



Families Together
in New York State

Testimony on the Office of Mental Health Budget

February 14, 2012

Submitted to the
Joint Fiscal Committees of the New York State Legislature

The Honorable John A. DeFrancisco
Chairperson, Senate Finance Committee

and

The Honorable Herman D. Farrell, Jr.
Chairperson, Assembly Ways and Means Committee

Submitted by:
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My name is Paige Pierce. I am the Executive Director of Families Together in New York State, a family-run organization that represents families of children with social, emotional, behavioral and mental health needs. We represent thousands of families across New York State whose children have been and are involved in many systems including mental health, substance abuse, special education, child welfare and juvenile justice. Our board and staff are made up primarily of family members and youth who have been involved with the various children's systems. Our families include foster families, adoptive families and families headed by relatives.

I am also a parent. My twenty-year-old son, Emmet, was diagnosed with Asperger's Syndrome at the age of three, and we have been navigating the complex systems to find him the help he needs ever since.

I'm sure you've heard it before, but my son doesn't fit into our service system. He doesn't qualify for mental health services because his primary diagnosis is a developmental disability. He doesn't qualify for developmental disability services because his IQ is too high. He's in need of many services but eligible for none. He needs mental health services due to his anxiety. He needs special education services due to his unique learning abilities. And he needs transition services for employment, housing and independent living.

My family has been fortunate. Emmet has not yet found himself in need of alcohol or substance abuse services. He hasn't been involved in the court system. But avoiding these systems has been an ongoing challenge.

Emmet has challenges, but he also has many strengths and abilities. He is intelligent, courageous and hard working. He has a great sense of humor and many plans for the future. But my family is left wondering... how will he succeed? Where is there a place for Emmet? I often refer to him as a "man without a country."

Of small comfort is the fact that my family is not alone. There are over a half million children and youth in New York State who have a mental, behavioral or addiction disorder associated with significant functional impairment. Without access to appropriate services many of our children end up dropping out of school. Only 30% of children with social, emotional or behavioral disabilities graduate with their classmates. Thirty percent! Where are the other 70%? They may end up with repeated, expensive hospitalizations, possibly for attempting

suicide. Suicide is the third leading cause of death in New York for 15 to 24 year olds. Too many youth will develop serious addiction problems or end up in the juvenile justice system. It's estimated that 85% of youth in the juvenile justice system require mental health treatment. It's hard to imagine that there are any youth in the system that haven't had exposure to trauma or have had unidentified behavioral issues that resulted in them even being there in the first place.

It still happens in this state that families relinquish custody of their children, sometimes voluntarily, sometimes unknowingly, and sometimes forced, in order to receive mental health services in residential settings. It is devastating that a family is forced to relinquish custody of a child in order to get them the mental health services that they need. When community supports such as respite, family support and mental health services aren't available in the community, and when there is limited availability of residential mental health services, youth are sent to the child welfare system to access residential services. Unfortunately, this requires the family to give up custody of their child. And to make matters worse, there is no guarantee that they will even receive the needed help while in custody. I cannot imagine having to make the devastating decision to have to give my child up so he can get services.

We're hearing more stories of families relinquishing custody in recent months. Last month alone, our office received six calls to our helpline about families who have voluntarily relinquished custody in order to receive treatment for their child. One family called from the Lower Hudson Region, two families from the Capital Region, two families from the Finger Lakes Region, and one family from Buffalo. What is particularly worrisome is that we only hear a tiny portion of what is really happening in the communities. When I attend meetings around the state and ask if this is a problem, I always hear stories about custody relinquishment.

The cost to New York for children to end up in state custody is extreme. It is estimated that it costs over \$150,000 per child for a placement in a child welfare Residential Treatment Center and over \$250,000 for a juvenile justice placement. But more importantly, the emotional cost to the child and family can be devastating.

The state needs to support families in raising their children with special needs. Prompt access to appropriate community-based services enables children to stay in their home and with

their family while they receive appropriate services or treatment. This saves the state money and improves the quality of life for children, youth and their families.

Here's what families have told me:

"They took my child away from me and put her in foster care. They provided the foster parent with a case manager, with respite and with training on parenting a child with behavioral issues. Why didn't they have those kinds of supports and services for my family? That way we could have stayed together."

"They sent my son to residential placement three hours away. There weren't enough Waiver slots in our county for me to keep my son at home."

What Families Want

Families have maintained that the services that are most important to them are those that work across systems and provide flexibility to meet the needs of the whole family. Family support, respite, transportation and waiver services are the services that families say are the most helpful to keep their child at home and out of residential programs.

The Good News

The current Office of Mental Health (OMH) Budget does not cut funding to community-based services and provides for reinvestment of savings from the downsizing of mental health facilities into housing.

Families Together would like to thank OMH, the Governor, and all the other child-serving systems for their thoughtful planning for children's services over the last few years. Last year OMH exempted children, Family Support and Peer to Peer programs in the OMH budget from local cuts. These programs, as I have noted before, are the programs that most help families keep their children at home and in the community. We also applaud the commissioners of the nine child-serving agencies for signing on to the Children's Plan for "improving the Social and Emotional Well-Being of New York's Children and their Families." This plan supports less costly service options and wiser use of available resources, combined with the values of cross-systems planning and the full inclusion of family and youth voice in planning of services for each family, for each community and for the state as a whole.

Our Concerns

The delivery of mental health and children's services are undergoing tremendous changes. As Medicaid is transitioned to managed care and Behavioral Health Organizations (BHOs) for those in need of mental health services we are concerned that the flexible services and services that help the family as a whole may not fit easily into this new "health care" delivery system. We are concerned that children won't qualify for services and that many will fall through the cracks.

Why are we hearing more stories of custody relinquishment lately?

Have cuts to preventive services and educational programs caused families to look elsewhere for help?

Are families falling through the cracks?

We think so.

Again, when I'm out in the communities, I hear concern from Family-Run Peer to Peer Support programs that funding from the state and counties is more and more limited at the same time they are finding that more and more families are being referred to their programs.

The current changes to Medicaid and community programs provide much opportunity to reinvent services to be more family-focused, individualized and more flexible. The Medicaid Redesign Team developed a plan for a waiver for children's services which is inclusive of all who need help and expansive in the services that are available. We fully support this plan. But it's important that we maintain support of these small Peer-Run Family Support programs during this transition. No more children should fall through the cracks. These small peer-run programs have expertise to share with the BHOs and an ability to engage families in need.

Families Together's Policy Priorities for New York State

New York must support the use of cross-systems, cost-effective, preventive services for families to improve outcomes and prevent expensive residential placements.

- 1. Funding must be maintained for community services including peer-run, peer to peer family support, respite and the Home and Community Based Waiver.**

Families have identified these services as the ones that help them the most. Children's services must be exempt from budget cuts. The safety net must be maintained.

Families Together supports plans to expand the current Home and Community Based

Waiver into a Super Waiver that will provide a wider range of services and include more children and youth.

2. **Funding is needed for Cross-Systems Family Teams** in every county to help high need youth and their families. \$10 million should be invested to fund a Cross-Systems Coordinator and a Parent Partner in each county and borough of the state. This funding would be under the coordination of the New York State Council on Children and Families which convenes the Commissioners' Committee on Cross-Systems Services for Children and Youth with representation of family members and youth.
3. **Funding is needed to help Peer-Run Family Support Programs Credential Family Peer Advocates, collect data to evaluate their programs and transition to the new technology systems.** These small programs must be supported during the transition to Behavioral Health Organizations, Health Homes and the new waiver. \$2 million would be needed the first year and then \$300,000 each year for the next three years.
4. **Reinvestment:** Savings from the reduction of beds in the OMH budget; and from the downsizing of juvenile justice facilities in the Office of Children and Family Services (OCFS) budget, must be reinvested into community alternatives for youth. We urge the Legislature to give discretionary authority to the commissioners of OMH and OCFS in implementing this reinvestment plan. Additionally, some savings from the implementation of Medicaid Redesign in the Department of Health (DOH) budget should be reinvested into children's services in the community.

We must use this difficult financial time to transform the system of care for children with social, emotional and behavioral disabilities and their families into a truly cross-systems, youth and family centered, community-based system. The need to do business differently is clear and unmistakable.

Summary

There is agreement that community-based services are needed to keep children and youth out of expensive placements and that when they need to be in custody of the state they should transition as quickly as possible back to a permanent family placement with supports for the whole family. It is clear that our communities must have capacity to support children in their communities to prevent expensive residential placements and realize better results. Developing a full array of community-based services including children's mental health

services and family support is not only cost-effective but is more effective in treating children and limiting trauma to the child and family.

The commissioners of the child-serving agencies have clearly designed their budgets to make the best use of limited funds. Evident in its budgetary decisions, OMH has demonstrated the importance of children's services - but these services are sure to strain under the pressure of Clinic Restructuring, Medicaid Redesign, the downsizing of the juvenile justice facilities and recent funding cuts in preventive services. More is needed to ensure adequate community supports for youth and families.

We agree that coordination across agencies is the best way to move forward and make use of limited resources. The Commissioners' Committee on Cross-Systems Services for Children and Youth, made up of nine child-serving agency commissioners, must be maintained and relied upon as a resource in promoting a restructuring of children's services to coordinate agency resources at the state and local levels.

We look forward to working with the Legislature, the Office of Mental Health, the Office of Children and Family Services, the Council on Children and Families and all child-serving systems to ensure that families and youth are appropriately served in their communities and able to stay in their homes to the greatest possible extent.

If there is a single message I would want to leave with you today, it is that families have a greater vested interest and expertise to ensure the success of our children than any other stakeholder in our state. We are a strong, informed voice that can be helpful to you as you make decisions that will affect our children's lives. Please view us as a resource and as strong allies and partners.

Thank you.