

**Systems of Care  
Promising Practices in Children's Mental Health  
1998 Series**

**VOLUME I  
NEW ROLES FOR FAMILIES IN SYSTEMS OF CARE**

**Federation of Families for Children's Mental Health**

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# Foreword

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It is with great pleasure that we present the first collection of monographs from the *Promising Practices Initiative* of the Comprehensive Community Mental Health Services for Children and Their Families Program. The Comprehensive Community Mental Health Services for Children and Their Families Program is a multi-million dollar grant program that currently supports 41 comprehensive systems of care throughout America, helping to meet the needs of many of the 3.5 to 4 million children with a serious emotional disturbance living in this country. Each one of the seven monographs explores a successful practice in providing effective, coordinated care to children with a serious emotional disturbance and their families.

The 1998 Series marks a turning point in this five-year-old federal effort, which is administered by the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration of the U.S. Department of Health and Human Services. The first generation of five-year grants is about to come to an end, and with that “graduation” comes a responsibility to add to the national knowledge base on how best to support and service the mental health needs of children with serious emotional disturbance. Until the very recent past, these young people have been systematically denied the opportunity to share in the home, community and educational life that their peers often take for granted. Instead, these children have lived lives fraught with separation from family and community, being placed in residential treatment centers or in-patient psychiatric centers, hundreds and even thousands of miles away from their home. For many of these young people, a lack of understanding of their psychopathology, underdeveloped or non-existing community resources, and a sense of frustration of what to do have led to their eventual placement away from home.

The *Promising Practices Initiative* is one small step to ensure that all Americans can have the latest available information about how best to help serve and support these children at home and in their community. Children with serious emotional disturbance utilize many publicly funded systems, including child welfare, juvenile justice, special education, and mental health, and they and their families often face many obstacles to gaining the care they need due to the difficulties and gaps in navigating multiple service systems. Systems of care provide a promising solution for these children and their families by coordinating or integrating the services and supports they need across all of these public service systems.

The information contained within these monographs by and large has been garnered within the original 31 grants of the Comprehensive Community Mental Health Services for Children and Their Families Program. The research was conducted in a manner that mirrored the guiding principles of the systems of care involved so that it was family-driven, community-based, culturally relevant, and inclusive. Methods for information collection included: site visits and focus groups; accessing data gathered by the national program evaluation of all grantees; and numerous interviews of professionals and parents. Family members were included in the research and evaluation processes for all of the monographs. Two of the papers directly address family involvement, and all of the papers dedicate a section to the family's impact on the topic at hand. The research was drawn from the community-based systems of care and much of the research comes from systems of care with *culturally diverse populations*.

The 1998 *Promising Practices* series includes the following volumes:

Volume I - *New Roles for Families in Systems of Care* explores ways in which family members are becoming equal members with service providers and administrators, focusing specifically on two emerging roles: family members as “system of care facilitators” and “family as faculty.”

Volume II - *Promising Practices in Family-Provider Collaboration* examines the fundamental challenges and key aspects of success in building collaboration between families and service providers.

Volume III - *The Role of Education in a System of Care: Effectively Serving Children with Emotional or Behavioral Disorders* explores sites that are overcoming obstacles to educating children with a serious emotional disturbance and establishing successful school-based systems of care.

Volume IV - *Promising Practices in Wraparound* identifies the essential elements of wraparound, provides a meta-analysis of the research previously done on the topic, and examines how three sites are turning wraparound into promising practices in their system of care.

Volume V- *Promising Practices: Training Strategies for Serving Children with Serious Emotional Disturbance and Their Families in a System of Care* examines theories of adult learning, core values, and four key areas (cultural competence, family-professional relationships, systems thinking, and inter-professional education and training), and looks at promising practices that are combining these concepts into a successful sustainable training program.

Volume VI- *Promising Practices: Building Collaboration in Systems of Care* explores the importance of collaboration in a system of care focusing on three specific issues: the foundations of collaboration, strategies for implementing the collaborative process, and the results of collaboration.

Volume VII - In *A Compilation of Lessons Learned from the 22 Grantees of the 1997 Comprehensive Community Mental Health Services for Children and Their Families Program*, the grantees themselves share their experiences in five main areas: family involvement/empowerment, cultural competency, systems of care, evaluation, and managed care.

These seven documents are just the beginning of this process. As you read through each paper, you may be left with a sense that some topics you would like to read about are not to be found in this series. We would expect that to happen simply because so many issues need to be addressed. We fully expect this series of documents to become part of the culture of this critical program. If a specific topic isn't here today, look for it tomorrow. In fact, let us know your thoughts on what would be most helpful to you as you go about ensuring that all children have a chance to have their mental health needs met within their home and community.

So, the 1998 *Promising Practices* series is now yours to read, share, discuss, debate, analyze, and utilize. Our hope is that the information contained throughout this Series stretches your thinking and results in your being better able to realize our collective dream that all children, no matter how difficult their disability, can be served in a quality manner within the context of their home and community. COMMUNITIES CAN!

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# Acknowledgments

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True to the values and principles of the system of care itself, the production of *Volume I: New Roles for Families in Systems of Care* has been a collaborative effort. Many individuals contributed to the work by providing stimulating ideas, constructive criticism, and support along the way. We thank you, collectively and anonymously, for it is not possible to list all of you.

The research for this document would not have been possible without the enthusiastic collaboration of the families and staff of the *Wings* project in Maine, the *PEN-PAL* project in North Carolina, the *REACH* project in Rhode Island, and the *Community Wraparound Initiative* in Illinois. Without their willingness to let us into their lives for a few days and their honest introspection in sharing their perspectives about the work they do, we could not have written this description. *Keys for Networking* in Kansas, and *Hawaii Families As Allies* also contributed valuable materials.

We are grateful to the faculty at the University of Maine at Orono and Machais, as well as the faculty of the Social Sciences Training Consortium of East Carolina University, for welcoming us into their classes, introducing us to their students, and providing curriculum materials and course evaluations.

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We must also thank the Center for Effective Collaboration and Practice for their generous loan of Erica deFur to conduct the literature review. And a final thanks goes to Linda Donohue for copy editing the document.





# Executive Summary

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Since Knitzer's 1982 wake up call to the mental health community, family members have gained knowledge, skills, and access to influence systems of care so our children with mental health needs receive better services and we get supports to raise them to be strong and healthy. We have found and developed our voice. We have become strong partners and assertive leaders in developing a better system of care for our children. We now serve as collaborators, advisors, providers, planners, administrators, evaluators, as well as advocates. Our work provides information and assistance to other families and professionals. We have begun to help one another coordinate the system of care and provide pre-service training to personnel who will be serving our children and families. The diversity and scope of our activities demonstrates the impact families have had on the systems of care emerging around the country.<sup>1</sup>

## **NEW ROLES FOR FAMILIES**

In this paper, we define and describe two roles for families that are promising practices at the cutting edge of this whole new world.

The term "system of care facilitator" was chosen by our writing team to describe one of the most prevalent and rapidly evolving of the new roles for families in systems of care. This term reflects the key feature of the role — namely, that the family member employed in this position uses a variety of strategies to help enrolled families become familiar with their community's system of care, learn how to effectively participate in it and, thereby, gain access to quality services that improve outcomes for their child and family. In short, they facilitate development of a positive working relationship between families and the system of care.

The term "family as faculty" is used to describe the role family members co-teaching with university faculty who are preparing the workforce for systems of care. This is a very promising practice, but not very widespread. We also include a description of a more traditional involvement of family members in university training programs — that of guest lecturer.

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<sup>1</sup> See Appendix A for a description of values and principles for the system of care.

## **DATA COLLECTION**

Information about the history, development, and impact of these roles was collected through a review of the literature, telephone conferences, and on-site interviews with families and staff of several projects funded by the Center for Mental Health Services under its Comprehensive Community Mental Health Services for Children and Their Families program. We also visited university campuses and meet with faculty associated with these grantees and their students.

## **LESSONS LEARNED**

### **System of Care Facilitator**

It is clear that the practice of employing of family members in a system of care facilitator role achieves better outcomes for all involved. Our study of the Illinois and Rhode Island projects points out several features that are essential to achieving this success and, therefore, are the lessons to be applied by any community wishing to replicate this approach. These include:

- Direct care staff and supervisors must have a genuine willingness to work with family members as equals in spite of the fact that they may not have the same level of formal education and training.
- System change planners and promoters of systems of care can not afford to underestimate the importance of attitudes or the effort it takes to make this paradigm shift.
- A job description with specific responsibilities and expectations has to be invented. The job description must be revisited and revised frequently, as the role matures to fit the context of each unique community setting.
- Persons in this position require support from their local family-run organization, as well as the day-to-day support within the agencies where they are working.
- Agency policies and procedures must be flexible to make it easy for family members working in this role to get into the community at any time of day or night and have funds at their disposal to meet immediate short term needs for family support.
- Compensation must be fair and reflect the level of responsibility expected, rather than the degree of formal education attained. In some cases, hiring family members without college degrees may necessitate redesigning personnel policies, renegotiating labor contracts, or changing state requirements for licensure or accreditation.
- On-going training and supervision are necessary for system of care facilitators to develop their role, expand their professional horizons, and transform their personal experience into effective strategies for improving the way services and supports are provided to children with mental health needs and the families raising them. Consideration should be given to a career ladder with opportunities to gain

certification, licensure, or a college degree.

## **Family As Faculty**

In order for the values and principles of the system of care to begin to take hold in communities, it is necessary for all involved to become a continuous learning community. Engaging family members as partners with university faculty is one practice that holds great promise for achieving this goal. Strong partnerships between family-run organizations and university faculty greatly facilitate the development and implementation of the family as faculty role. In addition, because this is a radical departure from the way universities typically conduct their business, strong state level leadership helps to leverage resources to support the initial program development.

The experiences of East Carolina University and the University of Maine (Orono and Machais campuses) offer the following lessons for others wishing to engage family as faculty. System of care philosophy needs to be taught in colleges and universities.

- The teaching of the system of care needs to be done by both faculty and the people who will be using the system – parents, youth, and other family members.
- When family members serve as faculty, there is an opportunity to model partnerships and mutual respect to students before they enter the service delivery work force.
- Students exposed to family as faculty enter the workforce already knowing how to communicate with families, be respectful when visiting families in their homes, work with family advocates, interact with family-run organizations, and attend family support groups, when they are invited.
- Students completing these programs start their professional work prepared and determined to positively engage with parents. The families they work with are feeling less blamed and more valued and increase their own level of involvement in the decision making about their child and the selection and provision of services and supports.

The role of family members serving as faculty is enhancing the image of families who are raising children with mental health needs. Family members who serve as faculty feel validated by the experience and are developing their communication and advocacy skills to a high level. Because of the support of their university based partners and the training they receive from family-run organizations, families have achieved a high level of public recognition for their expertise and credibility for the stories they tell.

## **LOOKING AHEAD**

The two roles described in this paper offer great promise in lifting the burden and eliminating these barriers to full family involvement. The role of family as faculty clearly has begun to influence the way the system of care functions by preparing the work force in an entirely new way – one that is family-friendly and collaborative and embodies the values and principles of the system of care.

Building and sustaining effective systems of care for children with mental health needs and their families depends, in large part, on the individual people who work in or with the myriad components of such systems. Family members who work as system of care facilitators and family faculty are stimulating behavioral change in their co-workers and development of family-friendly policies and procedures within the provider agencies in their communities. They are also changing themselves, developing new skills and confidence in their ability lead and teach others.

The challenge is for full family involvement in systems of care to become the rule rather than the exception. Change does not occur overnight, but we hope that this initial description of families as system of care facilitators and faculty training the workforce for systems of care will stimulate others to explore and develop these (and other) roles further and that, consequently, greater number of children with mental health needs and their families will reap the benefits of systems of care.

# Chapter I

## Background: Children with Serious Emotional Disturbance, Schools, and Systems of Care

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### INTRODUCTION

This monograph was written by a team of family members who collectively have over 75 years of experience raising children with significant mental health needs. The writing team members are all leaders in the family movement and have made a commitment to developing and promoting comprehensive, culturally competent, community-based, family-driven, systems of care for children's mental health. We have chosen to use first-person language in this document to illustrate the personal nature of talking about children with emotional or behavioral disorders and their families. While we have attempted to maintain the integrity and objectivity of any quoted or referenced material, we also want to ensure that readers recognize that children with emotional or behavioral problems *belong* to someone's actual family. Thus, we have attempted to create a sense of ownership by referring to children with emotional or behavioral disorders as "our children." Moreover, we want to establish that the concept of a *family* is defined by its members and each family defines itself. Families can include biological or adoptive parents and their partners, siblings, extended family members (called kinship caregivers), and friends who provide a significant level of support to the child or primary caregiver. Historically, the term "parent" has been used to describe the primary caregiver. While this term can still be found in certain references in this document, we contend that the term "parent" does not include the full spectrum of people who care for children in general and children with mental health needs in particular. This perspective is reflected in the 1997 Amendments to the Individuals with Disabilities Education Act (P.L. 105-17) in which the term 'parent' has been re-defined to include non-custodial relatives who are responsible for the daily care of a child.

The development of the family movement over the past 10 years, and specifically the emergence of family-run organizations, has resulted in a strong voice for families raising children with mental health needs, emotional disorders, or behavioral problems. The family movement has also created employment opportunities for family members. Family-run organizations serve as both a source of new talent and a training ground for family members to take positions as peer-to-peer mentors, support group facilitators, writers (for newsletters, brochures, curricula and training manuals, policy documents, grant applications, and much more), workshop leaders, program developers, keynote speakers, data collectors, receptionists, bookkeepers, advocates, researchers,

administrators, video technicians, respite care providers, service coordinators, conference organizers, and many other kinds of work necessary to operate family-run organizations on a daily basis and complete special projects. Family-run organizations give individuals, who may have no work experience or limited training, a genuine opportunity to develop their skills in a truly supportive environment. Through training and employment, family-run organizations have given some individuals a means to become less reliant on, or even independent of, public assistance to support their families. Once they develop their skills and confidence, many family members who get their start in a family-run organization, eventually take positions with other organizations, agencies, and businesses in their community.

It is only natural that agencies, programs, and providers in communities developing systems of care would also seek to hire these family members. After all, we bring not only our professional skills, but our experience in the family movement and the values associated with family involvement in systems of care, as well.

But this was not always the case. The role for families in systems of care has evolved over the past 15 years. We reviewed the literature to trace this history.

## **HISTORY OF THE ROLE OF FAMILIES IN SYSTEMS OF CARE**

In the last two decades, families have struggled to empower themselves and strengthen their roles in the system of care. As one researcher noted, “families themselves have been the catalyst in most situations when any positive action has occurred” in gaining support services.<sup>1</sup> Here we take a closer look at four ways families have participated in the system of care: (1) families as collaborators, (2) families as advisers and advocates, (3) families supporting one another, and (4) families providing community-based services.

### **Families as Collaborators**

Achieving an effective partnership with family members has proven to be one of the major challenges for those attempting to implement system change. While rhetoric has spoken of family involvement for decades, it is only recently that various service agencies have begun to make this a reality. Collaboration has become a code word for policy makers, researchers, and systems of care advocates.<sup>2</sup> The concept of people of diverse backgrounds coming together to work towards a common

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<sup>1</sup> Turnball, A. P. & Ruef, M. (1997). Family Perspectives on Inclusive Lifestyles for People with Problem Behavior. *Exceptional Children*, 63(2), p. 223.

goal has caught the imagination and hopes of families and professionals alike. Indeed, it has changed the vocabulary, as well as the philosophy, of caring for our children who have emotional or behavioral problems. Karp defines collaboration as “the recognition that both [or all] parties have special skills and knowledge that can contribute to the job of improving programs and services which will benefit the child.”<sup>3</sup> Collaboration means more than just including different professional agencies. It requires bringing parents and families to the table with providers and administrators as equal partners in the process. This means that families share equally with all the other players in planning and doing the work, reaping the benefits, and resolving the challenges faced along the way.

This shift in vocabulary has been particularly significant as professionals begin to speak of “collaborating” with parents rather than merely serving them, conveying an expectation of working together on a more equal basis. Unfortunately, this expectation has not always been fulfilled. There is a growing recognition among researchers that families and professionals often have very different views regarding family needs, family involvement, and the child’s progress.<sup>4</sup> These different perspectives influence the collaboration.

A 1994 survey of families of children with emotional or behavior disorders and service providers, identified four main components of collaboration:

- supportive relationships
- practical service arrangements
- forthright information exchanges
- flexible, shared approaches to gauging failure or success.<sup>5</sup>

Collaboration is a means to an end, rather than an end in itself. Bruner defines collaboration as “a process to reach goals that cannot be achieved acting singly (or, at a minimum, cannot be reached as efficiently). The desired end is more comprehensive and appropriate services for families that improve family outcomes.”<sup>6</sup> Collaboration involves shared responsibility, shared goals, and working together.

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<sup>2</sup> Swan, W. W. & Morgan, J. L. (1993). *Collaborating for Comprehensive Services for Young Children and Their Families: The Local Interagency Coordinating Council*. Baltimore, MD: Paul H. Brookes Publishing Co.

<sup>3</sup> Karp, N. (1992). *Collaborating With Families*. Prepared for the Virginia Department of Education, p. 4.

<sup>4</sup> DeChillo, N., Koren, N., & Schultze, K. (October 1994). From Paternalism to Partnership: Family and Professional Collaboration in Children’s Mental Health. *American Journal of Orthopsychology*, 64(4), pp. 564-576.

<sup>5</sup> DeChillo *et al.*, 1994, p. 572.

There are a growing number of examples of families and professionals working together and a growing amount of literature that addresses this issue. For example, Adams *et al.* identifies three common qualities in successful parent professional partnerships:

- The relationship was formalized through contracts between the provider entity or the system agency and a family network organization representing the families who used, or were at risk of needing to use, the mental health system.
- The professional partners were deeply committed to the inclusion of families in decision making. They worked well in diverse situations by utilizing specific skills to cross class and cultural boundaries.
- The relationship occurred within relatively “safe” social contexts with collegial-like interactions between the partners.<sup>7</sup>

These three basic tenets can be applied to individuals working together on a project, as well as to system-wide efforts. As more states and communities are creating interagency coordinating councils, they often establish council positions to be filled by family members or require family participation in other council activities. However, these councils can be overwhelming and intimidating when we, the family members recruited to serve, have not been prepared for this responsibility or when professionals have not made efforts to include us. When only one family member is being asked to represent *all* families, the task can seem impossible.<sup>8</sup> In some states, we have started providing support and information to other family members when they *first* join interagency councils.<sup>9</sup> Haynes & Comer’s 1996 description of education’s responsibility for collaborating with parents is applicable to all child-serving systems. The professional community has a certain responsibility to make collaboration with family members as easy as possible. “There is no other way for us, the people entrusted with the formal education of children, to practice true collaboration than to embrace and involve as many parents as possible in a true partnership of mutual respect and support.”<sup>10</sup>

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<sup>6</sup> Bruner, C. (1991). *Thinking Collaboratively: Ten Questions and Answers to Help Policy Makers Improve Children’s Services*. Washington, DC: Education and Human Services Consortium, p. 6.

<sup>7</sup> Adams, J., Biss, C., Burrell Mohammad, V., Meyers, J., & Slaton, E. (Nov. 14, 1997). *Family-Professional Relationships: Moving Forward Together*. National Peer Technical Assistance Network, pp. 1-2.

<sup>8</sup> Cheney, D., & Osher, T. (1997). Collaborate with Families. *Journal of Emotional and Behavioral Disorders*, 5(1), pp. 36-44; Research and Training Center on Family Support and Children’s Mental Health (Fall 1991/Winter 1992). Parents as Policy Makers: Challenges for Collaboration. *Focal Point*, 6 (1).

<sup>9</sup> Lourie, I. S., Katz-Leavy, J., & Stroul, B. A. (1996). Individualized Services in a System of Care. In B.A. Stroul (Ed.), *Children’s Mental Health: Creating Systems of Care in a Changing Society*. Baltimore, MD: Paul H. Brookes Publishing Co.



Barriers to collaboration are well documented — pointing to the challenges of restructuring entrenched bureaucracies and philosophies — and indicating that many people have difficulty conceptualizing what collaboration means. In 1993, Karp identified over 25 reasons why families do not get involved in the system of care, ranging from lack of transportation to lack of support or understanding from the system.<sup>11</sup> Bruner insists that “collaboration will succeed only if it changes the nature of the relationship between workers and families and has as its goal the alleviation of children’s very real needs.”<sup>12</sup> Many collaborative efforts fail because participants cannot overcome the perspectives from which they come.<sup>13</sup> For example, if a group of “collaborators” speak about a “high-risk teenager,” each will envision the child in a different way:

- An educator sees a *student* in danger of dropping out.
- A health-care provider sees a *patient* at risk of having a low-birth-weight baby.
- A social-service worker sees a *client* who may require public assistance.
- A juvenile justice worker sees a potential *runaway*.
- An employment specialist sees a *trainee* needing multiple services.
- A community or religious leader sees the troubled *offspring* of a personal friend.
- A family member sees a *sister, brother, daughter, or son* who has many needs [emphasis added].<sup>14</sup>

With so many labels for and views of the same young person, it quickly becomes clear how a categorical system makes it easy to pass along blame for failing to meet our children’s needs.<sup>15</sup> We see our children as people first. Their special needs come second. This is what makes our contribution unique. At the same time, by collaborating and putting all of these images together, a more complete picture of the child emerges. These diverse images of the same child circumscribe both the challenge and the promise of collaboration in building systems of care.

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<sup>10</sup> Haynes, N. M., & Comer, J. P. (1996). Integrating Schools, Families, and Communities Through Successful School Reform: The School Development Program. *School Psychology Review*, 25 (4), pp. 501-506.

<sup>11</sup> Karp, N. (1993). Building Collaborative Partnerships with Families: From Rhetoric to Reality. *Journal of Emotional and Behavioral Problems*, 1, p. 4.

<sup>12</sup> Bruner, 1991, p. 5.

<sup>13</sup> Dunkle, M. & Nash, M. (March 1989). Creating Effective Interagency Collaboratives. *Education Week*, 35 & 44.

<sup>14</sup> Dunkle & Nash, 1989, p. 44.

<sup>15</sup> Melaville, A. I. & Blank, M. J. (January 1991). *What it Takes: Interagency Partnerships to Connect Children and Families with Comprehensive Services*. Washington, DC: Education and Human Services Consortium.

## **Families as Advisors and Advocates**

In addition to gaining a place in the collaborative process of developing better ways to help our children, we, as family members, have worked to develop a collective voice. We have struggled and learned how to advocate more effectively for our children and to advise the service system about what we need to empower ourselves and help our children.

### **Advocacy at the Individual Level**

The passage of the Education for All Handicapped Children Act in 1975 (today known as the Individuals with Disabilities Education Act or IDEA), which ensured a free and appropriate education for all children with a disability, made family involvement in the educational process part of the law. The broader disability community, and parents in particular, have recognized the power of a strong advocacy movement in ensuring that our children with disabilities receive the services they need. Families in other disability arenas, such as mental retardation, physical disabilities, or sensory impairments, have been organized much longer than families of children with emotional or behavioral problems. Indeed, the lobbying efforts of these groups were a major impetus in passing this law 23 years ago.

Knitzer recognized in 1982 that families of children with emotional or behavioral disorders were not yet well organized into an effective advocacy voice. Her book, *Unclaimed Children*, helped give credibility and respectability to our own effort to galvanize an advocacy movement into action. Ours is largely a grass roots movement that really began with our families advocating for individual children with mental health needs at the community level. Koroloff *et al.* describe how many advocacy efforts begin with two family members sitting over coffee, comparing notes on how to negotiate a disconnected and confusing array of agencies, programs, and services.<sup>16</sup> Subsequently, the Center for Mental Health Services recognized the importance of family advocacy, and, using the Children and Adolescent Service System Program as a base, began to bring families together to involve them in service reform.<sup>17</sup>

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<sup>16</sup> Koroloff *et al.*, 1996.

<sup>17</sup> Bryant-Comstock, S., Huff, B., & VanDenBerg, J. (1996). The Evolution of the Family Advocacy Movement. In B.A. Stroul (Ed.), *Children's Mental Health: Creating Systems of Care in a Changing Society* (pp. 359-374). Baltimore, MD: Paul H. Brookes Publishing Co.

In 1986, the Research and Training Center on Family Support and Children's Mental Health at Portland State University in Oregon began a series of regional conferences called the Families as Allies Conferences. These were crucial in bringing family leaders from different states together to find a common voice. "Families were meeting face to face with professionals to discuss ways to improve services for them and their children."<sup>18</sup> We found we needed a national voice and, shortly after, created the Federation of Families for Children's Mental Health, an organization to represent us and advocate for our children.

### **Advocacy at the Group Level**

The Next Steps Conference in 1988 signified an important change as we came together and called for a national organization to represent the interests of children with emotional or behavioral disorders and the families raising them. This call led to the formation of the Federation of Families for Children's Mental Health. Since then, the Federation has served as the national advocacy voice for families with children who have emotional or behavioral disorders. The Federation's mission is to:

- provide leadership in the field of children's mental health and develop necessary human and financial resources to meet its goals;
- address the unique needs of children and youth with serious emotional disturbance from birth through transition into adulthood;
- ensure the rights of citizenship, support, and access to community-based services for children with serious emotional disturbance and their families; and
- provide information and engage in advocacy regarding research, prevention, early intervention, family support, education, transition services, and other services needed by these children and their families.<sup>19</sup>

In addition, the National Alliance for the Mentally Ill and the National Mental Health Association have developed advocacy goals for family members and have helped to link family members, professionals, and concerned citizens with advocates for adult consumers of mental health services.<sup>20</sup>

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<sup>18</sup> Bryant-Comstock, Huff, & VanDenBerg, 1996, p. 363.

<sup>19</sup> Federation of Families for Children's Mental Health (1994). *Federation of Families for Children's Mental Health's Mission Statement*. Alexandria, VA: Federation of Families for Children's Mental Health.

<sup>20</sup> Cheney & Osher, 1997.

## **Policy Making and Advocacy at the System Level**

Family members as policy makers (at the local community, state, and national levels) have the opportunity to describe to agency administrators and providers what we and our children really experience as well as how policy decisions affect our everyday lives. However, many of us may still experience a feeling of isolation and exclusion when we first join a system team at the state or local level. In contrast to the other team members, we are not likely to have past experience with collaborative teams, have existing and established professional relationships, know the jargon, or have other family members (as peers) to provide us with encouragement and reinforcement. Meetings may not be scheduled to accommodate our work schedules — often the meetings are scheduled during the business day because they are part of the job being done by the agency or program. The new role of policy maker can be overwhelming and frustrating, as one parent relates: “Usually, the committee has been in operation for a long time before you come into it...where everybody else knows the beginning. They know the script and you don’t, and you’re the parent to represent all parenthood.”<sup>21</sup>

Ironically, many of us have used this frustration and anger to fuel our continued involvement and renew our commitment to making an impact on the system. It spurs our determination to get more involved and strengthen our voice in setting policy. For example, families in Maine, frustrated by lack of home-based and family supports, successfully lobbied their state legislature to increase funding for respite care and other important services.<sup>22</sup> This effort had a dramatic impact on some family advocates and how their role is perceived. A family policy maker described the attitude shift that she has seen as moving from, “Well, you just happen to be a parent,” to “You have an expertise that no one else there has. And, none of the professionals have it — because they don’t see the people, they don’t see the kids on a regular basis.”<sup>23</sup>

## **Families Supporting One Another**

Caring for a child with emotional or behavioral disorders requires system-wide, comprehensive support. Families also need informal support mechanisms. Those of us who are raising a child with emotional or behavioral disorders experience isolation and frustration, particularly during times of crisis or chronic stress. Indeed, it is this need for peer support that has brought so many families together in the first place. Over the past few years, we have discovered the

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<sup>21</sup> Research and Training Center on Family Support and Children’s Mental Health (Fall 1991/Winter 1992). Parents as Policy Makers: Challenges for Collaboration. *Focal Point*, 6 (1), p. 4.

<sup>22</sup> *Focal Point*, 1991-92, p. 8.

<sup>23</sup> *Focal Point*, 1991-92, p. 2

importance of supporting one another in times of difficulty. For example, after going through a training program designed and run by their own family-run organization, *Hawaii Families as Allies*, family members serve as “buddies” for other parents. They provide advocacy, emergency respite, transportation, information, and supportive listening to one another.<sup>24</sup>

## **Family Support Groups**

Support groups have been a mainstay in the treatment process for families with children with emotional or behavioral disorders. They provide information, improve problem-solving techniques, increase positive attitudes, and can improve a family's perception of their children.<sup>25</sup> Although group sessions for families are sometimes led by professionals, through our family-run organizations, we are running support groups ourselves. The *Parent Participation Project* in the *Family Centered Care Project* in Lansing, Michigan, for example, has a parent coordinator who provides information and support to other families. The Parent Participation Project, serving children with all types of disabilities, is part of a mental health program at a children's hospital that conducts a series of family support groups across disabilities.<sup>26</sup> In Fairfax County, Virginia, bilingual parents serve as liaisons to the school system to help families with limited English proficiency communicate with personnel in the school and participate in parent activities at the school.<sup>27</sup>

Sometimes, support groups are not what we need. Some of us spend time with so many professionals talking about serious problems and dealing with traumatic issues that another opportunity to talk about this is not necessary. Indeed, some may perceive it as another burden. In Essex County, New York, very few families participated in the support groups, but nearly all attended the social events. The service coordinator (who was a parent) realized that times of relaxation and enjoyment were better forms of support than the more structured support groups.<sup>28</sup> Moreover, sometimes the informal phone calls and letters we provide one another serve as the most effective type of support. Statewide family-run organizations like the *Georgia Parent Support*

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<sup>24</sup> Koroloff, N. & others (August 1990). *Statewide Parent Organization Demonstration Project*. Portland, OR: Portland State University, Research and Training Center on Family Support and Children's Mental Health.

<sup>25</sup> Kutash, K. & Rivera, V. R. (1996). *What Works in Children's Mental Health Services? Uncovering Answers to Critical Questions*. Baltimore, MD: Paul H. Brookes Publishing Co.

<sup>26</sup> Michigan State Department of Public Health (September 1990). *Family Centered Care, Triennial Report 1986-1989*. Lansing, MI: Division of Services to Crippled Children/Children's Special Health Care Services.

<sup>27</sup> Halford, 1996.

<sup>28</sup> Tannen, N. (April 1996). *Families at the Center of the Development of a System of Care*. Washington, DC: National Technical Assistance Center for Children's Mental Health.

Network and the Vermont Federation of Families for Children's Mental Health make extensive use of a peer-to-peer telephone network to connect families who need support with those of us who have been through a similar experience.

## **Respite Care**

In her 1982 book, Jane Knitzer identified respite care as a service that families raising children with emotional or behavioral disorders desperately needed. Advocates of respite care point to the stressful and intensely emotional environment that often accompanies raising a child with emotional or behavioral disorders. The adults in this situation need an occasional break and change of pace to maintain their own mental and physical health.<sup>29</sup> Although each family will define respite care according to their own needs, respite care generally constitutes relief to family members from the stress and intensity of day-to-day living. All family members, including caregivers, siblings, and the child may utilize such services either at home or elsewhere. In-home respite may include having a sitter or a companion for a child or siblings, a homemaker, or an informal network of help. Out-of-home respite services may be provided in a respite provider's home, foster home, group daycare center, residential treatment center, or crisis/emergency care facility. In addition, some communities have developed parent cooperatives in which family members volunteer to care for each other's children on a planned or emergency basis.<sup>30</sup> Service systems can and do provide funding for a caretaker and dinner for the family, or simply arrange for volunteers to spend time with the child.<sup>31</sup> However, it is important to note that respite is not a cure-all — Bruns still found many stressors in families receiving respite care.<sup>32</sup>

## **Families Providing Community-Based Services**

As local systems of care become more family focused, we have worked to provide other family members with training, workshops, and information that can lead to self-empowerment and improving our

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<sup>29</sup> Kutash & Rivera, 1996.

<sup>30</sup> Ferguson, J. T. & Lindsay, S. A. (1986). The Respite Care Co-op Program: Professionally Guided Parent Self-Help. In C. Salisbury & J. Intagliata (Eds.), *Respite Care: Support for Persons with Developmental Disabilities and their Families*, Baltimore, MD: Paul H. Brookes Publishing Co.

<sup>31</sup> Tannen, 1996.

<sup>32</sup> Bruns, E. (October 1997). Impact on Respite Care Services on Children's Experiencing Emotional and Behavioral Problems and Their Families. (Dissertation). University of Vermont.

system of care. We often serve as agents of interim support — helping one another when needed services are not available. We also facilitate interagency coordination by distributing information, and linking service providers.<sup>33</sup>

As individual family members, and especially as family-run organizations, we are beginning to make administrative decisions and take leadership roles in delivery systems. Essex County, New York, for example, is implementing a system of care that is family-driven, and family-run. Here the lines between service provider and service recipient have blurred. Not only has this system successfully integrated a wide range of service agencies in a rural county, but it has also utilized families in implementing nearly every aspect of care.<sup>34</sup> Families coordinate services, provide transportation, informal support and advocacy, and emergency respite. The success of Essex County demonstrates the power of comprehensive service systems in which families are at the center.

## **HOW WE GATHERED DATA AND INFORMATION**

While doing background research for this paper, the authors held brief telephone conversations with key family contacts in the systems of care funded by the Center for Mental Health Services' Comprehensive Community Mental Health Service for Children and Their Families Program. Members of the writing team individually called the primary family contacts for the Comprehensive Community Mental Health Services for Children and Their Families Program grantees. Eighteen telephone interviews were actually completed. They followed a standard protocol and data were recorded in a simple table.<sup>35</sup> After hearing an explanation of the purpose of the call and the nature of the promising practices writing project, contacts interviewed were asked to list the various roles family members were engaged in at their site. For each role identified, they were asked to provide written job descriptions and briefly describe the history of the position and its impact on families served and the system of care itself. We also asked about making a site visit and if families and staff at the site would feel comfortable if we wrote about them.

The job titles identified by this environmental scanning process include:

- Family Advocate
- Family Service Coordinator
- Family Resource Developer

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<sup>33</sup> Koroloff, Friesen, Reilly, & Rinkin, 1996.

<sup>34</sup> Tannen, 1996.

<sup>35</sup> See Appendix B for a copy of the protocol and data catcher, and the data instrumentation form.



- Parent in Residence
- Wraparound Facilitator
- Intake Worker
- Interviewer
- Respite Care Coordinator
- Board Member
- Workshop Curriculum Developer/Trainer/Facilitator
- Parent Mentor
- Evaluator
- Community Resource Developer

We discovered a variety of conditions in which these roles occur. Family members work in systems of care both full and part time. Some family members are paid and others are volunteers or contribute “in-kind” for services received. Sometimes we work for a family-run organization, school, mental health agency, or other community provider — sometimes on a short-term special project, and sometimes we are public employees or independent contractors for our services.

It was necessary to select a few of these roles to describe in depth. The “promising practices” theme of this series of monographs suggested that we should focus on something relatively new. Hence the title *New Roles for Families in Systems of Care*. We established four criteria that a position had to meet to be considered for further study. These were:

- It must be a paid position – with system of care funds.
- It must have been operational for at least a year.
- It must impact directly on the implementation of the system of care.
- It must not be a role/function that family-run organizations have been providing historically.

We also realized, as we gathered information from the systems of care sites, that there were several different titles for similar jobs. For example, mentors, advocates, coordinators, managers, and facilitators are all terms that were used in the job titles of family members employed to help others participate effectively in the individual service planning process for their children. Yet they were expected to do very much the same kind of tasks. Therefore, we clustered the new roles identified by function rather than by title. This also served to reduce the number of roles, making the final selection easier.



This paper presents an in-depth discussion of two roles for family members that exist as a direct result of family involvement in developing systems of care. These are two roles among many that are available to families in systems of care. These two are recent developments (within the past five years) and extend the employment opportunities of family members into the broader community in which our children and their families live, learn, work, and play. Most critically, these two roles were originally described and written into the design of the specific interagency systems of care where they have emerged, evolved, and matured.

Because specific job titles varied greatly from community to community, we developed our own working titles for these two roles. They are *system of care facilitators* and *family as faculty*. In this paper, we will describe the nature of the impact these roles have had in their communities. In this paper, we will define these two roles and discuss how they function in currently operational systems of care. We will also present what the literature has to say about these roles and describe how these roles evolved (including training and supervision).

Our information is mostly based on the testimony of families enrolled in systems of care and people working in them. Throughout, we rely on written information as gathered from the systems of care themselves (e.g., contracts, evaluations, and job descriptions) that formally document the impact, evolution, and supervision of these roles. Our most valuable and most important sources of information are the many interviews the writing team conducted with groups and individual family members who are doing this work, family members benefiting from this work, program administrators supporting the work, and colleagues within the systems of care who work alongside or supervise family members serving in these roles.

Two or more members of the writing team personally visited and interviewed personnel associated with the *PEN-PAL Project* and East Carolina University which are both in Greenville, North Carolina; the *Community Wraparound Initiative* in LaGrange, Illinois; *Wings* in Bangor, Maine; the University of Maine at Orono and Machais; and *REACH*, a statewide project in Rhode Island. Phone interviews were conducted with personnel and family leaders from *KanFocus* and *Comcare*, both in Kansas; the *Southern Consortium for Children* in Ohio, and the *Dona Ana County Child and Adolescent Collaborative* in New Mexico. Information for the section on the history of training provided by *Hawaii Families as Allies* and other family-run organizations was gathered by family members in Hawaii. Descriptions of the projects and programs were reviewed for accuracy by administrators, providers, or families from whom we gathered the information, data, or ideas.



# Chapter II

## System of Care Facilitator Role

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### DESCRIPTION OF THE ROLE

#### Families as Service Coordinators/Case Managers

The mental health care field has long used the term “case manager” to refer to professionals who work with individual families coordinating service and supports. While the use of case managers is common, they have a wide range of responsibilities, training, and ways of serving “clients.” The Bulletin for the Research and Training Center on Family Support and Children’s Mental Health, *Focal Point*, lists five major functions of case management:

- assessment – the process of determining the needs or problems;
- planning –the identification of specific goals and the selection of activities and services needed to achieve them;
- linking – the referral, transfer or other connection of clients to appropriate services;
- monitoring – ongoing assurance that services are being delivered and remain appropriate, and the evaluation of client process; and
- advocacy – intervention on behalf of the client to secure services and entitlements.<sup>1</sup>

We, as family members, find that the term “case manager” depersonalizes us and distances us from addressing our real needs. We prefer the term “service coordinator” to describe the person who works closely with our family to help us negotiate the system of care, take responsibility for ourselves in caring for our children, and establish networks of contacts within the system.

The role of service coordinator has generally been reserved for professionals, and in some cases, requires a graduate degree. Recent changes in the system of care have included hiring paraprofessionals to assist case managers – especially when the case manager provides clinical therapy and does not have the time for taking care of less structured supports. Paraprofessionals are often parents of children with emotional or behavioral disorders themselves. Whether serving as paraprofessionals or service coordinators, this approach allows family members to serve as guides through the system — emphasizing strategies to overcome the specific barriers to accessing services,

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<sup>1</sup> *Focal Point*, 1993, p. 1.

rather than clinical or demographic characteristics of children and their families.<sup>2</sup> These barriers may be different for each family, but generally might include cultural and linguistic differences or other communication needs, financial resources, transportation problems, lack of child care, inaccessibility of services, inconvenient hours of operation, and inflexible appointment schedules.

There are a few examples in the literature that describe families doing the work of service coordination. According to Koroloff *et al.*, when family members serve as service coordinators, they not only help other families, but also sensitize administrators and providers and open up the system to involve and work with families more effectively.

Koroloff studied the *Family Associates Program* in Oregon, which trained adults who were raising children with emotional or behavioral disorders, to help other families negotiate the system of care. The Family Associate was a paid position with three main responsibilities: providing support, providing information, and linking families to resources.<sup>3</sup> The Family Associates attended two 2-day training sessions (four days total) prior to employment. Koroloff suggests that her research indicates Family Associates were successful in getting services and supports to families in new and unique ways. Family Associates used a Flexible Cash Support Fund to help families pay for essential support services, such as child care, transportation, clothing or personal care items, recreational activities outside the home, and respite care. In particular, these funds allowed Family Associates to pay for utilities, and assist with other household expenses on an emergency basis.

Koroloff's study of the Family Associate role brought to light significant issues rooted in the fact that none of the locations employing Family Associates had prior experience with family members as paraprofessionals. The administrators and Family Associates had to address philosophical misgivings, as well as pragmatic challenges of integrating both the role and the individual family members, into their service delivery system. There was concern about the appropriate way to train and supervise the Family Associates in this new and unique position. For example, they said, "paraprofessional training must always provide a balance between developing professional skills and capitalizing on the expertise and experience for which the paraprofessional was hired."<sup>4</sup>

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<sup>2</sup> Koroloff *et al.*, 1996.

<sup>3</sup> Koroloff, N., Elliott, D., Koren, P., & Friesen, B. (October 1994). Connecting Low-Income Families to Mental Health Services: The Role of the Family Associate. *Journal of Emotional and Behavioral Disorders*, 2 (4), pp. 240-246.

<sup>4</sup> Koroloff *et al.*, 1994, p. 245.

The literature describes the Family-Centered Intensive Care Management program in New York as utilizing Family Advocates as liaisons between families and professionals.<sup>5</sup> In this situation, case workers serve children, and advocates work with their families. Each Family Advocate is also raising at least one child with emotional or behavioral disorders. Family Advocates are expected to: represent the family perspective in policy meetings; provide communication between families and professionals; provide informal support to families through home visits and telephone calls; model self-advocacy; and help prepare for and attend Individualized Education Plan meetings.<sup>6</sup>

The *Regional Intervention Program* (RIP), originally founded in Nashville, Tennessee, in 1969 and replicated in the *Parents Educating Parents* (PEP) Program in Cleveland, Ohio, is a community-based, family-centered service for young children with behavioral problems. The program relies heavily on both volunteer and employed family members to provide training, services, and therapy, as well as the daily operations necessary to keep the program running. Families are expected to voluntarily “pay-back” RIP or PEP for the services they received after they complete the program. Payback may take the form of speaking at training sessions, serving as mentors for new family members, co-teaching groups of children, helping with transportation, or providing assistance in the office. In addition, the program hires and trains particularly skilled parents to serve as case managers for new family members. The experience of families and professionals working together helps break down barriers and empowers family members to help one another, as well as themselves.<sup>7</sup>

## **What Is A System Of Care Facilitator?**

As mentioned earlier, there are a variety of job titles used for the system of care facilitator role. The *system of care facilitator* is the term chosen by our writing team to describe one of the most prevalent and rapidly evolving of the new roles for families in systems of care. This term reflects the key feature of the role—namely, that the family member employed in this position uses a variety of strategies to help enrolled families become familiar with their community's system of care, learn how to effectively participate in it, and thereby gain access to quality services that improve

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<sup>5</sup> Evans, M., Armstrong, M., Dollard, N., Kuppinger, A., Huz, S. & Wood, V. (October 1994). Development and Evaluation of Treatment Foster Care and Family-Centered Intensive Case Management in New York. *Journal of Emotional and Behavioral Disorders*, 2(4), pp. 228-239.

<sup>6</sup> Evans et al., 1994.

<sup>7</sup> Timm, M. A. (November 1993). The regional intervention program: Family Treatment By Family Members. *Behavioral Disorders*, 19 (1), pp. 34-43.

outcomes for their child and family. In short, they facilitate development of a positive working relationship between enrolled families and the system of care. Among the strategies used by system of care facilitators are:

- making home visits;
- providing personal and individual support at all hours;
- supplying both written and verbal information in the family's native language;
- helping families understand and complete forms;
- coaching families in preparation for service planning meetings (and attending these as moral support);
- debriefing with families after meetings to insure a clear understanding of the discussion and any decisions made, as well as process any emotions brought to the surface by the experience;
- informing families about their rights and responsibilities and teaching them how to exercise them;
- conducting group activities for family training and peer-to-peer support;
- locating services and resources in the community and linking these with the family and the family's service planning team; and
- obtaining permission for families to use "flex funds" to pay for short-term or emergency needs.

All system of care facilitators have a number of characteristics in common. They have experienced both the agony and the ecstasy of raising a child with a mental health need. They have endless patience and compassion and are fabulous listeners. System of care facilitators accept the families, children, and youth they work with unconditionally – without judgment or blame for the problems they face. System of care facilitators have learned how to constructively negotiate the system and communicate with service providers and program administrators. They believe deeply in the values and principles of the system of care and work ardently to bring them about in their communities. In short, our system of care facilitators are the change agents necessary for systems of care to function successfully.

System of care facilitators experience joy and frustration on the job—joy, when a family gets the help they need and want, especially when the family successfully advocates on their own behalf; and frustration, when system change doesn't keep pace with the needs of families and children in the community. They notice that change is fearful for many traditionally trained providers and cumbersome bureaucracies. They celebrate with providers who do change and learn to accept and enjoy collaborating with them as professional equals.

We believe that systems of care could not evolve without families who serve as system of care facilitators, because they are the backbone of the process. Beverly Poirier, a supervisor at a Rhode Island mental health center states, “[The Family Service Coordinator] has added a whole new dimension and raised consciousness of all the staff.”<sup>8</sup>

This role occurs in many projects and communities around the country, but each has its unique approach emphasizing one or more of the strategies listed above. The following examples illustrate this variety and also provide specific information about how the system of care facilitator role is integrated into several of the Comprehensive Community Mental Health Services for Children and Their Families grantees funded by the Center for Mental Health Services.<sup>9</sup>

## **Examples to Illustrate**

### **Rhode Island**

Rhode Island is divided into eight mental health catchment areas or regions. Each of these regions employs at least one family member who works as a system of care facilitator under the general designation of Family Service Coordinator. Specific job titles, job descriptions and pay scales, benefits, and working conditions vary among the regions and are dependent on the personnel policies of the agency that actually employs them. In some instances, a bonus is added to the base salary for bi-lingual employees.

These positions are funded at a minimum salary of \$25,000 per year through a contract with the Rhode Island Department of Children, Youth, and Families. The contract describes the Family Service Coordinator position as being non-clinical and prohibits them from: “writing EPSDT plans; conducting clinical intake, evaluations, assessments and diagnosis; medication monitoring; emergency decision making; and secretarial duties.”<sup>10</sup> It specifies that Family Service Coordinators, “shall be parents of special needs children and shall have experience in special education and children’s mental health such as gained by parenting and advocating for their child or adolescent.” The contract also broadly lists the tasks a Family Service Coordinator must carry out. These include:

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<sup>8</sup> Interview on May 20, 1998.

<sup>9</sup> For more information about this grant program and the funded sites, see other monographs in this series, contact the Center for Mental Health Services, or visit <http://www.mentalhealth.org>.

<sup>10</sup> EPSDT stands for the Early Periodic, Screening, Diagnosis, and Treatment program. Services are usually paid for by Medicaid.

- meeting with families (preferably in their home) prior to the initial case review meeting to offer support and an opportunity to communicate effectively about the philosophy and process of the care review service planning;
- scheduling case review meetings;
- coordinating and scheduling appropriate participants to attend the case review meetings;
- supporting and advocating for family needs;
- documenting the confidentiality of client related information;
- completing and maintaining REACH Rhode Island Evaluation forms;
- following up with case review team members on their assigned tasks;
- working with families, parent organizations and related service providers to disseminate information about the Children's Mental Health System of Care, the Local Coordinating Council, the interagency case review process, and pertinent children's mental health issues.<sup>11</sup>

At the start of the *REACH* project in 1994, there were just a handful of Family Service Coordinators. These were the pioneers carving out a niche for family expertise in a traditional clinical environment, working totally isolated from each other and often isolated from co-workers in the agencies employing them. There are currently 17 Family Service Coordinators working in the eight regions of Rhode Island. They are all family members with extensive experience raising children with mental, emotional, or behavioral disorders and have a first-hand knowledge of how services are provided in their own community and in Rhode Island's human service systems in general. Today, they see themselves as a cadre of highly skilled and specialized professionals who perform a vital function in the system of care. Other see them this way also.

## **Kansas**

Another version of the System of Care Facilitator has recently been implemented in Kansas. Early in 1998, Kansas received a waiver from the health care financing administration to expand home and community-based services for children and youth who would otherwise require institutional care. Under this waiver, Parent Support Specialists are available to help parents "understand their options and how the service system operates."<sup>12</sup> Wraparound Facilitators assist

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<sup>11</sup> Contract between Department of Children, Youth & Families (DCYF) & East Bay Community Mental Health Center 10-1-97 to 9-30-98, pp. 2-3.

<sup>12</sup> HCBS Waiver in *KanFocus*, Volume 4.9, December 1997.



families in using the wraparound process to develop their plan of care. The services of Parent Support Specialists and Wraparound Facilitators are Medicaid reimbursable, so they are provided at no cost to families. Keys for Networking, Inc., the Kansas statewide organization of the Federation of Families for Children's Mental Health, has developed a training curriculum for Parent Support Specialists and Wraparound Facilitators.

In addition to having completed the Wraparound Facilitation training, Parent Support Specialists receive training in:

- appreciating the family culture of living with a child with serious emotional disabilities;
- assessing special education and Section 504 policies, procedures, and rights;
- defining outcomes;
- negotiating to get the services you need;
- designing strengths-based interventions;
- using positive reinforcement to shape behaviors;
- keeping and maintaining records; and
- assisting families during crisis periods.

Parent Support Specialists in Kansas can perform the following services for families. A letter introducing the role to families states that they can:

- coach and assist by increasing your knowledge of your child's needs, the process of interpreting choice offered by all service providers and explaining and interpreting policies, procedures, and regulations that impact your child living in the community;
- coach and assist in ensuring you voice, access, and ownership in developing the plan of care within desired costs and budget;<sup>13</sup>
- coach and assist in ensuring all resources are developed and delivered; and
- coach and assist in looking at the progress being made and assessing your satisfaction with the outcomes for each service in the plan of care.<sup>14</sup>

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<sup>13</sup> Voice, access, and ownership are concepts fundamental to the wraparound process. Families must have their say in the discussions (voice), all meetings and information must be easy to get to and understandable for families (access), and families must buy into (own) the plan that is developed.

<sup>14</sup> Letter to Parents, Keys for Networking, Inc., February 1998.

## Illinois

In the *Community Wraparound Initiative*, Illinois family members whose work facilitates the system of care are called Family Resource Developers. The position evolved from the role of Parent Partner, developed for a school-based initiative called *Project Wrap*. Family Resource Developers are employees of the Illinois Federation of Families (a statewide family-run organization) under a letter of agreement with Community Family Services and Mental Health Center. The 1996 agreement specifies a salary range of \$12.50 to \$15.50 per hour. The Illinois Federation recruits, trains, and co-supervises family members in this role and provides liability insurance and the same benefit package available to all of its employees.

Family Resource Developers are housed in a variety of community agencies and, therefore, work very closely with school personnel, other providers and clinical staff. Like the families in Rhode Island, Illinois families initially experienced isolation being the only family member working at a mental health agency or school.

The Family Resource Developer job description has undergone many revisions. The November 1996 description specifies that Family Resource Developers:

- engage families in the *Community Wraparound Initiative* by explaining its purpose and the family's role;
- participate in the development and updating of the wraparound plan;
- monitor the child and family team from the parent perspective;
- locate resources for families;
- provide additional support when the family is isolated or the team has not yet been developed;
- participate in the flex fund request process by providing the parent perspective so that the Flex Fund Committee can better understand the request and its ramifications;
- participate in parent support groups;
- assist staff in developing their skills in working with families with diverse backgrounds and in promoting positive, non-judgmental interactions with families;
- participate in weekly supervision, monthly training, and network meetings; and
- fulfill other duties as assigned, such as special training or writing for the parent newsletter.<sup>15</sup>

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<sup>15</sup> Family Resource Developer Job Description (DRAFT—November 11, 1996) provided by the Illinois Federation of Families.

## Maine

The *Wings Project*, serving rural Maine families in four counties has its headquarters in Bangor. Wings employs several family members as Parent Advocate Specialists. These family members, frequently enrolled in the *Wings Project* themselves, work closely with the Parent Intake Specialists and Case Managers – some of whom are also family members who started working for *Wings* as parent Advocate Specialists.

While it is not required for employment, half of the family members filling this position have a bachelor's degree. Most are working toward being licensed. The job description specifies that Parent Advocate Specialists report to the Case Management Program Supervisor and they:

- collaborate with the Family Support Intake Specialist, Case Manager, and Case Management Program Supervisor to determine entrance eligibility into Wings;
- provide information and referral support to families, including home visits when appropriate;
- ensure clients are receiving services that meet their needs, and that they are treated in a respectful and empowering way;
- meet with parents receiving services to provide support and education around their child's disability;
- provide limited school advocacy on behalf of families;
- assist families in accessing parent support groups and other community supports; and
- assist in identifying service gaps and developing community plans to address the needs of families.

They also are expected to maintain confidentiality, prepare reports of activities, and educate the community about Wings. Some of the Parent Advocate Specialists are engaged in a local systems change initiative and provide the family perspective to state leaders whenever given the opportunity to do so. United Families (Maine's statewide affiliate of the Federation of Families for Children's Mental Health), creates and supports many opportunities for input to state leaders. One such effort resulted in passage of legislation<sup>16</sup> to improve the delivery of mental health services to children. This legislation established an oversight committee that has three parent members (two appointed by the President of the Senate and one by the Speaker of the House.)

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<sup>16</sup>L.D. #2295. An Act to Improve the Delivery of Mental Health Services to Children, April 6, 1998.

Preference in hiring Parent Advocates is given to a “parent with a child who has received mental health services and who has been an active participant in the child’s service plan development.” They must have a high school diploma or equivalent. Qualifications include being:

- knowledgeable about services in the four-county area covered by *Wings*;
- able to “maneuver in a variety of home settings and weather conditions;”
- a public speaker;
- able to collaborate as part of a team;
- sensitive to the needs of families; and
- able to present a positive impression to the public.<sup>17</sup>

Parent Advocate Specialists work directly for and closely with a Case Manager and everyone involved recognizes that there is an inherent creative tension in this relationship – an issue they are continuing to work on within the organization. While this relationship creates a good opportunity for collaboration and communication on behalf of the enrolled families, there are some serious challenges to be faced in creating an equal and effective partnership. One of the challenges is an ongoing debate about appropriate boundaries. Case Managers, following the historically rigid ethics of their profession, do not socialize with the families they serve. The four counties served by *Wings* are small closely-knit communities and Parent Advocates live in the same community as the families they support. They use the same service providers and their children attend the same schools. Consequently, Parent Advocates must work closely with community-based family networks to strengthen parent-to-parent connections and reduce isolation by organizing and attending social events such as barbecues, picnics, and ice cream socials. The close contact of these personal relationships plays an important part in earning the trust of the children and families enrolled in *Wings*.

The Department of Mental Health and Mental Retardation in Maine supports another network of family members who work “together to help each other and their children with special needs.”<sup>18</sup> This group is called *GEAR* (Gaining Empowerment Allows Results). Support and services from *GEAR* are also available to *Wings* Project families. They offer:

- encouragement and support through group meetings and by phone – including a toll-free number supported by *United Families*;

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<sup>17</sup> Job Description provided by *Wings* – revised December 1995.

<sup>18</sup> *GEAR* brochure provided by Maine families.

- workshops on topics of interest;
- local conferences; and
- social opportunities.

In the next section, we focus in detail on the role of the system of care facilitator as it has evolved in two specific systems of care – LaGrange, Illinois, and the state of Rhode Island. These sites were selected because they had the most extensive history and the greatest number of families serving in this role. They were also selected because they are very different from each other. One is statewide, including both urban and rural regions serving a very diverse group of families. The other encompasses several neighboring suburban communities. These two examples also illustrate different employment and supervision patterns. It is important for our readers to understand that each community, like each child and family, has specific strengths and needs. Therefore, the system of care facilitator role reflects and has to be tailored to the community's characteristics, as well as those of the children and families to be served.

## **THE COMMUNITY WRAPAROUND INITIATIVE IN ILLINOIS**

### **Background**

The *Community Wraparound Initiative* in LaGrange, Illinois, is modeled on Project Wrap, an Illinois Department of Education initiative designed by Lucille Eber. Project Wrap pioneered using family advocates as Parent Partners in a school-based wraparound process<sup>19</sup> in Illinois.

The *Community Wraparound Initiative*, funded in 1994 by the Center for Mental Health Services, is a collaboration among three mental health centers and three special education cooperatives. The partnership includes the Community Family Services Mental Health Center, Pro Care Center, Youth Outreach Services, LaGrange Area Department of Special Education, Proviso Area Educational Cooperative, and the Argo, Evergreen Park, Revis, and Orland Park Special Education Cooperative. These agencies provide an integrated system of care for children with serious emotional disturbance and their families. The *Community Wraparound Initiative* actually involves 13 principal stakeholders and a suburban geographic area with a population base of nearly 300,000.

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<sup>19</sup> Wraparound is a process that allows providers to plan and provide fundamental supports and services with children and their families to sustain their strengths in their natural environment. For a more detailed discussion of wraparound, see the companion monograph describing the wraparound process.

Governance for the project is the responsibility of the InterLAN Council. The Council is comprised of representatives from the original partnership plus the Illinois Federation of Families for Children's Mental Health, the 708 Boards<sup>20</sup> of Proviso, Lyons and Riverside Townships, Des Plaines Valley Community Center, the State Department of Children and Family Services and the Office of Mental Health. All the Community Wraparound Initiative personnel, including the Family Resource Developers, work closely with staff from existing programs within the participating community agencies.

From the outset, all the partners agreed that parent-to-parent support was the best way to engage and support families through the wraparound process. The vehicle for doing this was a formal arrangement, a Letter of Agreement, between the *Community Wraparound Initiative* and the Illinois Federation of Families.<sup>21</sup> In spite of this commitment, however, in the beginning, the role of the Illinois Federation in the *Community Wraparound Initiative* was decidedly unclear.

### **Letters Of Agreement Establish A Role For The Family-Run Organization**

The first Letter of Agreement designated the Illinois Federation of Families as a pass-through agency to pay salaries for the Parent Resource Developers with no other responsibilities designated or defined. They were expected to: provide two half-time Parent Resource Developers; manage all personnel and accounting for these positions; submit a monthly invoice of hours worked and travel expenses; and maintain professional liability insurance to cover these employees. This pass-through was intended to surmount a problem raised by one of the participating agencies. They believed they could not legally or politically hire and pay the Parent Resource Developers as agency staff because of stipulations in their labor union contract. The issue centered on the lack of a degree requirement for the Parent Resource Developer position. The way around this problem was for the Illinois Federation of Families to technically be the hiring authority. But, they would have no control over decision making with regard to the actual hiring decisions. This did not feel like an equal partnership to the Federation's leadership.

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<sup>20</sup> P.L. 708 created community boards that built collaborations with agencies, providers, and stakeholders to bring mental health services for children and families to their communities. Most eventually became the LANs (Local Area Networks).

<sup>21</sup> The Illinois Federation of Families for Children's Mental Health, founded in 1993, is a statewide family-run organization providing information, training, and support. There are 5 staff housed in its central office in Hinsdale, IL, and an additional 15 scattered throughout the state – some working part time. There are currently 7 staff working for the *Community Wraparound Initiative*.

In 1994, the Letter of Agreement was rewritten.<sup>22</sup> This agreement expected the Illinois Federation to: provide up to six part-time Parent Resource Developers; participate in the selection of these individuals; and provide personnel oversight including performance evaluations. Specific involvement of the Illinois Federation of Families in partnership with the Community Wraparound Initiative was defined and included how the Federation would build a much-needed infrastructure to manage the personnel and financial responsibilities. The Federation still hires most of the Family Resource Developers, meets all the fiscal responsibilities for their positions, and provides their liability insurance. Health insurance is available for those employed more than 25 hours a week. All the Parent Resource Developers who do this work are employed under and held responsible to the Federation personnel policies and procedures.

Letters of agreement and job descriptions have been pivotal in defining the role of the host agency and the role and tasks of the Family Resource Developers. These have evolved over time, as all involved gained experience and began to understand the complexities of the work, the working conditions, and the working relationships.

### **Evolution of the Job Description Helps Clarify the Role**

The position evolved through several different titles and job descriptions. The Parent Partner position of the original *Project Wrap* served as the starting point for the Parent Resource Developer position when the grant proposal was first written and during the early years of the project. Later this became the Family Resource Developer.

The first three Parent Resource Developers worked in the *Community Wraparound Initiative* Office where the project administration and data collectors for the Initiative were also housed. The Parent Resource Developers were given no direction in performing their job. As a result, clinical directors in the community agencies were unable to assess their work or even hold them accountable for specific tasks. In the beginning, they waited for one of the partner agencies to request their services. One employee, who has been with the Initiative since the beginning, recalled being contacted by an agency only when a family went into crisis or decided to quit the Initiative.<sup>23</sup> It seemed that the clinical directors of the partner agencies only called on the Family Resource Developer when they needed help in re-engaging a family.

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<sup>22</sup> See Appendix C for a copy of the agreement.

<sup>23</sup> Interview with JoBeth Cullanea, April 13, 1998.

While this was a very narrow view of their skills, being asked to help re-engage families served to place the Parent Resource Developers into community agencies. Once inside, they “hung around” and very slowly became involved. They started taking information when new families called seeking services and making home visits to explain the *Community Wraparound Initiative*. They sat with parents and helped them complete the evaluation instruments.<sup>24</sup> The Family Resource Developers also provided immediate relief from stress for families by:

- providing temporary respite until more formal respite was arranged;
- accompanying families to court hearings;
- providing transportation to meetings; and
- obtaining SSI or food stamps.

Gradually, the Family Resource Developers took on more tasks. Today, they also help families identify and form a child and family team responsible for conducting the wraparound process. The child and family team membership is unique for each family; but typically it includes the family, the Family Resource Developer, the facilitator who is the agency representative, and any member of the Initiative providing services to the family. The Family Resource Developer helps the child and family team prepare flexible funding requests to pay for services normally not billable through the regular community service delivery system. For example, a family received flex funds to repair their car so the father could get to work and continue to support the family.

Once the team is formed and operational, each family determines how extensively the Family Resource Developer will be involved. The Family Resource Developer is a permanent member of some teams, temporary on others, and even absent from a few teams – depending on the family’s preference. Should the family decide that they no longer need support from the Family Resource Developer, she steps aside. Most of the time, however, they remain actively involved as each family continues to seek assistance with navigating the system of care. Continued involvement is also facilitated by the parent support network that exists among families.

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<sup>24</sup> Associated with the *Community Wraparound Initiative* and other Comprehensive Community Mental Health Services for Children and Their Families Program grantees is a national evaluation. There is a standard set of instruments used for this evaluation. Some are to be completed by families and youth enrolled in the projects.



In October 1995, Karen Gora was hired as Executive Director of the Illinois Federation of Families for Children's Mental Health. Seven months later, Timothy Gawron joined the *Community Wraparound Initiative* as the Project Director. Karen and Tim sought to bring order and formal definition to the role. They began by asking the Parent Resource Developers a simple question, "What do you do?"

Developing the job description was not simple; however, describing qualifications for the position was easy. The person hired must:

- be a parent or a guardian of a child with a serious emotional disturbance or other related disability;
- demonstrate an ability to share information and resources with other parents and systems; and
- be able to support, encourage and respond with empathy.

Beyond the qualifications for the job, interviews with the Parent Resource Developers revealed little consensus about the work itself. Karen and Tim posed some additional questions:

- How do you get assigned to a family?
- How do you get to know a family?
- How do you contact them? Do you call? Do you go to their home? Do you go alone or with a facilitator?
- When you are with the family, what do you do and when do you do it?
- Are you more likely to go early mornings, evenings, weekends?

On March 26, 1996, the first job description for the Parent Resource Developer position was drafted. The first job description was a composite of the work that was being done at the time. For example, it contained phrases like, "develops partnerships with clinical team leaders and wraparound facilitators to support individual wraparound plans."

The second draft of the job description reflected a much more comprehensive attempt to refine the work.<sup>25</sup> The new job description consciously expanded the role of Family Resource Developers beyond providing only crisis intervention and respite care. They were now to be in touch with families at the point of intake. They became full fledged members of the team and helped develop the entire service plan for a child and family. This time the process of developing the job description involved more players. Parent Resource Developers were interviewed along with the

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<sup>25</sup> See Appendix D for a copy.

clinical directors and the wraparound facilitator to obtain three different points of view. Karen and Tim wrote the draft and submitted it to the Parent Resource Developers to be edited. The edited version was given to the clinical directors who met as a group to do the same thing. This version was then brought to the Program Refinement Committee<sup>26</sup> which produced the final draft of the job description that was formally implemented.

## **Initial Recruitment and Hiring**

The first Parent Resource Developers were recruited through the Illinois Federation of Families, local school districts, other community agencies, advertisements in community newsletters and word of mouth. The initial hiring was done by a panel with representation from each provider agency, as well as the Illinois Federation of Families. Applications were scored, interviews conducted and a choice was made by group consensus. In May of 1995, the first three Parent Resource Developers were hired. Each was assigned to a specific agency (Community Family Services, ProCare, or Youth Outreach Services).

Some applicants for this position were also families enrolled in the Community Wraparound Initiative itself – providing a significant, and totally new, challenge for the Initiative. Because of this, many capable workers in schools and provider agencies actually began to wrestle with the practical daily application of the system of care values concerning family involvement. Before the Initiative, no one ever asked a “client” to serve as a mutual provider of services. Now, however, conscious and deliberate family recruitment strategies are one of the ways the Initiative operationalizes the value of family members as both parents and providers. Leadership maintains that parents have strengths, skill sets and sensitivity that are needed in the Initiative. Now agency staff ask parents with whom they work to take on a provider role and work in collaboration with clinical staff to serve other families. Tim Gawron recalled, “It was one thing to honor parent contracts in the abstract; quite another to actually open up participation...so that agency staff could work side by side with parents.”

Today, one special education cooperative and one child welfare agency have hired their own Family Resource Developer and there are five individuals hired by the Illinois Federation of Families who are assigned to host mental health agencies and special education cooperatives in the community. Additional Family Resource Developers are assigned to the Early Intervention Supplemental Grant serving children from birth to age seven. These positions are expected to become a permanent part of the infrastructure of the early intervention system.

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<sup>26</sup> The Program Refinement Committee is made up of all the clinical directors of the partner agencies, the Special Education Cooperatives, the Project Director and the Director of the Illinois Federation of Families.

## **Supervision Helps Refine the Role**

The Clinical Administrator of the Community Wraparound Initiative and the Executive Director of the Illinois Federation both provide supervision, as do the clinical directors in the agencies where the Parent Resource Developers were placed. The first three Parent Resource Developers had weekly supportive learning sessions with the *Community Wraparound Initiative's* first clinical supervisor, Carol Ann Reditt (1994-95). She helped them develop a consciousness and vocabulary to describe their work so that others could understand the nature of their special contribution to the Initiative as a whole. For example, during one of these early discussions Carol Ann Reditt commented, "You have empathy and use your personal experience to put families at ease." The Parent Resource Developers began to identify a range of specific skills and recognize themselves as service providers – a significant step beyond simply being a helpful neighbor and friend.

### **Language Progresses — Parent Resource Developers Become Family Resource Developers**

Parent Resource Developers were not the only ones whose understanding and knowledge became clearer over time. Agency staff recognized that the title Parent Resource Developer implied the parent rather than the child was the focus of the system's interventions. The position title was changed to Family Resource Developer to more closely match the values and principles of the system of care and the purpose of the *Community Wraparound Initiative*.

Parent Resource Developers became Family Resource Developers, the role continued to evolve, and relationships with enrolled families continued to change. Each new family member hired went through four stages of adjusting to and learning the work - this came to be recognized as a developmental pattern.

1. *Helpful Companion*— "Doing things for families."
2. *Empathetic Listener*— "I have been there."
3. *Collaborative Partner*— "What's the job?"
4. *Supportive Facilitator*— "Let's get it done together."

Typically, new Family Resource Developers start out enthusiastically doing all they can *for* every family they work with – an exhausting and endless task. Eventually they learn how to provide intensive support at first (to the level it is needed) and gradually transfer their experience and knowledge to other families so they can do things *for themselves*.

Data from the Early Intervention Supplemental Grant indicates that families open their doors much more readily to a Family Resource Developer than they ever will to a Social Worker or a Mental Health Worker. As a result, Family Resource Developers have been instrumental in getting children with substance abuse and mental health issues better health care, crucial family supports, and interventions (including immunizations, as part of early prevention). They accomplish this by becoming a liaison between the family and the Health Department.

## **Training**

Family resource developers have several different avenues for expanding their knowledge base and developing their skills. Training for Family Resource Developers is provided by the host agency and the agency's clinical director. Occasionally, outside specialists present to the entire staff of the Initiative on a specific topic such as the wraparound process. The Illinois Federation of Families provides training focused on the nature of advocacy and what the Federation offers families, the community, and the state.

## **The Challenges Of Co-Supervision**

Each partner agency defines the criteria and schedule for supervision differently. The Family Resource Developers receive ongoing supervision from the clinical director of their agency, as well as their employer – the Illinois Federation of Families for Children's Mental Health. Tim Gawron and Karen Gora call this *co-supervision*.

Supervision within the host agency where the Family Resource Developer is assigned is largely focused on the day-to-day issues of developing and implementing individualized service plans. As a group, the Family Resource Developers convene every other week for supervision by the Director of the Illinois Federation of Families. This provides peer support and allows them to brainstorm strategies for accessing nontraditional services for families.

Sometimes, the Family Resource Developer's position as a Federation employee advocating for a family comes into conflict with expectations of their host provider agency in the community. As these conflicts come to light, they are resolved through the process of supervision. Some of these

are complicated by social class, economic status, or cultural values and beliefs. To their credit, the Community Wraparound Initiative does not shy away from difficult challenges. A frequent topic in both supervisory situations is the Family Resource Developers' struggle to find a workable balance between insuring safety and keeping a family together- particularly when judgements about a family situation are vulnerable to cultural bias. Family Resource Developers see the need for, and respect, system requirements and procedures such as mandatory reporting of suspected abuse, neglect, or a potentially life-threatening situation. However, typically, Family Resource Developers feel strongly committed to being the family's advocate, feel compelled to support the family in every way possible, and leave no stone unturned before making a report that could result in separating family members. Yet, where safety is concerned, some really difficult challenges have to be faced. The following example, while not a pleasant scenario, illustrates this kind of conflict and its satisfactory resolution.

On a first visit, one Family Resource Developer found the home in disarray. The clinical director of the host agency, holding the Family Resource Developer accountable to the same professional standards as all staff at that agency, expected her to file an environmental neglect allegation on the family. She felt conflicted because her employer, the Illinois Federation of Families, expected her to gain the trust of the family and be a supportive advocate. Filing the neglect report would undermine achieving this objective and possibly cause the family additional stress. While the situation was not life-threatening, it was serious and all parties agreed that it did require attention. The final resolution, respecting the state's mandated reporting requirements, was to inform the family of the jeopardy posed by their environment and suggest that they self-report the problem and request help. In addition, a group of Federation members and staff offered to clean the house as a way to provide the family some immediate relief.

Supervision also often addresses issues about boundaries and confidentiality. These are valuable opportunities for clarifying responsibilities and expectations. Like the example above, frank and respectful discussions from different perspectives lead to new solutions for problems and issues faced by all staff associated with an agency or even the entire Initiative.

In summing up where she sees the role of the Family Resource Developers moving in the future, Karen Gora said, "The questions are, 'Are families getting what they need? When they need it? In a way they can accept it?' That is fidelity. Each of us comes to this understanding in our own way and until the level of evolution rises to a common level, we will continue to have conflict. Knowing that, we should not feel upset or let conflict stop us. We should not be afraid to try. We must tolerate the feeling of unrest that comes from change."

To some extent, it appears that Karen Gora's criteria for success are being met. Families enrolled in the *Community Wraparound Initiative* report that after six months of working with a Family Resource Developer their needs significantly decreased in a number of areas. Several areas were specifically mentioned:

- They knew more about their child's disability, services available for their child, and how to care for their child.
- They had obtained financial assistance from public agencies such as Medicaid, Supplemental Security Income, and Aid for Dependent Children.
- They had received home-based services such as short or long-term respite care which gave them time to complete household chores, run errands, or take a much needed weekend vacation.
- They had less of a need for help in getting counseling or therapy for their child, themselves, or other family members.

## **REACH RHODE ISLAND**

### **A Statewide Initiative Administered Regionally**

*REACH Rhode Island* is a statewide initiative supported by a grant from the federal Center for Mental Health Services. The Department of Children, Youth and Families administers the grant and provides leadership to the eight Local Coordinating Councils contracted to operate the initiative. The original application plan for this initiative stipulated that family members would be hired in each region. While the state's contract and oversight provide a general framework for these positions, each region, and each employee, has shaped the role of the Family Service Coordinator differently.<sup>27</sup>

There are currently 17 family members employed full or part time as Family Service Coordinators. The working environment in each of the eight regions has its own character. The fact that Family Service Coordinators work for different employers means they do not all experience the same expectations for their performance and they encounter different reactions to the problems they face and the work they do. This inconsistency, while providing variety and richness, is sometimes frustrating and troubling for family members, administrators, and providers seeking to insure a uniformly high level of care across the state. In the communities where there is only one family member working in this role, there is still a strong sense of isolation. Family Service Coordinators

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<sup>27</sup> See Appendix E for a sample of this contract.

see a strong need to communicate with and support each other and expressed a desire to develop standards for performing and evaluating the work they do.<sup>28</sup> Sonja Rodriguez, a Family Service Coordinator, in Pawtucket, Rhode Island, said it most directly: “We should have a support group just for us.”

## **Supervision as a Vehicle for System Change**

Rhode Island's Family Service Coordinators recognize their own ability to facilitate change within the system of care even when what happens is largely dependent on variables they cannot control. Their experience and values arm them with the information and expertise necessary to influence practice and take initiative to do things they know will work. They have, for example, helped supervisors and co-workers understand that family-based and community-based work requires flexible scheduling. Several Family Service Coordinators developed a paper describing family strengths and needs that provided background helpful to teams. They bring families new ideas and suggestions to solve their problems and achieve their goals, and they promote agency and provider practices that are culturally competent.

Changing pathways and policies has not always been easy for Family Service Coordinators. Success depends largely on support from a supervisor. “I have an open-minded supervisor who supports my project,” stated Iraida Williams, Family Service Coordinator for the Providence Day Treatment Program. Other Family Service Coordinators echoed, “When they [supervisors] don't know you well, they are resistant; when you are visible, they collaborate with you.” Not every Family Service Coordinator has a supervisor consistently available. Sometimes they have to rely on whoever is available, which means temporarily working with a different supervisor who is unfamiliar with the Family Service Coordinator personally or the family they are concerned about supporting. “It is hard to run up against a system (with) years of history when . . . you do not get regular supervision.” commented Renata Ford.

Supervisors face challenges too. There are no clear guidelines for supervision applied uniformly throughout the state. Supervisors themselves recognize that supervising family members is different. Their traditional training was focused on maintaining respectful boundaries with families, not on working side-by-side. According to supervisors, Family Service Coordinators who show a willingness to trust the system and discuss differing perspectives openly and respectfully make the best use of the supervisor-employee relationship.

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<sup>28</sup> Conversation with Family Service Coordinators, May 18, 1998, Providence, RI.



Family Service Coordinators are adding a whole new dimension that has raised the consciousness of all staff. Bruce Frickett, Liaison to the division of Children, Youth and Families, summed up the impact of the role of Family Service Coordinators. "When we started . . . [family members as co-workers] looked like an intrusion. Now there is a better understanding. It has been an evolutionary process that has come from everyone coming together at the table."<sup>29</sup> As the system of care has expanded the range of services and supports that communities offer, staff in general provide services to families in new ways – many of which they learned from Family Service Coordinators.

## **Impact of Family Service Coordinators on the Rhode Island System of Care and the Families Enrolled**

Lisa Conlon, Director of the Rhode Island Parent Support Network, sees the Family Service Coordinator as the most essential feature of the *REACH* project and the source of the project's success. Her own words were, "The Family Service Coordinator is the weaver. They are the ones who build trust with the family, bring everyone together, support the family as a decision maker through the individualized service plan process, do all the follow up, and look for the outcomes. They are the one's who are there to hear from the parent when a plan is not working out or when the family goes into crisis. They hold the web together."

At all levels, credit for the success of Rhode Island's statewide system of care initiative is given to the role and work of the Family Service Coordinators. Parents relate to Family Service Coordinators because they are seen as people who have walked in their shoes. As a result, families respond to the system of care and become engaged in the wraparound process. Relationships between enrolled families and providers are more collaborative. The range of service options in the community has expanded. Family supports and crisis intervention planning are routinely considered by teams. For example, the discharge planning that Family Service Coordinators are doing with youth at the Rhode Island Training School connects them to the system of care which provides community-based services and supports that help the youth reintegrate into the community and sustain a positive life style. This is one factor contributing to the dramatically reduced recidivism rate. The bottom line is that outcomes for children and their families are better.

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<sup>29</sup> May 20, 1998.



## **SUMMARY OF LEARNINGS ABOUT THE SYSTEM OF CARE FACILITATOR ROLE**

It is clear that the widespread use of family members in the system of care facilitator role achieves better outcomes for all involved. The histories of the Illinois and Rhode Island projects point out several features that are essential to achieving this success and, therefore, are the lessons to be applied by any community wishing to replicate this approach.

### **Willingness To Work With Families As Equals Must Be Genuine**

First and foremost, there must be a genuine willingness for direct care staff and supervisors to work with family members as equals, in spite of the fact that they may not have the same level of formal education and training. Attitudes towards families that are rooted in the history of the mental health field and ingrained through years of professional training need to change. System planners and promoters of systems of care cannot afford to underestimate the importance of attitudes or the effort it takes to make this paradigm shift. Time and resources to achieve this must be built into the plan from the very beginning.

### **Expectation Should Be Clear And Specific**

The nature of the work being accomplished by system of care facilitators is new. In most communities there is no history to draw upon in defining this position or establishing its place in the service system. A job description with specific responsibilities and expectations has to be invented. The job description must be revisited and revised frequently as the role matures to fit the context of each unique community setting. In Rhode Island, for example, while there is a core set of responsibilities common to all Family Service Coordinators. Family members working in schools are engaged in some activities that are characteristic of school programs, yet different from activities of family members who are working in community recreation centers, mental health clinics, or the juvenile corrections system. Adapting the role to these specific settings while keeping the core support and advocacy functions intact is key to success.

### **Support From Families And Agencies Is Required**

The persons in this position require support from their local family-run organization, as well as the day-to-day support within the agencies where they are working. The isolation experienced by family

members serving in this role at the early stages of its development (as well as when they first begin their work) can be avoided when more than one individual is hired to work from a particular location. Establishing, arranging for, and maintaining regular peer-to-peer support is critical.

## **Policies And Procedures Have To Value The Way Families Live And Work**

Agency policies and procedures must clearly value the perspective and expertise family members bring to systems of care, as well as their special ability to establish trust with and gain the cooperation of enrolled families. Eventually, traditionally administered agencies will have to make adjustments. Flexibility in working hours, for example, is essential. Stretching the traditional boundaries of professional relationships with 'clients' is another. Travel policies and reimbursement procedures should make it easy for family members working in this role to get into the community at any time of day or night and have funds at their disposal to meet immediate short-term needs for family support. Finding ways to overcome bureaucratic barriers to flexibility requires philosophical buy-in, administrative skill and political savvy.

## **Compensation Should Be Based On Level Of Responsibility, Not A Degree**

Compensation must be fair and reflect the level of responsibility expected, rather than the degree of formal education attained. Rhode Island, for example, provides an extra stipend for employees who are fluent in a language other than English. Health insurance and other benefits, including liability, should be affordable and accessible to employees. For some agencies, making such fringe benefits as these available to part-time staff (on a pro-rated basis) may require making changes to personnel policies. In some cases, hiring family members without college degrees may necessitate renegotiating labor contracts or changing state requirements for licensure or accreditation.

## **Training And Supervision Are Essential**

On-going training and supervision are necessary for system of care facilitators to develop their role, expand their professional horizons, and transform their personal experience into effective strategies for improving the way services and supports are provided to children with mental health needs and the families raising them. A career ladder with opportunities to gain certification, licensure, or a college degree should be explored. Linkages with higher education institutions in the community can result in special opportunities for family members to earn degrees or special diplomas. Lisa Conlon expressed it definitively. "[Training] has been a hot issue. I have always felt it was a strong need. These people are the backbone of the system and our workshops only meet some of their needs."

# Chapter III

## Family As Faculty

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### DESCRIPTION OF THE ROLE

#### **Training Is A Historical Role For Family-Run Organizations**

For over 10 years, family-run organizations around the country have played a critical role in supporting families raising children with mental health needs. For the most part, these organizations started by providing opportunities for families to share experiences by attending local grass-roots, peer-to-peer support groups. The role of family-run organizations has never been to tell families what they should be doing for their children. Rather it is to make sure that families have all the information, are aware of all their options, and get all the support they need in carrying through on their decisions.

Family-run organizations are uniquely qualified to support family-driven systems change to develop and improve services and supports that result in better outcomes for children. Our organizations hire family members directly from the communities they serve. These individuals are friends and neighbors familiar with the cultures and traditions of the community where they live. Their children play, go to school, participate in sports, attend church, and access the same services as the children of the families they serve.

Structured training for families was a natural outgrowth of the peer-to-peer support groups. Family-run organizations began developing curriculums on topics that were of interest to family members and eventually extended invitations to others in the community. Topics emerged directly from the information needs identified by families. These workshops are presented to families to expand their knowledge about children's mental health and enable them to become strong advocates for their own children, as well as develop their leadership skills to bring about and support system change. Our training for families is particularly effective because family-run organizations understand both what families and caregivers are going through and how providers operate in the community. We have walked in their shoes and cried their tears.

The Vermont Federation of Families for Children's Mental Health is an example of a family-run organization that has been instrumental in developing the respite training program for their state. A family member was key in conducting the literature review and writing the training curriculum for

respite providers. Family members have been taken leadership roles in the design, implementation, and subsequent reporting of the respite program evaluation. In a 1997 evaluation of the respite care program in Vermont, Bruns found that 25-30 hours of respite care a month decreased out of home placement, produced higher optimism, reduced personal strain, and negative behaviors.

Gradually, family-run organizations expanded the audience for their training programs to include professionals and providers in their communities. Because of their history, perspective, and experience as “clients,” family faculty educate providers and professionals about the impact raising a child with a mental health problem has on the entire family – not just the needs of specific children. Family faculty give providers and professionals the invaluable opportunity to hear first hand about what has worked from families who have designed and developed effective services for their children. Their personal experience brings to life what providers and administrators can only partially learn through textbooks.

Family as faculty, and the curricula offered by family-run organizations, provide families an opportunity to develop strategies that dissolve some of the barriers that make it difficult for local systems and providers to be creative in designing services and supports for children and their families. They have offered themselves as bridges to link families and professionals together as equal partners, working collaboratively together for the best interest of the children. When family are faculty, they work to support not only the needs of the child and family, but also the needs of the providers and administrators. Family Organizations have provided education and technical assistance to schools, law enforcement, courts, child protective services, child and family services, churches, homeless shelters, clinics, pediatricians, public health nurses, psychologists, psychiatrists, counselors, employers, substance abuse programs, abuse shelters, and day and after school care facilities, just to name a few.

### **Family-Run Organizations As Training Agencies— Hawaii Families As Allies Exemplifies The Role**

Like most family-run organizations, *Hawaii Families As Allies* began (approximately 12 years ago) simply to provide a network of support for families raising children and adolescents with serious emotional or behavioral disorders. They had a part time staff person and a few community family volunteers, who facilitated support groups. In the beginning, very little training was provided to these volunteers, due to limited staff and funding. Nevertheless, Family Volunteers hosted monthly meetings in their homes and served light refreshments to other families who were interested

and joined in. They offered to facilitate discussions, share their personal experiences, and referred families with technical or complicated questions to the Hawaii Families As Allies office in Honolulu. The Family Volunteers called into the Honolulu office to touch base and submitted monthly reports.

As simple as this sounds, it was not easy. These first groups were very small and inconsistently attended. Volunteer turnover, funding, cultural issues, locations, and lack of awareness and support from the service system were just some of the barriers. The scarcity of appropriate educational and mental health services statewide was a huge barrier. After a few years, families were no longer interested in just talking amongst themselves. They really needed information and help in developing strategies to establish and expand services for their children and their families.

These early years gave Hawaii Families As Allies an opportunity to evaluate their capacity to provide support and telephone technical assistance to families. They reviewed the kind of help that was requested, and assessed their strengths as an organization. Hawaii Families As Allies leadership came to realize they had become very knowledgeable about how successful family members supported other families and the importance of developing services and supports in their home communities. They received funding to provide training to family members, but understood the importance of including service providers in their workshops. *Hawaii Families As Allies* put together two curricula. *Developing Families as Allies*, based on a program shared with them by Mississippi Families As Allies, was revised use in Hawaii. It is presented in 10 sessions running from two to three hours each. This curriculum stresses the importance of families and professionals working collaboratively and teaches the essential skills to accomplish this. Attendees identify their needs and refine their roles as they develop an action plan for the care of their children and families. The second curriculum, *Impact on the Families*, builds on *Developing Families As Allies*. *Impact on the Families* emphasizes the effect that severe emotional and behavioral disorders have on the whole family. Professionals and providers are very comfortable joining the families and feel they get different perspectives of the information offered because they are mixed together.

Today, *Hawaii Families As Allies* employs 10 paid staff and over 14 volunteers. Four full-time employees develop, provide, and evaluate training. Hawaii Families As Allies now has a total of 16 curricula they offer statewide. *Why Managed Care?*, *Effective Communication and Negotiation*, *Behavior Intervention for the Child with a Serious Emotional Disorder*; *Oppositional Defiant and Conduct Disorder*, and *Wraparound Process* are just a few of the workshop titles. They average 130 regular workshops a year, with approximately 2,500 parent and primary caregivers, educators, service

providers and other stakeholders attending. Evaluations and interviews show that their workshops are well received; that all attendees feel the information presented is useful; and that they would recommend the workshops to their peers.

Each year, *Hawaii Families As Allies* develops new curricula and offers them on a quarterly basis when possible. They continue to survey family members from different communities to find out what topics they would like to learn more about. At times, they schedule special workshops featuring presenters from the service delivery system in Hawaii. Most workshops are open to families and anyone else who is interested. Over the years, *Hawaii Families As Allies* has responded to many requests for special presentations for school counselors, regular education teachers, special education teachers, public health nurses, hospitals, nuns and priests, case managers, principals, and many others in the community. Some highlights are:

- In 1995, *Hawaii Families As Allies* staff were part of a team of trainers, including staff from the Departments of Health and Education, who presented a statewide curriculum called *Together We Can* about the importance of collaboration. Participants were invited guests serving as administrators, line workers, legislators, families, law enforcement workers, and other service providers in local communities.
- In 1997, staff of *Hawaii Families As Allies* presented a three day case management training to professionals and paraprofessionals. They are now offering this same training statewide to mental health providers seeking certification. In addition, a two day wraparound training was requested and added to this curriculum.

Because of their commitment to continuous quality improvement, *Hawaii Families As Allies* takes a serious approach to evaluating their training activities. They compile data from the evaluations they collect at the end of each training session. From these, *Hawaii Families As Allies* determines:

- who is attending;
- what ethnicity they are;
- what area of the state they are from;
- how they heard about *Hawaii Families As Allies*;
- how competent the presenters were;
- whether they find the information to be useful;
- if they would refer their peers to future workshops; and
- what additional topics they would like *Hawaii Families As Allies* to follow up with.

This information has been extremely useful throughout the years in planning of activities and training and further understanding the needs of the community.<sup>1</sup>

*Hawaii Families As Allies* is pleased with their success as a training organization, and sees their training reflected in the advocacy work done by both families and professionals they have served. They are just one family organization out of hundreds nationally who have had similar success with providing community based training for families, providers, and professionals. These experiences demonstrate why family-run organizations should be used to their full potential and be viewed as colleagues to co-teach with those who, although formally educated in colleges and universities, do not have the extensive experiences and unique perspectives of families raising children with mental health needs.

## **What The Literature Has Recorded About Families Training Providers**

Researchers have discussed the importance of involving families in ongoing professional development for teachers, social service coordinators, and other professionals, even after pre-service training is completed.<sup>2</sup> In 1987, the Research and Training Center on Family Support initiated a curriculum and training program to promote professional-parent collaboration. *Working Together* involved 87 pairs of trainers from all over the country. Each pair of trainers (a parent and a professional) worked together to train other teams of families and professionals on collaboration. The training program was instrumental in breaking down stereotypes about families, and it paved the way for other training opportunities for family members.<sup>3</sup> A 1994 report on the project, concluded that "collaboration is only partially developed as a concept and only partially applied as a practice. . . . What is needed is a second wave of efforts to bring the concept and practice of collaboration to a higher level of development."<sup>4</sup> In early conferences on family-professional collaboration, many well meaning and caring professionals expressed shock at hearing, for the first time, about the amount of frustration and anger that many of us have towards a system that historically has failed to serve us well.<sup>5</sup> Pre-service teacher training often lacks the most basic information on how to work effectively with our children and how to involve us in the process.

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<sup>1</sup> See Appendix F for a sample evaluation form.

<sup>2</sup> Stroul, B. A., Friedman, R. M., Hernandez, M., Roebuck, L., Lourie, I. S., & Koyanagi, C. (1996). Systems of Care in the Future. In B. A. Stroul (Ed.), *Children's Mental Health: Creating Systems of Care in a Changing Society*, Baltimore, MD: Paul H. Brookes Publishing Co., pp. 591-612.

<sup>3</sup> Koroloff *et al.*, 1996.

<sup>4</sup> Williams-Murphy, T., DeChillo, N., Koren, P., & Hunter, R. (1994). *Family/Professional Collaboration: The Perspective of Those Who Have Tried*. Research and Training Center on Family Support and Children's Mental Health, Portland State University. p. 22.

<sup>5</sup> Friesen, B. J. & Huff, B (1996). Family Perspectives on Systems of Care. In B. A. Stroul (Ed), *Children's Mental Health: Creating Systems of Care in a Changing Society*, Baltimore, MD: Paul H. Brookes Publishing Co., pp. 41-67.



In an evaluation of teacher education programs and preparation for general family involvement, Shartrand *et al.* found that “while policy makers and educators endorse professional development, little is known about preparing student teachers to work with families. If teachers are to link learning in the classroom and in the home, how are they being prepared to accomplish this task? What knowledge and skills do they need? How should these be taught and learned?” Shartrand highlighted several programs that made family involvement an important facet of teacher training.<sup>6</sup>

- Trinity College in Burlington, Vermont. Parents give guest lectures to pre-service teachers on issues related to parenting, child care, raising a child with special needs, and transitioning children into the school system.
- California. Pre-service teachers are assigned to work closely with a single family for several weeks. The teachers interview the family, work with the child, and model teaching methods for the families. They must also write progress reports, lead a weekly parent discussion group and children's self-esteem group, and compile a resource notebook with the parents.
- Urban Teacher Education Program at Indiana University Northwest. Parents help design the teacher education program. The purpose of the program is to increase the number of teachers, particularly minority teachers, who work in urban settings. In three urban settings, the program established Professional Development Centers, each with a parent liaison. In addition, there is a parent advisory board, which designs community experiences for the teachers and sponsors a workshop, entitled, *Through the Eyes of a Child*.<sup>7</sup>

On the other hand, there is documentation of some resistance to including the perspective of family members in teacher training. Educators argue that there are too many requirements for pre-service teachers already, and adding a focus on families would require extending the length of the program.<sup>8</sup> Furthermore, there may be some resistance to asking families to provide training.<sup>9</sup> We believe that this resistance, in part, grows out of fear that we, family members, could threaten the “professional integrity” of the service agencies and that many professionals still do not think parent representation is important.

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<sup>6</sup> Shartrand, A. M., Weiss, H. B., Kreider, H. M., & Lopez, M. E. (1997). *New Skills for New Schools: Preparing Teachers in Family Involvement*. Cambridge, MA: Harvard Family Research Project, Harvard Graduate School of Education.

<sup>7</sup> Shartrand *et al.*, 1997.

<sup>8</sup> Bailey, D. B., Jr., Simeonsson, R. J., Yoder, D. E., & Huntington, G. S. (September 1990). Preparing Professionals to Serve Infants and Toddlers with Handicaps and Their Families: An Integrative Analysis Across Eight Disciplines. *Exceptional Children*, 57 (1), pp. 26-35.

<sup>9</sup> Bradley, A. (November 12, 1997). Teacher Training Ignores Students' Families, Study Finds. *Education Week on the Web*. <http://www.edweek.org/ew/vol-17/12family.h17>.



Literature on families serving as faculty in training the work force for children's mental health care is scarce. We hope that highlighting this promising approach to training will generate more interest for university faculty and researchers. The role of family members as faculty preparing the workforce for systems of care is a very promising practice, but it is not very widespread. We found only one example where the role truly met all our criteria (paid, developing directly from the system of care, and existing long enough for there to be evidence of its impact). This one example is located in Greenville, North Carolina, and is described in detail in the next section. We also include a description of a more traditional, but still not widespread, use of family members in university training programs – that of guest lecturer. The site we visited is in northern Maine. We selected Maine because of the enthusiasm for family involvement expressed by the university faculty and their high interest in replicating or adapting North Carolina's accomplishments.

## **THE PEN-PAL PROJECT IN NORTH CAROLINA IS ON THE CUTTING EDGE**

### **Background**

In order to implement change in systems, change must occur in those who lead and implement the systems. The workforce for systems of care must know, value, and practice their craft according to the values and principles of the Children and Adolescent Service System Program<sup>10</sup>. In the family arena, this means infusing respect for family experiences and training into working partnerships with families throughout training programs at both the in-service and pre-service level. The wealth of experience and knowledge about dealing with the real life challenges we have acquired raising our children needs to be communicated to practitioners in all child service systems. This is a challenge family-run organizations, individual families, and systems of care are just beginning to address. In North Carolina, families are valuable partners in these training processes.

In North Carolina, including family members as trainers in personnel preparation programs models the collaboration required in a system of care. Family members assist training teams and faculty in the development of content, review and critique of university curriculum, and effectively team teach in university classrooms. *WE CARE* (With Every Child and Adult Reaching Excellence)<sup>11</sup> recruits, trains, and supports families to serve as faculty.

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<sup>10</sup> See Stroul & Friedman (1994) for more information on the history and philosophy of CASSP.

<sup>11</sup> *WE CARE* is a non-profit, family-run advocacy organization and a chapter of the Federation of Families for Children's Mental Health. *WE CARE* operates a family resource center that houses a lending library, a computer lab, a family store, and also provides training and information.

## **It Started With A University Partnership**

In 1994, the Pitt County Area Mental Health, Developmental Disabilities and Substance Abuse Program developed relationships with several faculty members from East Carolina University. This was based on a history of consultations and student field placements through the School of Social Work, Department of Psychology, Department of Psychiatry, Marriage and Family Therapy Program, and the School of Nursing. The Pitt County Mental Health Center, along with the Edgecombe/Nash Mental Health Center spearheaded the implementation of the *PEN-PAL* grant. The inclusion of the Department of Social Services, Juvenile Justice, Public Health Department, Public Schools, and community organizations, along with East Carolina University, started the partnership that would make the creation of a system of care possible. This was the beginning of what North Carolina calls the Public Academic Liaison.

The Pitt, Edgecombe, Nash Public Academic Liaison (*PEN-PAL*) project is a federal grant awarded by the Center for Mental Health Services. The *PEN-PAL* grant site built in a strong university training partnership from the start. East Carolina University in Greenville, North Carolina, is responsible for training and supervising providers in implementing system of care principles. They developed both pre-service and in-service programs to accomplish these tasks.

Pre-service training is offered by a cross-disciplinary faculty team called the East Carolina University Social Sciences Training Consortium; a partnership between faculty in the departments of Psychology, Marriage and Family Therapy, Nursing, and Social Work. The Consortium integrates system of care principles and practices into their graduate and undergraduate curricula. The Consortium ensures a family voice and presence in its classes through a contract with *WE CARE*. *WE CARE* recruits, trains, and supports family members to work as Parents in Residence and collaborate with Consortium faculty in curriculum development, curriculum review, and/or teaching in these courses.

In-service training for providers and families in the *PEN-PAL Project* is offered by the East Carolina University, Training and Technical Assistance Resource Center. The Resource Center is operated as a partnership between the School of Education and the Department of Child and Adolescent Psychiatry. The Resource Center subcontracts with a training consulting company to organize and facilitate training teams. In-service training is provided by a collaborative team of family members, service providers from the surrounding community, faculty members, and a facilitator. The training team structure and presentations model parent/professional collaboration for trainees.

Before the emergence of *WE CARE* in September 1997, the Parents in Residence (as well as four Parent Advocates for the *PEN-PAL Project*) were individually hired by and housed as staff of the Resource Center. Families found the university bureaucracy inflexible and not very accommodating to the special circumstance they faced as individuals raising children with mental health problems. The Parents in Residence and the Parent Advocates decided that in order to have a family-friendly employer, they needed to work for a family-run organization and set about creating one in their own community. East Carolina University now has two contracts with *WE CARE*. One for the Parent in Residence program and one for the in-service training teams. *WE CARE* pays individual family members \$50 per day plus travel expenses and child care. They are paid for the days they receive training from *WE CARE* as well as the days they do training with the interdisciplinary teams. Family members who co-teach the interdisciplinary course are paid between \$1,200 and \$1,500 per course.

## **Evolution Of The Parent In Residence Model**

Having a Parent in Residence on the campus made it possible for faculty members from the East Carolina University Social Sciences Training Consortium to really listen to a parent's perspective as they developed an interdisciplinary course to teach systems of care principles to graduate level students in the four disciplines comprising the Consortium. It was quite a challenge getting this course—Interdisciplinary Practice—through four departments and coordinating four faculty schedules. The syllabus lists the course objectives and competencies as being to:

- define the significance of interdisciplinary collaboration in service provision for children with serious emotional disturbances and their families;
- differentiate between parallel practice, multidisciplinary, and interdisciplinary models;
- analyze the strengths and challenges of using interdisciplinary models for family service or care delivery;
- demonstrate how system of care principles can be integrated into all disciplines and define the implications for professional practice;
- compare/contrast treatment planning processes among disciplines; and
- develop interdisciplinary practice guidelines to promote holistic care using an interdisciplinary framework.<sup>12</sup>

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<sup>12</sup> Syllabus for *Interdisciplinary Practice: Services For Children with Serious Emotional Disorders and Their Families* (CDFR 6380, NURS 6380, PSYC 6380, and SOCW 6380). Provides an overview of the interdisciplinary, collaborative process and a system of care model to be used across disciplines in mental health services for children with serious emotional disturbances and their families. Prepares professionals to participate in holistic interdisciplinary team practice in a variety of settings.

The course became a reality in the fall of 1997. Family members from *WE CARE* were invited to tell their stories and participate in several of the classes that first semester. When the course was offered again in the spring of 1998, we were present in all classes except for scheduled exams.

The students in the class came from different disciplines of study and had different levels of work experience. Some were first year graduate students with little or no experience in the field. Other students, who previously worked as social workers, nurses, psychologists or therapists, were coming back to college to pursue a master's degree. There was also a wide age range. Some of the younger students, who had not yet been in the "real world," seemed to be more open to the parents involvement in the class. Hearing about the family perspective and experience with the various agencies was new to them and, perhaps, helped compensate for their lack of work experience. Students who had several years of field work with families used this opportunity to share their experience with the class.

### ***WE CARE Prepares Families To Be Faculty***

During the fall of 1997, the Consortium developed a contract with *WE CARE*, to recruit, prepare, and provide family members to participate in teaching the system of care course. *WE CARE* was given the course outline and the pre-reading material so that the organization would be prepared for the class and could assist other family members in preparing to co-teach the course.

The executive director of *WE CARE* supervises the staff as well as other family members that attend classes. It is the responsibility of the executive director to:

- make sure those participating in the course have the pre-reading materials, and are prepared to participate in classroom discussion;
- pay a stipend to family members who are not *WE CARE* staff;
- send at least two family members to each class (more family members might attend depending on the topic or class activity); and
- help families overcome the natural obstacles (such as finding a parking place and locating the right building) of being on the unfamiliar territory of a university campus.

Over time, the amount of preparation required by family members for this class became clearer and grew in its intensity. Sandra Spencer, the Executive Director of *WE CARE*, used feedback from the university faculty to improve the training of Parents in Residence attending the classes. Some particularly important concerns were expressed.

- Some family members would use the names of individuals or agencies in the telling of their stories. This created conflicts for some of the students in the class who were doing field placements with those individuals or agencies.
- Family members seemed compelled to share all of their struggles and challenges in one class period. The university faculty realized how personal and painful these experiences must have been, and they wanted to hear them but, it consumed too much time – especially when there were several family members in the class.

*WE CARE* took responsibility for training Parents in Residence in how to tell a story without naming individuals or agencies. Sandra Spencer explained that, “We learned how to tell our story, which may be full of hurt and anger, in such a way that students in the class, who would soon be service providers, would learn how to more effectively work with families.” She provided an example. “On one occasion, a parent told of how, in anger and frustration at repeated visits from inexperienced and insensitive social workers who did not understand her son’s mental illness, she told the investigator, ‘take my child away and get out.’ *WE CARE* staff processed this event with the mother – who did not really want to give up custody of her child and helped her identify what she needed to keep her child safe at home and in school.” She listed:

- support at home when he was aggressive;
- support for the teacher at school;
- respite care;
- a written crisis plan so everyone would not feel so helpless when one of these situations occurred; and
- a single care coordinator to help create a team with school, community, and agency representative so everyone involved with her family would know the history and the plan.

*WE CARE* used this information to help the mother reframe her story and tell students what interventions would help. *WE CARE* also helped her get some of these things in place to help her family survive the tough times. This approach prevented her from getting angry every time she told her story and made her a more effective Parent in Residence.

Some family members who shared their stories in class admitted to being frustrated at times. They were very disappointed that students (only one or two) who had had so much experience working with families could not hear beyond the frustration and pull out what systems issues, if any, could have caused the frustration in parents. Family members likened this experience to dealing with

the traditional agencies that serve them. “We would like to encourage providers to hear more than just the tone and emotion behind our story, and listen to the desperation of getting supports for our child and family.”<sup>13</sup>

## **Relationships Develop Between Families And Students**

Meeting in three-hour sessions, and with its special mixture of students, faculty and family members, the course created an ideal atmosphere for relationship building. The students got to know the family members in a more intimate way – and not as “clients.” A few of the students wanted to know more about *WE CARE*, meet more families, and hear more stories. On one occasion, a few students were invited to attend a support group meeting offered by *WE CARE*.

Parent in Residence relationships with the university faculty also evolved.

- The faculty was very supportive when one of us told of a ‘tough time’ with her child.
- David Dosser from the Department of Marriage and Family Therapy offered to have one of his students provide respite to one of us who was having a really hard time managing a job, family, and child with special needs.
- Susan McCammon from the Department of Psychology was asked by one of us to serve as extra support on her Individual Service Team that was a part of the local system of care.

Being a Parent in Residence had a positive impact on the family members serving in this role. “At first, some of us were scared.” said Veronica Outlaw, a *WE CARE* family advocate. She felt “intimidated because I did not have a degree myself.” Darlene Moody, another advocate, admitted, “I was scared. I did not think I would be listened to. However, as we actually participated in the first class, these fears melted away. They wanted to hear what I had to say about my child and our experience getting the help we needed.” Ms. Outlaw added, “They validated my opinion. Once I got there, I realized the students and faculty really wanted me there. The students accepted me as one on the teachers.”<sup>14</sup>

Other family members became excited at having the opportunity to speak to students. They also welcomed the pre-training that prepared them for each class. “I hope that what they learned they will practice in whatever field they go into.” said Sandra Spencer. “That will definitely have a positive impact on the service delivery and attitudes towards working with families.”

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<sup>13</sup> Interview with Sandra Spencer, April 2, 1998.

<sup>14</sup> Interview, April 1, 1998.

## **Parent In Residence Program Has A Significant Impact**

### **Impact On Students Enrolled In The Class**

Students in the class were highly affected by this experience. The East Carolina University faculty members noted that while student attitudes towards families were generally positive at the beginning of the class, by the end, they were even less blaming and more community oriented. Susan McCammon noted that one student, who wrote an interdisciplinary collaborative grant, attributed the proposal's success to her having been a part of this class. David Dosser stated the class had a significant impact on how students think. David Dosser felt gratified that, "They have taken the ideas of collaboration to heart."

Current and former students interviewed expressed similar changes in attitudes and identified family participation as key to the success of the course. Lisa, a student from the first interdisciplinary system of care class, commented on the change in atmosphere and content that resulted from having Parents in Residence co-teach the class. "I think it gave the class a completely different flavor. So much of these classes is usually theoretical and so little is practical application. . . . Once the parents came and shared their perspective everything "clicked" . . . . We had children there, as well as parents. It was interesting that they would share like that with us. We are going to be the professionals one day who will have to serve them. . . . If we are to really learn how to work with clients, we must get it from the people we will be working with — the families."<sup>15</sup>

Lauren, another student from the first class, told us how she thought other students would respond to a class where family members were co-teachers. Lauren said, "What I have seen is some cynicism. In the field of social work, in particular, there are so many people, who have been in the field for so many years, who are still stereotyping clients and have very low expectations. They don't get the empowerment of the parents piece. This class pulled it together for me and made parent participation more real."<sup>16</sup>

The positive impact on students is also reflected in the end of the semester Student Opinion of Instruction Surveys (a standard instrument used throughout East Carolina University). Students identified

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<sup>15</sup> Interview, April 2, 1998.

<sup>16</sup> Interview, April 2, 1998.



many strengths, including the family involvement. This survey also asked students what they would change about the course. None reported that they would change the involvement of Parents in Residence. A few typical responses follow:

- Families sharing their experiences/insights and working with other disciplines on the class presentations.
- Family participation and parent involvement.
- New fresh perspective. Team teaching and getting view points from different disciplines.
- The inclusion of so many “outsiders” like parents. It was wonderful to have the other points of view.
- The instructors and involvement of parents.
- Parent advocates! Professors modeling of principles.
- The parents were the best part of the class; I learned a lot from their perspective.
- Parent advocates were a great resource.

The course faculty, mindful of the importance of studying this new approach to personnel preparation, administers a number of pre- and post-test instruments to students. Their analysis of the results reveals more specifically just how students were influenced by the experience of having family members co-teach the class. The instruments used include:

- *Pre/Post Critical Incident Interdisciplinary Collaboration Measure*
- *Attitudes Towards Providing Services to Children with Emotional Disturbance*
- *Professionals Attitudes Towards Parents*
- *Community Mental Health Ideology Scale*
- *6380 Class/Unit Evaluation Summary*

*The Critical Incident Interdisciplinary Collaboration Measure* asks students to define key words associated with interdisciplinary collaboration. Dorothea Handron interpreted the results. The kinds of words students used at the beginning of the course (like team work, cooperation, and holistic) indicate that most students start out with a positive perspective on collaboration. “Most learners see collaboration as a process integrating different professional disciplines. Only one or two students included nonprofessionals and the community into the process. No one noted the hard work, emotional investment, and conflicts associated with the collaboration process.” However, she noted the richness of the descriptive words in the post test and the additions of collaboration with the service users and the community, shared



ownership, pooling of resources, confidentiality, and cultural competence. "These definitions are more realistic, inclusive and define the specific components of the collaborative process that learners will experience in the field." said Handron<sup>17</sup>. See below for some sample responses.

<b>CRITICAL INCIDENT INTERDISCIPLINARY COLLABORATION MEASURE</b>	
<b>PRE TEST</b>	<b>POST TEST</b>
Brainstorming	Trust
Creating	Honesty
Mediation	Client centered and involvement
Pooling of resources	Wraparound
Group therapy	Strengths-based
Input	Cultural Competence
Common resources	Community
Teamwork	Shared ownership/partnership
Respect	Confidentiality

The questions on the *Professionals Attitudes Towards Parents Scale* cover five categories: *blame, inform, validate, medicate, and instruct*. The post test shows a decrease in the extent students attribute blame to parents. There was very little change in attitudes about informing parents and validating parents. There was a small decrease in the perception of the need for medication and no change in the area of instruction for parents and providers.

### **Exposure To Parents In Residence Influences Later Work In The Field**

Graduates of the interdisciplinary courses described how this course impacted their work in the field after they left East Carolina University. The anecdote that follows illustrates how students take what they learn from their extensive interaction with families into the work place and how this serves as a catalyst for system change in these settings.

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<sup>17</sup> Dr. Handron's written summary of the Critical Incident Interdisciplinary Collaboration Measure.

Lisa described one “enlightening” experience out in the field. She had been employed at an agency that worked with preschool children who were at risk for, or already showing signs of, serious emotional disturbances. She conducted play groups to help parents interact more effectively with their children and asked what they wanted to achieve from these sessions. Parents told her that they needed to think about it because they had never been asked that question before. The parents began to respond, and Lisa started doing strength-based assessments to identify family goals. “The families look at the plan and see their own goals in it. They say, ‘Count me in!’ We then work on those skills in the play groups and they love it.” Lisa told her supervisor about this success. Other staff members wanted to know how to, “get this model working for them.” The class was validated for Lisa because of this experience. “The class improved my skills and now the play groups are empowering to parents and myself. I now feel like I have a valid place where I work.”<sup>18</sup>

One student, with several years experience as the director of a small county family center that provides family preservation and case management, was somewhat less enthusiastic about family members being faculty. She expressed concern about what the Parent in Residence role was in the class and thought the parents only taught her how frustrated they were when trying to access services and get providers to listen to them. “I learned that parents were very frustrated. Life had handed them a big problem and they wanted someone to help them deal with it. They expected a fix to be done. In the real world, part of it is helping parents understand our parameters.”<sup>19</sup> Yet, this same student pointed out that agencies also need supports to do this work. “We [agencies and professionals] are saying these are our [limited] resources and parents are saying ‘do something’.” Nevertheless, she felt that the parents in the class was a very worthwhile experience for the younger students and that she would recommend this course to others.

### **Impact On East Carolina University Faculty**

“We couldn’t do it with out them,” said David Dosser, referring to having the Parents in Residence present when teaching about parent-professional partnerships. He added that the university has always welcomed families to speak in classes. He tried initially to have a parent advocate attend all of his pre-practicum classes to keep the parent perspective in front of his students.

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<sup>18</sup> Interview, April 2, 1998.

<sup>19</sup> Interview with students, April 2, 1998.

Susan McCammon invites families to speak in her core psychology classes. She expressed the desire to have her students hear first hand what a family's experience is in seeking help from a therapist. McCammon takes this a step further by inviting the staff of *WE CARE* to review books and videos she will use in courses to ensure that the language and text is non-blaming and family friendly.

The other faculty members have also invited families to speak in classes that cover working collaboratively with parents in the core curriculum. The Social Sciences Training Consortium faculty's enthusiasm for co-teaching with family members has impacted faculty members outside of the consortium. Family members and staff of *WE CARE* have recently been invited to share their stories and perspectives in a number of other classes at East Carolina University.

### **Building Relationships Is The Key Outcome Of Parent In Residence Program**

Students, Parents in Residence and faculty members agree that the best outcome of this class was the relationships that developed. These relationships have continued and have an ongoing positive impact on the system of care in the surrounding communities. The East Carolina University faculty members continue to support *WE CARE* as an organization. They also continue to invite family members to other classes at the East Carolina University. Past and current students pair up with *WE CARE* families to offer respite care and mentor their children. Former students call *WE CARE* to enlist the help of a parent advocate for families being served by agencies that are outside of the area served by the *PEN-PAL* system of care. Faculty members serve, at the request of families, on individualized service planning teams within the *PEN-PAL Project*. In this way, they personally support families and lend their expertise and knowledge to the team developing a wraparound plan to support the family. These relationships:

- support community-based activities that occur in real time and real life;
- serve to familiarize pre-service personnel with the system of care values and principles;
- provide opportunities for them to practice using these new skills; and
- model parent-professional collaboration.

### **Evolution Of The Family Role On Training Teams**

Like all new and visionary endeavors, the Parent in Residence model has gone through an evolutionary process. A parent with a child enrolled in the *PEN-PAL Project* filled the first Parent in

Residence position. She was hired to work on the in-service training team. Her role was to provide a parent's perspective in training development and delivery. The Parent in Residence's duties at this early stage were:

- identifying family training needs;
- participating on collaborative training teams;
- facilitating family training events;
- coordinating and producing educational materials; and
- assisting in the development and delivery of university curriculum.

In the beginning, there was an imbalance in responsibility and authority on the team. Family members felt they were there as the "pop-up parent" on the in-service training team. The other members of the team took responsibility for teaching the principles and the family member told a portion of her story to illustrate that principle. As this team stayed together, they began to build relationships and the family voice expanded.

### **Family Members Develop Their Role As Trainers**

A change in the model took place as other members of the team realized that we, their family partners, had much more to contribute than just telling a personal story. At the same time, we learned a great deal about how the system of care operated and came to understand situations from the perspectives of the other members on the team. As all members of these teams spent time together preparing for training events, they became familiar with the procedures and protocols of different agencies. They also observed how difficult it was for parents to perform any task while away from home where their child could have a behavioral crisis at any time. A new level of mutual appreciation and understanding was developed among team members.

Family members noted the change in their role on the training team with satisfaction. "We felt valued in the training process. Our expertise was accepted. We were being seen as an equal on the team. It was still important that we tell our story; however, we learned to tell stories in such a way that not only sparked emotions in the listeners, but also provoked them to think of ways to change how systems serve children and their families. I like training providers and family members, because I have several years of dealing with different agencies; I know what works and how family members want to be treated." said Sandra Spencer, one family member of a training team. "It has

been great to watch a parent's self concept improve because they are asked to do something valuable. We are no longer on the receiving end of service delivery, but are able to offer a perspective that will ultimately cause a change in the system that serves us."<sup>20</sup>

### **Non-Family Members Of The Training Team Gain Perspective**

Other members of the training teams report being able to see families in a different light. Initially it was hard for them to be a member of a team with a person who also receives services from their agency. It was difficult (and a bit uncomfortable) to envision a "client" as a colleague, let alone an equal partner. Family members were not coming to them for help, but saying they have something to contribute to the process. However, the time spent together in planning and traveling created an opportunity to build new kinds of relationships, which ultimately led to a more unified team and a more balanced and effective presentation.

System of care providers and family members receiving training from these teams had the opportunity to see how well such partnerships can actually work. The training itself created an opportunity to talk about challenges and opportunities to change ways of doing business. Audiences asked how teams worked through differences in training styles, levels of education and parent's being critical of service providers and agencies. Questions such as these presented great "teachable moments."

### **Learning To Respect The Culture Of Family Members On Training Teams**

The training team model presented family members with teachable moments on issues related to respect and cultural differences. Sandra Spencer explained that, "Providers knew all of us pretty well. They have a case history of our entire family. They knew our family's strengths and challenges. We, on the other hand, only knew about the provider's professional life. This "information gap" fostered an imbalance in the relationship which expressed itself by professionals micro managing us once the training was over." The following scenarios illustrate this kind of situation.

- Family members were not given stipends or per diem money up front. This meant they had to ask the facilitator sponsoring the team to pay for things they needed when traveling (such as a meal or gas). At the end of one particularly long day of training, the team decided to do some site seeing and shopping. However, the family member of the team had not yet

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<sup>20</sup> On-site interviews with Parents in Residence, March 31, 1998.

received her stipend and did not want to ask for money from another adult. She took this opportunity to tell the leader of the team how humiliating the situation was. As a result, a plan was created so that family members could receive both the meal per diem and their stipend before leaving home.

- On another occasion, a service provider having prior, confidential knowledge of a history of alcohol abuse in the family, tried to prevent a family member from sitting in the bar with the rest of the team. When she later entered the bar, accompanied by other family members from the team, professionals had an opportunity to observe how families take responsibility for supporting each other and don't need supervision from service providers.
- One common problem concerns how children react to their parent being away from home. One parent's experience is typical. "If my child gets in trouble in school, or if his behavior escalates at all while I'm away conducting a training, they blame the problem on my not being at home. However, no such explanation is given when my child exhibits the same behavior problems while I am at home."

These stories are very personal and isolated examples; but each provides a "golden opportunity for us to express how much of our life is an open book to our training partners," and how other people who know something about our history judge us unfairly. These events also served to raise awareness of how people with different cultural values can successfully work together toward a common goal. Professionals have learned how to socialize with their family training partners. "They remove their professional hat and try not to counsel or manage family members."<sup>21</sup>

The family as faculty role and the relationship between *WE CARE* and East Carolina University is more highly developed than any other example of this role. What we found in Maine is more typical of the kind of relationships families involved with systems of care have with universities.

## **WINGS PROJECT IN MAINE: AN EMERGING PROMISING PRACTICE**

### **Wings Parent Advocates Guest Lecture In University Of Maine Classes**

The Parent Advocate Specialists who work with the *Wings* project in Maine have developed a productive working relationship with faculty at two campuses of the University of Maine - Orono and Machais. At both sites, Parent Advocate Specialists and parents from the community are guest lecturers in classes taught by specific faculty members. We interviewed these faculty members to learn how they became interested in having family members present in their classes, how this experience affected them, what impact it had on their students, and how they hoped to expand this practice in the future.

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<sup>21</sup> Interview with Sandra Spencer, April 2, 1998.

## **All Teachers-In-Training Hear From Wings Parent Advocates**

Leigh Lardieri is an assistant Professor of Education at the University of Maine at Machais where she teaches educational psychology and a class on the exceptional student in the classroom. These classes are required courses for undergraduate regular education teachers in training – all education majors take her course. She pointed out that, “the potential for impact is great because a high percentage of Machais graduates continue to teach in the vicinity of Washington County.”<sup>22</sup>

Lardieri was impressed with the System of Care and the involvement of parents. She got the idea of contacting Jackie Ackley, a *Wings* Parent Advocate, from a flyer that came across her desk. She believes it is critical to connect families with students in her classes, and has invited parents to speak about their experiences. “The growth in the knowledge base is exponential because students take this experience out of class and into the schools where they in turn share it with others.”<sup>23</sup>

The course where the Parent Advocates are guest speakers meets in the evening. About 20 students enroll per term. Lardieri believes that, “all teachers have to work with kids who have learning disabilities, physical disabilities and/or emotional or behavioral disabilities.” She added that, “Jackie has been a vital connection to what is going on in the community. Family members who guest lecture also transmit information about the culture of the community.”<sup>24</sup>

At this time, family members who participate in the guest lecture program are not compensated by the university for their participation. However, Lardieri and the Parent Advocates from Wings have been discussing how this might be changed in the future. Some of the family members who give guest lectures are working for agencies in the community, such as Wings, that supports their involvement with the university. Others are willing volunteers because they recognize being a guest lecturer gives them an opportunity to communicate vital information to soon-to-be teachers at a critical point in their pre-service training.

Lardieri hopes that in the future she can add a panel discussion and invite more family member to be guest speakers in her classes. She also wants to develop a program to prepare more parents to

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<sup>22</sup> Interview, May 1, 1998.

<sup>23</sup> Interview, May 1, 1998.

<sup>24</sup> Interview, May 1, 1998.

participate in the class. She thinks it would be great to expand the practice of family members presenting their experiences into the business courses – especially since they have to comply with the Americans with Disabilities Act.

Jackie Ackley, the *Wings* Parent Advocate in Machais, is pleased with the relationship as well. “It gives me connections and credibility with teachers in the community who are enrolled in the class and it provides an opportunity for students (prospective teachers) to understand the many challenges special families face on a daily bases. It is, at this time, the **only** forum for future teachers to gain that understanding and empathy.” She mentioned that many parents are taking classes at the university and they use this opportunity to speak up and share their life experiences also.<sup>25</sup>

Lardieri described the impact involving families has had on her as a university teacher. “It helps me stay focused. I recall my dissertation research and remember families I visited. With 30 students [in a regular education class] it is easy to get into an adversarial position [with families]. I recall my knowledge base being able to proactively problem solve and work collaboratively and constructively. In my university teaching, I try to listen to what parents are saying. I help my students focus and process what parents tell us.”

Lardieri continually seeks our practical experiences to attach to the course. One idea she has already implemented is a requirement that students prepare a detailed notebook in which they organize a wide variety of information about disabilities, services in the community, training opportunities, laws and mandates, critical issues and other items of importance to systems of care. As follow-up to the class with a guest parent, students complete a survey asking about their what they experienced as they listened to the parent’s presentation.

## **Families Speak To Graduate Social Work Students**

On the campus of the University of Maine at Orono, parents are also sharing their experiences. For the past three years, Gail Weerbach, Associate Professor at the School of Social Work, invites parents from *Wings* to share their stories with her graduate level students every semester.

Weerbach attended a Portland State University *Building on Family Strengths* conference in 1992. It was at this conference that Weerbach heard families speak about the challenges of raising children with serious emotional disturbances, getting the system to respect them, and the kinds of

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<sup>25</sup> Interview, May 1, 1998.



system changes needed for providers to work with parents as partners. This was a key experience for Weerbach because it provoked her to do a good self examination. "I could look back over my career and realize things I had done in my work with parents that were not family friendly. This was an enlightening experience for me."<sup>26</sup>

After this experience, Weerbach invited parents from Wings to visit her classes. She asked them to respond to just one question. "What do students need to know about working with parents before they enter the workforce?" Weerbach noted how the students are always impressed by the strength the parent still has in spite of the long term challenge of caring for a child with special needs.

Weerbach explained that she no longer schedules anything after the parents leave the class. "The students experience the same type of thing I experienced in Portland. I have to help them process what they have just heard. I use [the students' own] comments to show them the stereotypical attitudes they have already 'bought into' about parents. I want the students to be able to say the same things to parents that they say when the parents leave the class."

Family Advocates who guest lecture in universities are sometimes not quite sure what kind of an impact they have. Nevertheless, they all value the opportunity to be able to speak to these students and have seen some positive effects in the community at a later time. One parent shared an experience about needing crisis intervention services from a local agency. The person assigned to help her family remembered her from speaking in a class at the University of Maine at Orono. The intervention went smoothly and the worker collaborated very well with the parent as a partner. She felt her guest lecture was validated by this experience.

Chris Parsons, currently a case manager for *Wings*, was a former student at the University of Maine at Orono. He recalled that hearing parents present in the class about the system of care changed his career choice. He was originally interested in policy work at the state level, but decided that the work he could do at Wings was an ideal combination where the latest and best policy was being put to practice.

The *Wings* Parent Advocate Specialists are working with both universities to expand the parent involvement in classes to more departments. Discussions include how to involve more parents in meaningful ways in the classroom, and how to offer a stipend or other fair compensation for their effort.

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<sup>26</sup> Interview April 30, 1998.

## **SUMMARY OF LEARNINGS ABOUT FAMILY AS FACULTY**

In order for the values and principle of the system of care to begin to take hold in communities seeking to restructure the way services and supports are provided to children with mental health needs and their families, it is necessary for all involved to be a continuous learning community. Administrators and line staff have to develop a new way of doing business and new kinds of relationships with the children and adults in the families they serve. Family members also need to learn how to work with this restructured system. Engaging family members as faculty is one practice that holds great promise for achieving this goal. The experiences of East Carolina University and the University of Maine (Orono and Machais campuses) offer the following lessons for others wishing to pursue a similar approach.

### **System Of Care Philosophy Needs To Be Taught In Colleges And Universities**

Those who have seen the rewards of system change agree that the philosophy, values, and principles of the system of care should be taught in colleges and universities all over the country. This can not be taught in theory alone. We have clearly learned that teaching the ins-and-outs of the system of care needs to be done by both faculty and system users—parents, youth, and other family members. When family members serve as faculty, students observe and experience a practical modeling of partnerships and mutual respect before they enter the service delivery work force.

Students exposed to family as faculty have realize how important it is to listen to parents and respect their expertise. The experience of the university programs we studied clearly indicates the practice of using family as faculty does make a lasting and far reaching difference in how services are provided in the community. Students exposed to family as faculty:

- had an opportunity to practice collaboration and hear first hand from families what does work and also why the system “as is” has not been very effective for their children;
- enter the workforce already knowing how to visit with families in their homes, work with family advocates, interact with family-run organizations, and attend family support groups, when invite; and
- started their professional work prepared and determined to be positively engaged parents.

The families they work with are feeling less blamed and more valued and increase their own level of involvement in decision making about their child and the provision of services and supports.

This role of family as faculty is enhancing the image of families who are raising children with mental health needs. Family members who serve as faculty are validated by the experience and develop their communication and advocacy skills to a high level. Because of the support from university based partners and the training they get from family-run organizations, families have achieved a high level of public recognition for their expertise and credibility for the stories they tell.

## **Patient and Persistent Leadership From The Top Is Essential**

State leadership and upper level project management investment in family inclusion was essential to the development and success of the Parent in Residence program. The State Department of Health and Human Services, Division of Mental Health, Developmental Disabilities and Substance Abuse Services played a key role in assuring that all components of the *PEN-PAL* grant included family members. The State Mental Health agency held the purse strings for the project, and they challenged everyone involved to find creative ways to involve families in the project as a whole and in the training of personnel in particular. At the same time, they realized that building the necessary relationships, designing the program, and getting acceptance in the university at large would take time.

Lenore Behar, Chief Section Head of Child and Family Services for the North Carolina Department of Health and Human Services, and Martha Kaufman, *PEN-PAL* Project Manager, actively searched for university faculty ready to be trail blazers and visionaries. They sought leaders who would welcome this new phenomenon of family involvement in their classes, develop and implement the model, and actively advocate for it within the higher education community. Their success is evidenced by the results of the Parent In Residence Program and the Social Sciences Training Consortium at East Carolina University.

## **Key Supports Facilitate the Role of Family as Faculty**

While the pioneering work is being done in just a few locations, we identified some specific support strategies that are essential to making the role of family as faculty work in any setting.

- *Contract with a local family-run organization.* Foremost is building a strong partnership between the university and a family-run organization that is well connected to the community. Contracting with a family-run organization insures a diverse pool of family members who are well prepared and supported to co-teach courses and present guest lectures. A family-run organization can also help prepare university faculty for this new relationship and facilitate the resolution of any problems or misunderstandings arising along the way.

- *Compensation.* Regardless of their level of education, family members who serve as faculty or guest lecturers must be paid a stipend commensurate with the contribution they make to the course. Payment must also be sufficient to cover any additional costs such as preparing course materials, child care, and transportation.
- *Clear expectations.* The university faculty and the families collaborating with them need to define the role of the parent in the classroom . Family-run organizations should be hired to train parents to fulfill the role. The role and expectations have to be clearly communicated to students as well. At East Carolina University, for example, students are told during the first class that family faculty will be grading them on the family-friendliness of their class participation.
- *Communication and planning.* The vocabularies and cultures of the two communities – family and university – are dramatically different and misunderstandings can easily occur because of this. A time for planning before the class and de-briefing after is also necessary. There has to be open and honest communication between the family members and university faculty as well as a determination to take equal responsibility for working out any problems that arise.

## **Evaluation Of Outcomes Improves Teaching And Gains Support For Family As Faculty**

The university settings we studied track the immediate and long range impact families who co-teach or guest lecture have on students and the work they do after graduation. Broader acceptance of the concept and role of family as faculty has resulted from the pioneers being able to objectively demonstrate to the higher education community that this promising practice better prepares students to enter the work force.

# Chapter IV

## Conclusion

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### WE HAVE COME A LONG WAY

The Child and Adolescent Service System Program (known widely as CASSP) was designed to assist states in improving services for children with serious emotional, behavioral, or mental disorders. It has also stimulated family participation in system reform initiatives. In less than two decades, the participation of parents and other family members has expanded from limited “patient” or “client” roles to a wide range of planning, decision making, and evaluation roles.<sup>1</sup>

Historically, many professionals viewed us as equally or more troubled than our children or as the “source of the child’s problems.” More often than not, parents, and mothers in particular, were treated as targets for change. Professionals have often required corroboration from other professionals before they would believe the information we provided. It was common for them to probe for problems such as child abuse, neglect, substance abuse, or marital difficulties, with little or no sensitivity to how we feel about this line of inquiry. They rarely involved us in developing treatment plans.<sup>2</sup> In addition, many respected psychologists, doctors, and service workers have blamed mothers for their children’s disabilities, problems, and other difficulties.<sup>3</sup> In the past, many professionals viewed us as neither knowledgeable about our children nor interested in caring for them.<sup>4</sup>

The simultaneous evolution of how families are viewed within the system of care and the development of new roles for family members mirrors the growing recognition that we, as family members, hold true expertise on our children. As we become more enabled to effectively care for our children we increasingly participate as fully franchised team members in the system of care. The stigmatizing myths about the inadequacy of parents are slowly disappearing.

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<sup>1</sup> Koroloff, N. M., Friesen, B. J., Reilly, L., Rinkin, J., (1996), p. 409.

<sup>2</sup> Collins & Collins, 1990; Parent-Professional Relationships in the Treatment of Seriously Emotionally Disturbed Children and Adolescents. *Social Work*, 35 (6), pp. 522-527; Koroloff, Friesen, Reilly, & Rinkin, 1996.

<sup>3</sup> Caplan, P. J. & Hall-McCorquadale, I. (1985). Mother-blaming in Major Clinical Journals. *American Journal of Orthopsychiatry*, 55, pp. 345-353.

<sup>4</sup> Collins, B. & Collins, T. (November 1990).

Systems of care in some communities recognize us as true partners in the process of caring for our children. Professionals are beginning to seek out and rely on our expertise. We are serving in more roles than ever before where we capitalize on our experiences as family members sharing our unique understanding of our children and their needs. We are a real resource and invaluable assets to successful systems of care.

The implementation of a system of care rests on the vested interest that each agency takes in collaborating with families and other agencies and approaching the task as a team effort. The process of establishing an effective system of care requires a major overhaul of existing infrastructures and innovative approaches to problem solving to effectively organize and deliver services and supports for children with mental health needs and their families. There will always be some who feel threatened by such extensive change and will work to maintain the status quo. Systems of care offer an opportunity to bring practitioners and families together. Unfortunately, there is still a long way to go.

## **CHALLENGES TO INVOLVING FAMILIES IN SYSTEMS OF CARE STILL ABOUND**

The majority of families raising a child with an emotional or behavioral disorder still face fragmented or categorical service systems offering a limited array of services. They receive very little support in the complex task of negotiating the array of available services. Furthermore, many professionals still fail to treat us with respect and still tend to blame us for our children's problems. For substantial numbers of our children outcomes are still very poor. We grow weary of the isolation and stress that we encounter daily. For systems of care to actualize the values of family involvement they must address four key issues.

### **Information**

For the most part, families do not have a good working knowledge about how state policy is established and how established state policy influences policy development and program design at the community level. This includes knowing about the organizational structure of key state agencies, how they relate to local entities, the names of key decisions makers and how to contact them, as well as understanding budgets and how funding priorities are established. We also do not know about all the resources that exist or what kinds of service options can be developed. We usually do not have access to the latest technology or research. It is commonplace for families to get their information about mental health from the public media or the experiences of other family members and friends.

Systems of care must consciously and deliberately share information equally with families and make an effort to insure that they understand it and are prepared to use it to make informed decisions for their children and the system as a whole.

## **Equity**

The system does not support family members the same way it supports professionals. Parents, usually mothers, are expected to maintain their child at home, obtain needed services, and monitor the well being of the rest of the family without the kind of support and resources that would be provided to a professional (such as a foster parent) given the same task. Family members who participate on policy making groups pay for the privilege (e.g., lost wages or vacation time, cost of travel or related meeting expenses, respite or child care costs), whereas professionals are paid to participate in the same activities and events. The system's "9 to 5" schedule for client evaluations, individual service planning meetings, and service delivery usually conflict with the "working hours" of family members, excluding them from providing input or getting involved in service planning and delivery. Systems of care must consciously and deliberately establish and implement policies and practices that level the playing field and make it feasible for family members to get involved.

## **Isolation**

One voice is not powerful enough. We are out-gunned and overwhelmed by the number of professionals who sit around the table. This is true for both the development of policy and individual service planning. Professionals on a team or at a policy meeting usually have worked together on many cases or issues and know each other well. The intimacy they share is evident in the ease with which they interact before the meeting, banter among themselves, and their "inside jokes." It can be very clear to us that we do not belong and, consequently, we feel intimidated by the atmosphere at meetings, as well as the expertise surrounding us. Systems of care must consciously and deliberately build and provide ongoing support for a cadre of family members who can represent the diversity of the community yet speak with a unified voice on behalf of all the children and families in the community.

## **Dependence**

Family members who rely on the public system for essential services are not likely to openly criticize that system no matter how dissatisfied or frustrated we are. We, as families of children with emotional or behavior disorders, are so desperately in need of help and support that we will accept anything offered even if it is not what we really want or need because we fear being turned away by

or being judged by professionals. Experience teaches us that to reject an offered service or ask for an alternative is to be judged as uncooperative, unrealistic, or ungrateful and we are likely to be treated (or mistreated) accordingly. Systems of care must consciously and deliberately establish a safe environment for family leaders who do come forth, eliminate the possibility of retaliation, and provide support for any family experiencing repercussions for being honest about the strengths and weaknesses of the providers or agencies in the community.

As the system of care gradually takes hold throughout the country, family members, policy makers, researchers, and practitioners need to consider how to make these system changes endure. We all need to figure out how to incorporate change without stifling the creativity and flexibility of the family-driven system we are trying to implement. No stakeholder group can do this alone. Broad-based coalitions and collaborations that include a diversity of community perspectives have to be formed. Every policy and practice from eligibility to funding, from training to personnel evaluation, from staffing and hours to outreach and service locations must be held up to scrutiny. The question to ask is whether or not each policy or practice facilitates or inhibits the efficient delivery of a single plan for each child and family that encompasses all the services and supports they need to: raise their child safely at home; enable their child to attend school and make good academic progress towards a diploma; engage all family members in satisfying and productive community activities (including a spiritual community if they so choose); and enjoy healthy, strong and supportive relationships within the family and with others. Any policy or procedure that fails this test is inherently flawed and must be revised or discarded.

## **NEW ROLES FOR FAMILIES HOLD PROMISE FOR ELIMINATING BARRIERS TO FAMILY INVOLVEMENT**

The two roles described in this paper offer great promise in lifting the burden and eliminating these barriers to full family involvement. The role of family as faculty clearly has begun to influence the way the system of care functions by preparing the work force in an entirely new way—one that is family-friendly and collaborative and embodies the values and principles of the system of care. These new workers come to the system of care prepared to work with families as partners. System of care facilitators are changing the relationship families have to the service system at its most basic level. They work both within and outside of the formal provider agencies in their communities. They help both families and staff collaboratively plan services and supports that truly are built on family strengths and creatively and effectively address the mental health needs of children, youth, and families in ways that are congruent with their cultural values and spiritual beliefs.



Building and sustaining effective systems of care for children with mental health needs and their families depends, in large part, on the individual people who work in or with the myriad components of such systems. Family members who work as system of care facilitators and family faculty are stimulating behavioral change in their co-workers and development of family-friendly policies and procedures within the provider agencies in their communities. They are also changing themselves, developing new skills and confidence in their ability lead and teach others. Family members who serve in these roles, and many of the families whose lives their work has touched, are better informed, treated as equals, less isolated, and more independent than they have ever been before.

The challenge is for full family involvement in systems of care to become the rule rather than the exception. As family members, we are confident we will continue to gain a greater voice in caring for our children. We know that we can make our involvement and active participation in the system of care part of 'the way things are done.' Change does not occur overnight, but we hope that this initial description of families as system of care facilitators and faculty training the workforce for systems of care will stimulate others to explore and develop these (and other) roles further and that, consequently, greater number of children with mental health needs and their families will reap the benefits of systems of care.



# References

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- Adams, J., Biss, C., Burrell-Mohammad, V., Meyers, J., & Slaton, E. (November 14, 1997) *Family-Professional Relationships: Moving Forward Together*. National Peer Technical Assistance Network.
- Bailey, D. B., Jr., Simeonsson, R. J., Yoder, D. E., & Huntington, G. S. (September 1990). Preparing Professionals to Serve infants and Toddlers with Handicaps and Their Families: An Integrative Analysis Across Eight Disciplines. *Exceptional Children*, 57 (1), pp. 26-35.
- Bradley, A. (November 12, 1997). Teacher Training Ignores Students' Families, Study Finds. *Education Week on the Web*. [Http://www.edweek.org/ew/vol-17/12\\_family.h17](http://www.edweek.org/ew/vol-17/12_family.h17).
- Bruner, C. (1991) *Thinking Collaboratively: Ten Questions and Answers to Help Policy Makers Improve Children's Services*. Washington, DC: Education and Human Services Consortium.
- Bruns, E. (October 1997). *Impact On Respite Care Services On Children Experiencing Emotional And Behavioral Problems And Their Families*. (Dissertation) University of Vermont.
- Bryant-Comstock, S., Huff, B., & VanDenBerg, J. (1996). The Evolution Of The Family Advocacy Movement. In B. A. Stroul (Ed), *Children's Mental Health: Creating Systems of Care in a Changing Society*. Baltimore, MD: Paul H. Brookes Publishing Co., pp. 359-374.
- Caplan, P. J. & Hall-McCorquadale, I. (1985). Mother-Blaming In Major Clinical Journals. *American Journal of Orthopsychiatry*, 55, pp. 345-353.
- Caseau, D. L., Luckasson, R., & Kroth, R. (1994). Special Education Services For Girls With Serious Emotional Disturbance: A Case of Gender Bias? *Behavioral Disorders*, 20 (1), pp. 51-60.
- Cheney, D. & Osher, T.W. (1997). Collaborate with Families. *Journal of Emotional and Behavioral Disorders*, 5(1), pp. 36-44.
- Cole, R. with Poe, S. (1993). *Systems of Care for Children with Serious Emotional Disturbances and their Families: Partnerships for Care*. Washington, DC: Washington Business Club on Health and Mental Health Services Program for Youth.
- Collins, B. & Collins, T. (November 1990). Parent-Professional Relationships In The Treatment Of Seriously Emotionally Disturbed Children And Adolescents. *Social Work*, 35 (6), pp. 522-527.

- DeChillo, N. (Spring 1995). Empowering Families Whose Children Have Emotional Disorders. *Focal Point: A National Bulletin on Family Support and Children's Mental Health*. Jamaica, NY: Parent Resource Center of Queens.
- DeChillo, N., Koren, N., & Schultze, K. (October 1994). From Paternalism To Partnership: Family and Professional Collaboration In Children's Mental Health. *American Journal of Orthopsychology*, 64 (4), pp. 564-576.
- Dunkle, M. & Nash, M. (January 1989). Creating Effective Interagency Collaboratives. *Education Week*, 35 & 44.
- Evans, M., et al. (April 12, 1996). *Parent-Professional Collaboration in Research and Evaluation*. Presentation by the New York State Office of Mental Health.
- Evans, M., Armstrong, M., Dollard, N., Kuppinger, A., Huz, S. & Wood, V. (October 1994). Development and Evaluation of Treatment Foster Care and Family-Centered Intensive Case Management in New York. *Journal of Emotional and Behavioral Disorders*, 2 (4), pp. 228-239.
- Evans, M., Boothroyd, R. A., & Kuppinger, A. D. (February 1996). Preliminary Family Outcomes of a Field Experiment on Intensive In-Home Intervention For Children In Psychotic Crisis. Presented at the 9<sup>th</sup> Annual Research Conference on Children's Mental Health, Tampa, FL.
- Federation of Families for Children's Mental Health (1994). *Federation of Families for Children's Mental Health's Mission Statement*. Alexandria, VA: Federation of Families for Children's Mental Health.
- Ferguson, J. T. & Lindsay, S. A. (1986). The Respite Care Co-op Program: Professionally Guided Parent Self-Help. In C. Salisbury & J. Intagliata (Eds.), *Respite Care: Support for Persons with Developmental Disabilities and their Families*. Baltimore, MD: Paul H. Brookes Publishing Co.
- Friedman, R. M, Kutash, K., & Duchnowski, A. J. (1996). The Population of Concern: Defining the Issues. In B. A. Stroul (Ed.), *Children's Mental Health: Creating Systems of Care in a Changing Society* (pp. 69-96). Baltimore, MD: Paul H. Brookes Publishing Co.
- Friesen, B. J. & Huff, B. (1996). Family Perspectives on Systems of Care. In B. A. Stroul (Ed), *Children's Mental Health: Creating Systems of Care in a Changing Society* (pp. 41-67). Baltimore MD: Paul H. Brookes Publishing Co.
- Friesen, B. & Stephens, B. (December 6, 1996). *Expanded Family Roles In Children's Mental Health: Implications For Research and Practice*. Portland, OR: Research and Training Center on Family Support and Children's Mental Health.

- Friesen, B. & Stephens, B. (1998). Expanding Family Roles In The System of Care: Research and Practice. In M. H. Epstein, K. Kutash, & A. Duchnowski (Eds.), *Outcomes for Children and Youth with Behavioral and Emotional Disorders and their Families: Programs and Evaluation, Best Practices* (pp. 231-259), Austin, TX: Pro\*ed.
- Haynes, N. M., & Comer, J. P. (1996). Integrating Schools, Families, And Communities Through Successful School Reform: The School Development Program. *School Psychology Review*, 25 (4), pp. 501–506.
- Hunter, R. W. (June 1994). *Parents as Policy-Makers: A Handbook for Effective Participation*. Portland, OR: Families in Action Project and the Research and Training Center on Family Support and Children's Mental Health.
- Institute for Family-Centered Care (Spring 1994). *Advances in Family Centered Care*, 1 (1).
- Institute for Family-Centered Care (Fall 1994). *Advances in Family Centered Care*, 1 (2).
- Karp, N. (1992). *Collaborating with Families*. Prepared for the Virginia Department of Education.
- Karp, N. (1993). Building Collaborative Partnerships With Families: From Rhetoric To Reality. *Journal of Emotional and Behavioral Problems*, 1, p. 4.
- Karp, N. (1996). Individualized Wrap-Around Services For Children With Emotional, Behavioral, And Mental Disorders. In G. H. S. Singer, L. E. Powers, & A. L. Olson (Eds.), *Redefining Family Support: Innovations in Public-Private Partnerships* (pp. 291-309), Baltimore, MD: Paul H. Brookes Publishing Co.
- Knitzer, J. (1996). The Role Of Education in Systems of Care. In B. A. Stroul (Ed), *Children's Mental Health: Creating Systems of Care in a Changing Society*. Baltimore, MD: Paul H. Brookes Publishing Co., pp. 197-213.
- Knitzer, J. (1982). *Unclaimed Children: The Failure Of Public Responsibility To Children And Adolescents In Need Of Mental Health Services*. Washington, DC: Children's Defense Fund.
- Knitzer, J., Steinberg, Z., and Fleisch, B. (1993). *At the Schoolhouse Door: An Examination of Programs and Policies for Children with Behavioral and Emotional Problems*. New York, NY: Bank Street College of Education.
- Koppish, J. E. & Kirst, M W. (1993). Editor's introduction. *Education and Urban Society: An Independent Quarterly Journal Of Social Research With Implications For Public Policy*, 25 (2), pp. 123-128.
- Koroloff, N., Elliott, D., Koren, P., & Friesen, B. (October 1994). Connecting Low-income Families to Mental Health Services: The Role of the Family Associate. *Journal of Emotional and Behavioral Disorders*, 2 (4), pp. 240-246.

- Koroloff, N., Elliott, D., Koren, P., & Friesen, B. (January 1996). Linking Low-Income Families To Children's Mental Health Services: An Outcome Study. *Journal of Emotional and Behavioral Disorders*, 4 (1), pp. 2-11.
- Koroloff, N. & others (August 1990). *Statewide Parent Organization Demonstration Project*. Portland, OR: Portland State University, Research and Training Center on Family Support and Children's Mental Health.
- Koroloff, N. M., Friesen, B. J., Reilly, L., Rinkin, J. (1996). The Role Of Family Members In Systems Of Care. In B. A. Stroul (Ed), *Children's Mental Health: Creating Systems of Care in a Changing Society* (pp. 409-426), Baltimore, MD: Paul H. Brookes Publishing Co.
- Krauss, M. (February 1990). New Precedent In Family Policy: Individualized Family Service Plan. *Exceptional Children*, 56 (5), pp. 388-395.
- Kutash, K., Duchnowski, A. J., Sondheimer, D. L. (October 1994). Building The Research Base For Children's Mental Health Services. *Journal of Emotional and Behavioral Disorders*, 2 (4), pp. 194-197.
- Kutash, K. & Rivera, V. R. (1996). *What Works in Children's Mental Health Services? Uncovering Answers to Critical Questions*. Baltimore, MD: Paul H. Brookes Publishing Co.
- Lefley, H. P. (March 1989). Family Burden And Family Stigma In Major Mental Illness. *American Psychologist*, 44 (3), pp. 556-560.
- Lehman, C. M. (June 1, 1995). *Families Who Have Children With Emotional Or Behavioral Disabilities: Parent Perceptions Of The Effectiveness Of The Support Their Families Receive*. Report of a Study of Oregon Families. Monmouth, OR: Teaching Research Division, Western Oregon State College.
- Lichtenwalter, C., Bolerjack, M., & Edwards, J. (1997). Parents Are The Front Door In Family Court And Child Welfare: Developing Family Supports In The Juvenile Justice System. *Focal Point*, 11 (1), <http://www.rtc.pdx.edu/fp/spring97/front.htm>.
- Lourie, I. S., Katz-Leavy, J., & Stroul, B. A. (1996). Individualized Services In A System Of Care. In B. A. Stroul (Ed.), *Children's Mental Health: Creating Systems of Care in a Changing Society*. Baltimore, MD: Paul H. Brookes Publishing Co.
- Mannan, G., & Blackwell, J. (1992). Parent Involvement: Barriers And Opportunities. *Urban Review*, 24, pp. 219-226.
- Melaville, A. I., Blank, M. J., & Asayesh, G. (April 1993). *Together We Can: A Guide for Crafting a Profamily System of Education and Human Services*. Washington, DC: U.S. Department of Education, U.S. Department of Health and Human Services.

- McManus, M. C. & Friesen, B. J. (Summer 1989). Barriers To Accessing Services: Relinquishing Legal Custody As A Means Of Obtaining Services For Children With Serious Emotional Disabilities. *Focal Point*, 3 (3), pp. 1-5.
- Melaville, A. I. & Blank, M. J. (January 1991). *What it Takes: Interagency Partnerships to Connect Children and Families with Comprehensive Services*. Washington, DC: Education and Human Services Consortium.
- Michigan State Department of Public Health (September 1990). *Family Centered Care, Triennial Report 1986-1989*. Lansing, MI: Division of Services to Crippled Children/Children's Special Health Care Services.
- Minke, K. & Scott, M. (1993). The Development Of Individualized Family Service Plans: Roles For Parents And Staff. *The Journal of Special Education*, 27 (1), pp. 82-106.
- National Institute of Mental Health (1988). *The Child And Adolescent Service System Program: FY'88 Report 1*. Washington, DC: Child and Adolescent Service System Program, George Washington University Child Development Center.
- Quinn, K. & Cumblad, C. (April 1994). Services Providers' Perceptions Of Interagency Collaboration In Their Communities. *Journal of Emotional and Behavioral Disorders*, 2 (2), 109-116.
- Research and Training Center on Family Support and Children's Mental Health. (Fall 1991/Winter 1992). Parents As Policy Makers: Challenges For Collaboration. *Focal Point*, 6 (1).
- Research and Training Center on Family Support and Children's Mental Health (Winter/Spring 1993). Case Management for Families and Children. *Focal Point*, 7 (1).
- Riley, R. W. (September 1994). *Strong Families, Strong Schools: Building Community Partnerships for Learning, A Research Base for Family Involvement in Learning from the U.S. Department of Education*. Washington, DC: U.S. Department of Education.
- Rivera, V. R. & Kutash, K. (1994). *Components Of A System Of Care: What Does the Research Say?* Tampa, FL: University of South Florida, Florida Mental Health Institute, Research and Training Center for Children's Mental Health.
- Skiba, R., Polsgrove, L., & Nasstom, K. (1996). *Developing a System of Care: Interagency Collaboration for Students with Emotional/Behavioral Disorders*. United States of America: The Council for Children with Behavioral Disorders.
- Shartrand, A. M., Weiss, H. B., Kreider, H. M., & Lopez, M. E. (1997). *New Skills for New Schools: Preparing Teachers in Family Involvement*. Cambridge, MA: Harvard Family Research Project, Harvard Graduate School of Education.



- Singh, N. N. (1995). In Search Of Unity: Some Thoughts On Family-Professional Relationships In Service Delivery Systems. *Journal of Child and Family Studies*, 4 (1), p. 1.
- Smith, C. R. (February 1997). Advocacy For Students With Emotional And Behavioral Disorders: One Call For Redirected Efforts. *Behavioral Disorders*, 22(2), pp. 96-105.
- Stroul, B. A. (Ed.) (1996). *Children's Mental Health: Creating Systems of Care in a Changing Society*. Baltimore, MD: Paul H. Brookes Publishing Co.
- Stroul, B. A. (September 1993). *Systems of Care for Children and Adolescents with Severe Emotional Disturbances: What are the Results?* Washington, DC: Georgetown University Child Development Center, CASSP Technical Assistance Center.
- Stroul, B. A. & Friedman, R. M. (1986). *A System of Care for Children and Youth with Severe Emotional Disturbances*. (Revised edition). Washington, DC: Georgetown University Child Development Center, CASSP Technical Assistance Center.
- Stroul, B. A., Friedman, R. M., Hernandez, M., Roebuck, L., Lourie, I. S., & Koyanagi, C. (1996). Systems of Care in the Future. In B. A. Stroul (Ed.), *Children's Mental Health: Creating Systems of Care in a Changing Society* (pp. 591-612), Baltimore, MD: Paul H. Brookes Publishing Co.
- Swan, W. W. & Morgan, J. L. (1993). *Collaborating for Comprehensive Services for Young Children and their Families: The Local Interagency Coordinating Council*. Baltimore, MD: Paul H. Brookes Publishing Co.
- Tannen, N. (April 1996). *Families at the Center of the Development of a System of Care*. Washington, DC: National Technical Assistance Center for Children's Mental Health.
- Thomas, N., & Friesen, B. (1990). *Next Steps: A National Family Agenda For Children Who Have Emotional Disorders – Conference Proceedings*. Research and Training Center on Family Support and Children's Mental Health, Portland, OR: Portland State University.
- Timm, M. A. (November 1993). The Regional Intervention Program: Family Treatment By Family Members. *Behavioral Disorders*, 19 (1), pp. 34-43.
- Turnball, A. P. & Ruef, M. (1997). Family Perspectives On Inclusive Lifestyles For People With Problem Behavior. *Exceptional Children*, 63 (2).
- Tyack, D. and Cuban, L. (1995). *Tinkering Toward Utopia: A Century of Public School Reform*. Cambridge, MA: Harvard University Press.
- Wagner, M., Newman, L., D'Amico, R., Jay, E., Butler-Malin, P., Marder, C., Cox, R. (1991). *Youth With Disabilities: How Are They Doing?* Palo Alto, CA: SRI.



# **APPENDICES**



# Appendix A

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## VALUES AND PRINCIPLES FOR THE SYSTEM OF CARE<sup>1</sup>

### CORE VALUES

1. The system of care should be child centered and family focused, with the needs of the child and family dictating the types and mix of services provided.
2. The system of care should be community based, with the locus of services as well as management and decision making responsibility resting at the community level.
3. The system of care should be culturally competent, with agencies, programs, and services that are responsive to the cultural, racial, and ethnic differences of the populations they serve.

### GUIDING PRINCIPLES

1. Children with emotional disturbances should have access to a comprehensive array of services that address the child's physical, emotional, social, and educational needs.
2. Children with emotional disturbances should receive individualized services in accordance with the unique needs and potentials of each child and guided by an individualized service plan.
3. Children with emotional disturbances should receive services within the least restrictive, most normative environment that is clinically appropriate.
4. The families and surrogate families of children with emotional disturbances should be full participants in all aspects of the planning and delivery of services.
5. Children with emotional disturbances should receive services that are integrated, with linkages between child-serving agencies and programs and mechanisms for planning, developing, and coordinating services.
6. Children with emotional disturbances should be provided with case management or similar mechanisms to ensure that multiple services are delivered in a coordinated and therapeutic manner and that they can move through the system of services in accordance with their changing needs.
7. Early identification and intervention for children with emotional disturbances should be promoted by the system of care in order to enhance the likelihood of positive outcomes.

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<sup>1</sup> Stroul & Friedman (1994), p. 18.

## **APPENDIX A (Continued)**

8. Children with emotional disturbances should be ensured smooth transitions to the adult service system as they reach maturity.
9. The rights of children with emotional disturbances should be protected, and effective advocacy efforts for children and youth with emotional disturbances should be promoted.
10. Children with emotional disturbances should receive services without regard to race, religion, national origin, sex, physical disability, or other characteristics, and services should be sensitive and responsive to cultural differences and special needs.

# Appendix B

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## PROTOCOL AND DATA CATCHER FOR ENVIRONMENTAL SCAN TELEPHONE INTERVIEW

- 1) Introduction
  - a) Explain that the Center for Mental Health Services is supporting the writing of a series of monographs to describe promising practices that have developed as a result of communities receiving grants from the Comprehensive Community Mental Health Services for Children and Their Families Program.
  - b) Explain that, as part of this overall effort, the Federation is writing about new roles for families that have evolved from the system of care grants.
  - c) Explain that you are a member of the writing team for this document.
  - d) Ask if this is a convenient time for a 15 minute conversation about the roles families have at their site. If not, schedule another time.
  - e) Explain that you will be taking notes. [You can use the attached format if it helps you organize the information. Use a second sheet if there is more than one new role to describe at a site.]
  
- 2) Suggested questions to ask
  - a) What kinds of roles family members have developed in the site? [If the answer is none, thank them and skip the rest of the interview.]
  - b) Are there written materials describing these roles?
  - c) How these have evolved (how well developed are they)?
  - d) What impact have these new roles had on families raising children with mental health problems?
  - e) What impact have these new roles had on agencies or providers working with families raising children with mental health problems?
  - f) Is there anything that documents or measures this impact?
  - g) Would families and project staff at the site welcome being highlighted in our writing? How would they feel about a site visit from our writing team?
  
- 3) Conclusion
  - a) Thank them for their time and thoughts.
  - b) Explain that the writing team will be comparing notes and making decisions about which roles to describe and which sites to visit by the end of January.
  - c) Explain that they may hear from us again about being on a conference call with sites experiencing similar new roles.

## APPENDIX B (Continued)

### DATA INSTRUMENTATION

Person Interviewed: \_\_\_\_\_ Date: \_\_\_\_\_

Site Name/Location: \_\_\_\_\_

NEW ROLE FOR FAMILY MEMBERS – Title of role	
Written descriptions exist	<input type="checkbox"/> yes <input type="checkbox"/> no
Evolution/history	
Impact on families	
Impact on system	
Documentation of impact	
OK to write about this	<input type="checkbox"/> yes <input type="checkbox"/> no
OK to come and visit	<input type="checkbox"/> yes <input type="checkbox"/> no

# Appendix C

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## **LETTER OF AGREEMENT FROM ILLINOIS LETTER OF AGREEMENT PROJECT YEAR THREE**

The following reflects the agreement between **Community Family Services and Mental Health Center (CFS & MHC)** and the **Illinois Federation of Families (IFF)** for services to be provided to the federal grant project, Community Wraparound Initiative, (CWI) including the IFS Supplemental in LANs 57 & 60. CFS & MHC is contracting with IFF to provide the following:

1. IFF will provide the project with Parent Resource Developers (PRDs). The number of Parent Resource Developers will be determined based on the number of FTEs in the CWI and IFS budgets. For Project Year Three, 4 part-time (20 hrs/week) PRDs will be assigned to the CWI grant, with an additional 2 part-time positions (20 hrs/week) for the Educational Project. The IFS Supplemental will involve 2 part-time positions (20 hrs/week). If openings occur, the CWI ProPromising Practices in Children's Mental Health Director and the IFF Director will determine whether positions should become full-time.
2. IFF will provide all necessary accounting oversight. CWI Team Leaders will provide IFF with timesheets for all Parent Resource Developers on a biweekly basis. IFF will formulate bills and submit them directly to CFS on a monthly basis. IFF will provide the CWI Administrative Assistant with copies of timesheets and expense reports. Charges will include hours worked, travel and expenses incurred for services provided as well as administrative fees. The CWI Administrative Assistant will manage a separate policy cash account for the purpose of parent support group meeting expenses.
3. IFF will provide necessary personnel oversight. This will include participation in selection of candidates for positions with CWI as well as separate evaluation of Parent Resource Developers' performance as per the policies and procedures of IFF. Collateral information-sharing will occur between CWI and IFF to provide data for evaluations and performance enhancement recommendations. All IFF personnel, including CWI Parent Resource Developers, will maintain the standards set by the IFF personnel policies. In Project Year Three, direct supervision of the PRDs will be provided by the CWI Team Leaders at the various sites where the PRDs are situated. The thrust of activity during this year will be aimed at integration with IFF providing transitional, supplementary support for the PRDs in this process. During the transition period (anticipated to include the first quarter of the grant period), the IFF Director will provide (anticipated to include the first quarter of the grant period), the IFF Director will provide supervision aimed at developing the PRDs as integrated team members.

## **APPENDIX C (Continued)**

4. All holidays, vacations and compensatory time will be in accordance with the personnel practices of IFF.
5. IFF will maintain professional liability and workman's compensation insurance and will furnish CFS & MHC with copies of these policies and/or any notifications of status change which may effect employees.
6. Open positions will be posted at IFF.
7. Candidates for Parent Resource Developer positions will complete all hiring requirements for IFF prior to assignment and the first day of paid employment. CWI will provide IFF with job descriptions and statements of exception to job descriptions prior to the hiring of any candidate. The job descriptions will include a delineation of tasks and assignments.

CFS & MHC will provide the following:

1. CFS & MHC will reimburse IFF according to the terms specified in ***Addendum One: Reimbursement Schedule*** (see attached).
2. CFS & MHC will provide immediate supervision of staff by the CWI Team Leaders who work under the direction of the agency Clinical Directors or Emotional and Behavioral Disorders Network Coordinator. The CWI Project Director is responsible for evaluation of the letter of agreement and coordination of revisions between the CFS & MHC and IFF.
3. CFS & MHC will provide space at the CWI office or other offices in the community for Parent Resource Developers as needed.

CFS & MHC and IFF, through CWI Project Director and the IFF Director will communicate at least monthly to coordinate the relationship between CWI and IFF and to promote contract management and planning. The IFF Director or her designee will participate weekly on the CWI Parent Resource Developers Planning Team and on the CWI Program Refinement Team.

This letter of agreement shall become effective on October 1, 1996. This letter of agreement will be reviewed in August 1997 when approval is secured for the next year of the project.

Should funding for the grant be discontinued, CFS & MHC will notify IFF and provide a two-week notice to terminate services. Either party in this agreement may terminate participation; a 30-day notice to terminate must be given in this event. Any revisions or expansions will be set forth in writing as an addendum to this letter of agreement.



## APPENDIX C (Continued)

### Addendum One Letter of Agreement

### CFS&MHC and IFF 9.16.96

#### Reimbursement Schedule

**Base Salary** Base salaries are based on an hourly rate between \$12.50 and \$15.50 per hour.

Biweekly salary totals will be calculated as follows:

Staff person A \_\_\_\_\_ hours X \_\_\_\_\_ rate of pay = \_\_\_\_\_

Staff person B \_\_\_\_\_ hours X \_\_\_\_\_ rate of pay = \_\_\_\_\_

Staff person C \_\_\_\_\_ hours X \_\_\_\_\_ rate of pay = \_\_\_\_\_

Staff person D \_\_\_\_\_ hours X \_\_\_\_\_ rate of pay = \_\_\_\_\_

Staff person E \_\_\_\_\_ hours X \_\_\_\_\_ rate of pay = \_\_\_\_\_

Staff person F \_\_\_\_\_ hours X \_\_\_\_\_ rate of pay = \_\_\_\_\_

Total Base Pay = \_\_\_\_\_

Mileage (calculated at \$0.29 per mile) Total = \_\_\_\_\_

Actual cost of expenses incurred in providing services to CWI = \_\_\_\_\_

**Total Base Costs** = \_\_\_\_\_

**Taxes** A tax surcharge of 11% will be added to the **Total Base Costs**.

**Total Base Cost** \_\_\_\_\_ + 11% = \_\_\_\_\_

**Administrative Fees** An administrative fee of **\$750.00 per month** will be added to cover the cost of insurance, administrative overhead and bookkeeping.



# Appendix D

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## **POSITION DESCRIPTION FROM ILLINOIS FAMILY RESOURCE DEVELOPER**

(Revised November 11, 1996)

The position of Family Resource Developer is funded through a federal multi-year grant which is governed by the InterLAN Council represented by the State Departments of Mental Health and Children and Family Services, the Community Family Services Mental Health Center, Pro Care Center, Youth Outreach Services, LaGrange Area Department of Special Education, the Argo, Evergreen Park, Revis, and Orland Park Special Education Cooperative, the Proviso Area Educational Cooperative, the Illinois Federation of Families, and the 708 boards of Proviso and Lyons Townships. The purpose of the grant, including the supplemental, is to provide an integrated system of care for children with serious emotional disturbance and their families, utilizing a wraparound approach. Currently, the Agency of Hire for the Family Resource Developer position is the Illinois Federation of Families. Family Resource Developers work under the direct supervision of the Team Leaders and are housed in the Mental Health or School settings where the team is located. Additional support and skill development training is provided for Family Resource Developers as needed. Family Resource Developers work with family members, project staff and staff from existing programs within the participating agencies.

### **Position Description**

The Family Resource Developer encourages families to move toward self-advocacy in the attainment of their own, culturally-specific life goals for themselves and their children and helps them develop the skills to do so. In this regard, the Family Resource Developer works with each family involved in the initiative as part of its child and family team. As part of the intake process, the Family Resource Developer both gathers information regarding the family, its strengths and needs, as well as provides information which enables the family to make decisions in the child and family planning process and beyond. Throughout the work, the Family Resource Developer provides resource information and helps the family navigate through the processes of the education, mental health, juvenile justice and social services systems.

## **APPENDIX D (Continued)**

### **Qualifications**

It is desirable that the candidate have experience as a parent, foster parent, guardian of a child with or at risk of serious emotional disturbance. She/he must demonstrate good communication skills by being able to gather and share information and resources with parents and all members of the child and family team. Family Resource Developers need to be able to operate with a non-judgmental attitude while responding with empathy and clarity. The qualified candidate must also be able to encourage collaboration, use advocacy skills and have a knowledge of the systems of care in the community in which he/she is working. The ability to speak in front of a group or training skills is an asset to the position.

### **Responsibilities**

1. The role of the Family Resource Developer is critical to engaging families in the initiative, in explaining its purpose as well as the family's role, authority and responsibilities in the process. The Family Resource Developer works under the direction of the Team Leader and participates in the development and updating of the wraparound plan. Each family in the initiative is assigned to one of the Family Resource Developers who monitors the child and family teams from the parent perspective.
2. The Family Resource Developer assists the family in assessing its strengths, needs and goals. If requested, the Family Resource Developer may participate in the implementation of the crisis plan the family develops.
3. The Family Resource Developer locates resources for the families and may provide additional support when the family is very isolated and/or when the child and family team has not yet been developed.
4. The Family Resource Developer participates in the flex fund request process by providing the parent perspective as needed by the Flex Fund Committee so that the committee can better understand the request and its ramifications.
5. The Family Resource Developer participates in facilitating and coordinating the initiative parent support groups.

## **APPENDIX D (Continued)**

6. The Family Resource Developer assists the initiative staff in developing their skills in working with families with diverse backgrounds and in promoting a positive, non-judgmental atmosphere in interactions with families.
  
7. The Family Resource Developer is expected to participate in the following meetings, at a minimum:
  - Weekly Wrap Team Supervision (meetings with the Team Leaders/Team Teacher and the Wrap Facilitators);
  - Monthly Community Wraparound Initiative (CWI) and Illinois Federation of Families (IFF) Meetings (with the CWI Project Director and IFF Director);
  - Monthly Total Wraparound Network Meetings (formerly the Total Team Meetings);
  - Technical Assistance Training to identify systems issues.
  
8. Other duties as needed, i.e., developing the parent newsletter, special assignments, cultural diversity training for system of care staff, etc. [NOTE: When special activities are assigned, other duties/assignments will be adjusted and/or additional hours will be provided].



# Appendix E

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## **SAMPLE OF RHODE ISLAND CONTRACT BETWEEN DEPARTMENT OF CHILDREN, YOUTH, AND FAMILIES (DCYF) & COMMUNITY MENTAL HEALTH CENTER**

### **Addendum One Program Narrative - LCC Contract**

#### **Relationship Between the Fiscal Agent & the LCC**

The fiscal Agent and the LCC will create a mutual partnership to enhance, maintain and support the development of a community based Children's Mental Health system of Care in its designated catchment area.

The LCC is a voluntary coalition of Parents, Educators, children's Mental Health and child Family Service Providers, State Agencies and interested community individuals gathered to effect community based solutions to the troubles experienced by children and youths with Serious Emotional Disturbance (SED). The primary goal of the relationship between the LCC and the Fiscal Agent shall be facilitation of such community based efforts.

By serving as the Fiscal Agent, that agency expresses a commitment to supporting both the specifics of the contract that follows and the spirit and process embodied in the development of the Children's Mental Health System of Care. The placing of this contract with the Fiscal Agent is an acknowledgement of the contribution of time, resources and concerned effort which have been volunteered on behalf of the children of the State of Rhode Island.

#### **Overall Responsibilities of the Fiscal Agent**

- A. Support of the LCC: The Fiscal Agent as a Partner in supporting the capacity building of the Local System of Care will participate and support the LCC in its organizational development necessary to facilitate its network and performing its responsibilities.
  - 1. Monitoring of LCC Budget and Budget Reports:

The Fiscal Agent will support the LCC in managing an operation budget to facilitate all council activities.

## **APPENDIX E (Continued)**

The LCC budget must include the following items:

- a. salary, fringe benefits, in-state travel and supervisory costs for a minimum of one full-time equivalent Family Service coordinator;
  - b. salary and fringe benefits for an administrative assistance (secretarial support positions, if identified as necessary by the LCC);
  - c. parental stipends;
  - d. funds for the provision of wraparound therapeutic recreation and respite services;
2. The fiscal Agent and the LCC will develop procedures together for the Council to request payment for allocated budget items and maintain a cost center/fiscal reporting mechanism for the LCC budget.
  3. The fiscal Agent shall prepare and disseminate to the LCC membership monthly financial reports which indicate the amount of funds spent or encumbered from the budget. Expenditure for Wraparound, Therapeutic Recreation and Respite Services must reported by service category.
- B. Maintenance of the Family Service Coordinator Position
1. The Fiscal Agent shall hire, in accordance with LCC policies, and provide supervision for a Family Service Coordinator for the LCC using the following guidelines:
    - a. The Fiscal Agent will employ at a minimum: One full-time Family Service coordinator or two part-time Family Service Coordinators to be employed by the Fiscal Agent and assigned to the Local Coordinating Council.
    - b. The Family Service coordinator position is a non-clinical position.
    - c. As part of the Children's Mental Health System of Care, Family service Coordinators shall be parents of special needs children and shall have experience in special education and children's mental health such as gained by parenting and advocating for their child or adolescents.
    - d. The Fiscal Agent shall provide supervision for the position of Family Service coordinator which will be funded through the LCC budget. Supervision will be provided by an individual with a Master's Degree in a Children's Mental Health related field, who has experience supervision staff. Supervision should occur for no less than 1 hour per week. The Supervision must coordinate supervision with the LCC.
    - e. The Family Service Coordinator shall report to the supervisor assigned by the Fiscal Agent and be professionally responsible to the Fiscal Agent.
    - f. Out of state travel and supervision of the Family Service Coordinator will be fiscally supported by the LCC budget.
  2. The Fiscal Agent shall assure that the Family Service coordinator will carry out the following tasks in the Interagency Case Review process:



## **APPENDIX E (Continued)**

- a. meeting with families, preferably in their home, prior to the initial case review meeting to offer support and an opportunity to communicate effectively about the philosophy and process of the case review service planning;
  - b. scheduling case review meetings;
  - c. coordinating and scheduling appropriate participants to attend the case review meetings;
  - d. support and advocating for family needs;
  - e. documenting the confidentiality of client related information (e.g. release form);
  - f. completing and maintaining *REACH RI* Evaluation forms as required by Project Evaluator;
  - g. following up with case review team members on their assigned tasks resulting from the case review service plan; and
  - h. working with families, parent organizations and related service providers to disseminate information about the Children's Mental Health System of Care, the LCC, the interagency case review process, and pertinent children's mental health issues.
3. All identified duties must clearly be non-clinical in nature and should exclude writing Early Periodic, Screening, Diagnosis, and Treatment plans, clinical intake, evaluations, assessments and diagnoses, medication monitoring, emergency decision making, a secretarial duties.

### **Local Coordinating Council Responsibilities**

The core concept of the Local Children's Mental Health System of Care process is the inclusive nature of the group effort. Neither youth, their parents, their school or their service providers can carry the effort alone. The narrative which follows is to establish a mechanism for managing, organizing and distributing the funding for activities, services and staff within the LCC.

### **Overall Responsibilities of the LCC**

- A. The LCC will develop and maintain a community based system of care according to the following principles and guidelines:
1. Development and Maintenance of the LCC Structure  
The LCC will develop a formal organizational structure which will include but not be limited to the following elements:
    - a. a written Mission Statement;
    - b. written Guiding Principles;
    - c. written Governing By-Laws;

## **APPENDIX E (Continued)**

- d. written goals and objectives which reflect the development of the local infrastructure and individual LCC activities;
- e. an identified Administrative Assistant (secretarial support position), if deemed necessary by the LCC, to provide service to the LCC, which will include but not be limited to:
  - staffing all meetings related to LCC;
  - coordinating distribution of information between LCC members and between the LCC and DCYF.
  - secretarial support to the Parent Services Coordinator and the LCC chairperson(s).
- f. memoranda of Agreement with member agencies committing member agencies to participation in the LCC process;
- g. a minimum of 8 regularly scheduled meetings shall occur which may be held in conjunction with other community-based networks or organizations;
- h. a mechanism to develop and disseminate informational material on the individual activities of the Council, the Interagency Case Review process and the overall Children's Mental Health System of Care;
- i. a minimum of 1 public relations informational meeting a year, which may be in conjunction with other informational meetings; and
- j. attendance of the LCC Chairpersons or their designee and the Family Service coordinator at the State Children's Mental Health Advisory Committee Meetings;

### **B. Develop and Maintain the LCC Membership:**

The LCC will develop and maintain the council Membership, which will include but not be limited to the following:

1. Families of children and youth with emotional/behavioral disorders;
2. Local Educational Authorities;
3. Local State Agencies;
4. Juvenile Corrections;
5. Representative from Community Agencies;
6. Representative from DCYF Regional office;
7. Representative of the ethnic and linguistic make-up of the community;
8. Early Intervention;
9. substance abuse service providers;
10. Family Support/Family Preservation;
11. Child Opportunity Zone representatives and other community groups;
12. Business, Civic Leaders, Legislators and Advocates;
13. Clergy;
14. Recreational Providers; and

## **APPENDIX E (Continued)**

15. A representative from the Fiscal Agent.

C. Coordination of the Family Service Coordinators' Activities:

The LCC and the identified supervisor of the Family Service Coordinator will orient each other to the expectations, responsibilities and parameters of the role of the Family Service Coordinator.

D. Coordination of Administrative Assistant (Secretarial Support):

Should the LCC employ an Administrative Assistance, the LCC will assist the Administrative Assistant (secretarial support position) in coordinating his/her role, which will include but not be limited to the following activities:

1. staffing all meetings related to LCC activities;
2. coordinating distribution of information between LCC members and between the LCC and DCYF; and
3. secretarial support to the Family Service Coordinator and the LCC chairperson(s).

E. Development and Maintenance of the Interagency Case Review System:

The LCC will identify participants and maintain a minimum of one Interagency Case Review Team. The Case Review Team will be comprised of representative of the LCC to include but not be limited to the following:

- Parent Advocates
- Family Service Coordinator
- Educators/Special Education
- Children's Mental Health and Child & Family Service Providers
- Representative of the Community Culture
- Interested LCC Representatives
- DCYF Representative

Duties and responsibilities of the Interagency Case Review Teams include but are not limited to the following:

1. The case review teams will be structured by assigning clearly defined roles and responsibilities for team members.
  - a. Said roles shall include but not be limited to:
    - Designated members of a case screening team, chair person(s), recorders of data for documentation, and a Family Service Coordinator/ or Case Manager to support and implement the Individual Service Plan (ISP).

## **APPENDIX E (Continued)**

2. The case review teams will develop and IDEAL child and family centered ISP jointly with the parents which will focus on and support the child's and family's strengths. The ISP will be documented on the Interagency Resource and Outcome Data forms which will be sent to the Project Evaluators.
  3. A Copy of the ISP will be given to the family, and if the family is active with DCYF, a copy will also be given to the DCYF social worker.
- F. Management and Policy Development for the use of designated funding for Wraparound Supports and Services, Therapeutic Recreation and Respite.
1. The LCC will develop policies and procedures for the expenditure of funding, approved by DCYF for implementation.
  2. The Fiscal Agent and the LCC will work together to develop a mechanism for Case Review Teams to access funding for services.
  3. The LCC will allocate Wraparound funds according to the following guidelines:
    - a. LCC's will develop protocols for the use of Wraparound funds;
    - b. Funds are to be used for non-traditional community based services that are not reimbursed through existing insurance or other categorical programs, (EPSDT, for example). Funds may be used to prevent imminent out of home placement (bridging services for families waiting for other sources of funding) for a period no longer than 6 weeks without additional review.
    - c. Funds are to be used to meet the unique services needs of a child and family as identified in an Individual Service Plan. These needs must be determined by the child and family.
    - d. Suggested uses of Wraparound include, but are not limited to the following:
      - sports equipment
      - lessons
      - transportation
      - supplies (art materials, for example)
      - emergency relief for basic needs of families'
      - mentorships
      - stipends to us in "quasi" work placements
      - financial support for volunteers of mentors (e.g., transportation, day care)
      - snacks
      - community excursions
      - school supplies
  4. The LCC will allocate Therapeutic Recreational funds according to the following guidelines:
    - a. LCCs will develop protocols for the use of Therapeutic Recreational funds.

## **APPENDIX E (Continued)**

- b. Services should be available to youth who are unable to access traditional recreational services without assistance.
  - c. Funds may be used to pay fees for existing recreational programs
  - d. Funds may be used to train staff at existing recreational programs for provision of services to eligible youth.
  - e. Funds may be used to pay for staff from other mental health or social service agencies to facilitate the youth's access to existing recreational programs.
  - f. Funds may be used to create new programs for eligible youth.
5. The LCC will allocate Respite funds according to the following guidelines:
- a. The LCC will develop protocols for the use of Respite as a specialized child care service to the family for the purpose of temporary relief of the caregivers and or the child.
  - b. Liability must be assumed by the Provider Agency for Respite support services. The Provider Agency must have an existing personnel system which assures that any individual who provides services is cleared for employment according to the Child Care Regulations promulgated by the Department of Children, Youth and Families.
  - c. Funds cannot be given directly to family members to purchase respite services personally. Allocation of respite services is to be planned through the Case Review process.
  - d. Respite services may be planned or provided on an emergency basis.
6. The LCC will allocate Parental Stipends according to the following guidelines:
- a. The LCC will develop protocols for the use of Parental Stipends;
  - b. Suggested use of Parental Stipends include, but are not limited to the following:
    - child Care
    - transportation
    - time attending meetings (supporting LCC activities, Case Review meetings)
- G. Project REACH RI Evaluation:  
The LCC will participate in all phases of the project evaluation.



# Appendix F

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## HAWAII FAMILIES AS ALLIES WORKSHOP EVALUATION FORM

Workshop Title

Workshop Site

Date

Length of Workshop (Hours)

1. Workshop participant is a: (check all that apply)

- a.  Family member/Caregiver
- b.  Professional/Service Provider
- c.  Other (please specify)

2. Demographics

- a. Age of child with emotional, mental or behavioral disorder
- b. Child's diagnosis Unknown
- c. Child's is eligible for Special Education by Dept. of Education  Yes  No
- d. Child's ethnicity
- e. Workshop participant's ethnicity

3. Workshop Evaluation

- |   | Excellent    | Poor           |
|---|--------------|----------------|
| a. Overall the workshop was                 | / / / / /    |                |
|   | Clear        | Vague          |
| b. The objectives of this workshop were     | / / / / /    |                |
|   | Meaningful   | Not Meaningful |
| c. Overall content of the workshop was      | / / / / /    |                |
|   | Very Helpful | Not Helpful    |
| d. Hands-on activities of the workshop were | / / / / /    |                |
|   | Very Useful  | Not Useful     |

## APPENDIX F (Continued)

### Evaluation Form

- |  |            |   |   |                |   |
|--|------------|---|---|----------------|---|
| e. Workshop materials and hand-outs were     | /          | / | / | /              | / |
|  | Effective  |   |   | Ineffective    |   |
| f. Workshop presenter(s) was/were            | /          | / | / | /              | / |
|  | Definitely |   |   | Definitely Not |   |
| g. I would recommend this workshop to others | /          | / | / | /              | / |

#### 4. My interests

- a. If needed, I am interested in becoming a parent partner/facilitator for families of children with emotional, mental and behavioral disorders. \_\_\_\_\_ Yes \_\_\_\_\_ No
- b. I am interested in joining a community support group. \_\_\_\_\_ Yes \_\_\_\_\_ No
- c. I am interested in knowing more about:
- emotional, mental and behavioral disorders (specify)
  - Department of Education evaluation procedures
  - Department of Education individualized educational programs (IEPs)
  - other issues (specify)

My name

Address

City, State, Zip

Home Phone

Work Phone

Comments and Suggestions:









