CHILDREN'S MENTAL HEALTH IN THE COMMONWEALTH

Monday, May 20, 2002
8:30 to 9:00 - Breakfast
9:00 to 11:00 - Discussion

Omni Parker House Hotel
Tremont and School Streets
Boston

A Discussion Featuring:

Commissioner Marylou Sudders
Massachusetts Department of Mental Health

Robert Master, M.D.
Neighborhood Health Plan and Alliance for Health Care Improvement

Katherine Grimes, M.D.
Mass. Mental Health Services Program for Youth (MHSPY)

Lisa Lambert
Parent/Professional Advocacy League (PAL)

Mark Ghaly, M.D./M.P.H. candidate
Harvard Schools of Medicine & Public Health

Moderated by: Dean Jack Shonkoff
Heller School for Social Policy and Management
Brandeis University

Please pre-register with Michele King at 781-736-3979 or mking@brandeis.edu as soon as possible.

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Executive Summary

Children’s mental health services in Massachusetts are under severe strain. Determining precisely which issues challenge the system is important for developing appropriate policy responses. After a comprehensive examination of the system, two key issues emerge:

- Children and their families report significant difficulty accessing the mental health services they need.
- Children displaying early signs of emotional disturbances often do not get treatment until their symptoms worsen.

This Issue Brief examines both of these concerns and the system characteristics that contribute to them. Further, the Issue Brief includes recommendations to help address these issues and to improve the evolving children's mental health system in Massachusetts.

Four historical trends have, in large part, helped to shape the children's mental health system in the Commonwealth.

- Over the past decade, there has been a gradual move from a centralized children's mental health system, based around Gaebler Children's Center, to a system that incorporates many levels of care and serves children in various community-based programs.
- Medicaid has moved into managed care and most mental health services are being delivered through a "carve-out" plan. The advent of carve-outs has changed the payment structure for many mental health services, including those in the public sector.
- Since the emergence of consumer advocates for mental health services in the mid-1980s, there has been a slow shift in the therapeutic paradigm in children's mental health; it has begun to change from a deficit-based to a strength-based model. A critical element of the grant-funded “Systems of Care” model, this shift continues to impact service delivery.

Family-friendly, strength-based care has functionally expanded our view of children's mental health and appropriate services for the treatment of childhood emotional disturbances.

- The changes to the State's special education law have affected access to services by many families.

Together these events have merged to create a system weakened by significant service gaps but ripe for hopeful amelioration.

Two Key Issues

Children and Families Encounter Difficulties Accessing Services

The children's mental health system in Massachusetts theoretically incorporates services ranging from high-intensity acute hospitalization to early mental health intervention at the primary care level. The flow from service to service, however, is often disjointed. The fragmented nature of the system creates significant difficulties for families attempting to secure needed services. Specifically, parents have begun to demand "no wrong door" policies because each service sector has a different entry point and a cumbersome enrollment process. Agencies have developed programs independent of other agencies as a response to legislatively determined mandates and categorical funding streams or "silos." The result has been significant gaps and some redundancies in available services. The issue of “stuck kids”—children who remain in inappropriate mental health care facilities because appropriate placements are full—epitomizes a child's or her family's inability to access services. Because these stuck kids often consume high-end services and are themselves unable to access more appropriate services, other children become backed up throughout the system and many in need cannot gain access.

Emotional Disturbances Become Severe Before Children Receive Care

Restrictive “medical necessity” criteria and a historically limited view of children's mental health issues have contributed to children who are high-risk or who have early signs of emotional disturbance not accessing services until their symptoms are sufficiently “acute” or urgent. Traditional mental health models focus on a child's deficits, or extent of pathology, which dictates that insurance payments support care (i.e., medication, psychotherapy, hospitalization) that focuses on
these deficits. This deficit-based, narrow definition of what constitutes a child’s mental health problem is perpetuated by the categorically driven gap between prevention or early intervention programs and traditional children's mental health.

Recommendations

The two key issues identified above are important challenges in the Commonwealth's campaign to diminish the potential suffering of children burdened by emotional disturbances. Recommendations to address the issues involved in access to care include the following:

(1) Continue support for expansion of Systems of Care models.
Increase support and collaboration in the development of a statewide Systems of Care program by expanding components of existing Systems of Care pilots in the Commonwealth.

(2) Continue to promote an increased role for families.
Enhance recognition of the necessity for families to take part in every stage of care planning, care delivery, and outcomes assessment.

(3) Promote deeper interagency collaboration.
Collaboration at each level of organization and care is pivotal to children’s mental health and serves as a tool to facilitate more comprehensive program development and agency accountability. However, agency initiatives are limited by the structure of their funding and the organization dictated by the legislature.

(4) Support legislation to secure collaboration.
A lead agency for children’s mental health should be designated to coordinate and facilitate front-line collaboration and program development through shared funding. In addition, there is a need for continued support for reporting data, such as that which is being reported to the newly appointed Children’s Mental Health Commission.

(5) Increase private sector participation.
The need for deeper private sector involvement around children’s mental health issues is required in order to help alleviate strain throughout the children’s mental health system.

(6) Evaluate the implementation and effect of the mental health parity law.
Evaluation of how health plans have implemented parity and the legislation’s effect on children will inform future system change.

The three remaining recommendations are aimed at promoting access to services for high-risk children and those with early signs of emotional disturbances:

(7) Integrate mental and physical health care.
Policies promoting the integration of mental with physical health care include encouraging deeper relationships between primary care providers and mental health providers, as well as program development where both types of care are provided together.

(8) Broaden the spectrum of mental health services.
Promote the integration of prevention and early intervention programs with other mental health services, as well as deepen relationships between traditional mental health services and juvenile justice. These initiatives will enhance both the scope of services and their continuity across different service sectors.

(9) Encourage data collection and evaluation.
State evaluation of programming should be a priority in order to facilitate program change, direct financial support, and analyze the use of innovative models.
Introduction

Roughly 20 percent (15 million) of U.S. children and adolescents have diagnosable psychiatric disorders.\(^1\) Nine to 13 percent of all children meet the definition of “serious emotional disturbance” and 5 to 9 percent have “extreme functional impairment.”\(^2\) Sadly, only one in five emotionally disturbed children receive mental health services, with many fewer receiving comprehensive mental health evaluation.\(^3\) Because of increased prevalence and more complicated disturbances, demand for children’s mental health services is projected to increase by 100 percent in the next 20 years.\(^4\)

In September 2000, the U.S. Surgeon General convened a national conference on children’s mental health. The conference recommended that children’s mental health services become more widely accessible, focus on early intervention and the role of schools and families in children’s mental health, and widely implement collaborative programs aimed at bringing child-serving agencies and programs together so our response to children’s mental health is enhanced and effective.\(^5\)

The demand for children’s mental health services is inadequately met, although our national investment is significant. In 1998 treatment expenditures for children were approximately $12 billion, or $173 per child.\(^6\) In 1998 nearly $1.1 billion was spent on psychotropic medications for children, mostly stimulants and antidepressants.\(^7\) Although hospitalization costs are lower than in the early 1990s, the number of admissions has changed little; reduced lengths of stay and decreasing reimbursements have lowered costs. In 2000, Massachusetts’ Medicaid program spent nearly $128 million on children’s treatments and medications.\(^8\)

Prior State reports confirm fragmentation in Massachusetts’s system.\(^9\),\(^10\) The Commonwealth’s system has been typified by long waiting lists for services, a shortage of providers who accept Medicaid (and often other insurance), understaffed and inappropriately-staffed facilities, poorly-prepared schools, public agencies creating services in isolation from each other, poor coordination among caseworkers, inadequate funding, and the list continues. A survey of nearly 300 Massachusetts parents, conducted by Parent/Professional Advocacy League and Health Care For All in 2001-2002, highlighted many of these problems and showed exactly how they affect families (preliminary results as of May 1, 2002).\(^11\) Simultaneously, many central stakeholders have been taking steps to identify and address gaps in service and system problems. Many ameliorative efforts have been pursued.

The Commonwealth faces numerous challenges in children’s mental health. While additional funding is an important component of solutions, there is a fiscal crisis with widespread budget cuts; the state’s social services are vulnerable and additional funds are unlikely to bolster programming. Therefore, potential organizational and structural changes that may enhance our ability to serve all children in need of mental health services are discussed here.

History

Shift into Communities

In the 1950s, the Gaebler Children’s Center opened in Massachusetts to provide children with innovative acute and long-term psychiatric care. In 1992, upon the recommendation of the Governor’s Special Commission on the Consolidation of Health and Human Services Institutional Facilities,\(^12\) Gaebler closed and the plan was to replace it with a community-based continuum of care that included decentralized inpatient hospital facilities, residential care, and other local services designed to address different levels of need. The services available today are outlined in Table 1. Many such services require additional growth.
After a four-year contract with Mental Health Management of America, the state awarded its carve-out contract to the Massachusetts Behavioral Health Partnership in 1996. The Partnership’s contract addresses which services are to be covered, how providers and facilities are to be paid, and generally seeks to strike a balance between the State’s expectations and the needs of the enrolled populations. Their incentive-based contract stipulates that the Partnership will receive significant payment for achieving goals as determined annually by a group of mental health stakeholders, including providers and advocacy groups, and approved by both the DMA and the Partnership. Among the incentive-based goals toward which the Partnership is currently working is the design and implementation of the Comprehensive Family-Focused Care (CFFC) model. This suggests a long-term commitment between the Partnership and the State.

### Systems of Care
At the same time that Medicaid carve-outs emerged, another movement also began to take hold in small pockets of children’s mental health advocacy and provider groups across the nation. The therapeutic paradigm advocated by these groups was a shift from a deficit-based to a family-centered, strength-based care model. These models, collectively called “Systems of Care,” are networks of integrated services and supports for children and their families (family supports) at the community level. Services are “nontraditional” in that they are wrapped around a child to meet his/her unique needs within each child’s home. Services are to be culturally appropriate, and strength-based rather than deficit-based. Most importantly, services are delivered in close collaboration with parents and other caregivers. Of note, Systems of Care is not a program per se. Rather, it is a process of care delivery that can be applied to any given group of children in need of mental health services, from early intervention or prevention groups to seriously emotionally disturbed children. Although initial studies showed that Systems of Care models improved access to services and family satisfaction, it showed no change in clinical outcomes. According to the 2000 Surgeon General's report on Mental Health, current Systems of Care research shows reduced rates of residential placements, out-of-state placements, and improved functional behavior as well as increased parent

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**TABLE 1**

**Spectrum of Children’s Mental Health Services in Massachusetts**

<table>
<thead>
<tr>
<th>SERVICE</th>
<th>EXAMPLES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Health Promotion</td>
<td>Public education Schools Early intervention</td>
</tr>
<tr>
<td>Primary Care Services</td>
<td>Pediatricians Family doctors Nurse practitioners</td>
</tr>
<tr>
<td>Conventional Outpatient Services</td>
<td>Social workers Psychologists Psychiatrists</td>
</tr>
<tr>
<td>Innovative Non-Residential Services</td>
<td>MHSPY, WCC, CAP, others</td>
</tr>
<tr>
<td>Acute Residential Treatment</td>
<td>Franciscan Children’s Hospital, Family Continuity Program (Hyannis)</td>
</tr>
<tr>
<td>Hospitals</td>
<td>Cambridge, Providence, others</td>
</tr>
<tr>
<td>Residential Placement</td>
<td>DSS, LEAs, DMH Residency Programs</td>
</tr>
<tr>
<td>Secure Long Term Care</td>
<td>IRTPs, Continuing care</td>
</tr>
<tr>
<td>Non-DMH Secure Facilities</td>
<td>DYS facilities</td>
</tr>
</tbody>
</table>

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**Carve-Outs**
This new “continuum of care” model was injected into a dynamic milieu of financial/reimbursement change within mental health. In 1992, Medicaid, after obtaining a Federal Section 1915(b) waiver, moved publicly funded mental health care into a for-profit carve-out. A carve-out is an arrangement through which an insurance entity subcontracts management of health services to a separate health care management company. Although the Massachusetts Division of Medical Assistance (DMA) was the first state to hire a carve-out, by 2000, 21 other states also used them. After the DMA did so, many of the State’s private health plans also hired carve-outs. By 1997, carve-outs covered 120 million Americans, or over half the insured population.
satisfaction compared to traditional delivery systems. In Massachusetts, two Systems of Care model programs have received attention: Massachusetts Mental Health Services Program for Youth in Cambridge and Somerville, and Worcester Communities of Care in Worcester.

**Special Education Law**

In addition to the important trends discussed above, changes in the Commonwealth’s special education law have significantly impacted the children's mental health system in the State. Two new provisions are of particular importance. First, a Local Education Authority (LEA) can take cases to the Bureau of Special Education Appeals, whose hearing officer “may determine, in accordance with the rules, regulations, and policies of the respective agencies, that services shall be provided by the Department of Social Services, the Department of Mental Retardation, the Department of Mental Health, the Department of Public Health, or any other state agency or program, in addition to the IEP [Individualized Educational Plan] services to be provided by the school district.” Second, there may be a more narrow selection of services available for students with an emotional disability due to the change from the state's old special education standard of "maximum feasible benefit" (MFB) to the adoption of the Federal standard "Free and Appropriate Public Education" (FAPE). This narrowed service definition has the potential to weaken the ability of families to access the services they need so that the affected child can receive an education.

Although many other developments have shaped the children's mental health story in Massachusetts, the four historical trends stated above have an important role in the current policy discussion. The system’s history has created limitations. However, state agencies and advocacy groups have been strengthening resources and slowly preparing for large-scale system change.

**Two Key Issues**

However complicated children's mental health in Massachusetts appears, two key issues emerge from current system characteristics.

- Many emotionally disturbed children are not eligible for mental health services because their conditions are not sufficiently “acute” or urgent.

Discussion of these issues sets the stage for the policy recommendations that follow.

**Difficulty Accessing Services**

Difficulty accessing services results from one of two situations: Either there is an imbalance between the supply and demand of available services or services are logistically difficult to access.

**Demand and Supply**

The issue of “stuck kids” is an effective illustration of the relationship between demand and supply of services. A “stuck kid” is a child who, although ready for discharge from a psychiatric facility, hospital, or residential treatment center, is unable to leave that facility because an appropriate placement is not available. From October 2000 to March 2001, Massachusetts’s children spent 15,796 days stuck in hospitals waiting for discharge. Stuck kids occupy desperately needed acute care beds, and as a result, providers and crisis teams experience great difficulties placing acutely disturbed children. In the past these children had to wait hours in emergency rooms during a psychiatric crisis or they are transferred to a non-psychiatric bed on a pediatrics ward (becoming a “boarder”) for days, weeks, or even months, where they are at risk for receiving inappropriate care that may lead to further deterioration. Sixteen percent of children in the PAL/Health Care For All survey waited at least 13 hours before being admitted to the hospital during their most recent crisis.

In 1998, on average only 17 kids were stuck throughout the state. Today, approximately 100 of 350 hospitalized kids are stuck. Although the stuck kids issue is only one aspect of a larger children’s mental health situation, many consider it to be a barometer for the state of children’s mental health care. Over the long run, the number of stuck kids is directly proportional to demand and inversely proportional to service availability. Because of this relationship, the trends in stuck kids are important markers of the system’s well being.

How can we account for changes in the stuck kids rate over the past five years? First, examining demand, there has been a “boomlet” in the adolescent population in Massachusetts.” This
increase in the adolescent population in Massachusetts has corresponded with some increase in the number of children with mental health needs. For example, the Boston Medical Center experienced a 55 percent increase in its pediatric psychiatric census, to nearly 60 patients per month, from 1996 to 2000.\textsuperscript{23} Similarly, prevalence has increased, according to senior clinicians who “are seeing an unprecedented number of children with serious [emotional] impairment.”\textsuperscript{24}

<table>
<thead>
<tr>
<th>Massachusetts’ Children Statistics*</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Children (under 18 years of age)</td>
<td>1.5 Mil</td>
</tr>
<tr>
<td>Uninsured children†</td>
<td>134,000</td>
</tr>
<tr>
<td>Privately insured children</td>
<td>961,000</td>
</tr>
<tr>
<td>Children w/ Medicaid (MC &amp; PCC)‡</td>
<td>408,000</td>
</tr>
<tr>
<td>Children w/ Medicaid Managed Care</td>
<td>355,000</td>
</tr>
<tr>
<td>Children w/ mental health needs</td>
<td>115,000</td>
</tr>
</tbody>
</table>

Sources:

*Warring WE, Division of Medical Assistance Presentation to the Boston Bar Association on Children’s Mental Health. February 28, 2002.
‡Managed Care and Primary Care Clinician Plan.

Examining the denominator of our stuck kids proportion, service supply, also reveals why the number of stuck kids has increased. A 1998 Department of Mental Health (DMH) Report on children’s mental health services in Massachusetts cited long waiting lists for community-based services. In certain areas, such as in the southeastern part of the state, over 100 children in 1998 were waiting to obtain community-based services. In order to better meet the demand of eligible children, the DMH reports suggest that services become more flexible, home-based, and family-centered. The DMH Report also suggests the need for a greater capacity to purchase services such as respite care and after-school services in this area. In northeastern Massachusetts, the problem was of a different etiology but a similar outcome. No agency had taken responsibility for long-term treatment of children, yet there “may [have been] quite a few youth who [required] such treatment,” reports Christina Crowe in her 1999 field review. Dr. Crowe added, “There is confusion and lack of clarity as to which agency sets the standards…. DMH seems to have adopted a role as service provider for a limited population of youth, and there is no one agency clearly identified as setting the standards for publicly-funded mental health for the Commonwealth’s children.”\textsuperscript{26} The implied lack of responsibility has indeed played into the stuck kids problem and is an important point to address in suggested reforms. It should be noted that in response to Dr. Crowe’s report, and to the credit of DMH, DMA, and the Partnership, many community-based services have been developed. These include additional residential treatment centers, family stabilization teams, community support program, partial hospitalization and intensive clinical management, and collateral services. The need, however, for further programming and longer duration enrollment has been recognized by these stakeholders.

The stuck kids problem is not only bad for kids, it is also expensive for the Commonwealth. Although there is no such analysis in Massachusetts, a recent cost-benefit analysis examining the stuck kids issue in Nebraska\textsuperscript{27} demonstrates a cost savings of nearly $6.5 million/year for that state if stuck children were efficiently moved to more appropriate, less restrictive programs. The study reports that an inability to transfer kids from inpatient to an alternative level of care had an estimated cost of $3.6 million. This figure would have been higher if some stuck children had not been transferred (inappropriately) to emergency shelters. The cost of failing to move children from residential placements to other levels of care was estimated at $1.5 million. Nebraska also reports that, “a [stuck] child experiencing lengthy delays often regresses both behaviorally and emotionally. The child may feel hopeless, helpless, unwanted, or abandoned.” These oscillations in behavior can make it even more difficult to place children in appropriate settings. Although these data are specific for Nebraska, Massachusetts likely stands to gain much, both financially and in terms of a child’s welfare, by continuing to seek solutions to manage stuck kids.

In an effort to alleviate the stuck kids problem, in 1999 the Massachusetts legislature allocated $10 million to DMH and the Department of Social Services (DSS), with which they purchased 45 intermediate, residential care beds for DSS youth ($4.9 million), 20 community residential treatment beds for emotionally-disturbed children ($2.2 million), 16 beds in a locked behavioral intensive residential treatment program (IRTP) for emotionally disturbed and behaviorally disordered children ($2.1 million), two pediatric psychiatric hospital beds ($400,000), and six clinical care coordinators for DSS ($375,000).\textsuperscript{28} However, in
spite of this effort, two years later the stuck kids problem does not appear to have been solved.

Why have proposed solutions such as the $10 million allocation in 2000 not improved our stuck kids situation and thereby helped to relieve the system as a whole? As DMH Commissioner Marylou Sudders points out, “There are no easy answers.” Though increasing service availability is an important step, putting more services into a broken system may only compound the problem. Regardless, concerned people and groups are demanding that more be done. According to State Senator Theresa Murray (D-Plymouth), “These kids aren’t stuck, [they] are imprisoned, and the Commonwealth is violating their civil rights…someone should sue us [for these violations].” Recently, the Center for Public Representation filed a complaint against DMA, on behalf of individuals seeking expanded home-based supports under EPSDT. Such a legal action is not unique to Massachusetts. For example, in New York, a lawsuit representing hundreds of stuck kids is demanding enhanced services for residential treatment and community services. Early last year, a Los Angeles judge ruled in favor of children stuck in California mental hospitals or other locked facilities who demanded wraparound services.

Other avenues for litigation also exist around the stuck kids issue. A letter of intent against the Massachusetts Department of Education (DOE) has been filed on behalf of families that claim their children’s right to an education, as provided by the federal Individuals with Disabilities Education Act (IDEA), is being violated. In a recent Boston Globe article discussing the letter of intent, the story was presented of a young girl who, during a long hospitalization at Cambridge Hospital, was stuck waiting for appropriate school placement anywhere in New England. She eventually had to settle for a school in Texas because no appropriate placement was available in the area. As the girl’s mother reports, “The whole experience was very, very painful.” Her father said, “The state needs to solve the waste not only of money but of these kids’ lives.” Also, because of the 1999 decision, Olmstead v. L.C., in which the U.S. Supreme Court ruled in favor of two adult women from Georgia with mental retardation and mental illness who claimed that they had been “needlessly segregated in institutional settings in violation of the Americans with Disabilities Act,” states must end discrimination through unnecessary institutionalization of mentally ill individuals.

According to a report by the Bazelon Center for Mental Health Law, Olmstead regulations require states to develop and/or expand plans to identify those individuals who are institutionalized unnecessarily and must provide services for these individuals to live in their native communities. As with EPSDT, Olmstead compliance may be achieved by expanding Medicaid services and eligibility.

Another factor contributing to the stuck kids problem is the quantitative and qualitative shortage of children’s mental health providers and other staff. Although Massachusetts has the highest ratio of child and adolescent psychiatrists in the country, there remains a provider shortage in psychology, social work, and related children’s mental health specialties. Because of staff shortages, the state can operate only 60 to 80 percent of children’s mental health beds despite a documented need, according to DMH Commissioner Marylou Sudders. The paucity of providers is concerning from the point of view of our inability to care adequately for children in need but also because of other consequences. The provider shortage also creates a situation where there is greater demand for than supply of staffed program placements. This is compounded by the fact that with changes in reimbursement and profit-incentives, there is a trend in hiring less-skilled workers while simultaneously providing less supervision. This high demand allows programs to choose the patients they want to accept and deny others. A dangerous pattern of discrimination can result in that the more often a child is rejected for placement, the more likely she will be rejected in the future; stuck kids are not considered easy to treat or to place.

**Service Supply and the Private Sector**

In addition to the impact of stuck kids on the supply of services, privately insured children with mental health needs are sometimes “dumped” into public sector care, thereby further straining the public sector service supply. The evidence for this is seen through the limiting of children's mental health benefits provided by private health plans. A steady reduction of provider reimbursements narrowed the scope of services available to the privately insured. As recently as June 2001, Boston Children’s Hospital dropped Harvard Pilgrim Health Care (HPHC) clients because the managed care organization offered “inadequate” reimbursement. The loss of Children’s Hospital mental health providers eliminated an important source of care for HPHC beneficiaries and led to a
Inaccurate or out-of-date provider lists maintained by managed care plans are an additional barrier to care that frustrates families who are unable to arrange appointments with listed practitioners. A June 2001 Boston Globe article discussing so-called “phantom panels” explains that, “for mental health care, customers and doctors say the problem [of phantom panels] has grown worse in the last year because more providers are rejecting lower-paying managed care plans.” Meanwhile, these providers are listed as “in network” by plans with whom they no longer contract. Massachusetts health plans have begun to make improvements over the last year. Reimbursement rates that had remained low over the past several years have begun to increase. This is a positive trend, but it does not address another concern of some providers: namely, that some providers may drop from networks because they believe the carve-outs or health plans require them to assume treatment responsibilities that are inconsistent with good care practices and burden them with significant liability.

Employers’ health care purchasing practices have a tremendous impact on access to mental health services for many children. It is important to note that the children’s mental health working group of the Massachusetts Chapter of the American Academy of Pediatrics (AAP) has invited managed care organizations and employer groups to discuss the issues around reimbursement rates and mental health care premiums.

Directly relevant to private sector coverage is mental health parity legislation. In May 2000, after extensive negotiation among public officials, providers, and advocacy groups, the Massachusetts Legislature passed a comprehensive mental health parity bill. This mandate required employers with more than fifty employees to have implemented mental health parity by January 2001; smaller employers needed to comply by January 2002. Medicaid, Medicare, and employers who self-insure under the Federal Employee Retirement Income Security Act of 1974 (ERISA) are exempt from the mandate. However, Medicaid, Medicare, and many ERISA-exempt groups have implemented parity nonetheless.

Since the mental health parity statute was enacted, there has been little known about how health plans are implementing changes to meet regulations and how these changes affect children. This is an area that needs further evaluation. We cannot just assume that parity legislation can be equated with adequate access and availability of appropriate children’s mental health care.

With regard to children, the mental health parity law does specify that children under age 19 must be covered for ten categories of “scientifically-recognized, biologically-based” mental disorders, as well as some other disorders that substantially limit a child’s functioning or social interaction. Parity also expands outpatient therapy coverage from 8 to 24 visits and increases coverage for inpatient hospitalizations. Substance abuse is covered under parity only when present concurrently with a covered mental illness. Importantly for children, parity legislation stipulates that neuropsychological assessment services are to be covered as a medical/surgical benefit, a change that is important in light of the sliding-scale fee now assessed to psychiatric evaluations required for special education eligibility determinations.

It is noteworthy that other efforts to improve private coverage have begun. As mentioned above, the Massachusetts Chapter of the American Academy of Pediatrics (AAP) has gathered employers and private insurers to discuss the impact of inadequate private children’s mental health coverage on employees, in addition to facilitating important discussions involving providers and state agency officials. Also, the directors of five not-for-profit health plans have led their own initiative. The Alliance for Health Care Improvement (Alliance) consists of chief administrators and medical directors from Tufts Health Plan, Harvard Pilgrim Health Care, Neighborhood Health Plan, Blue Cross Blue Shield of Massachusetts, and Fallon Community Health Plan. They meet to develop collaboration around important health issues, and they adopted children’s mental health as a priority issue in 2001 (personal communication, Robert Master, M.D., March 5, 2002). Two prominent goals have emerged from the Alliance:

- To increase the sense of responsibility for providing quality mental health services to the children each plan covers.
- To develop innovative, practical solutions for gaps in children’s mental health care.

All of the plans, except for Tufts and a portion of Blue Cross Blue Shield of Massachusetts, currently use carve-outs and, therefore, may play a limited
role in the supervision of many mental health services; using a carve-out potentially shifts responsibility for care away from the individual health plan, and may lessen the plan’s accountability for the quality of services.

Tightening oversight of health plan carve-outs may be one means to improving private sector care. As for developing practical solutions for gaps in children’s mental health care, the Alliance is discussing the creation of a 1-800 number that connects callers to a central children’s mental health triage center. Operators transfer families to the appropriate carve-out or insurer for service planning. Additionally, some private plans (i.e., Neighborhood Health Plan) are beginning to enhance services upstream of hospitalization, like collateral services, in order to provide better quality and decrease costly inpatient care. If such progress materializes, private sector care will improve, “dumping” will decrease, and the public sector can be left to respond to the sickest children and those without insurance.

Logistical Difficulties in Accessing Care—The Service Maze
In Massachusetts, the current children’s mental health system can be characterized as a multi-pipe labyrinth that is often difficult to enter and hard to maneuver through. This management mayhem around children’s mental health exists because of multiple, but separate, categorical funding streams, so-called “silo” funding, and subsequently, many service delivery systems, each with different eligibility criteria. Parents attempting to secure resources for their emotionally disturbed children report a “wrong door” phenomenon, where agencies deny services categorically, that is, based on a determination that the services sought fall outside of the agency’s mandate, and advise families to obtain services from another agency (personal communication, Katherine Grimes, M.D., May 12, 2002). Because of silo funding, each agency has an incentive to avoid paying costs that another agency may cover. Meanwhile, as children are referred from agency to agency time is wasted, frustrations grow, and children worsen clinically and service needs increase.

It is important to note that agency-level forces are a response to, not a cause of, categorical funding—both state and federal. Legislative budget allocations dictate a specific mandate for each agency, which directs how each agency can spend its money. This mandate limits a commissioner’s ability to pursue collaborations and innovations.

From a top-down perspective, cost-shifting is an illusion; each separate agency’s budget comes from a larger central source. Although individual budgets should not be ignored, spending may in fact become more efficient after children’s mental health funds are made more flexible at the legislative level and shared funding collaborations are pursued.

But spending constraints are only part of the story. Cost shifting and agency dumping are exacerbated by poor delineation of stakeholder responsibilities. Although each stakeholder agency has a legislative mandate, few have clearly demarcated obligations for securing mental health services for children. Because of ambiguous boundaries it is difficult to identify gaps and redundancies in services. Furthermore, this ambiguity creates a poor environment to explore change and pursue collaboration. Agencies are less likely to collaborate if there are differences of opinion about each one’s responsibilities driven by legitimate differences in interpretation of statutory language. Ideally, responsibilities for children’s mental health would be crystal clear, and the ebb and flow of collaboration would be greatly facilitated. However, currently, responsibility determinations can present a challenge for any agency.

The aforementioned system gaps and redundancies, the “wrong door” syndrome, which result from poor interagency collaboration, have exhausted children and their guardians. Multiple caseworkers and conflicting treatment plans make compliance with a provider’s recommendations difficult for even the most organized and diligent family. Twenty-seven percent of respondents to the PAL/Health Care For All survey said insufficient or poor case management often or always poses a problem in getting their children mental health care. The resulting frustration creates an apathetic attitude among patients and families that inhibits children from receiving appropriate treatment. Furthermore, poor collaboration is a barrier to entrance into the system. Often parents who take home stabilized kids have such a difficult time maneuvering through the system to arrange prescribed maintenance therapy that the child deteriorates to the point where those prescribed services quickly become insufficient.

Two widely discussed methods of interagency collaboration that operationally expand service availability without enormous financial investments are funding integration and collaboration between state and local agencies.
**Funding Integration:** Over the past fifteen years, public mental health policy has promoted funding integration. By merging, or “blending,” funds from two or more agencies, programs can be developed with greater flexibility, less duplication, and fewer gaps. However, strategies to blend funding must clearly meet the needs of each contributing agency. For example, the Department of Youth Services might not contribute to an early intervention project, but the Department of Public Health would. In Massachusetts, blended funding models have been in place since the mid-1990s. These examples are described below.

**State Level–Local Level Collaboration:** Thus far in Massachusetts most collaboration is between state agencies. However, the ethic of collaboration must result in tangible process changes (e.g., co-chairing a committee or joint-purchasing specifications). Without such collaboration, the intent of central level programming may not fully materialize.

It is important to note that although collaborative programming has enormous potential to be cost-saving and efficient, current funding mechanisms do not provide incentives for agencies to do so; for example, the dollars saved by DSS, through its participation in MHSPY, do not return to DSS for redeployment into other mental health services. Rather, the dollars are returned to the State’s General Fund. This may hinder collaborative programming and efficiency.

**Emotional Disturbance Becomes Severe Before Children Receive Care**

Eligibility criteria for mental health services are often based on three parameters—duration of symptoms, severity of symptoms, and disease burden. The latitude for providing service as presented through these eligibility criteria is quite narrow and creates opportunities to access care only at a fairly advanced point on the spectrum of disease, that is, when deficits are well documented and have taken a significant toll on a child’s life. However, with the advent of the Systems of Care process and a progressively deeper understanding of childhood development and the impact of environment on a child’s mental health, we are beginning to better understand the range of issues that mental health services can improve. The innovations in mental health care and research have supplied us with an opportunity to expand our concept of what constitutes mental health and thereby include prevention and early intervention services as integral components of caring for a child’s mental well being. Continuing to transform this mindset will be critical to helping children access services that may protect against the secondary and tertiary manifestations of childhood emotional disturbances.

Before discussing what should be done to foster a more expansive notion of mental health, three of the many important issues of the current system are considered here.

**Few prevention programs:** According to DMH Commissioner Marylou Sudders, the state has few mental health prevention services for children. This is partly because the application of knowledge of prevention practices may be limited, but also a result of funding priorities set by the legislature, without resources earmarked specifically for providing services to prevent mental illness.

**Inadequate mental health screening by primary care providers:** Primary health care providers are also the primary mental health providers for most children. However, pediatricians and family practice doctors do not screen for mental health uniformly. A startling 49 percent of respondents to the PAL/Health Care For All survey said their child’s primary care provider rarely or never asks about mental health. However, to address this concern, one of the incentive-based goals for the Partnership this year is to “identify and implement a behavioral health screening tool for pediatricians at willing, high-volume practice sights.”

**Disconnect between traditional mental health sectors and other programming:** Historically, there has been uneven cooperation and communication between the major mental health service sectors and child service sectors such as schools, early intervention programming, and primary care providers/networks.

In Massachusetts, the challenge to increase the availability and utilization of preventive and early intervention services as a means of decreasing the prevalence of severe emotional disturbances requires at least two advances.

- Specific child-serving state agencies must deepen their collaboration and cooperation and develop a broader continuum of mental health services for children.

- The Commonwealth must continue to promote a strength-based paradigm of care and move away from specific aspects of deficit-based care models.
Deepened Collaboration & Cooperation

An examination of the children's mental health system in Massachusetts shows specific relationships between traditional children’s mental health agencies and other agencies involved in providing mental health services, which, if augmented, might enhance the ability of the system to address a child's needs. The five such relationships discussed here include:

- Primary care physicians
- Schools
- DPH Early Intervention
- DPH Substance Abuse
- DYS/Juvenile Courts

Primary Care Physicians: At the March 11, 2002, Massachusetts legislative hearing on children’s mental health, Senator Richard T. Moore, State Senate Chair of the Joint Committee on Health Care, asked about the possibility of mandating mental health screening at routine health visits. This question is essential and points to the fact that primary care physicians have a significant role to play in children's mental health. If prevention and early intervention services are to be enhanced, primary care providers must increase their involvement. In Georgia, a recent law mandates such involvement; providers are required to perform a mental health screening at the 2-year well-child check-up. Massachusetts does not have such a law, but should consider its merits.

Schools: Schools are often the first to identify children with mental health disturbances, either in the preschool special education screening or through school-based health clinics (currently half of all visits are for mental health related issues). Also, through special education programs and school-based health clinics, schools have assumed a key role in serving the needs of children with emotional disturbances. Naturally, then, the role of schools and teachers in children’s mental health is critical.

School-based children’s mental health initiatives have been shown to be effective. They help reduce symptoms and increase positive coping strategies; they also include cognitive interventions to modify adolescents’ depressive behaviors and promote social problem-solving skills. Despite successes in the behavioral and emotional support of some children within schools, the Federation of Families for Children’s Mental Health claims that nationally 55 percent of students in special education for emotional disturbances do not complete high school and, of these, almost three-quarters are arrested within five years of leaving high school. This point should be one of great concern for educators who have a responsibility primarily for the child’s education.

At a basic level, poor collaboration with schools results when there is little trust and confidence between the DOE/schools and other stakeholder agencies. Schools are under constant pressure to expand their goals and to provide services that go well beyond the education mandates. In addition, school-based services occasionally are not reimbursed by other agencies that could contribute.

An important collaborative effort, led by DSS Commissioner Harry Spence and the Urban School superintendents, has focused on how children’s mental health agencies can work with local schools to care for emotionally disturbed children. Commissioner Spence notes that nearly 85 percent of DSS clients are in 21 of the 386 state school districts. By collaborating with these 21 districts, a more manageable task, changes for many target kids in the system would be achieved.

DPH Early Intervention: Traditionally, early intervention (EI) has meant “the provision of support and resources to families of young children from members of informal and formal social support networks that both directly and indirectly influence the child, parent, and family functioning.” The relevance of EI programs to children’s mental health is enormous. A 2000 report by the Child Mental Health Foundations Agencies Network, entitled “A Good Beginning,” indicates that social and emotional school readiness is critical for a young child’s early school success, and may even set the stage for success later in life. Such readiness depends on how children interact with their environment and, therefore, is part of emotional well-being. In another report, “From Neurons to Neighborhoods: Science of Early Childhood Interventions,” Dr. Jack Shonkoff discusses early childhood development and mentions that course of development can be altered in early childhood by effective interventions that change the balance between risk and protection, thereby shifting the odds in favor of more adaptive outcomes. Dr. Shonkoff’s ideas highlight what U.S. Representative Patrick Kennedy (D-Rhode Island) said, that treating kids under five is “the most cost effective, meaningful investment you can make at the formative stages of a child’s life.”
In Massachusetts, the Department of Public Health manages Early Intervention. Any disconnect between EI and mental health service delivery creates the potential for further fragmentation across children’s mental health agencies. For example, a child who is enrolled in EI programs until the age of 3 may then transition to a typical school setting where the child may be placed in special education or into a DMH placement. Although the initial EI assessments might be helpful to special education or DMH staff caring for the child later, if these files are not transferred to the new placement, evaluations must begin anew. Therefore, improved EI programs alone are insufficient; coordination must be supported between the DPH as the EI provider and other agencies caring for a child’s mental health.

**DPH Substance Abuse:** The 1999 Massachusetts Youth Risk Behavior Survey (MYRBS) shows that alcohol and drug abuse continue to be concerning issues for the Commonwealth’s youth:

- Most high school students (80%) have had an alcoholic drink in their lives.
- Over half of all adolescents (52%) reported having alcohol in the previous month. One third drank heavily.
- Alcohol use was associated with drug use, fighting, suicide attempts, and dating violence.
- Half of adolescents have tried marijuana.
- 31% reported marijuana use the month before survey.
- One tenth had used cocaine, 14% had used inhalants, 8% had used methamphetamine, and 4% had used heroin.

In a small but significant number of cases, mental health services may be required in addition to substance abuse prevention education and treatment services for children and adolescents. However, there are very few resources available for mental health as well as addiction and prevention services for children. Collaboration here is critical.

**DYS/Juvenile Courts:** Every day children with emotional disturbances are boarded in DYS facilities because mental health services are unavailable. Juvenile justice has become the system of final resort, “where [emotionally disturbed] children go when all the other systems fail—the school system, the welfare system, the mental health system.” Additionally, once detained, emotionally disturbed children may stay in DYS weeks before placement is found, often moving from site to site only to be bounced back to the detention center because they remain untreated. In a nationwide survey of juvenile detention centers conducted by the Pittsburgh Post-Gazette, 10 percent of centers reported that 8 of 10 residents “had a diagnosable psychiatric problem.”

In Massachusetts, over half of DYS committed youth are served by at least one other state agency, commonly DSS. This fact identifies another inter-agency relationship that may facilitate care improvements. Deeper collaboration with DYS may help transform thinking about emotionally disturbed youth offenders. According to DMH Commissioner Marylou Sudders, “There is a growing prevalence of mental health disorders among youth involved in the juvenile justice system. And, there is a high incidence of co-occurring disorders.”

Some collaboration does exist and has been fruitful. For the past two years, the DMH has managed the juvenile court clinics. Commissioner Sudders reports that “the number of evaluations has increased from 3,800 to 4,200 in one year (2001). These requests must be prioritized and therefore many less acute cases are not evaluated.” And often evaluation does not guarantee treatment.

**Data Collection & Analysis:** The Mental Health Commission for Children

The FY2002 State budget included an important section for children’s mental health. Outside Section 77, enacting House Bill 1206, An Act to Ensure Accountability and Provide for the Mental Health Needs of Children, established a commission to study and evaluate the delivery of mental health services to children. Known as the Mental Health Commission for Children, the section requires child mental health serving agencies in the state as well as insurance companies and state-contracted organizations to collect data and to make the information available to legislative policymakers and the public on a quarterly basis. The entities represented on the Commission, led by the Executive Office of Health and Human Services (EOHHS), include, but are not limited to, the Department of Mental Retardation (DMR), Department of Public Health (DPH), Department of Education (DOE), Department of Mental Health (DMH), Division of Medical Assistance (DMA), Department of Social Services (DSS), Division of Insurance (DOI), Department of Youth Services (DYS), and provider and advocacy groups.
The data to be collected include information regarding the status of community-based services and outpatient care, the number of children on waiting lists for such services and how long they typically wait. In addition, the Commission will report on the ratios of child psychiatrists accepting and not accepting Medicaid to the total number of eligible children per DMH region (the state is divided into varying “regions” depending on which agency is involved). The Commission is also collecting in-patient data on the number of stuck kids, the mean and maximum length of stay for such children, the number of boarder kids, readmission rates, and program capacity. Wait-list data will be collected for residential care centers and other services.

The Commission aims to gain a better handle on each “pipe” in the “multipipe” children’s mental health system. These data can be catalysts for changing and developing programs, can be pivotal to improving individualization and effectiveness of service delivery, can provide evidence to support sustainability of specific initiatives, and can encourage a more critical, responsible, and accountable ethic among those agencies and groups required to supply the data. The information obtained by the Commission will help state and private agencies “assess what the system offers for these children and what it lacks.”

Yet for all the good accomplished by this Act, the momentum must not stop here. According to the bill’s sponsor, State Representative Ellen Story of Amherst, the Commission “is a worthy idea, as far as it goes, but it has to go further.”

**Transition to Strength-Based Care Models**

Already the Commonwealth has supported two strength-based, Systems of Care pilots: In Worcester, the Communities of Care program, and in Somerville and Cambridge, the Massachusetts Mental Health Services Program for Youth (MHSPY). On the horizon is the Comprehensive Family Focused Care (CFFC) model, which is said to be designed to incorporate aspects of these pilots on a wider scale.

**Worcester Communities of Care (WCC)**

WCC has served children with serious emotional disturbances since 1999. WCC provides services according to a Systems of Care model that recognizes that children with emotional disturbances require a variety of services that cut across agency boundaries and that these services must be coordinated. Parents/guardians are active participants. Services are unconditional, comm.-unity-based, and individualized. The wraparound planning process attempts to address each family's cultural and spiritual needs. Flexible funding supports non-traditional services that might not otherwise be available to families; these are critical to supporting the child's ability to remain with his family and in his community. WCC services are prescribed according to an assessment of the child's strengths. Included among the services are the following: diagnosis and evaluation, crisis response, intensive home-based and day-treatment services, case management, and respite care.

To be eligible for WCC a child (1) must be between 6 and 15 years old, (2) have a serious emotional and/or behavioral problem with a psychiatric diagnosis (such as depression or bipolar disorder), (3) have a parent or legal guardian living in Worcester, (4) have a significant difficulty that has lasted or is expected to last a year or more in two or more settings such as the home, school, or the community, (5) the child must receive support from two or more systems, and (6) the child must have been placed, or be at risk of being placed, outside of the home due to emotional disturbance.

Worcester Communities of Care began with a grant from the Federal Substance Abuse and Mental Health Services Administration (SAMHSA). The $1 million grant was augmented with blended funding from state agencies to total $12 to $16 million through the course of the five-year pilot project. Over the five years, there is a requirement to increase non-Federal, State matching resources. WCC is sponsored by the Massachusetts Department of Mental Health and operates within the University of Massachusetts Medical School. A vulnerability of WCC is that the funding mechanisms are not entirely secure. Because the pilot program was heavily supported by federal dollars, state financial investment was secondary. In years such as this, when budget crises make investments less secure, local programs heavily dependent on federal dollars are jeopardized.

**Massachusetts Mental Health Service Program for Youth (MHSPY)**

MHSPY is a Systems of Care collaborative among the DMA, DOE, DMH, DSS, and DYS, the school systems of the cities of Cambridge and Somerville, and Neighborhood Health Plan, a local not-for-profit managed care organization. MHSPY’s aim is to integrate medical health, mental health, social support, and non-traditional services for
emotionally disturbed children in an overall Systems of Care. The pilot project in Cambridge and Somerville began in 1997 with planning money from the Robert Wood Johnson Foundation. Services are provided through blended funding from the agencies included in the collaborative.

The program pilot was created for 100 clients, but funding has limited enrollment to 30 for the first three years. Children are referred by a participating agency but then are subject to eligibility screening according to guidelines set out by MHSPY. A child must be (1) Medicaid (MassHealth) eligible, (2) receiving services from at least one other participating agency, (3) a resident of Cambridge or Somerville, (4) between 3 and 17.5 years of age, (5) tested at a score 40 or higher on the Child and Adolescent Functional Assessment Scale (CAFAS), (6) diagnosed as having at least six months of symptoms or functional impairments, (7) at risk for out-of-home placement, and (8) living with an adult able to participate in service planning.

Design and implementation of MHSPY was managed by an interagency Steering Committee, an entity made up of high-level agency representatives. Additional area level oversight (via the Area Level Operations Team) serves as a forum to bring participating agencies into closer working relationships. An example of this infrastructure might be that the Steering Committee allows MHSPY to spend money on “therapeutic after-school programs”; however, the state agency representatives from the area office had to work together to support development of adequate capacity of this resource in order for individual MHSPY Care Planning teams to purchase the service. Each agency involved has recognized that the success of MHSPY and programs similar to MHSPY depends on continued commitment by these partners.

Although DSS, DMH, DOE, DYS, and DMA have all been financially committed to MHSPY in the long term, agencies that are typically not required to deliver mental health services face a challenge in doing so. In order for agencies to maximize the cost savings and outcomes benefits of MHSPY, the program must be expanded to more children. However, expansion requires agencies to invest additional money. It is difficult to transfer money from business-as-usual distributions to innovative systems if economies of scale cannot be accessed. (Recall the issue of collaborating agencies not being able to benefit from dollars saved through collaboration.)

MSHPY’s approach to providing care begins with a no-reject, no-eject policy. This means that referred children who are eligible cannot be turned down by MHSPY (so long as program funding can theoretically support additional enrollees), and, once enrolled, these children cannot be dropped involuntarily from the program. This important characteristic of MHSPY decreases the potential for “risk selection” or preferentially enrolling healthier children. Also, the therapeutic tenets of MHSPY are founded on a strength-based rather than a deficit-based approach to care. This means that assessments are child-centered and family-focused, and are developed through a comprehensive interview with the entire family regarding that family’s individual needs and resources. Care Managers, who are Master’s-level clinicians, carry small caseloads (eight cases per case manager) and work intensively with families to meet the child’s needs within his natural environment. The Care Managers along with the entire Care Planning Team—family members, teachers, clinicians, and other influential persons in the child’s life—create a treatment plan. The Care Managers include the child’s physical health as part of the care planning process.

Functional outcome scores indicate consistent improvements across all areas (school, home, community, and psychiatric disturbance). Service utilization analyses show that for the entire population of these children, 85 percent of the days are spent at home. Family satisfaction measures reveal 93 percent satisfied or very satisfied, and costs to the state on average are 68 percent less than would be expected if the children were not being maintained in their homes.

The MHSPY project has been led by Dr. Katherine Grimes, a pediatric psychiatrist and former director of child and adolescent services at Harvard Pilgrim Health Care. To date, 77 children have been served by MHSPY with an average enrollment time of 17 months per child.

Funds for the operating budget are contributed by each participating agency and are managed by DMA. DMA also calculates the amount eligible for Medicaid federal matching dollars. At the program’s current size, the annual dollar amount is $1.1 million. The money is then paid out from DMA to Neighborhood Health Plan as a per member capitation—in 2002, the rate is $3283/month or $108/day. DMH, DSS, and DOE each contribute $842/month for each child in MHSPY, or $10,104/year. DMA contributes
$541/month per child, or $6,492/year. DSS contributes $216/month for each child in MHSPY, or $2,592/year. Individually, DMH, DSS, and DOE pay 8 percent annually for every MHSPY enrollee of the expense each agency would bear for placement if these children were not being maintained in their homes. DYS is paying two percent of what any one child would cost them for placement. DMA is paying their standard rating category II (RCII) rate, while avoiding the level of hospital and ER costs usually associated with this population. All five agencies together are spending only 33 percent of what the average cost per child would be for a child in placement.

Other States’ Experience with Strength-Based Systems of Care Models

Wraparound Milwaukee: Wraparound Milwaukee was started in 1994 with a $15 million, five-year grant from the federal Center for Mental Health Services Grant. It is based on a blend of managed care and wraparound techniques. The program utilizes resources such as mobile crisis units, care management, a provider network with many services, and various managed care tools. In its first year, the program began by enrolling 25 kids in Residential Treatment Centers (RTCs) who had no immediate discharge plans. Within 90 days the program returned 17 of the 25 children to their homes. The project expanded over the next many months to include nearly 600 youths at 60 percent of the cost of a residential placement. Outcomes have been reassuring. Hospitalization rates are down from over 5,000 per year to less than 500. For Wraparound Milwaukee youth, schooling rose from 60 percent of eligible school days to 85 percent following enrollment in the program. Wraparound Milwaukee is considered by many to be a model program and receives significant national attention.

Statewide Systems of Care—Rhode Island and Connecticut: Some states have implemented a full Systems of Care approach for children’s mental health, including Rhode Island’s REACH initiative and Connecticut’s KidCare program. With KidCare, Connecticut, a state with a stuck kids problem, has implemented progressive children’s mental health reform. This collaborative initiative between the Connecticut Department of Social Services and the Connecticut Department of Children and Families aims to eliminate the major system gaps and service barriers that have challenged state agencies, practitioners, and families. Although the results of Connecticut’s KidCare are not yet known, mere implementation of such an initiative is a step in the right direction. Key components of KidCare include: mental health care from a carve-out; community-based and culturally competent care; families involved and supported in a decision-making role with strengthened family advocacy; comprehensive training for staff and parents; and integrated funding for a broad benefits package.

Issues to Consider in Expanding a Systems of Care Model Statewide

In the midst of discussions and debates regarding how to expand the Systems of Care approach statewide under the auspices of the Comprehensive Family Focused Care program, many important considerations must be accounted for, including the following:

Make Systems of Care Philosophies Part of Prevention or Early Intervention Programs

MHSPY and WCC have not been a panacea. For example, thus far, MHSPY has only been shown to be clinically effective and cost-effective for children with serious emotional disturbances. These kids are not only among the most emotionally disturbed, but also are the children who have been among the most challenging and costly to treat. This is important because MHSPY is not viewed as an early intervention or prevention program (although, arguably, MHSPY services reach other high-risk children who might live with a MHSPY-enrollee); it focuses on children with significant impairment who often have long-standing relationships with multiple child-serving agencies. The application of Systems of Care models to early intervention programs and other potential prevention programs should be explored. Such an application may maintain children functioning at higher levels than would allow for current MHSPY or WCC eligibility. MHSPY, however, is already an important foundation or building block for new EI and prevention initiatives. Because the model requires community-based resources to be fully integrated, it essentially reduces the initial Systems of Care program set-up that is often a barrier to successful intervention ideas.
**Therapeutic Paradigm Shift**
Provider attitudes must shift from a focus on a child’s deficits to focusing on their strengths and the strengths of their families. As work by Glisson and Himmelgarn has shown, the organizational culture and context within which mental health professionals work impacts their attitudes, motivations, and behaviors. Significant training and supervision can secure this transformation. Stakeholders can play a critical role in the support of implementation of new programming.

**Collaboration with a Managed Care Organization**
Many successful Systems of Care model programs have been founded on deep collaboration and minimal seed money. This is important because these projects survive beyond initial start-up dollars; programs that depend heavily on Federal dollars are more vulnerable to coming apart once these dollars are spent. This funding is an important difference between WCC (mainly federally funded) and MHSPY (state funded). However, as Systems of Care program expansion goes forward, administrators should look to managed care organizations (MCO) well equipped to integrate services, both within the spectrum of mental health services and between mental and physical health services. Given the importance of both physical and mental health needs, linkages between providers are especially important. MCOs also have an inherent “fiscal advantage” in contracting, and often have established arrangements to collect information.

**Family-Focused**
Families must continue to be included as full participants on care teams in any statewide Systems of Care program. Because many families feel powerless over their child’s care in traditional children’s mental health systems, the participation of families in the planning, organization, and delivery of care is critical to the success of Systems of Care replication. Families also serve as a resource for providing care and essentially can be crafted into skilled providers. In addition, “parent partners” who participate in the MHSPY project are a great source of support for new families in the program.

**Robust Evaluation**
MHSPY and WCC care plans are individualized and incorporate services adopted from a wide range of those available. Data regarding which specific program component or service is both financially and technically efficient are critical to enhancing future programs. Creation of evaluative measures and studies are needed to generate more robust information and data about traditional children’s mental health services and outcomes so Systems of Care programs can be compared with the traditional care paradigm. Evaluation in the short term involves additional resources, but in the long term would be aimed at documenting greater efficiencies in care delivery.

**Capitalize on Economies of Scale**
Expansion of Systems of Care models statewide should capitalize on the economies of scale both financially and clinically. Systems of Care projects have high and fixed start-up costs. But as established projects expand, the marginal cost of including an additional child diminishes. Because the paradigm of care will shift from a deficit-based model to a strength-based model, over time communities and providers will adopt the strength-based approach more fully and subsequently the need to expend resources for “converting” communities and providers to this new paradigm is lessened. From an economic standpoint, as long as the marginal dollar costs of caring for one additional child are diminishing, then scale economies have not been fully realized. The ideal number of children to be managed by a given regional project is still unknown. Research to discover this ideal number of project participants is important.

Also, in designing expansion and replication strategies, administrators should consider expanding programs out from a central locus. That is, as Systems of Care projects are established in one site, expansion should move out to communities or cities adjacent to this established site (i.e., in the case of MHSPY, out from Cambridge). This allows economies of scale to be realized financially, clinically, and philosophically, as discussed above, and gives the programs a better chance at success, as start-up costs would be lower due to a “piggy-backing” of the new program on its established and deep-seeded neighbor.

**Ensure the Design and Implementation Process is Inclusive and Transparent**
Recent evaluations criticizing Systems of Care models have themselves been criticized as selecting programs with few Systems of Care components to evaluate. In order to avoid similar criticism in Massachusetts, broad participation by stakeholders such as family members, child-serving agencies, providers, and policy makers is necessary. Openness of the planning process to all stakeholders supports “buy-in” and ultimate sustainability of the resulting design.
Recommendations

Identifying the system problems and discussing their causes is insufficient if practical solutions do not follow. This Issue Brief concludes with recommendations for reform that may help ameliorate these problems.

Difficulties Accessing Services

(1) Continue Support for Expansion of Systems of Care Models
Massachusetts already has Systems of Care model programs that are being piloted throughout the Commonwealth (i.e. Mental Health Services Program for Youth [MHSPY] and the Worcester Communities of Care [WCC]). The state should continue to expand on these models to cover children in need of such services statewide. Buttressed support for Systems of Care programs will help move us further toward a strength-based approach to care and, subsequently, will help transform current payment systems to support such services by reimbursing these providers and covering the services they require (i.e., wrap-arounds). The Comprehensive Family-Focused Care (CFFC) model is anticipated to be one example.

(2) Continue to Promote an Increased Role for Families
Enhance recognition of the necessity for families to take part in every stage of care planning, care delivery, and outcomes assessment.

(3) Promote Deeper Interagency Collaboration
Collaboration among agencies is pivotal to children’s mental health in Massachusetts. Many interagency relationships have been initiated while others have long been in existence. However, current interagency working groups should be supported in developing a distinct and detailed agenda. Although goals and time schedules should be flexible, the need to establish these points is not trivial. Current working groups should consider the following:

- Compile information on which agency is responsible for providing specific services in which region of the state and for what group of children (e.g., the 1998 DMH report by Dr. Crowe purports that no agency was supplying long-term care to children in the northeastern part of the state). Identifying who is responsible for providing such services is an important first step to filling gaps and promoting collaboration.

- Each potential collaborating agency should outline its annual spending on services that address children’s mental health. This information will inform each agency’s investment in collaborative projects.

- Legislate flexible funding so agency budgets can be blended more easily and collaborative programs pursued.

- Emphasize collaboration at the central agency level, as well as between agency staff at the grassroots level. This might be accomplished by requiring children’s mental health workers to meet together periodically at the district or regional level. These efforts will increase morale among agency workers, increase trust between these agencies at the grassroots level, and facilitate greater continuity within a child’s treatment plan.

- Develop compatible technology systems to ensure efficiency across systems (e.g., single, simple, universal agency intake forms). This will help move the system toward a single point of entry.

(4) Support Legislation to Secure Collaboration
A lead agency for children’s mental health should be designated to coordinate and facilitate front-line collaboration and program development through shared funding. In addition, there is a need for continued support for reporting data, such as that which is being reported to the newly appointed Children’s Mental Health Commission. Through legislation, we ensure current efforts are formalized and preserved, and that the fruits of collaboration continue to be recognized as important steps in improving our children’s mental health system.

(5) Increase Private Sector Participation
The benefit offered through private insurers, who provide mental health services to nearly three-quarters of Massachusetts children, has added strain to the state’s public health system. Ensuring greater private sector participation in children’s mental health is an important step in relieving public sector strain. Efforts to this end, initiated by groups such as the Massachusetts Chapter of the American Academy of Pediatrics and the Alliance for Health Care Improvement, are already underway.

As these and similar initiatives continue, stakeholders should consider greater information
sharing between the public and private sectors. Public programming should seek to inform private programming. For example, programming innovations that evolve from public sector working groups should be shared with private sector planning committees in order to promote innovation and enhance continuity at all levels. Information also should move from the private to the public sector.

(6) Evaluate the Implementation and Effect of the Mental Health Parity Law
Currently, the full impact of the state’s mental health parity law on children is unknown. Greater evaluation of the impact of parity legislation on the mental health of children is required. Evaluations should include: (i) how each plan is implementing parity, and (ii) how the law is actually affecting children’s mental health. These evaluations will highlight issues around private sector responsibility and accountability.

Accessing Services Before Emotional Disturbances Become Severe
(1) Integrate Mental and Physical Health
Policies should be considered that encourage a greater integration of the mental and physical health systems. Integrating mental with physical health care will decrease the mental health stigma by aligning mental health with mainstream physical health care, ameliorate logistical barriers to access to care (i.e., decrease the number of intake visits required to obtain mental health services in each of these care sectors), encourage screening by primary care physicians, and facilitate continuity of care for children. Practically, integration can occur if we:

- Consider adopting legislation that mandates mental health screening by primary care physicians. Georgia adopted a law requiring primary care practitioners to complete a mental health screening assessment at the 2-year-old well-child visit.
- Encourage closer relationships between mental health providers and primary care providers.
- Continue evaluation of MHSPY, which offers a convenient model to examine alternative structuring for mental-physical health care integration.

(2) Broaden the Spectrum of Mental Health Services
Preventing kids from becoming “stuck” requires the bolstering of programs that improve early intervention and prevention programming and also integrate such programs more closely with traditional mental health services and the schools. Therefore, agencies should:

- Deepen the collaboration with schools. This includes (i) continuing the initiatives begun by Department of Social Services Commissioner Harry Spence and the Urban School Superintendents, (ii) exploring new collaborating between school based health centers and traditional mental health services, and (iii) involving schools in discharge planning for kids returning to their home schools from out-of-district placements.
- Deepen the collaboration with the Department of Public Health, which is currently supervising Early Intervention and substance abuse programming.
- Deepen the collaboration with the Department of Youth Services so that we might begin to transform our view of treating many committed youth who have significant unmet mental health needs. Through such collaboration, these children may have greater access to services.
- Promote more research into the development and implementation of prevention programs. Considering the great wealth of academic resources in the state, collaboration between agencies and academic institutions may help in program development.
- Encourage a thorough analysis of how initiatives, such as the Comprehensive Family-Focused Care, might enhance prevention within families utilizing the service and within communities where the services are offered. This is key to improving future prevention programming across the state and reaping the full benefits of Systems of Care model innovations.

(3) Encourage Data Collection and Evaluation
State evaluation of programming should be a priority. Programs such as MHSPY and WCC that have unique and effective approaches to caring for children in need should aim to develop more
rigorous evaluation methods. Specifically, MHSPY and WCC directors should separately evaluate each component of this system (case management, wraparound, etc.) to determine each component’s efficacy. Program directors should also produce cost-effectiveness data and information so legislators and agency heads can evaluate the program and plan future reforms and investments. Data for and evaluation of traditional children’s mental health services are also required so that they can be compared to Systems of Care and other community-based initiatives.

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## Appendix A
A Sample of Other State Collaborative Programs

<table>
<thead>
<tr>
<th>PROGRAM</th>
<th>AGENCIES</th>
<th>FUNCTION-CHARACTERISTICS-RESULTS</th>
</tr>
</thead>
</table>
| Collaborative Assessment Prog. (CAP) | DMH & DSS                    | - Single entry point into DSS and DMH  
- Prompt and intensive community-based care  
- Uses family members and care managers  
- Goal to decrease out-of-home placements |
| Enhanced Residential Centers (ERC)   | Partnership, DSS, & DMA      | - Coordinate & integrate treatments in child's environment  
- Decrease hospitalizations and number of placements  
- Train and support ERC staff  
- Between August 1999 and March 2001 served 192 kids  
- 83% decline in acute service use  
- Led to 34% reduction in costs vs. previous year |
| Transitional Care Units (TCUs)       | DSS & Partnership             | - Serves DSS kids on Cases Awaiting Resolution/Dispo. list  
- Full array of services provided  
- Number of beds: 28 in 3 facilities |
| Enhanced Day Care                    | Office of Child Care Services & Partnership | - Blend funds to provide a full-time therapist at 7 large daycare centers and plans to expand to 4 more in the near future. |
| Restraint/Seclusion Reduction Prog.  | DMH, DSS, DMA & Inpatient Facilities | - Reduce use of restraint/seclusion in inpatient facilities  
- Cambridge Hospital  
- Providence Hospital: Incidents from 30/mo to 3-5/mo |
References


7. Ibid.

8. Warring WE, Massachusetts Division of Medical Assistance. Presentation to the Boston Bar Association, February 28, 2002.


15. Massachusetts Behavioral Health Partnership, “Projects to Enhance Service and Quality of Care” at p. 3.


Chapter 159 of the Acts of 2000, sec. 149-183 (Massachusetts) and 603 CMR 28.00 et seq.

603 CMR 28.08(3). Available from: http://www.doe.mass.edu/lawsregs/603cmr28/603cmr28c.html#28.08.


Larzeler, R, Chmelka, B, Irvin, R. The Cost of Delays in Moving Children and Adolescents Through the Mental Health System of Care in Nebraska, October 2001, in presentation at the Children and Family Coalition of Nebraska Meeting.

Massachusetts Psychiatric Hospital Association, Personal Communication, David Matteodo.


Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) is the child health component of the Medicaid program. Under EPSDT, all eligible children are entitled to periodic screening services, including comprehensive physical examinations, and vision, dental and hearing screens. All eligible children are entitled to any medically necessary service within the scope of the federal program that is to correct or ameliorate defects, and physical and mental illnesses and conditions, even if the state in which the child resides has not otherwise elected to include that service in its state Medicaid plan.

20 USC §§1400 et seq.


Massachusetts Behavioral Health Partnership, “Projects to Enhance Service and Quality of Care” at p. 5


Ibid.


Massachusetts Mental Health Services Program for Youth (MHSPY) data provided to author by Katherine Grimes, M.D.


http://www.state.ct.us/dcf/index.html