FEDERATION OF FAMILIES
for
CHILDREN'S MENTAL HEALTH

Testimony Before the Senate Committee on Governmental Affairs

Trina W. Osher, Coordinator of Policy & Research

July 15, 2003

Introduction

My name is Trina Osher. I am speaking on behalf of the Federation of Families for Children's Mental Health, the nation's only family-run organization focused exclusively on children with mental health needs and their families. Our 150 affiliates reach into communities as different from each other as Dover-Croft in Maine, San Diego in California, Warwick in Rhode Island, Topeka in Kansas, or the Pine Ridge Reservation. Our mission includes providing and sustaining leadership for family-run organizations and harnessing the passion of our members as a potent force for change so that our children and families can have a decent quality of life. On behalf of thousands of families I thank you for the opportunity to present testimony today.

It is seventeen years since my husband and I, desperate for help and with no other options, relinquished custody of our middle child - an adopted son who was only 10 years old – so he could go to a therapeutic, residential school in Connecticut. At the time, we faced the shame and blame alone. It was a devastating experience with life-long repercussions for every one in our family. It is appalling that families are still being asked to relinquish custody as we meet and here today. I am greatly encouraged by the attention this cruel social policy is now getting and hope that Congressional action will soon put and end to it.

General overview of the problem

The insufficient mental health coverage in private and public insurance plans (or not having any insurance) causes families to exhaust benefits before the mental health needs of their child are fully addressed. This is especially true when the child's condition is chronic and intensive intervention is periodically required.

1101 King Street, Suite 420 • Alexandria, VA 22314
(703) 684-7710 • Fax: (703) 836-1040
E-mail: ffcmh@ffcmh.org • Web: www.ffcmh.org

Families in such situations are then either urged or required to relinquish custody of their child to access funding that will pay for the essential mental health services so desperately needed. A recent study of 176 Maryland families showed that 62.5% of families whose children had 7-15 hospital visits in the two years prior to the study were told to relinquish custody.[1] How many of you would do this?

Children who are relinquished in order to get mental health services are deprived of their right to be connected to their family although their parents, siblings, and extended family should be a consistent and unconditional, lifelong source of emotional support. How would you feel if you could on see or talk with your child with the permission of a judge and under the watchful supervision of a social worker?

Concern for a child's or other's safety at home, at school, or in the community is a critical factor contributing to custody relinquishment. A family in Oregon, for example, sought help from Children's Services for their 16 year old son who was running away, not cooperating with his special education program, refusing to take medication, and living on the streets. Children's Services recommended residential treatment, went to court, obtained custody of the child, and placed him in a foster home from which he continued to run away.[2]

The practice of requiring parents, who have exhausted all other resources, to relinquish custody in order to obtain essential mental health services for their children must cease. But simply banning the practice is not sufficient to solve the problem. What is needed is a "combined approach that bans the practice while providing increased access to mental health treatment for children."[3]

---

[1] Karen Friedman and Jane Walker. *Relinquishing Custody: An Act of Desperation,* Maryland Coalition of Families for Children's Mental Health, Columbia, MD, 2002, (p. 33).

[2] Stephanie Limoncelli. *Custody Relinquishment Case Studies*. Oregon Family Support Network and the Research and Training Center on Family Support and Children's Mental Health. Portland, OR, 2003, (Case 1).

[3] Barbara Friesen, Mary Giliberti, Judith Katz-Leavy, Trina Osher, Michael Pullmann. Research in the Service of Policy Change: The "Custody Problem" in *Journal of Emotional and Behavioral Disorders,* Spring 2003, Vol. 11, No. 1, (p. 46).

Barriers FFCMH families face in trying to access needed mental health services and supports for our children.

Families of all kinds, are doing their very, very best to care for and get treatment for children whose mental health problems require intensive interventions and constant supervision or attention. But they can't get the help they need, when they need it, and how they need it. Continually being denied access to needed services exhausts and eventually defeats even the most resourceful and stable of families.

Our children with mental health problems need to have outlets for physical activity and social interaction with peers but they typically can't participate in after school activities or community recreational programs without some kind of support (like a mentor or coach to help them with social skills and behavioral control). There is no insurance program that will pay for such assistance. It is not considered a "medically necessary" service.

Our families who are raising children with mental health problems need a break from time to time. Unlike most parents who get a relative or babysitter to care for their children while they go out for dinner and a movie, there is no one who is willing to take care of our children who have challenging behavior. Few communities have a pool of respite care providers with training to serve this population – and it is more expensive than conventional care. It seems unfair that families who have a child with development disabilities or mental retardation have ready access to respite care that is subsidized with public funds and families whose child has mental health needs don't.

Schools are not effective for most children with mental health needs. Our children experience higher rates of suspension and drop out from school than typical children or children with other disabilities. According to the U. S. Department of Education, "About 50 percent of students identified under IDEA as having emotional and behavioral disorder drop out of school. Once they leave school, these students lack the social skills necessary to be successfully employed; they consequently suffer from low employment levels and poor work histories."[4]

[4] U. S. Department of Education. *Twenty-third Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act,* Washington, DC. 2001, (pp. xx-xi).

Many of our families have to give up working to care for a child who is repeatedly suspended from school, expelled from day care, or denied admission to after school programs. A Maryland parent has, "not been working for over a year since by son's diagnosis because he needs adult supervision at all times."[5]

Families bringing children home from hospitals or residential treatment programs need intensive and flexible transition services in their homes and in natural community settings for their children. Yet, most children return home without any follow-up simply because they have reached the maximum number of days for which insurance will pay. Typically, these children have a recurrence of acute problems because they were not stabilized in the first place and linkages with, schools, community-based mental health treatment services and home-based family supports were not made on discharge.

Children with mental health needs and their families need more options besides the typical 50 minute therapy hour – which is often scheduled at a time and place that is inconvenient or impossible to get to. Our children must have special help help to develop skills for social interaction or self-control that transfer into the natural school and community settings in which they are having trouble. But, mental health professionals don't work in these settings. We often need extra help and specialized strategies for managing to do normal family tasks like getting ready for school, fixing lunch, doing laundry, supervising homework, visiting relatives, shopping for groceries, or having a peaceful family supper together. Mostly we learn about these from our peers – if we are lucky enough to be connected with a Federation chapter or other family support group. Many parents cannot take advantage of these services when they exist with out getting help with transportation. And all of us need to find someone willing and able to care for our children in order to go to support groups. Ironically, as much as we may need and want the benefits of a support group, sometimes we are just too tired to go.

Deep budget cuts are making it even more difficult to get appropriate services. In Clackamas County, OR for example, since January 2003, the community mental health center has had to cut its children's staff from 19 to 4.

[5] Karen Friedman and Jane Walker. *Relinquishing Custody: An Act of Desperation,* Maryland Coalition of Families for Children's Mental Health, Columbia, MD, 2002, (p. 38).

The only children's service available now is group therapy;[6] which is clinically insufficient to address the wide range of children they are serving.

Our families often find themselves between a rock and a hard place trying to balance the conflicting mandates, requirements, and demands of several different services or systems. I recall one county-based meeting on my own child where we were confronted with case managers from four different systems who could not agree on what the problem was, which programs our son was eligible for, where we should go for help, or which agency was responsible for providing services. We asked to leave the room while they continued to debate amongst themselves and told we would get a letter from them in two weeks with their decision. Lack of common definitions, terminology, and eligibility criteria across systems and providers and the paucity of incentives for states and communities to develop effective community-based systems of care contribute significantly to the problem.

What federal and State governments can do to develop better "systems of care" to provide community-based mental health services and supports for children and their families.

Families need an array of service options, good information for deciding which services to choose, and a significant voice in determining where these will be provided. State and federal policies must make it possible for us to keep our children in their neighborhood and living with us - the family that will love and care for them as no one else ever will. This means being able to realistically choose a temporary out-of-home placement when needed to stabilize or resolve a crisis and to have ongoing access to a wide range of assistance, including at a minimum: home-based services and supports, culturally relevant spiritual healing, traditional clinical mental health treatments; and appropriate special education services necessary.

Congress should prohibit states from requiring parents to transfer legal custody of a child with a mental health problem for the sole purpose of obtaining necessary treatment, services, supports, or out-of-home placements or to enable the child to become eligible for Medicaid or access funding from any other federal source.

[6] Personal communication by phone with Theresa Rea July 8, 2003.

Congress should increase the appropriation for the state mental health block grants by 20% and designate all of these funds specifically for the development of family-driven support services and the expansion of effective community-based treatment services for children with mental health needs and their families.

Congress should establish and fund a long term higher education program to expand the pool of qualified professionals to serve children with mental health needs and their families in a manner that is consistent with family-driven practice and the values and principles of systems of care.

State agencies should be required to develop effective working interagency agreements that create the infrastructure necessary to insure coordination of services and braiding of funding streams from all child serving agencies so that children with mental health problems and their families have affordable and convenient access to a comprehensive array of family-driven supports and services and effective, culturally competent, community-based mental health treatment services. Such agreements should:

- ✓ encourage and allow the use of existing federal funds from all child serving agencies to pay for home-based supports and community-based services for children with mental health needs and their families to prevent or forestall temporary out-of-home placement when appropriate;
- ✓ require the use of existing federal funds from all child serving agencies to develop home-based supports and community-based treatment services to help families stay together and enable their children to graduate from school, enjoy the friendship of peers, and participate in community life; and
- ✓ require that families have voice and choice in decision making.