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Children's Hospital Boston

Children's Mental Health in the Commonwealth: The Time Is Now

The Massachusetts Society for the Prevention of Cruelty to Children (MSPCC) & Children's Hospital Boston in Collaboration With:

Boston Medical Center Department of Pediatrics
Boston Public Health Commission
Catholic Charitable Bureau of the Archdiocese of Boston, Inc.
Children's Friend and Family Services
The Children's Law Center of Massachusetts
The Children's League
Codman Square Health Center
The Collaborative of Boston Area School Based Mental Health and Social Services
Dorchester House Multi-Service Center
The Guidance Center, Inc.
Health Care for All
Health Law Advocates, Inc.
The Health Foundation of Central Massachusetts
Institute for Community Health
Judge Baker Children's Center
Massachusetts Alliance for Families
Massachusetts Association for Mental Health, Inc.
Massachusetts Chapter of the Academy of Pediatrics
Massachusetts Head Start Association, Inc.
Massachusetts Medical Society
Massachusetts Office of Victim Assistance
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Medical-Legal Partnership for Children/Boston Medical Center
MetroWest Community Health Care Foundation
Mental Health Legal Advisors Committee
Mental Health & Substance Abuse Corporations of Massachusetts, Inc.
National Alliance on Mental Illness of Massachusetts
National Association of Social Workers, Massachusetts Chapter
The New England Council of Child & Adolescent Psychiatry
Parent/Professional Advocacy League
Tufts-New England Medical Center and The Floating Hospital For Children Department of Psychiatry

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On January 26, 2006, U.S. District Court Judge Michael A. Ponsor issued an almost 100 page decision that the Commonwealth of Massachusetts violated the federal Medicaid Act by failing to provide appropriate home based mental health care to an estimated 15,000 children. This landmark decision in the case of *Rosie D. v. Romney* has broad implications for the diagnosis, assessment and treatment of children with serious emotional disturbance and support for their families. This decision and the subsequent remedies put forth by the Commonwealth will profoundly alter the mental health system for children with public insurance (Medicaid). It is our belief that this landmark case also serves as a call to action for our Commonwealth to address the needs of ***ALL*** children needing mental health care and treatment, regardless of their insurance type or level of need.

Children diagnosed with mental health disorders and their families must receive timely and appropriate diagnostic assessment and treatment. For too long, the health care system, including its reimbursement structures, has minimized mental health as a core component of health care. Families seeking help often find themselves in a complicated maze of fractured care, with inadequate insurance reimbursement, programs too few and far between, and coverage defined by limitations in covered diagnoses and services.

There has been incremental progress: the passage of mental health parity insurance; promising community based interventions; a growing body of best practices; the voices of families advocating for their children; and the acknowledgement that stigma is real and damaging. However, the time has come for bold vision and systemic change, not incremental efforts. Our vision is of a children's mental health system focused on prevention, timely diagnostic assessment and appropriate intervention.

The best public policy is shaped by public discourse, debate and negotiation. On occasion, the Courts take action when public will is lacking and there is an obvious wrong that must be righted. *Rosie D. v. Romney* provides the lightening rod of change for children with serious emotional disturbance; it is our hope that together we seize the opportunity to provide a high quality, mental health care system for all children of the Commonwealth. Nothing less should be acceptable.

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We also want to thank the many families in Massachusetts who shared their stories and experiences of heartache and hope. It is their voices that will lead to reform and creation of a quality mental health system for their children.

Endorsers

Boston Medical Center Department of Pediatrics

www.bmc.org/pediatrics

The Department of Pediatrics at Boston Medical Center is dedicated to children, adolescents and young adults, and is committed to keeping them healthy by promoting safety and preventative medicine, and by delivering prompt, efficient care for illnesses and injuries.

Boston Public Health Commission

www.bphc.org

The nation's first health department, the Boston Public Health Commission protects, promotes and preserves the health and well being of all Boston residents through a wide range of health initiatives that target preventable disease and injury.

Catholic Charitable Bureau of the Archdiocese of Boston, Inc.

www.ccab.org

Catholic Charities, the social service agency of the Archdiocese of Boston, is dedicated to improving the lives of the needy in Eastern Massachusetts. Founded in 1903 as a child welfare agency, Catholic Charities has consistently expanded its services to meet the needs of impoverished children, teens, working families and senior citizens, in concert with its mission of building a just and compassionate society rooted in the dignity of all people.

Children's Friend and Family Services

www.childrensfriend.net

Children's Friend and Family Services improves the lives of children and promotes strong families by partnering with community organizations to provide services to strengthen individuals, families and community life.

The Children's Law Center of Massachusetts

www.clcm.org

The Children's Law Center of Massachusetts is a private, non-profit, legal-advocacy and resource center. The mission of the Children's Law Center is to: 1) provide legal representation to low-income children with complex legal problems; 2) provide information and training to parents, advocates, school personnel, social workers, and other child welfare workers; 3) provide resource and referral information on education, child welfare and juvenile justice issues; 4) assist in developing child welfare, juvenile justice, and education policies with a special emphasis on access to equal opportunity for low-income youth and families.

The Children's League

www.childrensleague.org

The Children's League of Massachusetts is a statewide association of more than fifty private and public organizations that, collectively, advocate for public policies that will ensure the well being of children, youth and their families in the Commonwealth.

Codman Square Health Center

www.codman.org

The Codman Square Health Center is a major provider of medical and other clinical services, in addition to a variety of community services including, civic health, education, youth, and public health. Its mission is to be a resource to improve the physical, mental and social health of the community.

The Collaborative of Boston Area School Based Mental Health and Social Services

The Collaborative's mission is to promote quality school based mental health and social services for the Metro Boston School population. Toward this end The Collaborative may engage in: collaboration among providers and with schools, funders, public officials and other organizations; information sharing and provider support; and advocacy for the availability and adequacy of funding of school based services.

Dorchester House Multi-Service Center

www.dorchesterhouse.org

Dorchester House Multi-Service Center (DHMSC) is a full-service, state-of-the-art community health center providing primary and specialty medical services to a diverse population while also offering an array of public health, wellness, recreational and social services that support health on multiple levels.

The Guidance Center, Inc.

www.gcinc.org

The Guidance Center, Inc. (GCI) is the largest provider of developmental, mental health and family support services in Cambridge and Somerville, MA. From pregnancy through age 22, GCI strives to meet the unique needs of each child they serve in partnership with families and community colleagues.

Health Care for All

www.hcfama.org

Health Care for All is dedicated to making quality and affordable health care accessible to everyone, regardless of income, social or economic status.

Health Law Advocates, Inc.

www.hla-inc.org

Health Law Advocates, Inc. (HLA) is the only non-profit law firm in the country affiliated with a grass roots organization and dedicated solely to ensuring access to health care for society's most vulnerable members. HLA provides free legal representation to eligible consumers who live or work in Massachusetts and seek access to health care.

The Health Foundation of Central Massachusetts

www.hfcm.org

The mission of The Health Foundation is to use its resources to improve the health of those who live or work in the Central Massachusetts region with particular emphasis on vulnerable populations and unmet needs.

Institute for Community Health

www.icommunityhealth.org

The Institute for Community Health is a unique collaboration of three Massachusetts health care systems to improve the health of Cambridge, Somerville, and surrounding cities and towns through community-based research, assessment, dissemination and educational activities. Founding members are the Cambridge Health Alliance, the Mount Auburn Hospital of CareGroup, and the Massachusetts General Hospital of Partners HealthCare.

Judge Baker Children's Center

www.jbcc.harvard.edu

The Judge Baker Children's Center promotes the best possible mental health of children through the integration of science, practice, training, and advocacy.

Massachusetts Alliance for Families

www.mspcc.org/maff

Massachusetts Alliance for Families (MAFF) is an advocacy association dedicated to enhancing the quality of life for children who cannot live with their biological families and the families who care for them.

Massachusetts Association for Mental Health, Inc.

www.mamh.org

Through its network of volunteers, the Massachusetts Association for Mental Health (MAMH) provides education, advocacy, leadership, and information to agencies, individuals, and families on national, state and local mental health issues.

Massachusetts Chapter of the Academy of Pediatrics

www.mcaap.org

The members of the Massachusetts Chapter of the American Academy of Pediatrics are physicians dedicated to improving the quality of life for children by providing quality health care and advocating for them and their families.

Massachusetts Head Start Association, Inc.

www.massheadstart.org

The Massachusetts Head Start Association, Inc. is a non-profit organization comprised of MA Head Start and Early Head Start programs that provide early education, comprehensive services and family support to meet the needs of low-income families and achieve successful outcomes for children in order to prepare them for future success in learning.

Massachusetts Medical Society

www.massmed.org

Every physician matters, each patient counts.

Massachusetts Office of Victim Assistance

www.mass.gov/mova

The Massachusetts Office for Victim Assistance (MOVA) is an independent state agency devoted to upholding and advancing the rights of crime victims. MOVA strives to provide innovative victim advocacy through outreach and education, policy and program development, direct service, legislative advocacy, and grants management.

Massachusetts Psychiatric Society

www.psychiatry-mps.org

The Massachusetts Psychiatric Society (MPS) is a District Branch of the American Psychiatric Association (APA). MPS members are physicians who are committed to providing outstanding psychiatric care through accurate diagnosis and comprehensive treatment of mental illnesses.

Massachusetts Psychological Association

www.masspsych.org

The purpose of the Massachusetts Psychological Association is to advance psychology as a science, as a profession, and as a means of promoting human welfare.

Medical-Legal Partnership for Children/Boston Medical Center

www.mlpforchildren.org

The Medical-Legal Partnership for Children allies pediatric clinicians with lawyers to ensure that families can meet their children's basic needs. MLPC (formerly known as the Family Advocacy Program) combines the strengths of law and medicine to address non-biologic factors (food, housing, education, and safety) known to influence child health.

MetroWest Community Health Care Foundation

www.mchcf.org

The MetroWest Community Health Care Foundation provides annual financial support to meet the unmet health needs of the twenty-five communities in the MetroWest area of Massachusetts.

Mental Health Legal Advisors Committee

www.mass.gov/mhlac

In 1973, the Massachusetts Legislature established the Mental Health Legal Advisors Committee (MHLAC) to secure and protect the legal rights of persons involved in mental health and retardation programs in the Commonwealth. The legal staff of MHLAC provides legal referrals, information, and advice to individuals, lawyers, mental health professionals and the general public.

Mental Health and Substance Abuse Corporations of Massachusetts, Inc.

www.mhsacm.org

Mental Health and Substance Abuse Corporations of Massachusetts, Inc. (MHSACM) is a statewide provider association whose member organizations are the primary providers of mental health and substance abuse services in Massachusetts.

National Alliance on Mental Illness of Massachusetts

www.namimass.org

NAMI is a grassroots organization of individuals with brain disorders and their family members whose mission is to eradicate brain disorder and improve the quality of life of persons of all ages who are affected by them.

National Association of Social Workers, Massachusetts Chapter

www.naswma.org

The Massachusetts Chapter of the National Association of Social Workers advances professional social work practice and promotes human rights, social and economic justice, and unimpeded access to services for all.

The New England Council of Child & Adolescent Psychiatry

www.neccap.com

The New England Council of Child & Adolescent Psychiatry was formed in 1962 as the local affiliate of the American Academy of Child and Adolescent Psychiatry. Currently NECCAP represents over 430 child and adolescent psychiatrists with members in MA, NH, ME and CT. NECCAP promotes scientific research into the causes and best treatments for childhood onset mental illnesses and advocates for policies promoting best practices on behalf of patients and families.

Parent/Professional Advocacy League

www.ppal.net

The Parent/Professional Advocacy League is the statewide organization of the Federation of Families for Children's Mental Health and provides support, education, and advocacy around issues related to children's mental health.

Tufts-New England Medical Center and the Floating Hospital for Children Department of Psychiatry

www.nemc.org

The Department of Psychiatry at Tufts-New England Medical Center and the Floating Hospital for Children is the psychiatric component of a world-class academic medical center offering outstanding patient care to both adults and children, teaching generations of future physicians the most advanced medical science and breaking new ground with ongoing, innovative research.

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Executive Summary

Given all that needs to be done to reform the mental health system for children in the Commonwealth, this paper could have resulted in many volumes with countless recommendations. Instead, we distilled all of the research and recommendations into five core overarching principles with corresponding specific action steps. These recommendations serve as a platform for reform.

In recent reports, peer reviewed journal articles, and other publications the term "mental disorder" is used interchangeably with "mental health problem" and "mental illness." For the purpose of this paper, we are using "children's mental disorder" in place of any of the aforementioned terms.

We define a mental disorder as a term which refers to all diagnosable mental health problems. A mental disorder is characterized by alterations in thinking, mood, or behavior and associated with distress and/or impaired functioning. For this paper, mental disorders are defined as including, but not limited to, the conditions listed in the Diagnostic and Statistical Manual of Mental Disorders and pervasive developmental disorders, autism spectrum disorders (non-mental retardation),* mood disorders, anxiety disorders, attention-deficit and disruptive disorders, schizophrenia and other psychotic disorders, somatoform disorders, and eating disorders.

1) Massachusetts must create coherent mental health policy and dynamic state leadership in order to ensure access to culturally competent, linguistically appropriate, and effective mental health services for all children in need.

Recommendations:

- Formally designate the Commissioner of Mental Health as the leading voice and authority in the design of the Commonwealth's mental health services for all children. The Department of Mental Health must review and approve all service delivery models involving the mental health of children including, but not limited to, those provided to children in the care and custody of the Department of Social Services and the Department of Youth Services.
- Initiate a serious strategic planning process and implement a revised operational structure within the Executive Office of Health and Human Services to improve the delivery of mental health services to children across state agencies with the Department of Mental Health in the key leadership role.
- Require the Commissioner of the Department of Mental Health, in conjunction with the Executive Office of Health and Human Services, to annually submit to the Governor and Legislature a consolidated service and budget report which identifies demand, delivery, cost, and gaps in mental health services for children and adolescents across state agencies.
- Create a Children's Mental Health Cabinet as a formal mechanism for interagency communication and collaboration across all state agencies within the Governor's Office.
- Include an earmarked pool of funds for the Department of Mental Health in the annual state budget for interagency-involved children. These funds should be used to meet their service needs while public agencies resolve primary agency responsibility.
- Establish a formal mechanism for internal and external review of the treatment and support needs of children and adolescents with complex needs.
- Expand eligibility for MassHealth to cover all transition-aged youth through their 21st birthday.

2) Private insurers must be required to play their part in addressing this crisis.

Recommendations:

- Pass comprehensive mental health parity legislation that once and for all provides full coverage for mental disorders, including substance abuse and eating disorders, on the same terms and conditions as physical disorders.
- Grant explicit authority to the Division of Insurance, in consultation with the Department of Mental Health, to regulate "carve out" companies as well as the behavioral health components of managed care companies.
- Create opportunities and mechanisms for private payors that ensure the development of appropriate community based mental health interventions.

3) Children must have access to culturally competent and linguistically appropriate early identification and prevention services.

* Massachusetts, through the Department of Mental Retardation (DMR), has begun to address children with autism spectrum disorders, but it was an incremental step towards solving a larger problem.

Recommendations:

Pediatric Primary Care

- Assure that pediatric practices regularly screen for mental and developmental disorders in their patients using a clinically sound, formal screening tool. All insurance companies, public and private, should reimburse for this service.
- Provide financial incentives for medical and mental health professionals to work in a collaborative manner to adequately provide integrated health and mental health services to children.
- Create explicit program design and evaluation standards so that programs which enhance collaborative work and have been proven effective are funded by public and private insurers.
- Reimburse mental health clinicians for "collateral contacts" made with key external service providers (e.g. teachers, school personnel, medical personnel).
- Encourage pediatric training programs to include developmental and behavioral health information through both formal residency and continuing medical education programs. Develop incentives that can be offered to pediatricians who complete such training.

Early Education and Child Care

- Fully fund and support mental health consultation and intervention services in preschool and early child care settings.

Public Schools

- Establish benchmarks and evaluation criteria through the Department of Education for assessing the capacity of individual schools to meet the educational needs of students with mental disorders.
- Utilize the results of this effort to inform the development of a health infrastructure for every school that can support delivery of state funded mental health promotion, prevention, and treatment programs.
- Establish mental health referral systems in each of the schools based upon consistent standards.

4) Special emphasis must be given to the implementation and delivery of mental health and substance abuse services to youth in state care or involved with the state juvenile justice system.

Recommendations:

Children in Need of Services (CHINS)

- Assure that CHINS reform efforts include mechanisms for meeting the needs of children with mental disorders in appropriate settings.

Juvenile Justice

- Develop and implement a plan for significantly reducing the number of children with mental disorders who become involved with Juvenile Courts and the Department of Youth Services.
- Provide Juvenile Courts with timely access to mental health consultation through the Juvenile Court Clinics.
- Provide all necessary mental health and substance abuse services and treatment to youth in the Department of Youth Services' custody.

5) The children's mental health policy of the Commonwealth must be based on current knowledge of children's mental health and promote culturally competent, linguistically appropriate, evidence based standards and best practices.

Recommendations:

- Appropriate a minimum of $10 million to commence the implementation planning for the Rosie D. v. Romney decision.
- Establish funding streams and policies which promote and support wraparound mental health service planning for all children and families throughout the Commonwealth. Design all mental health services to enable children to remain in the least restrictive environment possible.
- Establish a fund for ongoing identification, provider training, and provider consultation in best practices.
- Engage in external evaluation of mental health program effectiveness, and support continuous quality improvement services.

Introduction

In 2000, the U.S. Surgeon General issued a report affirming that children's mental health is essential to children's overall health, development, and ability to learn. The report declared that the promotion of mental health and treatment of mental disorders in children should be public health priorities. Despite this proclamation, children's mental health services in Massachusetts are in crisis: 70% of the children and adolescents who need mental health services in Massachusetts do not receive them.[1]

Children living in Massachusetts: 1,464,198 [2]
Children who need mental health services: 146,419 [1]
Children who need and do not receive mental health services: 102,493

The Massachusetts Department of Mental Health (DMH) is the state agency charged with providing "access to services and supports to meet the mental health needs of individuals of all ages."[3] The agency regularly assesses the prevalence of mental disorders among children. For fiscal years 2005-2007 it is estimated that 111,692 Massachusetts children will experience a serious emotional disturbance (SED).* This number is based on a DMH study funded by the National Institute of Mental Health (NIMH) and examines the number of children in Massachusetts with an SED. Our estimation of children in need of mental health services is higher based on a broader definition and national studies examining the prevalence of mental disorders in children.**

Children with mental health needs are found in all socio-economic, racial, religious, cultural, and ethnic groups. They are found among single parent, two-parent, biological, adoptive and foster families. Every child with a mental health need requires an accurate assessment, appropriate therapeutic, educational, social and recreational programs, services, and treatment. The families of these children need support to help their children learn, develop and grow within their own homes and communities.

The existing private and public mental health systems provide limited focus on disease prevention and management strategies, and an almost exclusive emphasis on the treatment of disease in medical settings. The current approach to mental disorders needs to be supplemented with a comprehensive, preventive approach that reaches far more children. While not all children's mental disorders can be prevented, the field of prevention "has now developed to the point that reduction of risk, prevention of onset, and early intervention are realistic possibilities."[1]

It is necessary to reorient care toward disease prevention and early intervention, reach children in familiar settings, and strengthen partnerships between healthcare providers, educational settings, and community-based organizations with families.

Over the years, a multitude of committees, councils, commissions and task forces have studied barriers to children accessing mental health care in the hopes of avoiding negative outcomes and restructuring the service delivery system. Many have urged policymakers and citizens to bring about desperately needed reform. Numerous reports have been issued with many recommendations.[4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19] But lack of political momentum, inadequate funding, and the stigma of mental illness has prevented the necessary changes from being executed. As a result, children and families in Massachusetts continue to needlessly suffer.

In 2006, the Massachusetts Society for the Prevention of Cruelty to Children (MSPCC) and Children's Hospital Boston joined forces to focus attention on some of the most pressing, persistent concerns that prevent children who need mental health services from accessing the appropriate care. It is our intention that this paper, "Children's Mental Health in the Commonwealth: The Time is Now," will serve as a platform for change for children in Massachusetts.

Recognizing that the issue of Children's Mental Health is owned by no single agency, insurance company, Legislator, provider, or person, we brought many voices to the table to help shape our policy recommendations. To this end, we conducted a survey to capture the perspectives of the many parties who

* See Appendix for definition of SED.
** See Appendix for definition of mental disorder.

are invested in the success of the children's mental health system. The survey simply asked participants what administrative or legislative interventions or recommendations they would make to positively affect children's mental health in Massachusetts. This question yielded nearly 500 individual policy recommendations from academics, advocates, attorneys, case managers, clinical supervisors, families, Legislators, mental health service providers, nurses, parents, physicians, psychiatrists, psychologists, and social workers.

The following policy recommendations are a result of survey responses, conclusions of past research, and policy recommendations made by previous groups and policy papers. Implementation of the recommendations is critical to improving the lives of children suffering from mental disorders. It is time for swift action sufficient to address this public health crisis.

1) Massachusetts must create coherent mental health policy and dynamic state leadership in order to ensure access to culturally competent, linguistically appropriate, and effective mental health services for all children in need.

Recommendations
Formally designate the Commissioner of Mental Health as the leading voice and authority in the design of the Commonwealth's mental health services for all children. The Department of Mental Health must review and approve all service delivery models involving the mental health of children including, but not limited to, those provided to children in the care and custody of the Department of Social Services and the Department of Youth Services.
Initiate a serious strategic planning process and implement a revised operational structure within the Executive Office of Health and Human Services to improve the delivery of mental health services to children across state agencies with the Department of Mental Health in the key leadership role.
Require the Commissioner of the Department of Mental Health, in conjunction with the Executive Office of Health and Human Services, to annually submit to the Governor and Legislature a consolidated service and budget report which identifies demand, delivery, cost, and gaps in mental health services for children and adolescents across state agencies.

***Family Voices**: The interagency collaboration is a big part that is missing from the system. The agencies aren't playing nice together and the consumers suffer.*

The term "mental health system" is often used to collectively refer to all available mental health services. But, as one parent observed in a report of the Parent/Professional Advocacy League (PAL), "There's no point of entry to the so-called system, and there is actually no system. It's up to the parents to find their way through the maze and piece together a program for their child."[20]

Meaningful reform must begin with the development of an infrastructure that supports a working "mental health system." This begins with a high level strategic planning and evaluation process at the Executive Office of Health and Human Services (EOHHS) level; aggressive, streamlined coordination of mental health services across state agencies; an annual consolidated budget and service report by EOHHS and DMH to the Legislature; and the establishment of clear lines of authority and accountability for the delivery of mental health services within and across systems. This must include the identification of a principle authority charged with development and implementation of mechanisms necessary for the seamless delivery of mental health services to all children requiring publicly supported mental health services, regardless of what state agency door they enter.

While there are a number of state agencies charged with providing certain types of assistance to children with mental disorders, DMH is uniquely qualified for the task of leading a comprehensive reform effort. DMH is the only agency mandated to provide mental health services as its primary mission. In addition, by

***Family Voices**: I think that there's a whole trauma piece that...kids become, because of their trauma, they aren't really mentally ill, they just don't function. Within the Department of Mental Health there needs to be an understanding of abuse and neglect and how that relates to mental health.*

virtue of Section 1 of Chapter 19 of the Massachusetts General Laws, DMH has the authority to, "take cognizance of all matters affecting the mental health of the citizens of the Commonwealth." The Department already has the legal authority to work across systems. In order for DMH to assume this role, the Governor and Secretary of Health and Human Services must empower the agency as the sole mental health authority.

Once empowered, DMH must collaborate with other state agencies and stakeholders in developing a coherent children's mental health system. This collaboration must be active and robust without compromising the clarity of leadership roles and accountability mechanisms. To that end, the process should commence with a shared understanding that the following three elements of leadership must be firmly in place:

1) DMH alone should retain ultimate authority and responsibility for planning, organizing and administering mental health services, whether financed by Medicaid or state appropriation;

2) As the state's mental health authority, the Commissioner of DMH must set the mental health policy for all children's agencies in order to ensure consistent policy and programmatic coherence;

3) Children in the custody of the Department of Social Services (DSS) and the Department of Youth Services (DYS) should receive mental health care services designed, delivered, purchased, or approved by DMH prior to implementation.

Recommendation
Create a Children's Mental Health Cabinet as a formal mechanism for interagency communication and collaboration across all state agencies within the Governor's Office.

In Massachusetts, children's mental health services, from acute inpatient care to parent support services, are provided by many state agencies and agency partners. While some of the services offered are unique to the particular agency, many provide the same or similar services. For example, case management services (sometimes called service coordination) are provided to children by the Massachusetts Behavioral Health Partnership (MBHP), DMH, DSS, DYS, and the Department of Public Health (DPH).[21]

The lack of a structured system of interagency coordination has lead to unnecessary gaps and/or duplication of services, simultaneous provision of contraindicated services, promulgation of inconsistent eligibility criteria, shifting of case management responsibility to parents, and other circumstances that put children at risk and/or waste precious resources.

Fragmentation should not be accepted as an inevitable byproduct of decentralization. Service and treatment coherence can be achieved through the establishment of a vehicle for mandated cross-agency engagement and accountability at all levels**.** An active and functioning Governor's Child Mental Health Cabinet would provide the structure necessary to minimize fragmentation while also sending a clear message of the need to prioritize children's mental health issues within government.

The members of the cabinet should include the heads of all state agencies that serve children, private agencies providing mental health services to children, and parents of children with mental health issues. The cabinet should be required to meet regularly for the purpose of removing barriers to cross-agency provision of services, and making recommendations on the policies, practices and resources necessary to meaningfully address the mental health needs of the children of the Commonwealth. The co-chairs of the cabinet should be a member of the Governor's staff and the Commissioner of Mental Health.

Recommendation
Include an earmarked pool of funds for the Department of Mental Health in the annual state budget for interagency-involved children. These funds should be used to meet their service needs while public agencies resolve primary agency responsibility.

Inconsistent mental health policy among the child serving state agencies has resulted in inconsistent and fragmented funding streams. This problem has grown as state agencies have developed programs independent of each other as a result of legislative mandates, making the children's mental health system a "multi-pipe labyrinth that is often difficult to enter and hard to maneuver through." [22] This management mayhem around children's mental health is in part due to multiple but separate, categorical funding streams, so called 'silo' funding, and subsequently creates many service delivery systems.[22]

The concerns about interagency collaboration and its relation to the funding of services are persistently and widely published:

- In 1998, the Committee on the Status of Mental Health Services for Children wrote that EOHHS should establish a cross-agency child's services budget planning process with particular attention paid to expansion activities;
- In 2001, Massachusetts Citizens for Children published, "A State Call to Action: Working to End Child Abuse and Neglect in Massachusetts," which recommended the creation of "blended" funding pools within state agencies serving children to maximize services, and support inter-departmental coordination and collaboration to encourage flexible and creative use of resources.

Complete elimination of siloed funding may not be an achievable goal. However, the Commonwealth can and must establish a policy whereby the swift delivery of services is given priority over the resolution of bureaucratic entanglements. Establishing an appropriation account that allocates funds to meet the needs of children involved with more than one agency will provide the mechanism for that policy to be implemented.

Recommendation
Establish a formal mechanism for internal and external review of the treatment and support needs of children and adolescents with complex needs.

Parents of children with serious emotional or mental health issues should not be forced to address their needs in a piecemeal fashion. In cases where the various state agencies are unable to create a holistic treatment and funding plan that crosses agencies, parents should have the ability to request a formal cross-agency review of the situation. Initial review could be accomplished through a designated hearing officer or ombudsman, with a limited right to appeal to the court system in specific cases. This framework is derived from existing "fair hearing" processes available at the agency level, but recognizes the need in these types of cases to address all issues in one setting.

***Family Voices**: I have a daughter with significant mental health issues who was adopted. When she turned 19, because she dropped out of school, she didn't qualify for my insurance. And you can't get her to work! She is not getting the appropriate services, and she would be if she were on MassHealth.*

Recommendation
Expand eligibility for MassHealth to cover all transition-aged youth through their 21st birthday.

Youth who are left without health coverage, even for a short time, go without preventive care. Minor issues can become major, expensive health problems. Those with serious conditions, like depression, can be devastated by a lack of regular treatment. Youth without health coverage are forced to rely on emergency services, which are expensive, sporadic and not cost-effective for the state.

Furthermore, transition-aged youth without health coverage can become burdened by hefty medical bills at a time when they are struggling to be self sufficient.

DSS cites lack of basic health insurance as a major barrier to intensive mental health services for youth leaving its custody and care. Some youth who meet SED criteria to receive services from DMH do not meet the Serious and Persistent Mental Illness criteria for services as adults. Thus, these children may lose DMH eligibility when they turn 19. All children who are eligible for DMH child services should be "grandfathered" into DMH adult eligibility. As a matter of public policy and as the Commonwealth embraces maximum health care coverage for the citizens, Medicaid eligibility should be extended for youth through the age of 21.

2) Private insurers must be required to play their part in addressing this crisis.

Recommendation
Pass comprehensive mental health parity legislation that once and for all provides full coverage for mental disorders, including substance abuse and eating disorders, on the same terms and conditions as physical disorders.

On May 2, 2000, mental health advocates applauded the passage of mental health parity insurance after many years of failed legislative efforts. The law substantially improves the insurance coverage of mental health benefits for certain statutorily covered commercial insurance plans. Signed by Governor Cellucci, the law requires private insurers, Blue Cross Blue Shield, and Health Maintenance Organizations to cover treatment of mental health conditions on a non-discriminatory basis. The law also applies to health plans offered to state employees and retirees by the Group Insurance Commission.[23]

Under the mental health parity law, insurers cannot impose limits on the number of visits or dollars spent on the diagnosis or treatment of certain biologically-based mental illnesses for children and adults, but insurers are still permitted to strictly limit reimbursement for illnesses for adults which are considered "non-biologically" based. For children under the age of 19, the law provides for a broader benefit. As detailed in a Division of Insurance (DOI) bulletin, Chapter 80 directs covered plans to provide mental health benefits on a non-discriminatory basis for non-biologically-based mental, behavioral or emotional disorders that substantially interfere with or substantially limit the functioning and social interactions of children under the age of 19.[24] The interference or limitation must be documented or be evidenced by conduct including, but not limited to: an inability to attend school as a result of the disorder, the need to hospitalize the child or adolescent as a result of the disorder, or a pattern of conduct or behavior caused by the disorder that poses a serious danger to self to others. The law further mandates that the benefits for ongoing treatment continue beyond the adolescent's 19th birthday until the treatment is completed. Psychopharmacological services and neuropsychological assessment services must be treated as medical benefits and must be covered to the same extent as all other medical services.

> ***Family Voices****: One of the challenges for families that have MassHealth is that you can't get the same quality of care as when you have a different plan that pays better. It's pretty frustrating when there is a specialty treatment your family needs and you can't get that care because it's limited and based on private insurances. The quality people don't want to get the fees that MassHeatlh is paying. You should be treated based on your need, not the insurance reimbursement rates.*

While the parity law was a significant improvement in commercial insurance coverage for mental disorders, individuals with mental illness and their families must still cope with treatment limits, a shortage of child and adolescent psychiatrists willing to accept insurance, and the feelings of being less deserving of treatment than people with a physical illness.[25]

There are also elements of the parity law which remain confusing in their implementation. The current law gives the Commissioners of DMH and DOI authority to add to the list of "biologically-based" disorders subject to full parity, but does not explain how they will decide if a disorder is biologically-based.[23]

Additionally, the current law exempts insurers from having to pay for services that a school committee would provide under Massachusetts General Law Chapter 71B. MGL 71B ensures that children with special needs will receive treatment through the schools, but excuses a school committee from paying for "health care goods or services to the extent that such goods or services ... would be covered by a third party payor."[26] This ambiguous language has created the familiar payor merry-go-round between schools and insurers[23] and often treatment is delayed, based in an incomplete diagnosis, or never administered.

No studies specific to mental health parity implementation in Massachusetts currently exist, but national data shows that full parity implementation has proven to be effective in reducing barriers to treatment.[1] Studies also show that concerns around skyrocketing costs after full parity implementation are unfounded: on average, premiums for families increased by less than 1%.[27]

Recommendation
Grant explicit authority to the Division of Insurance, in consultation with the Department of Mental Health, to regulate "carve out" companies as well as the behavioral health components of managed companies.

In Massachusetts, the majority of public and private insurers sub-contract subscriber's behavioral health benefits to national, for profit "carve-out" companies. DOI does not feel that they have the authority necessary to gather and report service data from these "carve outs" despite their authority over the parent companies. This creates an inability at the systems level to assess the quantity and quality of mental health services provided to children.

By ensuring that the DOI and DMH have explicit authority to set standards for and/or regulate the "carve outs" as well as the behavioral health components of managed care companies, there will be greater understanding of services provided, gaps and disparities, and, most important, greater consistency and coherence in the mental health services provided to children.

Recommendation
Create opportunities and mechanisms for private payors that ensure the development of appropriate community based mental health interventions.

The Massachusetts Child Psychiatry Access Project (MCPAP) is a program that was established to ensure that community based pediatric clinicians overcome mental health treatment barriers. The program is currently funded by DMH and administered by MBPH. MCPAP is currently available to children and families regardless of their insurance status through their primary care provider. Through regionally based consultation teams, primary care providers can get a telephone consultation with a child psychiatrist Monday through Friday while the family is in the office. Through that telephonic consultation, families are also helped in accessing local behavioral health services or may be referred directly to a MCPAP psychiatrist for diagnostic consultation. Additionally, the regional teams provide education sessions tailored to the needs of the practices to which they consult. The program currently covers 1,004,000 children and adolescents, 67% of the Commonwealth, and has become a nationally recognized model. As a result of MCPAP services, primary care providers are significantly more satisfied with their ability to meet the behavioral health needs of their patients.[28]

All insurers should financially support MCPAP or similar programs so that primary care providers are successful in meeting the needs of children with mental disorders.

3) Children must have access to culturally competent and linguistically appropriate early identification and prevention services.

There is widespread agreement that there should be "no wrong door" for accessing mental health services for children. Creating a system in which all doors are the "right door" will require an investment in training and resources to increase capacity to deliver or facilitate delivery of culturally competent, linguistically appropriate services in the places where children are found; in their pediatrician's offices, pre-schools, day care settings, and schools.

The following recommendations are specifically targeted toward improving capacity to deliver children's mental health services in those key settings.

Pediatric Primary Care

Many parents rely on their pediatric primary care providers (pediatricians, pediatric nurses, practitioners, etc.) to accurately diagnose their children's mental illness.[29] Pediatric providers are the health professionals who are the most knowledgeable about a child's medical history and status, and parents report feeling comfortable turning to these providers for help with addressing a variety of their concerns about their child's psychosocial well being.[30] A child's pediatric provider can treat certain mental disorders or serve as a gateway, not a gate keeper, to receiving appropriate treatment.

The American Academy of Pediatrics (AAP) agrees that there is a need for pediatricians to screen for and treat children's mental disorders, but express that a lack of necessary resources has created service gaps.[31] Resources for pediatricians in the form of training, reimbursement, and care coordination services will offer the needed support to pediatricians and begin to bridge the existing service gaps.

Screening

Recommendation
Assure that pediatric practices regularly screen for mental and developmental disorders in their patients using a clinically sound, formal screening tool. All insurance companies, public and private, should reimburse for this service.*

While parents can always *approach* a pediatrician about a mental health issue, 48% of parents in Massachusetts report that their child's primary health provider never or rarely asks about mental health.[32] Some mental disorders, like a major psychosis, would most likely present symptoms that would raise the concern of a parent, but other mental disorders, like depression, may manifest in a less noticeable way and require a medical screening tool to be recognized. As with other medical problems that affect children, like asthma or diabetes, pediatricians administer tests that can lead to further questioning or a diagnosis.

Such screening tools have been developed and implemented in certain Massachusetts medical settings. The Pediatric Symptom Checklist (PSC) is a parent-completed screening questionnaire designed to facilitate recognition and referral of psychosocial problems.[33] Neighborhood Health Plan of Massachusetts is currently piloting use of the PSC as a routine part of well-child visits and their research suggests that, "psychosocial screening with the PSC is associated with increased mental health referrals, decreasing child symptom scores, and increased parental satisfaction."[34] National data affirms that early detection and treatment of mental disorders can result in a substantially shorter and less disabling course of illness.[35]

* Private insurers currently reimburse pediatricians for mental health screening.

Collaboration and Referrals

Recommendations
Provide financial incentives for medical and mental health professionals to work in a collaborative manner to adequately provide integrated health and mental health services to children.
Create explicit program design and evaluation standards so that programs which enhance collaborative work and have been proven effective are funded by public and private insurers.
Reimburse mental health clinicians for "collateral contacts" made with key external service providers (e.g. teachers, school personnel, medical personnel).

If a mental disorder is accurately recognized and diagnosed, treatment can sometimes be administered by the pediatrician, but a referral to a mental health professional is often imperative. In Massachusetts, 77% of parents reported that their primary care provider was not at all or only somewhat helpful in linking families to other resources such as support groups and educational information about their child's behavioral health diagnosis.[32] Significant barriers to referral include lack of available specialists, and appointment delays. Nationally, more than two thirds of primary care clinicians report appointment delays after a referral is made with many families waiting three to four months for an appointment with a specialist, and 59% having zero visits to the specialist.[29]

Numerous pilot programs, in Massachusetts and nationwide, exist to link primary care more closely to mental health services. These types of programs fall into three general categories:

1) Coordinated services - services are coordinated by a designated individual, but do not exist within the same practice location;
2) Co-located services - services are provided within the same practice location; and
3) Integrated services - medical and behavioral health (and possibly other) components are within one treatment plan for a specific patient or population of patients.[36]

All of these methods of service integration have demonstrated an improved clinical outcome for children and improved access to services.[36]

When making a referral (by phone or in person) or consulting with another professional to make an accurate diagnosis, pediatricians and other medical and mental health providers are engaging in what is called a "collateral contact." These additional communications are important for diagnosis and treatment, as management of mental disorders is thought to be more time consuming than the management of physical disorders.[37]

Training

Recommendation
Encourage pediatric training programs to include developmental and behavioral health information through both formal residency and continuing medical education programs. Develop incentives that can be offered to pediatricians who complete such training.

Pediatricians are trained on a variety of children's health issues, but limited training opportunities are provided which integrate "psychosocial issues into primary care."[38] The residency requirements for future pediatricians are regulated by the Accreditation Council for Graduate Medical Education (ACGME) which considers training in "psychosocial disorders" a "subspecialty" of a doctor's residency. ACGME states that, "it is not possible for each resident to have a formal rotation through every subspecialty…it is required that

all residents be exposed to the specialized knowledge and methods of the pediatric subspecialties."[39] Certain training methods, such as specialized fellowships and collaborative office rounds, have proven effective in improving pediatricians' ability to identify and manage children's psychological problems.[40]

Early Education and Child Care Settings

Recommendation
Fully fund and support mental health consultation and intervention services in preschool and early child care settings.

The Massachusetts Department of Education (DOE) estimates that 70% of 0-5 year old children (preschool aged children) spend time in non-parental care:

- 5% are in Head Start programs;
- 61% are in center-based programs;
- 13% are in public preschools;
- 8% are in family child care homes; and
- 6% are cared for by relatives, friends or neighbors

These preschool aged children are not too young to show symptoms of social, emotional needs. According to a recent PAL study, 48% of parents said their child showed signs of a mental health problem by age four.[32] Often these "signs" are recognizable, but do not result in referrals to treatment or services, but instead result in expulsion from their preschool or childcare setting. In fact, more children are expelled from preschool than from all other grades, but expulsion rates decrease significantly with access to classroom-based mental health consultation.[41]

Massachusetts health care, childcare, child welfare, and social service agencies have already acknowledged the growing problem within this population and founded the Together for Kids (TFK) Project. The project, funded by the Health Foundation of Central Massachusetts and the United Way of Central Massachusetts, began three years ago as a pilot program to implement a mental health consultation model in two preschools and a Head Start Program. The results of the intervention model are exceptionally positive:

- Children enrolled in the program are less aggressive;
- The majority of parents felt they had better ways to handle their child's behavior and discuss problems with their child's educator;
- Teachers felt they had more adequate training in handling child behavior problems; and
- Suspension rates dropped, and preschool expulsions were all but eliminated.[42]

Early mental health screening and consultation services will help traumatized children get support services as soon as possible to eliminate later, more costly interventions and negative outcomes.[43]

Public Schools

Recommendations
Establish benchmarks and evaluation criteria through the Department of Education for assessing the capacity of individual schools to meet the educational needs of students with mental disorders.
Utilize the results of this effort to inform the development of a health infrastructure for every school that can support delivery of state funded mental health promotion, prevention, and treatment programs.
Establish mental health referral systems in each of the schools based upon consistent standards.

Family Voices: *All of our children, every single child has a different way of learning. Teachers should be able to respond to that.*

With 95% of children in Massachusetts enrolled in school,[44] schools are an unrivaled venue for reaching children with mental health needs. On five out of seven days in most weeks, the school system encounters nearly the entire child and adolescent population of Massachusetts, 1 in every 10 of whom are in need of mental health services. As a result, schools have become the default, primary provider of mental health services to children even though they have not been given adequate resources to provide such services. Schools are an important part of the larger mental health system, providing mental health services and service referrals through school-based health centers, social workers, school nurses, and guidance services.[45, 46] They need resolute support to succeed.

There are 44 functioning school-based health centers in Massachusetts[47] that have been successful providing services to children who otherwise might not access them.[48] School-based health centers provide services similar to any community-based health center, and are nationally largely used by students for mental health purposes.[49] School-based health centers in Massachusetts identified "emotional" issues as the second largest diagnostic category of the 10,526 children they treated in a recent school year; the first diagnostic category was "health supervision."[50] In schools where health centers are not established, there are often other resources such as guidance counselors, psychologists and social workers available, but there are no requirements, such as student to staff ratios, in place.[51]

Despite these well intended efforts, untreated mental health problems are taking an enormous toll on education: 8% of Massachusetts teens (21,000) are high school drop outs,[2] and it is estimated that nearly half of these teens failed to complete school because of a mental health problem.[52] Increased efforts to identify and address mental health issues in school children is necessary not only because schools are an effective point of entry, but also because the successful education of Massachusetts children depends on it. Providing services through the schools minimizes certain barriers that often prevent children from accessing services like transportation to and from appointments, but also provides a comfortable, familiar environment in which to engage the child and family while minimizing stigma.

Family Voices*: Our children with mental health needs transition from a pre-kindergarten setting to the public schools and they get thrown into the cracks. When they get into the public schools, everything is developmentally inappropriate. And they wonder why kids are exploding in the classrooms.*

4) Special emphasis must be given to the implementation and delivery of mental health and substance abuse services to youth in state care or involved with the state juvenile justice system.

The Juvenile Justice System

Nationally, the juvenile justice system has become the children's mental health "system of last resort"[53] and "a warehouse for children suffering from mental illness."[54] Far too often, this is where children end up when the school system, the child welfare system, and the mental health system have not coordinated the appropriate care. While we in no way are advocating that children with mental disorders should seek involvement with the juvenile justice system to access services, the reality is that there are many mental health needs within this community which need to be addressed.

In Massachusetts, DYS is the juvenile justice agency charged with protecting the public, preventing crime, and promoting positive change in the lives of the youth committed to their custody.[55] But, DYS is not the only portal to mental health services within what some would call the "juvenile justice system" in Massachusetts.

There are four major ways a juvenile may encounter Juvenile Court, and through the Juvenile Court, mental health services through the juvenile justice agency (DYS) or child welfare system (DSS):[56]

1) A parent or legal guardian, police officer, or school attendance official can file a "Child in Need of Services (CHINS) petition," thereby petitioning the court to order services for the youth. Juvenile Probation may refer the youth for mental health services on an informal basis prior to formal court involvement, or youth may be placed in the custody of DSS for the purpose of accessing mental health and other services available through the state child welfare system.

2) A child, parent, school, or DSS official can file a Care and Protection petition if the child is without the proper care of a parent or guardian. The filing of a petition leads to a Care and Protection hearing and possibly trial. If the child is found in need of care and protection, the judge can commit the child to DSS custody which is then responsible for the provision of mental health and other needed services for the duration of the period of commitment.[57]

3) A police officer arrests a juvenile, or files an application for a "delinquent complaint" which is similar to a criminal complaint filed against an adult. Although most youth adjudicated delinquents are placed on community probation, youth may also be put in the care of DYS which is then responsible or provision of mental health and other needed services.

4) A youth may be indicted and tried in Juvenile Court as a "youthful offender" if the youth is between the ages of 14 and 17 and committed to the care of DYS, the offense involved the infliction or threat of serious bodily harm, or the offense violates the firearms law.[56] Just as in delinquency cases, mental health and other services are provided through DYS for the duration of a period of extended commitment to age 21.[56,57,58]

In 2005 there were 9,164 CHINS petitions, 2,929 Care and Protection petitions, 13,804 delinquency complains, and 170 juveniles were indicted as youthful offenders.[59] National data estimates that as many as 50% of youth in these situations and settings have a diagnosable mental health disorder.[60]

Mental health system reform must include a comprehensive effort to identify and address the gaps in services which result in juvenile justice involvement for children with mental disorders. It is a travesty that so many children with mental disorders are entangled with the juvenile justice system.

CHINS

Recommendation
Assure that CHINS reform efforts include mechanisms for meeting the needs of children with mental disorders in appropriate settings.

For some families, the CHINS system has unfortunately become an option of last resort for accessing mental health treatment for children**.** The CHINS law was enacted in 1973 to provide care and services for children who are truant, runaways, "stubborn" or "habitual school offenders" exhibiting "difficult" behaviors. The principle behind the system was to decriminalize these behaviors which are not offenses against society but rather against a youth's own self-interest, and separate the intervention from the juvenile justice system that responds to delinquent behavior.

When a CHINS petition is filed the court may take one of three steps to ensure the child's safety and help them access the

> ***Family Voices****: CHINS shouldn't criminalize mental disorders. My child has a mental disorder and has missed a lot of school because of it. The truancy officer filed a CHINS because they didn't acknowledge mental health as a real medical problem.*

appropriate services: 1) Provide counseling or guidance services while the child lives at home with his or her parents, 2) Place responsibility for the child with a relative, probation officer, or other adult or private agency, or 3) Place the child in the care and custody of DSS.

There are many problems with this current system which have been extensively documented but continue to go unaddressed:

- There is no one, clear-cut authority over the CHINS system;
- It is child focused, rather than family focused;
- There is sometimes a lack of understanding of what filing a CHINS application in the court will lead to; and
- Resources invested in CHINS cases are not systematically integrated. [58,61,62,63,64]

While a CHINS petition may be helpful for some families, "54% of all CHINS youth were arraigned for adult criminal offenses or delinquent offenses within three years of their first CHINS petition.[65]

Efforts are underway to address these systemic problems, and create a system that focuses on preventing problems from escalating to the point where court involvement is needed. In 2004, State Representative Paul Donato, working closely with the Children's League of Massachusetts, filed legislation calling for the repeal of the existing CHINS law declaring that it was time for significant, not incremental, reform. State Senator Karen Spilka, co-chair of the Joint Committee on Children and Families, has formed an active work group charged with studying the issue and drafting legislation for reform. Legislative leaders should embrace this initiative and commit to passing CHINS reform in the coming year.

Juvenile Justice

Recommendations
Develop and implement a plan for significantly reducing the number of children with mental disorders who become involved with Juvenile Courts and the Department of Youth Services.
Provide Juvenile Courts with timely access to mental health consultation through the Juvenile Court Clinics.
Provide all necessary mental health and substance abuse services and treatment to youth in the Department of Youth Services' custody.

In 2003, there were 14,964 juvenile arrests in Massachusetts.[66] As discussed earlier, we believe a concerted effort to reduce the number of children with mental disorders who are currently part of this number is necessary. Inevitably some children with mental disorders will commit crimes, be arrested, and adjudicated, but preventive steps can and should be taken when ever possible.

After an arrest, most youth appear before a judge for arraignment where the charges are read and the juvenile enters a plea. This can be a stressful process and often the youth present with critical mental health needs that call for action, including suicidal thoughts, anxiety disorders, or the risk of toxic reactions associated with recent drug or alcohol use.[67]

The Juvenile Court Department of the Massachusetts Trial Courts, with the DMH, has implemented a statewide system of juvenile court-based mental health clinics. Juvenile Court Clinics employ a range of mental health professionals (including psychologists, psychiatrists, and social workers). Juvenile Court Clinicians provide court-ordered evaluations, referral services, and limited treatment services for youth and families involved in delinquency, status offense, and child abuse and neglect proceedings. However, current court clinic capacity permits referral of only 4-11% of youth before the courts, and an under-funded salary structure has resulted in significant recruitment, retention and staff morale challenges.

In 2005, 4,988 juveniles were committed to detention centers and placed in the care of DYS. The Center for Mental Health Services Research at the University of Massachusetts Medical School found that 60% to 70% of youth in the Massachusetts DYS Detention and Correction programs were clinically in need of mental health care.[68]

Mental health services provided to juveniles in the care of DYS increases the chances of success when they are released from care. A recent study of delinquent youth found that recidivism rates decreased by 25% for those who receive structured, meaningful and sensitive treatment.[54]

5) The children's mental health policy of the Commonwealth must be based on current knowledge of children's mental health and promote culturally competent, linguistically appropriate, evidence based standards and best practices.

Recommendation
Appropriate a minimum of $10 million to commence the implementation planning for the *Rosie D. v. Romney* decision.

On January 26, 2006, U.S. District Court Judge Michael Ponsor issued a ruling stating that Massachusetts does not provide appropriate mental health treatment for children with an SED. The long-awaited ruling brought a decision to a class action lawsuit filed on behalf of eight children and adolescents who were not provided with appropriate outpatient and community-based care by the state.[69] The lawsuit, known as *Rosie D. v. Romney*, found that the Commonwealth is in violation of the federal Medicaid Act and that approximately 15,000 children in Massachusetts are not receiving the appropriate care.[69]

Implementation of the remedy will change the way mental health services are delivered to children, and money must be set aside to begin to facilitate those changes.

Recommendation
Establish funding streams and policies which promote and support wraparound mental health service planning for all children and families throughout the Commonwealth. Design all mental health services to enable children to remain in the least restrictive environment possible.

The Judge's decision in *Rosie D. v. Romney* also outlined the successes of "wraparound" service planning models which develop unique plans based on children's needs. The services "wrap" around the child, instead of the child chasing the services. In Massachusetts, wraparound service planning is provided in limited locales by programs such as Mental Health Services Program for Youth (MHSPY), Worcester Communities of Care, and Coordinated Family-Focused Care program (CFFC). These programs provide comprehensive assessments, service coordination, crisis intervention, and in-home support services through one agency. This method of service provision has proven to be infinitely more effective than seeking the needed services through individual state agencies:

> *Over six years, SED children in the program* [MHSPY] *experienced a 50% reduction in hospitalization and residential treatment days. Foster care days declined from 1327 days in the year prior to enrollment to 317 days following enrollment. The program's expenditures on integrated care for participating children, estimated at approximately $4500 per child per month, are substantially less than the cost for usual treatment in the Commonwealth's uncoordinated, multi-agency approach to care*[70].

In his decision, Judge Posner did not dictate that these programs be made available to every child across Massachusetts, but he did highlight them as exemplary ways for the State to fulfill its obligation to children in need of these services.

Recommendations
Establish a fund for ongoing identification, provider training, and provider consultation in best practices.
Engage in external evaluation of mental health program effectiveness, and support continuous quality improvement services.

For many years, service options have been developed and/or modified in response to funding requirements and eligibility criteria which have no basis in either science or sound economic policy. The process of reforming the children's mental health system presents an opportunity to revamp services to include a growing body of "best practices," or practices that have been proven effective in serving children and families. Implementing best practices often requires training staff to make a shift in service delivery. The cost of making such a shift can sometimes be prohibitive. To properly identify and implement best practices throughout the system, special funds are needed and should be set aside.

As the needs of children and families continue to change, the best practices around service delivery will also change. Evaluation of programs is essential to ensure that all children of the Commonwealth are receiving effective services.

Closing Thoughts

In examining the literature on children's mental health in Massachusetts, we cannot help but think of the longstanding stigma that exists and perpetuates a lack of commitment to ensuring mental health care access. If children were not getting the appropriate treatment for leukemia, we believe that swift legislative, systemic, and fiscal changes would be implemented. Yet, mental illness in children and adolescents is more prevalent than leukemia, diabetes and AIDS *combined*.[71]

As stated earlier in the paper, there have been some incremental changes that are beneficial to children and families seeking treatment. The passage of mental health parity, while not complete, was a step towards equality of coverage. We hope the existence of the Mental Health Commission for Children will continue to raise the visibility of issues related to children's mental health.

But most advocates agree that the biggest win for children with a mental disorder in Massachusetts over the past decade was not the legislative victories, but the resounding ruling in the *Rosie D. v. Romney* class action law suit. The ruling affirmed what advocates, parents, and families already know – children are not getting appropriate care for their mental illnesses. While we embrace the changes that will stem from the ruling, we are also discouraged that it takes an adversarial process such as litigation to spark necessary action.

It is our hope that future litigation which is not only adversarial, but lengthy and costly to everyone involved, can be avoided. We believe the implementation of these policy recommendations will take a significant leap forward in creating a more efficient, accessible, prevention focused mental health service delivery system for families. We hope that these recommendations will be met with the attention fitting of Massachusetts' most vulnerable children and families.

Appendix: Children's Mental Health Definitions

Experts agree that defining mental health presents several challenges:

1) Mental health is subject to personal and cultural perception. From a cross-cultural perspective, it is nearly impossible to define mental health comprehensively.[72]

2) Mental health is often interwoven with an individual's physical health. Mental and physical health must often be defined, treated, and discussed together.

3) Mental health is not only the absence of a mental disorder, but may be best understood as points along a continuum with severe mental illness at one end and complete well-being at the other.

For the purposes of this policy paper, the following terms will be used to bring clarity to the concept of mental health and guide the implementation of recommendations.

Children's mental health: A concept which refers to a child's emotional, psychological, and cognitive wellbeing. Mental health is demonstrated through a child's successful mental functioning, productive activities, fulfilling relationships with other people, and the ability to cope with stressful situations.[1]

Mental disorder:* We define a mental disorder as a term which refers to all diagnosable mental health problems. A mental disorder is characterized by alterations in thinking, mood, or behavior and associated with distress and/or impaired functioning. For this paper, mental disorders are defined as including, but not limited to, the conditions listed in the Diagnostic and Statistical Manual of Mental Disorders and pervasive developmental disorders, autism spectrum disorders (non-mental retardation)**, mood disorders, anxiety disorders, attention-deficit and disruptive disorders, schizophrenia and other psychotic disorders, somatoform disorders, and eating disorders.

Serious emotional disturbance: A Serious Emotional Disturbance (SED) is a diagnosable mental disorder in children and adolescents that severely disrupts their daily functioning in the home, school, and/or community. Types of SEDs include, but are not limited to, pervasive developmental disorders, mood disorders, anxiety disorders, attention-deficit and disruptive disorders, schizophrenia and other psychotic disorders, somatoform disorders, and eating disorders.

*In recent reports, peer reviewed journal articles, and other publications the term "mental disorder" is used interchangeably with "mental health problem" and "mental illness." For the purpose of this paper, we are using "children's mental disorder" in place of any of the aforementioned terms.

**Massachusetts, through the Department of Mental Retardation (DMR), has begun to address children with autism spectrum disorders, but it was an incremental step towards solving a larger problem.

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