

10



Families Together
in New York State

Testimony on the Office of Children and Family Services Budget

February 13, 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:
Paige Pierce
Executive Director
Families Together in New York State

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 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 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 that system that haven't had exposure to trauma or have had unidentified behavioral issues that resulted in them 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 New York State Office of Children and Family Services (OCFS) has implemented a number of initiatives over the past few years to help children in their care, or those who are at risk of being in their care, receive better access to a variety of services including the Bridges to Health (B2H) Waiver, the Family Assessment Response (FAR) program, Alternatives to Detention program and preventive services. Youth are being moved out of juvenile justice programs and back to their home communities.

OCFS Commissioner Gladys Carrión has been one of the leaders in the Commissioners' Committee on Cross-Systems Services for Children and Youth that includes the commissioners of the nine child-serving agencies. These commissioners have signed 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.

We applaud OCFS for its Supervision and Treatment Services Program for Juveniles (STSJP) Initiative and its Close to Home Initiative to return youth to their home communities and

closer to their families and natural supports. These initiatives offer local solutions to local problems allowing communities to take care of their own. So many communities are written off as “having no resources” when indeed they are brimming with a most valuable resource: their citizens. The parents who serve as Family Advocates, through their own life experiences, are so knowledgeable, and can help support and maintain children and families right in their own community. Shifting investment in facilities to investment in communities will create jobs and create capacity, harnessing this unique resource.

The STSJP and Close to Home Initiatives are both designed to make visitation accessible and allow families to continue to connect and bond with their child, making the transition home easier. Studies have shown that alternatives to detention programs have a significantly lower recidivism rate at residential facilities. This initiative is absolutely more cost effective and will meet the individual needs of children and youth. The Close to Home Initiative is being addressed in a well thought out way and should involve family members and communities in the planning.

Our concerns

The delivery of mental health and children’s services are undergoing tremendous changes. Many of these services are provided through OCFS and this can create an incentive for underfunded systems to move children into the custody of the state. 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 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 or wind up in OCFS custody.

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 concerns 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 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 the small preventive Peer-Run Family Support programs during this transition. These small peer-run programs have expertise to share in preventing unnecessary placements. No more children should fall through the cracks.

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 B2H Waiver.** Families have identified these services as the ones that help them the most. OCFS must help to support these programs and as youth are returned to their home community there must be funds available to help them transition to community services. There must be Peer Advocates and Family Peer Advocates to help support the family as they reunite. We are happy to report that, through the support of the Office of Mental Health (OMH), Families Together now credentials Family Peer Advocates, ensuring these advocates have training in peer to peer support.
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 meetings with representation of family members and youth.
3. **Reinvestment:** Savings from the downsizing of juvenile justice facilities in the OCFS budget and from the reduction of beds in the OMH budget, must be reinvested into community alternatives for youth. We urge the Legislature to give discretionary authority to the commissioners of OCFS and OMH 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 the 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 and their families 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.

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 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 Children and Family Services, the New York State 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 and youth 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.

FTNYS' Legislative Luncheon is tomorrow, Valentine's Day, in the Convention Center. You are all invited. This is an opportunity to meet with your constituents and hear directly from them. We have over 600 family members coming to have their voices heard. Our theme this year is "Listen Families for Change." Thank you.