo7@aol.com*

**Christina Kloker Young**

*C. K. Young and Associates Creative Planning Systems, 208 Connors Circle, Oak Ridge TN 37830, 865-220-8062, fax: 865-688-085, ckyoung@bigplanet.com*

**Patricia Ashford, B.Med., M.M.**

*Cleveland State University, 21636 Jonathan Drive, Strongsville, OH 44149, 460-846-0242, fax: 460-846-0242, email: jashf13639@aol.com*