



# **IMPROVING CHILDREN'S MENTAL HEALTH IN MASSACHUSETTS**

April 16, 2008

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The National Alliance on Mental Illness of Massachusetts  
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April 16, 2008

**EXECUTIVE SUMMARY:**

In releasing this position paper, the National Alliance on Mental Illness of Massachusetts (NAMI Mass) intends to inform its members, the media and policy makers that children and adolescents with mental illness and their families are desperate for help. Advocates, policy-makers and legislators must listen and respond now.

Children and adolescents are suffering due to inadequate, ill-coordinated, and ineffective care and their families are stretched to a breaking point. It is time to dismantle and rebuild a mental health care system for children and adolescents that recognizes that mental illness in a child or adolescent affects the whole family. Recent reform efforts in Massachusetts present a rare opportunity to fix what is broken and the National Alliance on Mental Illness of Massachusetts demands that any system change must involve and strengthen families to best serve vulnerable children and adolescents.

NAMI Mass is an experienced and effective voice for consumers with mental illness and their families in the Commonwealth, with over 2500 members and 23 local affiliate offices in the state. We provide resource and referral services to consumers and their families and offer supportive education programs for families and consumers. NAMI Mass advocates have the insight that uniquely prepares them to lead this effort. They can and will ensure that the system that failed their children will not fail another generation.

NAMI Mass looks forward to working with lawmakers and policymakers on these much needed reforms. The future of our children depends on it. The following recommendations would provide the best chance for recovery for all children and adolescents with mental illness in the Commonwealth:

- **Treatment must be family-driven if children and adolescents and their families are to survive mental illness.**
- **Early screening and diagnosis spares children and adolescents from losing years of their lives to mental illness.**
- **Schools must be part of the solution in treating mentally-ill children and adolescents.**
- **Adolescents and young adults must be given services to allow them to transition into independent adults.**

## INTRODUCTION

### **Parents of children and adolescents with mental illnesses are desperate to help their children receive effective services that promote recovery.**

As of 2003, 6,433,422 children, adolescents, and adults were living in Massachusetts.<sup>1</sup> According to the Federal Center for Mental Health Services, approximately 8,476 children aged 0-8 (2.5%) and 96,740 children and adolescents aged 9-19 (11%) face mental illness or serious emotional disturbance. Our current system is failing them and their families.

### **The failings of the current system have led to a crisis for children and adolescents with mental illness and their families.**

Rather than providing a therapeutic haven, too many families are stressed to the breaking point. Children and adolescents with mental illnesses are too often removed from their homes and placed in residential settings or foster care. Here, they are isolated from the peers and loved ones most concerned with their welfare. They fail to improve and too many spiral further downward.

Many young children and adolescents living with mental illness struggle in school when symptoms flare. They often lack the skills necessary to effectively participate in school. Adolescents with mental illness commonly turn to drugs or alcohol and are more likely to become involved with the juvenile justice system.<sup>2</sup> When these adolescents “age out” of children’s services, they often have few resources or skills to allow them to become independent and productive adults.<sup>3</sup>

*NAMI member Paula has been navigating the children’s mental health system for a decade. Paula lives in Hatfield with her husband and two children, including her nineteen year old son, John. When John was diagnosed with schizoaffective disorder ten years ago at the age of nine, the family lived in Connecticut.*

*Since moving to Massachusetts three years ago, Paula has struggled to access qualified and coordinated care for her son. On both Paula’s private insurance while he was a minor and now on MassHealth since turning nineteen, John has been unable to access the kind of care and coordination necessary to help him and his family work toward lasting recovery. Paula describes several hospitalizations with forced drugging, restraints, and even serious injuries to John’s head from being tied down. They have traveled to various hospitals all over the state from the Berkshires to Boston and have been greatly disappointed each time. Paula and her family have experienced firsthand how critical it is to have policies that ensure access to evidence-based, family-driven care for children living with mental illness.*

### **Effective Treatment Transforms Lives.**

Adequate and effective treatment allows children and adolescents with mental illnesses to lead full and productive lives from childhood into adulthood. With effective care, young people can experience a significant reduction in self-harm and suicide-related behaviors, improved school performance and attendance, and improved relationships with their families and peers. Hospital admissions, institutional care, and other types of out-of-home placement are greatly reduced.<sup>4</sup>

### **CURRENT EFFORTS TO REFORM THE CHILDREN’S MENTAL HEALTH SYSTEM**

By the year 2000, it had become alarmingly clear that the mental health system in Massachusetts was not only inadequate, but at times damaging to children living with serious mental illnesses and their families. Many children in crisis were not able to access the services that they needed. Those who received acute care in hospitals and needed less restrictive care had no place to go. They remained hospitalized and became widely known as “stuck kids.” The growing concern of “stuck kids” in Massachusetts received much public attention and created a sense of urgency for systems’ change.<sup>5</sup>

### ***Rosie D. v. Romney* provides the opportunity to build an effective mental health care system for Medicaid eligible and enrolled children and adolescents.**

Under federal law, all Medicaid recipients under the age of 21 are entitled to Early and Periodic Screening, Diagnosis and Treatment (EPSDT) and “reasonable promptness” in receiving mental health services. Research shows that early identification and intervention with effective services can lessen the long-term disability associated with mental illnesses.<sup>6</sup> Without early identification and treatment, “these childhood disorders may persist and lead to a downward spiral of school failure, poor employment opportunities, and poverty in adulthood. No other illnesses damage so many children so seriously”.<sup>7</sup>

In Massachusetts, approximately 500,000 children have MassHealth. Many of the benefits they are entitled to are dictated by federal law under EPSDT. The nonprofit public interest law firm, the Center for Public Representation (CPR), began talking to families of children enrolled in MassHealth (the Massachusetts Medicaid program), who required community-based mental health services. They found that these families were unable to access EPSDT services and were not provided with mental health services in a reasonably prompt

manner. This discovery of serious flaws in the mental health service system led to CPR filing a lawsuit, *Rosie D. v. Romney*, in 2001. The class action lawsuit asked the federal court to force the state to comply with the federal statutory EPSDT requirements and to increase access to community-based mental health services for children under age 21.

The decision, handed down by Judge Ponsor on January 26, 2006, was an unqualified victory for children of Massachusetts receiving MassHealth and for their families. The judge stated that he saw the federal EPSDT mandate as a commitment to the nation's children and expressed the need to honor this commitment to the children of our state. In Massachusetts, according to Judge Ponsor, "The undisputed evidence offered at trial made it clear that children with serious emotional disabilities are among the most fragile members of our society; their medical needs frequently extend across a spectrum of service providers and state agencies. Prompt, coordinated services that support a child's continuation in the home can allow even the most disabled child a reasonable chance at a happy, fulfilling life. Without such services a child may face a stunted existence, eked out in the shadows and devoid of almost everything that gives meaning to the gift of life..."<sup>8</sup>

Judge Ponsor's ruling required the MassHealth program to notify enrolled families with children under the age of 21 of their right to EPSDT services. These services included screening and identifying children with serious emotional disturbances; providing comprehensive assessments of children; providing care management; and providing home-based services including mobile crisis intervention for children identified as needing services.<sup>9</sup>

***Omnibus Children's Mental Health Bill (SB. 2518) is the first step in building an effective mental health care system for children, adolescents, and their families.***

During the 2007 - 2008 legislative session, Massachusetts lawmakers have acknowledged the crisis in our children's mental health system. These lawmakers recognize that reforms are also needed for privately-insured children who will not benefit from the outcome of the *Rosie D* case. Representative Ruth Balser and Senator Steven Tolman have filed a bill that would change the mental health service delivery system for all Massachusetts' children and their families, regardless of their insurance coverage. Senate Bill 2518, *An Act Relative to Children's Mental Health*, was filed in 2007 and is strongly supported by NAMI Mass and a large coalition of organizations, legislators, family members, providers, consumers and other key stakeholders throughout the state.<sup>10</sup>

This bill addresses the needs of publicly and privately-insured children with mental illnesses in Massachusetts. If the bill is enacted, the resulting law would promote behavioral health screening of children during their well-child visits with their primary care providers and require that children be screened in childcare and preschool settings to identify children with mental illness as early as possible. In addition, the bill requires insurance companies to compensate professionals for collateral services or care between health care providers and other professionals working with children, such as teachers. This job often falls to parents, who must work as case manager and caregiver. The bill aims to reduce the number of “stuck kids” by requiring the Executive Office of Health and Human Services to implement policies and programs that aim to move children out of hospitals and into community-based programs as soon as clinically appropriate.

Together, *Rosie D.* and SB.2518 have the potential to initiate much needed reforms and improve the lives of families struggling to survive and thrive through the challenges of mental illness. These initiatives represent a shift in the mental health care standard from institutionalization to home and community based services. However, these reforms are only the beginning of systems’ change. In order to fulfill the promise of the bill and the lawsuit, children’s mental health advocates and supporters must ensure that the *Rosie D.* lawsuit is fully implemented in a way that strengthens families and to extend the rights defined under *Rosie D.* to all children in the Commonwealth through the passage of SB. 2518.

## **NAMI MASS RECOMMENDATIONS FOR AN EFFECTIVE SYSTEM OF CARE**

### **Family-driven services produce the best outcomes for children and adolescents with mental illnesses and their families.**

When a child or adolescent suffers from mental illness, the entire family feels the impact. Parents must scramble to find providers, coordinate services, and advocate for treatment. Families are under constant stress, they are exhausted, and they often feel hopeless. Brothers and sisters must learn to cope with frightening changes that they see in their siblings. Family-driven care effectively treats the child with mental illness in her home or community, whenever possible, and supports and strengthens the entire family. Reform of the child and adolescent mental health care system should ensure that all families have access to family-centered treatment. The array of available services must include evidence-based interventions and wrap-around services.

## **Evidence-based practices improve the outcomes of children and adolescents with mental illnesses.**

Evidence Based Practices (EBP) have been shown through multiple research studies to be effective. Many EBP models recognize that parent participation is vital to effective treatment and that interventions should leverage a family's strengths. *Family Therapy, Behavior Therapy, Family Education and Support, and Parent Management Training* services support families and provide home and community-based care for children and adolescents with mental illnesses. All family members need support and strategies to understand and cope with mental illness. Without access to effective home and community-based interventions, parents often lack the resources necessary to keep their child at home.<sup>11</sup>

*NAMI member Teri lives in Halifax and describes herself as a “mother of four children, two with severe mental illness and two who suffer the fallout of living with them.” Her four children range from 21 years old to Mandy age 13. Her middle daughter Sandy, age 16, was diagnosed at 10 years old with schizoaffective disorder. She is privately insured and receives DMH services. Unfortunately, Sandy has shown little improvement since beginning treatment. Caring for Sandy is Teri’s full-time job and Teri has not been able to leave the house in over a year, even for an hour. Respite care would allow her to recharge and give much needed time to her other three children.*

Respite care is a critical, family-centered, evidence-based intervention that helps to strengthen a parent's ability to care for a child or adolescent with mental illness at home. It provides families with trained caregivers for short periods of time to allow parents to have a break from the every day stress of caring for a child with special needs. These breaks keep parents strong so that they can effectively handle extreme behavioral challenges that often exist with mental illnesses. Respite helps to reduce out-of-home placement and costly institutional placements.<sup>12</sup> All families should have access to respite services so that children and adolescents with mental illness thrive in their homes and communities.

*Teri also knows that “mental illness is hard on the whole family, not just the one suffering from mental illness.” Teri and her family need a mental health service that DMH doesn't provide: family therapy. Because of her sister's illness, her youngest child, Mandy has never been able to have friends visit and has never had a birthday party. Mandy is usually the target of Sandy's anger, is terrified that she will grow up to be like her sister and is showing symptoms of PTSD.*

*Teri's eldest daughter, age 21, is engaged to be married and is afraid to have children of her own. Family therapy could help both siblings understand and cope with the extreme nature of their sibling's illness and the complex emotions that they feel.*

**Family Based Wrap Around Services should be made available to *all* families.**

Family wrap around programs are effective and would guarantee long-term wellness for children and adolescents with mental illness and their families. The wrap around model is an intervention that includes the family in goal-setting and treatment planning while supporting the family so that the plan may be carried out most effectively.<sup>13</sup> The model's goal is to develop individualized community services and supports for each child and family to help strengthen the family so that home and community-based care are possible in the long-term. Over a twelve to eighteen month period, the wrap team including parents and other important people in the child's life (minister or rabbi, friend, therapist, and others) are assembled and the family's needs and strengths are identified. A plan is then developed to meet the needs of the child and family, including plans for psychiatric emergencies. The plan is then implemented and adjusted as needed in ongoing meetings. Once the child is stabilized, the team crafts a long-term plan for home and community-based care.<sup>14</sup>

**Early screening and treatment is essential.**

Research shows that early screening and diagnosis of mental illness in children is essential for improved long-term outcomes.<sup>15</sup> Consequently, it is critically important that all child-serving professionals understand how to recognize the early warning signs of mental illnesses in children.

Pediatric primary care physicians often have the most regular contact with children and their families during well-child visits. These visits are designed to ensure that the child is healthy and developing well. Healthy development includes mental and physical health. These visits present the ideal opportunity for early and regular mental health screening. If a concern arises, the primary care physician is in the best position to either treat the condition or to refer the child to a mental health provider. Increasingly, national leaders are calling for mental health to be recognized as a public health concern and for the integration of mental and physical health care.<sup>16</sup> NAMI Mass supports early screening and diagnosis for children throughout Massachusetts, regardless of their insurance coverage.

**Collateral services strengthen families and create the optimal therapeutic environment.**

Senate Bill 2518 calls for certain "collateral services" to be provided to children with private health insurance. Currently most families provide case management for their child with a mental illness placing a significant burden on families already struggling with caring for their

child. Senate Bill 2518 would mandate that all insurers reimburse mental health clinicians for time spent coordinating care with caregivers such as pediatricians and teachers, thus improving care management and alleviating parents' burden so they can concentrate on caring for their child or adolescent at home. NAMI strongly supports passage of the bill. A broad range of collateral services should be available to *all* children and adolescents with mental illness, regardless of their insurance coverage.

### **Schools must play a role in the mental health of students.**

In developing an effective children's mental health system, it is important to recognize the vital role of schools in this process. Many children have the most regular adult contact outside of the family with their teachers and other school personnel. School staffs are often in the best position to first identify mental health related concerns in students. The Massachusetts Department of Elementary and Secondary Education must play a significant role in mental health reform efforts and there must be mental health professionals on staff at that department. All school personnel should receive training and resources to understand the early warning signs of mental illnesses in students, how to link them with effective services, and how to meet their academic and functional needs.

It is critical to educate all school personnel on methods for addressing the challenging behaviors that children may present with as part of the symptoms of their mental illness. It is also important to coordinate services and care across child-serving systems including schools and the mental health system. This is true for children enrolled in MassHealth and private insurance plans.

*NAMI member Denise is the mother of two children and lives in the North Shore. She has spent many years advocating for her two sons, Paul, age 14 and Steven, age 18, who are living with serious mental illness. Both Paul and Steven are currently insured through MassHealth. Denise has been forced to navigate a system that often would rather not address the mental health concerns of her kids. She has struggled to involve the schools, knowing that they are a crucial participant to ensure that her sons have comprehensive and coordinated care to help meet their academic and functional needs.*

*Paul's school refused to address his mental health needs in his Individualized Education Plan (IEP). Adamant that it was for learning disabilities only and her son's challenges were not due to a learning disability, the school refused to address these critical issues in his IEP. Denise fought to make the school understand that his anxiety created challenges for him in the school environment every day; she tried to explain that something that creates such a clear challenge to his academic life is exactly the kind of concern that the IEP is designed for. Describing her frustrations with Paul's school, Denise said, "They don't want to include mental health in a student's IEP. They just don't want to deal with it."*

**Transitional services for adolescents and young adults aged 16 to 25 allow them to lead independent and productive adults lives.**

As adolescents with mental illness become young adults, they desire the transition to independence that other young adults and their parents take for granted. When young adults with mental illness are unable to become independent adults, they become increasingly isolated, and in turn, symptoms of mental illness can be exacerbated. Without appropriate supports and the skills and knowledge to manage their own health, independent living is frequently impossible.

*NAMI member Karen lives with her husband and three children in Methuen. One of her children is Tim, age 25. Since he was 19, Tim has suffered from schizophrenia and has faced increasing isolation. After a suicide attempt, hospital staff advised him to join a Clubhouse to get back on his feet. When Karen accompanied Tim to the Clubhouse, all he could see was “crazy old people”. She says that while she knows the value of Clubhouses “if there were people my son’s age and people who looked like my son... he may have gone back...” Tim spends most of his time alone in his room.*

According to a Massachusetts consumer-authored publication, transitional age youth are most interested in programs that help them complete their education, find suitable employment, develop independent living skills, balance a budget, locate appropriate housing, manage family relationships, and develop a social network.<sup>17</sup> Focusing on a youth’s strengths rather than disability, several programs based on the Transition to Independence (TIP) model have been responsible for higher graduation rates, higher employment rates, less criminal justice system involvement, reduced welfare benefit expenditures, and reduced SSI benefit spending for young people completing the programs.<sup>18</sup> In this model, youths are connected with “transitional facilitators” to assist them and their families to find appropriate programs. These facilitators can mix and match programs across systems and have the ability to quickly access appropriate services.

Adolescents and young adults in Massachusetts need similar services that are tailored to their unique needs. The Department of Mental Health (DMH) has begun to address these concerns by rolling out a number of small programs. Currently, the Department is providing peer-mentoring, job-searching techniques education, resume writing assistance, job interview coaching, and housing-search workshops to a small number of transition age youth. The Department of Mental Health has also launched the Transformation Center where transitional age youth learn the importance of social connections and peer networks in the transition into

adulthood. The Department of Mental Health provided the Genesis Clubhouse of Worcester with two Transitional Age Youth staff and the results are very promising. The Department of Mental Health has a Youth in Transition Committee that the Mass Clubhouse Coalition is a part of but DMH needs to increase funding. The DMH received \$6M in new funding for transitional age programs for FY2008, but, clearly the Commonwealth needs to make a *substantial* investment if transitional age youth are to live well and independently.

Further complicating matters, young adults face a potential gap in services when their eligibility for child and adolescent services currently ends at age 18. Young adult DMH clients must apply for adult DMH services and not all transition age youth meet the DMH eligibility requirements for adults. A seamless transition from adolescent to adult services is vital.

## CONCLUSION

Taken together, the Omnibus Children's Mental Health Bill (SB. 2518) and reforms required by the *Rosie D. v. Romney* court decision lay the foundation for improved care for children living with mental illness. However, to ensure that children living with mental illness survive, thrive, and become healthy adults -- an effective system of care must be developed for all children across the Commonwealth. NAMI Mass looks forward to working with lawmakers and policymakers on these much needed reforms. The future of our children depends on it.

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<sup>1</sup> Mental Health in Massachusetts Community Mental Health Services Block Grant application for FY2008, Pg 40.

<sup>2</sup> Skowrya, K, Cocozza, J., *Blueprint for Change: A Comprehensive Model for the Identification and Treatment of Youth with Mental Health Needs in Contact with the Juvenile Justice System*. 2006 (available online at [www.ncmhjj.com](http://www.ncmhjj.com)).

<sup>3</sup> Davis, M, Koyanagi, C, *Summary of Center for Mental Health Services Youth Transition Policy Meeting – National Experts Panel*, June 2005.

<sup>4</sup> Gruttadaro, D., Burns, B., Duckworth, K., & Crudo, D., *NAMI: A Family Guide – Choosing the Right Treatment: What Families Need to Know About Evidence-Based Practices*. May 2007 (available online at [www.nami.org](http://www.nami.org)).

<sup>5</sup> *Children face delays in mental health care*, The Boston Globe, 4/13/07.

<sup>6</sup> New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MH: 2003.

<sup>7</sup> *Id.* at p. 58.

<sup>8</sup> *Rosie D. v. Romney*, 410 F.Supp.2d 18, (Jan. 26, 2006).

<sup>9</sup> *Id.*

<sup>10</sup> Children's Mental Health Campaign, [www.hcfma.org/cmhc](http://www.hcfma.org/cmhc). CMHC includes, but is not limited to the following organizations: Health Care for All, Children's Hospital, Massachusetts Society for the Prevention of Cruelty to Children, Parent/Professional Advocacy League, Health Law Advocates.

<sup>11</sup> Gruttadaro, D., Burns, B., Duckworth, K., & Crudo, D., *NAMI: A Family Guide – Choosing the Right Treatment: What Families Need to Know About Evidence-Based Practices*. May 2007 (available online at [www.nami.org](http://www.nami.org)).

<sup>12</sup> *Id.*

<sup>13</sup> *Id.*

<sup>14</sup> National Wrap Around Initiative, information accessed at [www.rtc.pdx.edu/nwi/](http://www.rtc.pdx.edu/nwi/).

<sup>15</sup> New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MH: 2003.

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<sup>16</sup> Presentation by Terry L. Cline, Ph.D., Administrator, Substance Abuse Mental Health Services Administration, Plenary Session, Florida Mental Health Institute/University of South Florida, Research Conference on Children's Mental Health, February 2008.

<sup>17</sup> Delman, Jonathon, Jones, Amanda, *Voices of Youth in Transition Report*, Dorchester, MA: Consumer Quality Initiatives, Inc. 2002.

<sup>18</sup> The TIP model was developed at the University of South Florida by Dr. Hewitt Clark. See also *Transition to Adulthood: A Resource for Assisting Young People with Emotional or Behavioral Difficulties* by Hewitt "Rusty" Clark, Ph.D., and Maryann Davis, Ph.D. 2000.