

Fighting Stigma, Changing Fragmented Service Delivery and
Increasing Expectations to Ensure the Emotional Well Being, and
Academic Success of Children with Mental, Behavioral, Attention,
Social and Emotional Disorders in New York City

Testimony

On Family Support Programs Funded in the New York State Budget for
Individuals with Disabilities

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Before the

New York State Assembly Standing Committee On Mental Health

The Honorable Assemblymember Felix Ortix

Chairperson, Assembly Mental Health Committee



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Good day, I am Euphemia S. Adams, Executive Director of Families On the Move of New York City, Inc. (FOTM). FOTM is a citywide organization that works with and on behalf of families of children that have emotional, behavioral, and or mental health challenges in the five boroughs of New York City. We are the first family run, family driven organization to emerge out of the SAMSA System of care in New York City. The urban families and youth that we represent are currently involved in, or have had, multiple system involvement which includes mental health, juvenile justice, child welfare, special education, and or substance abuse services. In New York City alone, there are literally thousands of young people that receive mental health services on a weekly basis. Together with our network of members and service provider partners, we seek to improve systems of supports and services, connect families, inspire communities and influence public policy.

Thank you for this opportunity to come before you on behalf of the Family Support Community providing services to New York City families of children and youth with mental, social, emotional, attention and or behavior disorders. Whether one views national, state or municipal data, the information is uniformly troubling across most child serving systems, especially in today's economic climate. The few examples below are merely a glimpse of the trends spurring us to a different set of responses:

- Sixty-seven to 70% of youth in the juvenile justice system have a diagnosable mental health disorder
- Children and youth in military families have a higher rate of mental health problems, especially during their parents deployment
- Preschool children face expulsion rates three times higher than children in grades K-12, due in part to their social-emotional needs

- About 3 out of 10 youth expressing thoughts about suicide in the prior year receive mental health services
- In 2008, the rate of drug related arrests per 10,000 youth between the ages of 16-21 was 202.6 per 10,000 youth in New York State 2008 in New York State. In New York City this rate was 376.4 per 10,000 for the same age group
- In New York City between the years of 2006-2009 only 35.3 % of the special education students in grades 3-8 scored on levels 3+4 in English
- Again in New York City only 4.4% of the Special Education Students in the High School Cohort of 2007 graduated with a regular diploma and only 6.1% with an IEP diploma
- Although the prevalence of SED youth ages 9-17 in New York City is 111,963, only 9,610 were served and of the children 8 years old and below 2812 children were served.

There are many reforms designed to resolve and reverse these negative trends. They include: The Children's Plan, reform of the Rockefeller Drug Laws, the establishment of the Addictions Collaborative to Improve Outcomes for New York (ACTION) and many other across the states systems, including the educational reforms geared to increasing expectations and outcomes for students with severe disabilities graduation from our state's high schools. For many of the systems creating these reforms, including the municipal structures entrusted with implementation, the methods utilized to ensure the delivery of the services embellished in these plans, are ineffective in reaching the families that need them the most.

It is not that the intent of these reforms are flawed; they are based upon evidence based practice, sound research and documentation of positive outcomes. It is also not simply a matter of the problems with the

existing structures or methodology, even though these are significantly more challenging when there are changes in processes and a need to increase functional capacity. Most often, however, it is that the vehicle necessary for child serving systems to reach individual families is a large matrix of community based support. Only community based programs, and in particular family run organizations can increase family access to the reforms created to help them and their children. The need and support for these programs that are integral to implementing these reforms is too often underestimated. In most cases, implementing reforms in NYS is like planning a huge birthday party, wedding or other event. The system has hired a caterer, a venue, paid for the flowers, balloons and food and even hired an outstanding staff. There was just no money spent on buying and sending out invitations. So everything is beautifully in place for the event, but there are no guests, because they were not notified.

The second challenge in reverting these negative trends for members of the mental health community, remains the barriers created by the ever present, multiple manifestations of stigma. Stigma still impacts and limits family access to services, because many families still find it difficult to acknowledge that the source of their dear child's difficulty might be related to a mental illness. Stigma is not only fueled by cultural beliefs and commitments, but too often it is fertilized by a society that accepts, or at the very least minimizes the preliminary behaviors associated with bullying, hate, smoking, drinking, truancy and even behaviors associated with sexual activity. Until someone is hurt, too often the need for mental health intervention, across too many domains of our society, is dismissed or negated. When behaviors are identified in many systems, it does not mean that the students will get the services they need to address these behaviors, or, if they do, they may simultaneously lose access to other services that are the mainstay of their academic and/or social, emotional and lives.

The greatest hope for successfully providing services to change our dismal data profiles, increase access to quality care and combat the multiple sides of stigma, all really rest upon cross system implementation of comprehensive services based upon the strengths, interests and needs of the children and youth with social, emotional, mental and/or behavior disorders and their families. All systems and their reforms acknowledge and support the need for cross system collaboration; but few systems have the resources (time, staff etc.) to make it happen. When it does, when families sit with multiple providers to create a comprehensive plan of activities based upon a rich discussion with the family, what emerges is an array of doable services that all participants feel optimistic about and committed to implementing. You cannot have buy in from a family, if there is not enough buy in from the providers to support their attendance at these valuable meetings. Similarly, you cannot have buy in from a family regarding medication, if the decision to medicate a child is made by a nurse practitioner or even a psychiatrist that can only meet that child and make this tremendous decision in fifteen minutes, because of the constraints created by their case loads and insurance limitation.

So, what does all of this have to do with family support? The family support program directors, family and youth advocates are the primary mechanism to fight stigma, one family at a time as we support parents and help them to understand and accept their child's behaviors as sign of mental, attention or emotional malady. Family Run Organizations are the glue that holds cross system activity from the beginning through implementation and transition. And last, but not least, family support workers, not only invite families to the "parties" associated with reformative agendas, we pick them up and bring them there, so that they can have access and participate fully in all activities associated with a major reform.

In New York City the activities of family advocates encompass everything from system navigation through accompaniment to courts, schools, hospitals and doctor's offices, providing information and referrals regarding other life issues, such as identification snags, food needs etc., providing information about mental health services and programs like the mobile crisis team and information about medication through the clinical partners, and facilitating family networks and providing parenting classes.

To enhance and sustain this valuable work we recommend the following:

- Protect existing funding to all family run organizations and family support organizations to promote family driven, youth guided care to achieve the following:
 - Proliferation of true, strength based, cross systems family networks that are implemented by “true” family advocates with cross system experience
 - Creation of service strands that help the family to fully participate in care on an ongoing basis and to continue the treatment that their child needs
 - Continuation of first stop services for families that may be reluctant to go to mental health practitioners, therapists etc. due to stigma or cultural perceptions
 - Improvement of care coordination in, through and after all residential programs, including residential treatment centers and facilities, as well as community residences and home based treatment programs
 - Creation of bridges between early intervention programs and activities and the child serving systems, as well as mechanisms between the child serving and adult systems to facilitate positive transitions for adolescents

- Continuation of the establishment of partnerships with pediatricians and hospitals where children are treated to solidify the system of care and support sustainable services and treatment for children and youth
- Request each child serving system to dedicate resources to support the presence of family advocates to specifically focus on the implementation of that systems reform, while working with the other staff of each family run organization. Although many child serving systems have hired workers to work with families – they are first and foremost, not all parents of special need children, nor are they placed in an environment that allows them to work with families in ways that increase access and participation in programs that leads to the positive outcomes we seek. For example, juvenile justice, social service and education could contribute resources to support specific family advocates to work collaboratively with all of the providers involved with a child or youth. This would occur through a family support system that has trained family and youth advocates, enabling them to not only begin in the system where the child or youth is currently serviced or stuck, but also to pool resources to support collaborative funding and the concept of resources following the child. Ideally they could be employed by the family run organization working with families, pediatricians, hospitals, schools, courts and others to nurture the development of cross systems processes and to work with teams all ready established to address the trends we seek to reverse.
- Increase funding to allow family support organizations and family run organizations to hire youth advocates full time. Even though our youth advocates are often in school and work part time, the lines that fund them are for part time work only. No one can confront and resolve issues associated with the stigma experienced in our city’s youth better than a youth advocate. No one can help a young person maximize service options better than a young person who knows the system first hand. It is also important to establish a “Senior Youth Advocate” position to allow

seasoned advocates to help train younger advocates and thereby establish a continuum of peer advocacy.

- Establish a commission to examine the status of housing for families of children with serious emotional issues. Such a commission could examine if there is a relationship between the multiple hospitalizations of some children and their living conditions. We seldom think of personal space as a therapeutic intervention; but we are noticing that the lack of it may be significantly impacting students with serious emotional disturbances.
- Expand legislative actions to promote loan forgiveness for physicians to attract child psychiatrists. Encourage the Board of Regents and the State Education Department to examine alternate pathways for professionals to become licensed child psychiatrists.
- Examine funding disparities to ensure that mental and emotional wellness is supported throughout New York State. Despite the horrific stories we hear about individuals killing their parents, children attacking other children and the increase in children needing services, mental health funding may not be commensurate with other systems or the spiraling needs within our state.
- Provide earmarked funding for family run organizations to provide materials and translation services for families speaking languages that are often not available, such as Chinese, Korean, Russian, Haitian-Creole and Hindi. Family run organizations are in the community and know what language supports are necessary beyond English and Spanish. Currently it is difficult to find information of home and community based waiver services in Chinese or Russian, for example.

In summary, we are, in our efforts in New York State, in a better place than we were years ago, yet we are not quite where we need to be. With both the increase in the number of families in our state, and the number of children and youth needing care, including the swell of military families, we are

stretched. Yet we are all required to meet an even greater mandate if we are to correctly and fully support the implementation of current reform. Family support is the vehicle that systems need to reach and properly serve families. We are the link that nurtures cross system solutions to be generated and implemented. We are the support that families need, but also the support that SED, OCFS, ACS, and JJ all needs to implement their plans and successfully provide for New York City children, youth and their families.

If I could leave you with just one image of family support it would be this. When you think of family support think of an oyster, sand, and the pearl. The oyster represents family support programs, and the sand represents all of the families that are in need of services. A grain of sand enters the oyster. The oyster seeing the potential in the sand embraces it. The oyster nurtures the sand and sticks with the sand through the process of becoming a pearl, much like family support workers with families and youth that come to these programs for support. Once the process is complete, the grain of sand emerges not as the sand it was when it entered the oyster, but as a beautiful pearl, something of value. This is the value of family support programs to families. The families emerge feeling supported, more knowledgeable, empowered and able to advocate for themselves and their families. So, the next time you see pearls think of families and family support services.