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# Children's Mental Health:

An Overview and Key Considerations for Health System Stakeholders



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### EXECUTIVE SUMMARY

One of every five children and adolescents has a mental disorder, and one in ten has a serious emotional disturbance that affects daily functioning. But four out of five children who need mental health services do not receive them. At the highest levels, government policymakers and public health experts recognize the need to transform the mental health service system, including its early intervention components, to assure children who need services get them.

Childhood and adolescence are critical periods for promoting social and emotional development and preventing mental disorders—many major mental health disorders now are recognized to have their onset in childhood. Fortunately, prevention and early intervention efforts can minimize negative consequences for children and their families, as well as costs to society.

Mental health care for children and youth needs substantial improvement. Well-recognized barriers to care include inadequate insurance coverage and geographic, racial and ethnic disparities in access to and quality of care. While improvement efforts are underway, the mental health system is highly fragmented, under-resourced, and chiefly organized around the needs of children and youth with severe mental disorders. For children and youth, fragmentation is compounded by the multiple systems they and their families encounter. Advances in treatment and federal policy developments have helped spur system reforms.

States, communities, health systems and providers are responding with new programs and evidence-based and innovative practices. New research and emerging issues present continual challenges for key health system stakeholders, including policy makers, state program administrators, health plans and providers.

This issue paper provides an overview and highlights of key considerations for health system efforts to promote and improve the mental health of children and youth. It was written as background for the National Institute of Health Care Management (NIHCM) Foundation forum, *Children's Mental Health: New Developments in Policy and Programs*, held on May 13, 2004 in Washington, DC.

### Important Facts About Current Mental Health Services for Children

- **A range of financing sources support elements of comprehensive mental health systems for children and youth.** Medicaid financing for children's mental health services is substantial. Although over two-thirds of children have private insurance coverage, less than half of children's mental health treatment is paid by this source. Federal grants provide some support for prevention and early intervention, including through Head Start, Maternal and Child Health, and Early Intervention under the Individuals with Disabilities Education Act. Federal grant support for treatment comes from mental health, child welfare, and juvenile justice funds. Federal grant funds also support system development and coordination. Additionally, states invest significant funding in children's mental health, primarily for treatment services, and increasingly as Medicaid matching funds.
- **The evidence base for medications and psychotherapies effective for treating mental health disorders in children and adolescents is limited but growing.** Attention deficit hyperactivity disorder (ADHD) has received the most research attention. For depression, new warnings about the safety of many adult antidepressant medications prescribed for youth bring new challenges in treating this relatively common disorder, and the Food and Drug Administration (FDA) recently asked antidepressant manufacturers to add a warning regarding increased suicidal tendencies in some children.
- **A System of Care is a widely accepted framework for implementing mental health services and supports for children, youth and their families.** This framework has resulted in systems improvements, including reduced residential and out-of-state placements. The coordinated public-private approach also has improved provision and financing of service components beyond the scope of medical and specialty care. Its impact on clinical outcomes, however, is less clear.
- **Numerous national initiatives and resources are focused on the mental health of children and youth.** This paper

concludes with a brief review of some of these initiatives. Resources for further information and assistance are included at the back of the paper.

### Key Policy Considerations for Promoting and Advancing Comprehensive Mental Health Systems for Children and Youth

- **Public-private partnerships and active involvement of multiple child and family service systems are necessary for child mental health promotion, prevention and treatment.** Children and youth, particularly those with mental health problems, are served and seen by multiple systems—child care, schools, health care, mental health, child welfare, juvenile justice, and substance abuse to name a few. Services for children and youth need to be child-centered and family-centered, and coordinated or integrated to assure comprehensive services.
- **Primary care providers and systems serve as a first point of contact, especially for very young children, and need further support.** Primary care providers' roles in providing mental health treatment have increased greatly with advances in psychotropic medications. Developmental services including anticipatory guidance, screening, parent education and counseling, and referral for specialty services are key areas of focus in care delivery. Areas for quality improvement have been identified, especially in diagnosis and counseling with medications. Primary care providers need additional support to combat a lack of time, insufficient training, and inadequate community referral resources.
- **Mental health promotion and prevention efforts need to start early in fostering optimal social and emotional development.** Population-based strategies are essential, and public health services such as home visiting are key elements of comprehensive systems for children's mental health. Other approaches receiving attention by states and community-based systems are parenting education, and school-based programs that promote social and emotional skill development and create safe school environments.
- **Effective early intervention efforts must promote routine and systematic screening and assessment in multiple settings where children and youth are seen.** The dynamic nature of child development makes it difficult to distinguish problems within the range of normal development. Screening and assessment can identify potential mental, social, emotional, or learning problems or disorders. Evidenced-based screening and assessment tools are available and important to assist primary care providers, mental health specialists and other professionals in this

challenge. For school-age children and youth, identification of mental health problems occurs most often in schools. However, available teacher training and screening systems may be underutilized in school practice.

- **Use of available quality measurement and improvement tools should be increased.** Available measurement tools address the quality of developmental services, and of services for children with special health care needs. More guidelines and toolkits for quality improvement are necessary.

This issue paper provides an overview of child and adolescent mental health, and considerations and resources for health care providers, health plans, and policymakers in addressing the mental health needs of children, youth and their families. Many national and state reform efforts are being directed at reorienting current systems towards prevention, early intervention, and treatment efforts that lead to recovery. While reforms are occurring in multiple systems addressing child and adolescent well-being, such as child welfare and education, this paper chiefly focuses on efforts and resources related to the health care system. Finally, this paper is written with the premise underlying many analyses of this issue—efforts need to start early to promote overall mental wellness and help avoid or delay the onset of mental disorders.

## BACKGROUND ON CHILDREN'S MENTAL HEALTH

Renewed understanding about the importance of children's social and emotional development on child outcomes and scientific advances in mental health treatment have led to a heightened interest in and recognition of the importance of children's mental health. Several landmark national reports including those by the Surgeon General, the National Research Council and Institute of Medicine as well as the President's New Freedom Initiative recognize the fundamental role that mental health plays in children's overall health, well-being, and academic and life success. According to the Surgeon General, "mental health is fundamental to overall health and productivity."<sup>1</sup>

Health care providers and plans are integral partners in promoting children's and youth's mental health, providing early detection of potential concerns, and ensuring access to mental health treatment. The health care system is perhaps the most common system that families come into regular contact with during a child's early years. Next to schools, it is also the system most frequented by school-age children, youth, and their families. As such, the health care system has a unique opportunity to impact the mental health of all children through comprehensive and coordinated prevention, early detection, intervention, and treatment programs and services.

### Why is Children's Mental Health Important?

Childhood is a critical time for promoting social and emotional development, and preventing mental disorders. In fact, the precursors for many adult mental disorders can be found in childhood.<sup>2</sup> Optimal mental health is marked by the achievement of key milestones—those critical points in children's and adolescents' lives when they attain expected developmental, cognitive, social and emotional markers—and by secure attachments, satisfying social relationships, and effective coping skills.<sup>3</sup> Children's mental health and wellness warrant unique considerations for a number of reasons, including the fact that children and youth are reliant on their parents and caregivers for nurture and support, and signs of mental health problems and disorders may be different in youth than in adults.

Mental problems and disorders affect children and youth from all socioeconomic and racial/ethnic backgrounds. According to national estimates, one in five children and adolescents has a mental health disorder. At least one in ten—or as many as six million children—suffers from a serious emotional disturbance that severely disrupts daily functioning at home, in school, or

in the community.<sup>4</sup> However, in any given year less than 20% of these children receive mental health services.<sup>5</sup> According to the National Advisory Mental Health Council's Workgroup on Child and Adolescent Mental Health, "no other illnesses damage so many children so seriously."<sup>6</sup>

Even though all children and adolescents can experience mental health problems, several factors predispose some children to greater risk for developing a mental disorder. These factors include:<sup>7</sup>

- Poverty,
- Low birth weight,
- Exposure to environmental toxins,
- Child abuse and neglect,
- Exposure to traumatic events or violence,
- The presence of a mental disorder in a parent, and
- Prenatal damage from exposure to alcohol, illegal drugs, and tobacco.

### The Economics of Children's Mental Health

The economic costs for treatment of mental health disorders in children and youth are staggering. Expenditures for children's mental health services were nearly \$11.75 billion in 1998—a three-fold increase from 1986.<sup>8</sup> Outpatient care accounts for a significant proportion of mental health expenditures for children and youth (nearly 60%) followed by inpatient care (about 33%).<sup>9</sup> It is suspected that a significant proportion of these outpatient costs are attributable to school-related services by mental health professionals. Use of psychotropic medications in youth has increased; more than \$1 billion was spent in 1998 on psychotropic medications for children ages 6 to 17.<sup>10</sup> Pharmacy benefits manager Medco Health Solutions reported a 77% increase between 2000 and 2003 in spending on behavioral medications for the group of 300,000 children and youth under age 19 whom it studied.<sup>11</sup>

Research suggests that many mental health problems and disorders in children might be prevented or ameliorated with prevention, early detection and intervention. Overall, prevention and early intervention efforts targeted to children, youth and their families have been shown to be beneficial and cost-effective and reduce the need for more costly interventions and outcomes such as welfare dependency and juvenile detention.<sup>12</sup> Indeed, early intervention efforts can improve school readiness, health status, and academic achievement and reduce the need for grade retention, special education services, and welfare dependency.<sup>13</sup>

### Access to Mental Health Care and Coverage

In most states and communities, significant barriers to mental health care services exist, including fragmentation of services, high service costs, provider and workforce shortages, lack of availability of services, and stigma associated with mental illness.<sup>14</sup> Access to mental health services is so inadequate in some cases that some families are driven to place their children in child welfare or juvenile justice systems in order to obtain care for severe mental health needs.<sup>15</sup> For children and youth, the fragmentation is compounded by the fact that this population is seen and served by multiple systems. Barriers to mental health care exist for all children with mental health needs—four out of five children do not receive mental health services<sup>16</sup>—but they are more pervasive for some groups.

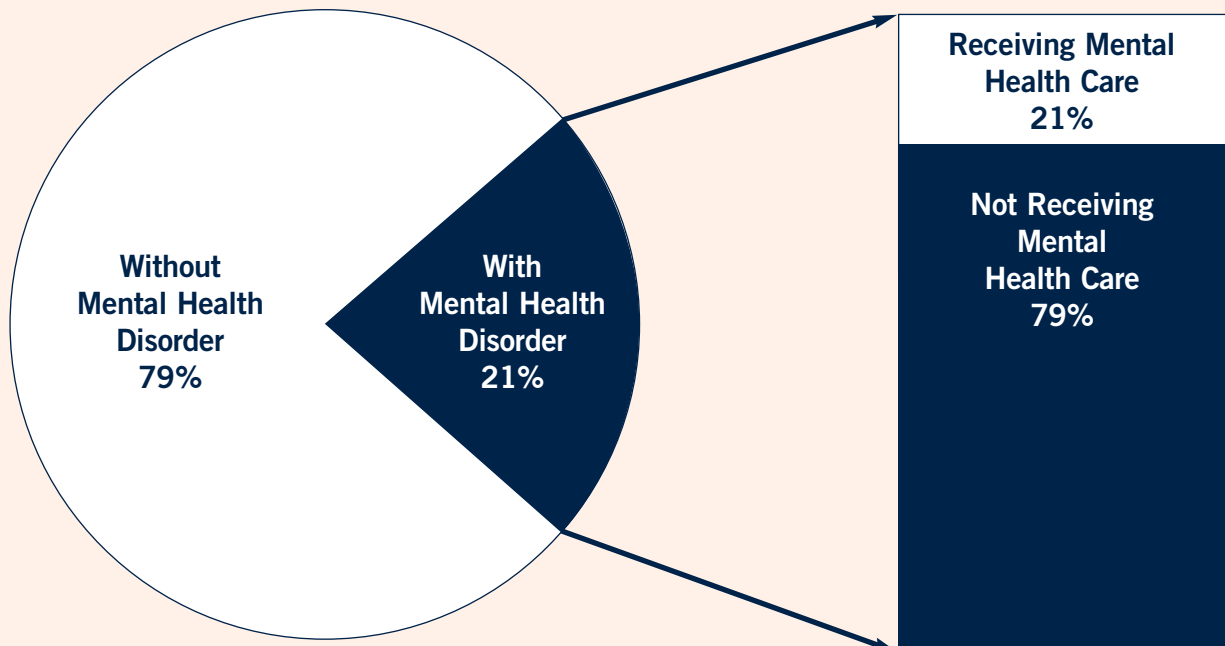
Racial and ethnic disparities are evident in children's access to and receipt of mental health services. While the prevalence of mental disorders in racial and ethnic minorities is similar

to that of their white counterparts, minorities are less likely to have access to mental health services, less likely to receive needed care, and more likely to receive poor quality of care than whites.<sup>17</sup> In children, Hispanics are the most likely of all racial/ethnic groups followed by African-Americans to have the highest rates of unmet need for mental health services.<sup>18</sup>

Nationwide, geographic disparities in service use and unmet need for children's mental health care are also prominent. In comparing states, a recent study found that large differences in service use and unmet need existed. The differences were likely attributable to variations in state policies and health care market characteristics rather than differences in the sociodemographic make-up of the states.<sup>19</sup>

Over three quarters of children and youth who are publicly- or privately-insured or uninsured report unmet needs for mental health care.<sup>20</sup> Moreover, uninsured children are more likely to have unmet needs for mental health care. Nearly 90% of uninsured children report unmet needs for mental health care

### Use of Mental Health Services for Children and Adolescents



Source: Center on an Aging Society, "Child and Adolescent Mental Health Services," October 2003.

as compared to 73% of publicly-insured children and 79% of privately-insured children.<sup>21</sup>

## Trends and Shifts in the Evolving Mental Health Care System

System reforms, advances in mental health treatment, and changes in federal policy are some of the factors that have had an impact on the mental health system. Over the past several decades, system reforms, particularly efforts to deinstitutionalize individuals with mental disorders, have led to shifts in how and where mental health services are provided. Today, more treatment is provided through community-based systems of care than in institutions. Inpatient care has also declined. In 1996, the number of children receiving mental health care in general hospital inpatient facilities had fallen to only 33%.<sup>22</sup> Hospital inpatient units are increasingly providing crisis care and

discharging seriously ill children for community follow-up.<sup>23</sup> A small but significant proportion of youth (5% of children under 18 who received mental health services in 1997) are served in residential care programs (RCPs).<sup>24</sup> A sizeable proportion of these youth (almost two-thirds) have been referred from the social service and juvenile justice systems.<sup>25</sup>

In addition, several key policy issues and federal laws have stimulated change in the mental health system including the Supreme Court ruling in *Olmstead vs. L.C.*, mental health parity, and the Health Insurance Portability and Accountability Act of 1996 (see text box). These issues present significant challenges to state systems, health plans, and providers. Particularly for states with severe budget shortfalls, these mental health issues compete for limited state resources and can hinder states' ability to maintain or expand services and coverage.<sup>26</sup>

## Key Policy Issue Highlights

- In **Olmstead vs. L.C.** (June 1999), the Supreme Court ruled that it is a violation of the Americans with Disabilities Act (ADA) for states to discriminate against persons with disabilities by requiring an individual to be institutionalized when community-based services are more appropriate. One way states can demonstrate compliance with the ADA is to develop a comprehensive, effectively working plan to serve persons with disabilities in the most appropriate setting. As of February 2003, 21 states had issued plans or reports. Some advocates argue that states' emphasis on children with serious emotional disturbances in state Olmstead plans is significantly limited.
- **Mental health parity laws** indicating that parity should exist between mental health and physical health coverage are in place in 23 states; 23 other states have laws mandating some lesser level of mental health coverage. Studies indicate that implementing parity coverage results in minimal-to-no increase in the total costs of health care, and mental health services utilization is no higher in states with parity laws as compared to those without such laws. On the federal level, the Mental Health Parity Act of 1996 has been extended until December 31, 2005. The Senator Paul Wellstone Mental Health Equitable Treatment Act of 2003, which is more expansive in what is required of health insurance plans than its predecessor, has not been voted on by Congress, to date.
- Among a number of provisions, the **Health Insurance Portability and Accountability Act of 1996** required that uniform national standards for electronic health care transactions be established by the Department of Health and Human Services (HHS). Behavioral health plans and providers face particular burden under the new transaction rules. For example, the uniform transaction and code sets put forth by HHS do not adequately reflect codes used by public and private behavioral health care programs.

Sources: *The State's Response to the Olmstead Decision: How Are States Complying?* National Conference of State Legislatures. Washington, DC: February 2003; *Merging System of Care Principles with Civil Rights Law: Olmstead Planning for Children with Serious Emotional Disturbance*. Washington, DC: Bazelon Center for Mental Health Law, November 2001; *State Laws Mandating or Regulating Mental Health Benefits*, National Conference of State Legislatures. Washington, DC: July 2, 2002; Feldman S, Bachman J, and Bayer J. Mental health parity: A review of the research and a bibliography. *Administration and Policy in Mental Health*, January 2002; 29(3); *HIPAA's Electronic Transactions Rule: Implications for Behavioral Health Providers*. Center for Health Services Research and Policy, The George Washington University. Washington, DC: December 2002.

## FINANCING MENTAL HEALTH SERVICES FOR CHILDREN AND YOUTH

Financing of children's mental health programs and services is diverse and variable across and within states, reflecting in part the multi-agency, public-private sector nature of mental health services across the developmental age span. Major categories of financing include private health insurance, federal health insurance programs for low-income children, federal grants, and other sources that include state and foundation funds.

### **Private health insurance**

Private health insurance is the largest payor for children's mental health treatment. While nearly half (50%) of children's mental health treatment is paid for by private insurance, this share of the cost is significantly less than the proportion of children (70%) who are privately insured.<sup>27</sup> Federal legislation to provide parity with benefits for general health was enacted in 1996, but it has a number of limitations. The legislation only requires parity if mental health coverage is offered, and it applies only to annual and lifetime dollar limits and not to copayments, deductibles, or limits on days or visits.<sup>28</sup>

### **Medicaid and the State Children's Health Insurance Program (SCHIP)**

With expansion of Medicaid in the 1980s and creation of SCHIP in 1997, by 1998 one in five children with diagnosed mental health problems were publicly insured. Medicaid historically has borne a disproportionate share of mental health service costs for children, paying nearly 30% of the costs while covering 20% of children with mental health concerns. The categories of children these programs cover—low income, in-state care, with disabilities or extraordinary medical costs—tend to have higher rates of mental health problems than children who rely primarily on private insurance. Additionally, Medicaid's benefit package for children is much richer than for most private insurance plans or even for SCHIP programs that are separate from Medicaid. As noted below, the increased "Medicaidization" of mental health services may raise unintended consequences for the roles and resources of the public mental health system.<sup>29</sup>

The Early, Periodic, Screening, Diagnosis and Treatment (EPSDT) program requires Medicaid coverage for services that are medically necessary to treat conditions identified in screening. Nevertheless, Medicaid coverage of specific treatment options varies across states, with therapeutic foster care, family treatment, and respite care being among the less frequently covered services.<sup>30</sup> Additionally, a recent study found that close to half of states' EPSDT screening tools do

not address behavioral health at all, despite federal requirements for mental health screening.<sup>31</sup> Some states, such as those participating in the Commonwealth Fund's Assuring Better Child Health and Development (ABCD) initiative, are identifying ways to improve Medicaid coverage of preventive early childhood developmental services, including appropriate screening, care coordination, home visiting, and parent counseling.

Increased use of managed care by state Medicaid programs has had an effect on children's mental health service delivery and coverage. States are using a range of options, including fee-for-service reimbursement, "carve-outs" for mental health services, and managed behavioral health care plans that include children. Other states, Hawaii, Indiana, Oregon, and Wisconsin, have created Medicaid programs designed specifically for children with mental health problems. While mental health cost savings resulting from managed care have been documented, studies assessing the overall impact on child mental health and well being have not been conducted.<sup>32</sup> A review of evidence concludes that "although the negative potential effects of managed behavioral health care do not seem to have materialized, neither have many of the hoped-for benefits."<sup>33</sup>

### **Federal grants**

A number of federal grant programs are supporting elements of the continuum of children's mental health services across the developmental age span. The mix and specific uses of grant funds vary significantly from state to state. On the preventive end of the continuum, federal maternal and child health block grant (Title V, Social Security Act) funds support programs in areas such as maternal depression, home visits, and school-based health programs. Major federal programs supporting early screening and intervention with very young children include Head Start, Early Head Start, and birth to three Early Intervention programs under Part C of the Individuals with Disabilities Education Act. Welfare, social service and child care funds also support mental health promotion and prevention services for children, youth and families.

Community-based child mental health treatment similarly is supported by multiple federal grant sources, including child mental health systems development grants initiated 20 years ago. The federal Community Mental Health Services Block Grant is the single largest federal contribution to improving mental health services for all age groups. Also available to children and adults, primary health care delivered by community health centers may be a growing resource for mental health services. While provision of mental health services through these centers is uneven, federal community health center funding is increasing, with some of the increase targeted to expanding services for mental health and substance abuse.<sup>34</sup> Additionally, some of the federal primary care funding is directed to school based health centers, which provide mental health services.



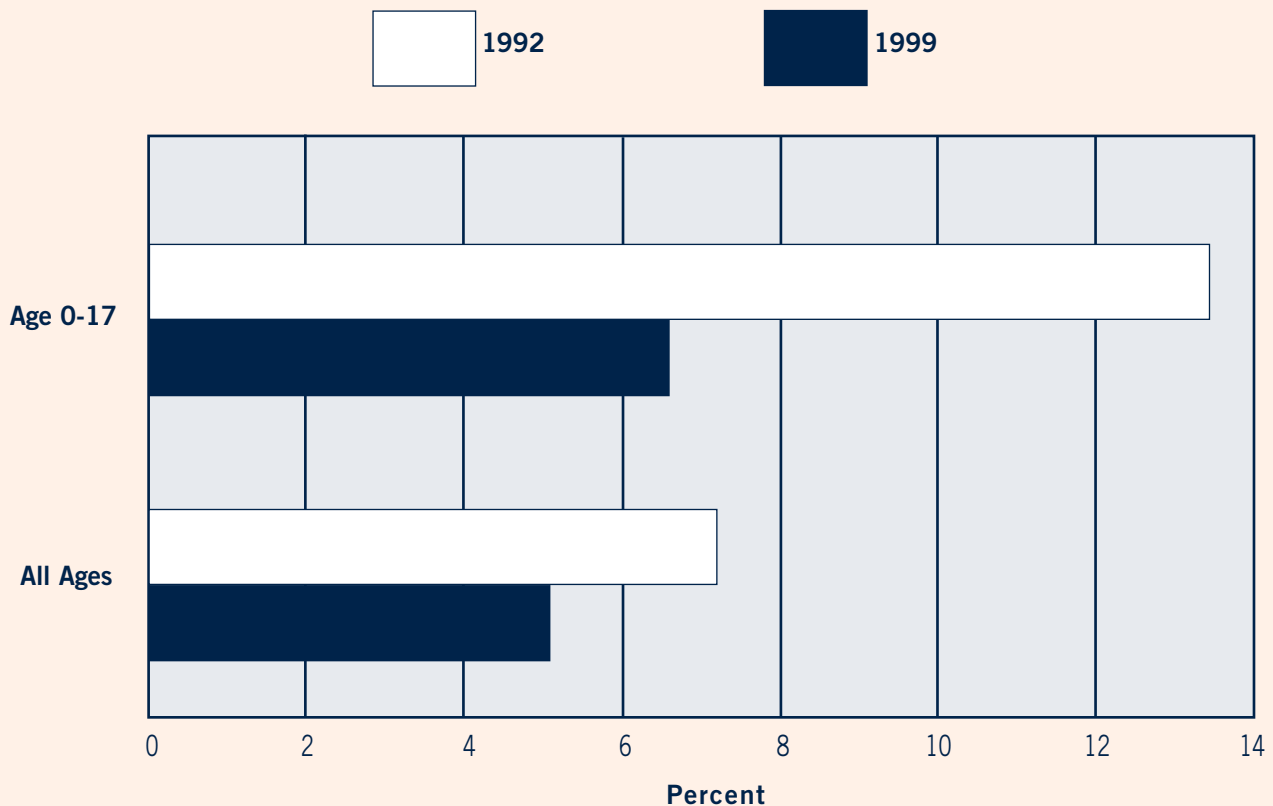
Special education, child welfare and juvenile justice federal funds support a range of services for children and youth served in these systems, and thus also are part of the support for the mental health service continuum.

**Other financing sources**

States also invest their own resources in child and adolescent mental health services. Over 20% of children’s mental health costs are paid by state and local agencies from sources other than public or private insurance. In addition to federal grants and state revenues, these sources may include local and foundation funds. States have developed innovative and creative systems and mechanisms for maximizing and coordinating funding from multiple sources.<sup>35,36</sup>

State funding may be used to “draw down” federal Medicaid matching funds when states are providing Medicaid reimbursable services to Medicaid eligible children. States’ successful efforts to maximize Medicaid funding in this manner have had a major impact on the public mental health system, not all of which may be for the better. With the emphasis on using state funds for Medicaid match, resources for assuring a safety net for growing numbers of uninsured are constrained. Additionally, as services increasingly are privatized through Medicaid managed care arrangements, the role of public mental health agencies has been diminished. One consequence of this shift is that the specialized expertise of these public agencies may be utilized less extensively in state policy and regulatory activities.<sup>37</sup>

**Percentage of Total Private Health Care Spending for Mental Health and Substance Abuse Services for People with Employer-based Private Insurance, 1992-1999**



Source: Mark, TL, Coffey, RM. What drove private health insurance spending on mental health and substance abuse care, 1992-1999? *Health Affairs* (2003); 22(1):165-172.

## Highlights of Selected Prevention Programs and Initiatives

- The Nurse Home Visitation Program provides nurse home visits to at-risk pregnant women from pregnancy to age three of the child in order to improve pregnancy outcomes, child health and development, and families' self-sufficiency. Participation in the program has been associated with fewer subsequent pregnancies, fewer reports of child abuse and neglect, less dependency on welfare, and reductions in costs due to foster care placements, hospitalizations, emergency room visits, and other interventions. More information about the Nurse-Family Partnership Program is available from the National Center for Children, Families and Communities at [www.nccfc.org](http://www.nccfc.org).
- The Offspring Depression Prevention Program of Blue Cross Blue Shield Southeast Regional Center targets health plan members ages 5 to 17 years who have a parent identified as having Major Depressive Disorder (MDD) (identified from behavioral health claims data), and their parents. The goals of the program are to: educate parents with MDD about the higher risks of MDD in their children and how to increase resilience in their children and provide protective factors, educate primary care providers about these issues, promote early detection of depression in this group of children and youth, and promote appropriate follow-up for youth showing signs of depression. More information is available by contacting: Dr. T.B. Kennedy:  
e-mail: [btkenedy@magellanhealth.com](mailto:btkenedy@magellanhealth.com)  
phone: (678) 319-3806.
- The Vermont Child Health Improvement Program is partnering with the National Center for Healthier Children, Families and Communities at UCLA, and the National Initiative on Children's Healthcare Quality to consolidate evidence about best practices in developmental services and create a curriculum to integrate a focus on child development services into primary care practices. This project will support the work of 15 primary care practices around the state to implement office systems to improve the delivery of anticipatory guidance, parent education, systems to assess concerns and detect children at risk of psychosocial and behavioral problems, and other developmental services to children up to five years of age. More information is available at: <http://www.med.uvm.edu/vchip/HP-DEPT.ASP?SiteAreaID=513>.

## BUILDING SYSTEMS TO SUPPORT THE MENTAL HEALTH NEEDS OF CHILDREN AND YOUTH

Children's mental health is clearly a public health issue. Numerous national reports underscore the importance of addressing child and adolescent mental health from a population-based approach that is comprised of a continuum of programs and services ranging from health promotion and prevention to treatment. In order to effectively address children's mental health, community health systems that balance health promotion, disease prevention, early detection and intervention, and treatment are needed.<sup>38</sup> Without such a system, children, youth and families suffer because of missed opportunities for prevention and early identification of mental health needs, fragmented services, and low priorities for resources.<sup>39</sup>

Research indicates that starting prevention efforts early may help protect children from mental and behavioral health problems in adolescence and young adulthood.<sup>40</sup> Comprehensive prevention efforts aim to promote optimal social and emotional development, and emotional well-being in children and youth. Healthy social and emotional development is an essential underpinning to school readiness, academic success, and overall well-being.<sup>41</sup> Emotional well-being has been described as a range of aspects of psychological functioning, such as coping, self-regulation (emotions and behaviors), perceived autonomy and control, and social competence.<sup>42</sup>

### Promotion and Prevention

A number of health promotion and prevention initiatives aimed at addressing health problems other than mental health-related concerns also have mental health benefits for children and youth. For instance, vaccination against measles prevents neurobehavioral complications, and efforts to control alcohol use during pregnancy can help prevent fetal alcohol syndrome.<sup>43</sup> In addition, states and communities are implementing a range of mental health promotion and prevention programs that clearly have important ramifications for preventing mental health problems and disorders in children (see text box). Examples of prevention efforts include:

- Parenting education programs targeted to new parents and/or high-risk families,
- Anticipatory guidance by primary care providers for developmental problems and delays,
- School-based programs that promote social and emotional skills in students, and create safe environments,

- Public awareness activities to reduce the stigma associated with mental illness, and
- Home visiting programs.

Prevention approaches based on building youth assets—positive factors that have been found to be important in promoting young people’s healthy development—have been shown to positively impact school success and reduce the likelihood of youth engaging in risk behaviors (e.g., drug use).<sup>44</sup> For adolescents, mental health programs that use comprehensive, integrated approaches appear to be most effective in preventing such problems as conduct disorder, attention deficit hyperactivity disorder, and alcohol and drug

abuse.<sup>45</sup> Furthermore, analyses of evaluated prevention programs for children and adolescents indicate that effective coordinated prevention programming have the following six characteristics:<sup>46</sup>

- Uses a research-based risk and protective factor framework that involves families, peers, schools, and communities as partners to target multiple outcomes;
- Is long-term, age-specific, and culturally competent;
- Fosters development of individuals who are healthy and fully engaged through teaching them to apply social-emotional skills and ethical values in daily life;

## Interconnected Systems for Meeting the Needs of All Children

### Providing a Continuum of School and Community Programs & Services Ensuring Use of the Least Intervention Needed

#### School Resources

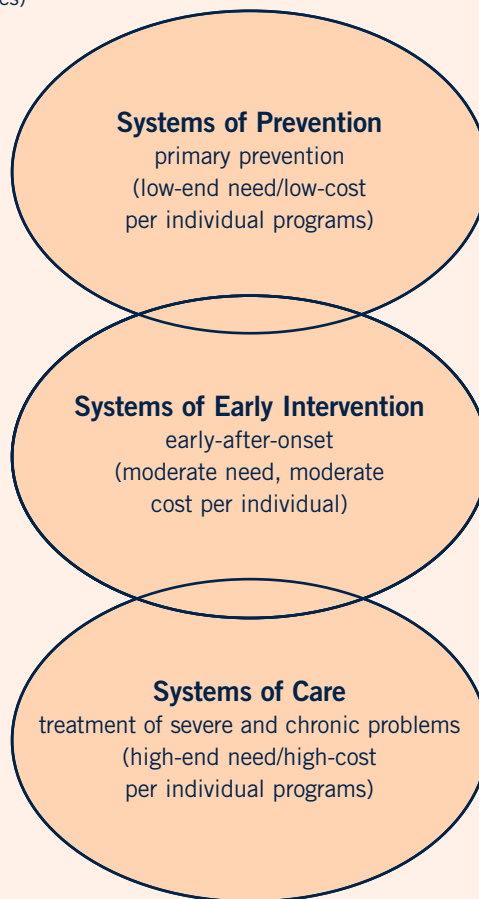
(facilities, stakeholders, programs, services)

Examples:

- General health education
- Drug and alcohol education
- Support for transitions
- Conflict resolution
- Parent involvement

- Pregnancy prevention
- Violence prevention
- Dropout prevention
- Learning/behavior accommodations
- Work programs

- Special education for learning disabilities, emotional disturbance, and other health impairments



#### Community Resources

(facilities, stakeholders, programs, services)

Examples:

- Public health and safety programs
- Prenatal care
- Immunizations
- Recreation & enrichment
- Child abuse education

- Early identification to treat health problems
- Monitoring health problems
- Short-term counseling
- Foster-placement/group homes
- Family support
- Shelter, food, clothing
- Job programs

- Emergency/crisis treatment
- Family preservation
- Long-term therapy
- Probation/incarceration
- Disabilities program
- Hospitalization

Source: Center for Mental Health in Schools (UCLA) and Center for School Mental Health Assistance (University of Maryland), “Integrating Agenda for Mental Health in Schools into the Recommendations of the President’s New Freedom Commission on Mental Health,” March 2004.

- Aims to establish policies, institutional practices, and environmental supports that nurture optimal development;
- Selects, trains, and supports interpersonally-skilled staff to implement programming effectively; and
- Incorporates and adapts evidence-based programming to meet local community needs through strategic planning, ongoing evaluation, and continuous improvement.

## Early Intervention

Effective early intervention efforts routinely and systematically

### Examples of Selected Early Intervention Programs and Initiatives

- Guilford Child Health (North Carolina) is a large pediatric practice that is part of Guilford ACCESS Partnership—one of the state's community-based Medicaid demonstration programs. The practice has implemented a developmental screening model that includes developmental screening, referral, service coordination, and parent education. Parents complete the Ages and Stages Questionnaire (ASQ) at intake when their child is 6, 12, 24, 36, and 48 months old. The ASQ is scored by a physician or nurse practitioner and used as a teaching tool with parents. The practice's Early Intervention Specialist reviews each child's ASQ score and when a problem is detected, makes a referral to the state's local Early Intervention Program. In addition, families are provided referrals for necessary services and parenting classes, and educational materials. More information is available at: [www.nashp.org](http://www.nashp.org).
- The TeenScreen Program, based at Columbia University, creates partnerships with schools and communities nationwide to implement early identification programs for suicide and mental illness in youth. The Program uses simple and widely-evaluated screening tools to detect depression, the risk of suicide, and other mental disorders in adolescents. More information is available at: [www.teenscreen.org](http://www.teenscreen.org).

Source for Guilford Child Health: VanLandeghem K, Curtis D, and Abrams M. *Reasons and Strategies for Strengthening Childhood Development Services in the Healthcare System*. Portland, ME: National Academy for State Health Policy, October 2002.

screen and assess all children and youth for potential mental, social, emotional, or learning problems or disorders, and do so in multiple settings. Early intervention efforts are highly dependent on the ability of providers to appropriately assess for social and emotional development problems and mental health needs in children and youth. These efforts are also dependent on the ability of other professionals—child care providers, teachers, and social workers—to adequately detect if a child may be experiencing a mental health problem. Indeed, only 50% of children with developmental and behavioral disabilities are identified as having a problem prior to starting school.<sup>47</sup> Once in school, children are often misdiagnosed as having a learning disability rather than an emotional disturbance.<sup>48</sup>

Medicaid's EPSDT mandated benefit requires that all Medicaid-enrolled children under the age of 22 be regularly screened for physical and mental health problems. Youth who are detected as having a mental health problem must receive any federally-authorized Medicaid service, whether or not the service is covered under a state's Medicaid plan. A recent report by the U.S. Government Accounting Office indicated that the extent to which children in Medicaid are receiving EPSDT services is not fully known, but available evidence indicates that many are not receiving these services.<sup>49</sup>

It is widely accepted that human development is the result of a complex interplay between genetic and environmental factors that occurs more rapidly in young children but is also life-long.<sup>50</sup> The very nature of child development, however, can make it difficult for parents, providers, caregivers, and others who come into contact with children to distinguish between behaviors that are part of normal development and those that lie outside the normal range. This consideration is particularly true for young children. For young children, the American Academy of Pediatrics cites a developmental model to screen young children and infants for developmental delays that involves:<sup>51</sup>

- Developmental surveillance (e.g., communicating with parents about parental concerns, observations of children, assessing for risk factors);
- Developmental screening (i.e., brief developmental assessment procedure); and
- Developmental assessment or evaluation (i.e., in-depth evaluation that could lead to diagnosis, remediation, or other determination).

In school-age children and youth, mental health identification and early intervention occurs most often in the school system. In general, children with mental health needs are usually referred for screening or identified as having a mental health need as the result of behavior problems in the classroom. Routine and systematic screening of children and youth for mental health needs by trained professionals is not a regular practice in most of our nation's school systems. Cost-efficient systems for mental health screening in school-age children, and

methods for training regular and special education teachers in early detection of mental health disorders are available but seldom used effectively, if at all, in school practice.<sup>52</sup>

## Child Development and Behavioral Screening and Assessment Tools

Several evidence-based child development and behavioral assessment tools are available. Each tool possesses unique strengths and weaknesses. For instance, a number of states use the Denver Developmental II screening test.<sup>53</sup> The tool, however, is known for having modest sensitivity and specificity depending on the interpretation of questionable results.<sup>54</sup>

While there is no single universally-accepted tool for detecting developmental delays in young children, primary care providers increasingly are looking to evaluated and evidence-based parent-report tools. These tools can address the significant time burden that physician-administered tools create. The Ages and Stages Questionnaire and the Parents' Evaluation of Developmental Status (PEDS) are two examples of tools favored for their integration into a primary care setting.<sup>55</sup>

Comprehensive and specialized mental health screening and assessment tools that can be used with children and adolescents are also available. For example, the Pediatric Symptom Checklist, a screening tool featured in Bright Futures, asks families to rate their child's behavior, emotions and learning using a 35-question checklist. More specialized assessment tools include the Vanderbilt ADHD Diagnostic

Rating Scales, the Checklist for Autism in Toddlers, and various assessment tools for depression.

## System of Care

Children and youth with mental health disorders and their families need access to a comprehensive array of interventions, treatments, and supports. These services include: outpatient treatment, medication and monitoring, crisis intervention services, outpatient services, hospitalization and inpatient services, and respite and support services for families.

The System of Care concept was developed to provide an overarching philosophy about the way in which services should be provided to children with serious emotional disturbances (SED). It outlines a set of program and service components as well as the mechanisms, structures and strategies necessary to ensuring comprehensive and coordinated care. Based on the input from numerous experts in the mental health field, System of Care has come to be widely accepted as the basis for services and supports to treat children with SED. More recently, the concept of "wraparound" has been advanced to describe principles and a process for planning and individualizing services for children and families at the individual level and a way to implement a System of Care.<sup>56</sup>

Evaluations of Systems of Care suggest effectiveness in certain system improvements, such as reduced use of residential and out-of-state placements, and improvements in parent satisfaction outcomes. The effects on cost or on

## System of Care Overview

- System of Care is a comprehensive spectrum of mental health and other necessary services that are organized into a coordinated network to meet the multiple and changing needs of children and adolescents with severe emotional disturbances and their families. Along with a set of guiding principles, three core values are emphasized in the System of Care: care must be child-centered and family-focused, community-based, and culturally-competent.
- In a System of Care, local public and private organizations and providers work in teams to plan and implement a tailored set of services for each individual child's physical, emotional, social, educational, and family needs. Services are culturally competent and provided in natural settings (e.g., schools). The Components of a System of Care are: mental health services, social services, educational services, health services, family advocates, substance abuse services, vocational services, recreational services, and operational services. Examples of services include: case management, community-based inpatient psychiatric care, crisis residential care, day treatment, counseling (individual, group, and youth) and legal services.

Sources: Stroul BA and Friedman RM. "A System of Care for Children and Youth with Severe Emotional Disturbances." University of South Florida, Research and Training Center for Children's Mental Health. 1994; and Systems of Care Fact Sheet. U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services. Rockville, MD: 1997.

individual clinical outcomes are less clear.<sup>57</sup> Systems of Care approaches have been important to providing and financing service components that are beyond the scope of what medical and specialty care sectors can provide. Studies suggest, however, that interagency coordination and Systems of Care alone do not improve children's outcomes. Indeed, in some specific areas, emphasizing coordination can contribute to diffusion of responsibility and poor results.<sup>58</sup>

### Federal Leadership

Many health and human service agencies and programs are embracing systems approaches. The federal Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA), and the Surgeon General's Office have promoted concepts of family-centered, comprehensive, community-based, culturally-competent systems of care for all children with special health care needs, including those related to mental health.<sup>59</sup> As MCHB defines children with special health care needs to include at-risk children, its systems concept covers the continuum of

### Examples of Selected Mental Health Care Systems Initiatives

- The Caring for California Initiative (CCI) is a public-academic consortium dedicated to improving the quality of care for children and youth with serious emotional and behavior problems served in California's public specialty mental health care system. The initiative examined: the differences in clinical care processes for children served in California's outpatient child mental health programs as determined by policy and program characteristics, providers' knowledge and skills in cultural competence, and how California counties are using Medicaid's EPSDT. Data from the initiative is being used to inform quality of care efforts in the state. More information is available at: <http://www.hscenter.ucla.edu/research/cci.shtml>.
- The Delaware Diamond State Health Plan's Public/Private Partnership for Children's Behavioral Health Care is a partnership between commercial managed care plans and the state Division of Child Mental Health Services (DCMHS). The approach is an integrated design with a partial carve out. Commercial managed care companies under contract to the state Medicaid agency manage the physical health benefit and a basic behavioral health benefit. DCMHS, acting as a public MCO, manages all behavioral health services beyond the basic behavioral health benefit, utilizing, in effect, a case-rate from the State Medicaid agency, as well as mental health and some child welfare dollars.
- The Hennepin County (Minnesota) Children's Mental Health Collaborative is a partnership of parents, schools, county staff, private service providers, and other community members who collaborate to improve children's mental health services in the county. Children with severe emotional disturbances (SED) and their families who are served by the Collaborative have access to a range of services tailored to the child's unique needs. A Collaborative Family Service Plan is developed for each child that schools, social services, corrections, and other agencies can follow so that care is coordinated. Children are eligible for the program if they are under age 18, live in the county, have an SED, and are involved in two or more systems including school, county services, corrections, public health, medical assistance, SSI, or mental health services. More information is available at: <http://www.sed-kids.org>.
- Wraparound Milwaukee is a behavioral health care carve-out. Its primary focus is children who have serious emotional disorders and who are identified by the child welfare or juvenile justice system as being at-risk for residential or correctional placement. Wraparound Milwaukee serves about 600 children a year. A combination of several state and county agencies, including child welfare, Medicaid, juvenile probation services, and the county mental health agency, finance the system. Wraparound Milwaukee involves families at all levels of the system and aggressively monitors quality and outcomes.

Source: Excerpted from *Promising Approaches for Behavioral Health Services to Children and Adolescents and Their Families in Managed Care Systems: Managed Care Design and Financing*, Health Care Reform Tracking Project 2002, available at: <http://rtckids.fmhi.usf.edu/study05.cfm>.

prevention through treatment. The Surgeon General's National Action Agenda for Children's Mental Health was grounded in the assumption that cross-sector efforts to address children's mental health are needed. Key principles in the agenda include "integrating family, child and youth-centered mental health services into all systems that serve children and youth"; and "developing and enhancing a public-private health infrastructure to support these efforts to the fullest extent possible."<sup>60</sup> As discussed later, both the Substance Abuse and Mental Health Services Administration (SAMHSA) and the MCHB are supporting states and communities in developing systems for children's mental health. A number of technical assistance, training, research and policy centers focused on systems also are supported by federal agencies (see National Initiatives).

### Building Comprehensive Systems at the State Level

Many states and communities are collaborating to promote children's social and emotional development, screen and detect problems early, and provide mental health treatment. The aim in several efforts is comprehensive, coordinated, and integrated approaches across multiple systems reaching children, adolescents and their families. One example of the many efforts underway across the country can be found in Illinois.

The Illinois Children's Mental Health Partnership (ICMHP) was officially established in January 2004 as the result of Illinois legislation—the Children's Mental Health Act—calling for statewide reform of the children's mental health system. The ICMHP is comprised of 25 gubernatorially-appointed members representing mental health, health care, education, child welfare, substance abuse, violence prevention, juvenile justice, families, and other key systems and groups. A strategic plan for building a comprehensive, coordinated system of prevention, early intervention, and treatment is due to the work of the Illinois Governor and General Assembly in June 2005. While the ICMHP work is still in its planning phase, early successes include: a Task Force report outlining recommendations for reforming the system; changes to the way children and youth are pre-screened for mental health treatment; school district policies for promoting social and emotional development required of all Illinois school districts by August 31, 2004; and integration of social and emotional development standards into the Illinois State Board of Education's Learning Standards. More information about the ICMHP is available at: [www.ivpa.org](http://www.ivpa.org).

### The Importance of Family and Caregiver Involvement

Families and caregivers are at the core of a comprehensive continuum of mental health programs and services. They play a central role in promoting the social and emotional

development of children, and are often the first to recognize problems in children and youth. Most parents understand the important role they play in their child's health and development, and mental wellness. In a national survey, 71% of adults understood that brain development can be impacted very early and 76% realized that a child's early experiences have a significant impact on abilities that appear much later in a child's life.<sup>61</sup>

In addition, families and caregivers are critical partners in care for children with mental health needs and serious emotional disturbances. Family support and participation can produce multiple benefits including:<sup>62</sup>

- Reduce the need for inpatient treatment,
- Shorten the length of inpatient stays,
- Improve service coordination, and
- Increase family and caregiver satisfaction.

### The Role of Primary Care in Children's Mental Health

Despite the significant role that other child-serving agencies and systems play in children's mental health, primary care providers remain the first point of contact for most children, particularly in infancy and the preschool years. In those years especially, when prevention and early intervention can have significant long-term impact, primary care providers and organizations have a critical role to play in developmental and behavioral screening, parent counseling, and referral to community resources.

Federal agencies and national organizations such as the American Academy of Pediatrics have placed particular emphasis on the role of primary care providers in early childhood development and children's mental health through the concept of a *medical home*. The medical home's role in linking with other child and family services, including those related to children's mental health, is emphasized in the federal MCHB-sponsored initiative *Bright Futures*.<sup>63</sup> Bright Futures has produced practice guides, including one on mental health that addresses mental health promotion as well as screening and diagnosis. The MCHB also provides grant support for building medical home capacity, and for assuring that medical homes are integrated with *State Early Childhood Comprehensive Systems*.

Primary care plays a substantial and growing role in mental health treatment for children and youth. From the mid 1980s to the late 1990s, the percentage of children's physician visits that included a mental health diagnosis nearly tripled, and nearly all of this increase was for visits at which psychotropic medications were prescribed.<sup>64</sup> In one report, more than one-third of mental health visits by privately insured children were made to a primary care provider rather than a specialist.<sup>65</sup>

Whether primary care providers are prepared fully to take on this increased role in mental health treatment is not entirely clear. There is some evidence to suggest that primary care providers often misdiagnose mental health conditions, have less than optimal outcomes with medications, and generally do not provide psychosocial services along with medication.<sup>66</sup> Lack of time, insufficient training, and inadequate specialized and community referral resources and financing have been cited as barriers to maximizing the role of primary care in addressing the mental health needs of children.<sup>67,68</sup>

Unity Health System in Rochester, New York is an example of an effort underway to integrate behavioral health in primary care. Modeled after the Integration Project in Canada, and funded by MCHB, the program consists of consulting therapists working with primary care practices, which now number 26. The program has evolved from a pilot project to an independent program working with 160 primary care providers, including 57 child and adolescent providers.<sup>69</sup>

Other health plans also have developed initiatives to assure appropriate behavioral services for children in their plans. Kaiser Permanente Northern California is piloting an Autism Spectrum Disorders (ASD) Center. Among its activities is training network providers who work with children on early identification of ASD.<sup>70</sup>

### Quality Measurement and Improvement

As with the evidence base for many aspects of child and adolescent health, less attention has been devoted to measuring quality of care for children than for adults.<sup>71</sup> However, there are some efforts underway to rectify this imbalance, and within those efforts, some attention to mental health.

A key leader and resource in efforts to measure and improve quality of children's health care is the Child and Adolescent Health Measurement Initiative (CAHMI). To date, CAHMI has developed three tools, and more are underway. These tools are intended to complement other efforts, such as the National Committee for Quality Assurance (NCQA) Health Plan Employer Data and Information Set (HEDIS) measures and the Consumer Assessment of Health Plans Survey (CAHPS). All of CAHMI's tools can be utilized by health plans and by states to assess quality of mental health care for children and youth.<sup>72</sup>

The Promoting Healthy Development Survey (PHDS) measures quality of preventive and developmental services for children under age four. The Young Adult Health Care Survey (YAHCS) measures quality of preventive services for youth age 14 to 18. Both use enrollment and encounter data for sampling and to construct key analytic variables related to type of provider, system of care, geographic area, and utilization of services. Measures address areas such as provision of mental health-related anticipatory guidance and parental education, follow-up for children at risk for developmental, behavioral or social

delays, and youth counseling and screening for depression and mental health concerns. In a three-state Medicaid sample, over half of parents reported that they were not asked by their child's pediatric clinician(s) if they had concerns about their child's learning, development or behavior. In another study of youth enrolled in Medicaid in one state, less than one in four youths with depressive symptoms reported that their providers talked with them about their feelings, emotions or moods.<sup>73</sup>

The third CAHMI tool is the Children with Chronic Care (CCC) module. The CCC module is designed to be used with CAHPS or other patient experience-of-care surveys and includes sampling strategies, supplemental survey questions, and guidelines for scoring and presenting quality measure results. A brief screener—the CSHCN Screener—is used to identify children with special health care needs (CSHCN). The screener results can be broken out into subsets of CSHCN with mental, emotional and behavioral consequences. Use of services, unmet needs, and medical home can then be examined for these subsets. Medical home is measured by aspects such as usual source of care, care coordination, and family-centeredness. In a statewide Medicaid managed care plan sample, over half of the CSHCN identified using the screener qualified on the basis of a mental health-related condition. In this same sample, higher rates of problems getting needed care were reported for the CSHCN with mental health-related conditions than for CSHCN without these conditions, or for children without special needs.

A number of other organizations provide leadership and assistance in quality improvement efforts for children's mental health in the context of health systems. Referenced earlier in relation to ADHD, the National Initiative for Children's Health Care Quality (NICHQ) aims to accelerate improvements in primary care. Other areas of NICHQ focus that are relevant to children's mental health include medical home, children with special health care needs, and children in foster care. The Center for Health Care Strategies (CHCS) has focused on Medicaid managed care quality improvement. As part of its Best Clinical and Administrative Practices (BCAP) series, CHCS is developing tools for *Improving Managed Care Quality for Adolescents with Serious Behavioral Health Disorders*. A workgroup of managed care organizations will develop and pilot best practices, which will be documented and made available in a toolkit targeted for publication in early 2005.



## SELECTED NATIONAL INITIATIVES FOCUSED ON CHILDREN'S MENTAL HEALTH

Recent major national reports and legal decisions have both reflected and spurred action at the national level to address mental health. Federal leadership on mental health is visible in both the executive and legislative branches. For example, mental health receives prominent attention in the current set of national health objectives—*Healthy People 2010*. Mental health is one of ten “Leading Health Indicators” identified to represent the major health concerns in the nation.<sup>74</sup> Recent Congressional interest is apparent, for example, in a Senate Substance Abuse and Mental Health Services Subcommittee hearing in April 2004 on *Mental Health in Children and Youth: Issues Throughout the Developmental Process*.<sup>75</sup> Also, Senators Gordon Smith (R-Ore.) and Chris Dodd (D-Conn.), introduced the Youth Suicide Early Intervention and Expansion Act of 2004 (S. 2175).<sup>76</sup>

New and emerging issues also have stimulated further development of national policy and program initiatives related to children's mental health. Such issues include concern about the impact of terrorism on children's mental health, new findings about negative health and social consequences of bullying, and evidence linking chronic obesity with behavior and depressive disorders in children.<sup>77</sup> Highlights of major and many new national initiatives follow.

### President's New Freedom Commission

The report of the President's New Freedom Commission on Mental Health was released in July, 2003. This commission was part of the broader New Freedom Initiative launched in 2001 in response to the Olmstead Supreme Court decision. The commission's report recommends profound changes in mental health policies and programs, embracing six major national goals of a transformed mental health system:<sup>78</sup>

- Goal 1: Americans Understand that Mental Health is Essential to Overall Health
- Goal 2: Mental Health Care is Consumer and Family Driven
- Goal 3: Disparities in Mental Health Services are Eliminated
- Goal 4: Early Mental Health Screening, Assessment, and Referral to Services are Common Practice
- Goal 5: Excellent Mental Health Care is Delivered and Research is Accelerated
- Goal 6: Technology is Used to Access Mental Health Care and Information

All of these goals have implications for children and youth. Federally-funded technical assistance centers on mental health in the schools have produced a brief guide to how all six of the Commission's goals apply to mental health in schools.<sup>79</sup>

Substantial federal funding has been invested in a number of new programs under the broader New Freedom Initiative, including demonstration programs for Community-Based Treatment Alternatives for Children in psychiatric residential treatment facilities. Part of the Real Choice Change Grants for Community Living, these grants are administered by the Centers for Medicare and Medicaid Services (CMS).

### Substance Abuse and Mental Health Services Administration (SAMHSA)

Within SAMHSA, the Center for Mental Health Services is a focal point for children's mental health services. Among its initiatives is the longstanding *Comprehensive Community Mental Health Services Program for Children and Their Families*, providing grants for improving and expanding systems of care for children with serious emotional disturbances and their families. Since 1992, 92 grantees across the country have been supported. More recently, in 2001 the *National Child Traumatic Stress Initiative* was established and supported to bring together academic best practice with community centers treating a range of trauma types across various settings where children are found. Also, SAMHSA's *School Violence Prevention* initiative includes the *Make Time to Listen, Take Time to Talk \*15+* campaign to provide practical guidance to parents. SAMHSA's National Health Information Center includes hotlines and a web-based state mental health service directory. SAMHSA's budget request for Fiscal Year 2005 includes funding for a new program of State Incentive Grants for Transformation to assist states in addressing the New Freedom Commission recommendations, as well as a small increase in the child mental health system grants.

### Health Resources and Services Administration (HRSA)

With its mission encompassing health promotion, preventive and primary care access, and specialized services for women, children, youth and families, the federal MCHB within HRSA has moved to address children's mental health on all of these fronts. MCHB has provided longstanding support for school-based health centers and related policy and technical assistance services, including the Federal Mental Health in Schools Program. This program, in which SAMHSA joined as a co-sponsor in 2000, supports two centers in California and Maryland helping schools and their community stakeholders address mental health of children and youth. These school health-related resources have been joined by a number of relatively new MCHB-sponsored initiatives addressing mental health. Among these are grant

initiatives addressing depression and promoting mental wellness among pregnant women and mothers.

MCHB also has awarded grants to all states to support building comprehensive early childhood systems. The systems include developmental and mental health services for at-risk children, and parenting education and support. A smaller number of grants address *Integrated Health and Behavioral Health Care for Children, Adolescents and Their Families*. The purpose of these grants is to develop systems of care models that integrate primary care, comprehensive mental health services, and substance abuse prevention and treatment services. The goal is to replicate these models in other settings.

HRSA, MCHB's parent agency, has launched a new campaign, "Stop Bullying Now!" With web-based components, resources and tool kits, and public service announcements, the campaign helps parents and educators understand the gravity of bullying and how to stop it. SAMHSA school violence prevention programs also provide tools to address bullying. These initiatives respond to new research conducted by MCHB in collaboration with the National Institute of Child Health and Development, which found that the prevalence of bullying is substantial<sup>80</sup> and that it is a marker for more serious violent behaviors.<sup>81</sup> Studies also have found that bullying is associated with school behavior problems and smoking and drinking, as well as lower grades.<sup>82</sup>

### Centers for Disease Control and Prevention (CDC)

Primarily through the Division of Adolescent and School Health (DASH), CDC supports a number of child mental health relevant initiatives, particularly in relation to surveillance and prevention through school health programs. Mental health services are addressed as one of eight components of a coordinated school health program. CDC provides funding support in 20 states for coordinated school health programs. The Youth Risk Behavior Survey (YRBS) is implemented every two years in schools across the country to monitor youth risk for leading causes of morbidity and mortality. YRBS includes questions on suicidal ideation and behavior, and states can add questions to the core federal instrument. The School Health Policies and Programs Study (SHPPS) is a periodic national survey to assess school health policies and programs, including those related to mental health. The School Health Index (SHI) is a self-assessment and planning tool for schools. The Health Education Curriculum Analysis Tool (HE-CAT) enables educators to evaluate curricula based on elements of effective health education, including in relation to mental and emotional health.

### Foundations

Private foundations also are providing national leadership in addressing children's mental health. For example, the

Commonwealth Fund has sponsored two rounds of grants to states for the ABCD program, designed to assist states in improving the delivery of early child development services for low-income children and their families. ABCD state initiatives have emphasized Medicaid reimbursement strategies for child development services. ABCD II is designed specifically to build state capacity to deliver care that supports children's healthy mental development. An ABCD Toolbox, including resources for providers, can be found on the web site of the National Academy of State Health Policy, which administers the initiative. Other national foundations also have invested in children's mental health. Both the Robert Wood Johnson Foundation and the Annie E. Casey Foundation have played major roles in supporting system of care models for children's mental health. Other state and community foundations, including conversion foundations, are supporting projects to redesign systems or improve specific service components.<sup>83</sup>

## CONCLUSION

The mental health of children and youth is receiving increased attention for a number of reasons. Serious emotional and behavioral disorders now are recognized to have their origins in childhood and affect at least one in ten children. With childhood being a critical time period for promoting healthy emotional development, public health approaches of prevention and early intervention are now recognized as essential to preventing and ameliorating the consequences of mental disorders in children and youth.

For children and youth with mental health conditions, care has shifted from institutions to the community. The Systems of Care model, offering a range of service options, is being implemented across the country. Only one in five children with serious mental health disorders receive services, however, and disparities exist across racial and ethnic groups as well as geographic areas. Schools and primary care providers play major roles in identifying children with mental health service needs, but may not have adopted evidence-based tools for screening, nor have adequate specialized community referral resources. Complicating provision of services for children and youth are the multiple systems serving them and their families, including child care, child welfare, and juvenile justice. Comprehensive system approaches that assure coordination of services and financing are needed.

The evidence base for treatment of child and adolescent mental health disorders is limited, but growing. Specific school-based and family interventions have shown success, as have specific forms of psychotherapy, although most evidence is from experimental rather than actual practice settings. Behavioral medications also have had documented success with some

conditions, although the number of medications approved for children is more limited than for adults, and some concerns exist about risks and side effects for specific medications. Quality of care measures and improvement strategies for child and adolescent mental health are similarly limited but growing.

Federal initiatives and leadership for child and adolescent health are evident. There are many resources available to assist those concerned with children's mental health, especially health providers and plans. Particularly with these resources, health providers can take a number of steps to address the mental health of children and adolescents and prevent the costly consequences of serious behavioral and emotional conditions. Providers and plans can strengthen their focus on child development, and assure that they are utilizing evidence-based tools for both developmental and behavioral screening. Quality measures addressing mental health for children can be adopted and used for improvement. Given the limitations in the evidence base, providers and plans can contribute to the much needed knowledge base by conducting or participating in research and evaluation. It is especially important for private health care systems to coordinate with public systems, particularly schools. Taking these and other steps to promote child and adolescent health and intervene early and effectively will have significant pay off in health system savings and child, family and societal benefits.

## APPENDIX:

### **Evidence and Issues for Specific Mental Health Treatments for Children and Youth**

In 1999, the Surgeon General concluded that “a range of efficacious psychosocial and pharmacologic treatments exists for many mental disorders in children, including ADHD, depression, and the disruptive disorders.” However, the evidence comes largely from controlled research settings, rather than studies in practice settings. While additional research is under way, a review published more recently still notes that “healthy skepticism about current evidence-based practices is not unreasonable.”<sup>84</sup>

Now adding to such general cautions about current limitations of the evidence base for child and adolescent mental health services, come some new concerns about the safety of pharmacologic treatments for depression, and some new information on long-term effectiveness and impact on growth of medications for treating ADHD.

The following discussion first summarizes the evidence for major categories of treatment, and then touches on some of

the issues specific to major disorders manifesting in childhood and adolescence.

#### ***Psychopharmacology***

Although prescription rates have been increasing, randomized controlled studies of medications to treat mental disorders in children and adolescents are limited. As is the case with drugs prescribed for physical conditions, prescriptions for mental disorders often are based on standards for adults or on physician experience. The National Institute of Mental Health (NIMH) commissioned scientific reviews in 1999 of published studies on the safety and efficacy of six classes of psychotropic medications for children.<sup>85</sup> NIMH also is sponsoring a number of current clinical trials for child and adolescent mental health treatments.<sup>86</sup> In 2000, the consumer oriented National Mental Health Association issued a position paper on *The Use of Psychotropic Medication to Treat Children's Mental Health Needs*, which outlines principles concerning the role of medication in the treatment of emotional, behavioral, and mental disorders in children.<sup>87</sup>

#### ***Psychotherapy and Family Focused Treatments***

Meta-analyses of experimental trials suggest a beneficial effect of psychotherapy for children. However, such analyses of the more limited number of studies in clinical practice settings found almost no difference between the group who received treatment versus those with no treatment. Studies in clinical practice settings are underway. Meta-analyses and controlled trials of family-focused treatments indicate effectiveness for a number of conditions.<sup>88</sup>

#### ***School-Based Interventions***

As most mental health service delivery for children and adolescents occurs in schools, the effectiveness of interventions in these settings is particularly important. Review of evidence here suggests a number of effective interventions. These include targeted classroom contingency-based management for children with conduct problems, including ADHD. Behavioral consultation to teachers also has shown some positive effects.<sup>89</sup>

#### ***Integrated Community-Based Treatment***

Studies also have focused on models including intensive case management, therapeutic foster care, and home-based services for children with multiple disorders. Positive results have been documented in some of these studies for these services. Results have been particularly strong for multi-systemic therapy, a home-based intervention for youth with behavioral problems and their families. This therapy addresses problems across environmental contexts.<sup>90</sup>

#### ***Evidence and Issues for Treating Specific Disorders with Onset in Childhood and Adolescence***

A number of major mental disorders are now seen as possibly beginning in childhood and adolescence. These include: anxiety disorders; attention deficit and disruptive behavior disorders;

autism and other pervasive developmental disorders; eating disorders (e.g., anorexia nervosa); mood disorders (e.g., major depression, bipolar disorder); schizophrenia; and tic disorders. Bed-wetting and soiling may be symptoms of a mental disorder in some circumstances.<sup>91</sup> There is limited evidence for the efficacy of specific medications and psychotherapy for most of these disorders, although evidence exists only for medications in the case of schizophrenia.<sup>92</sup> Discussion follows on two disorders that have received heightened attention recently.

### **Attention Deficit Hyperactivity Disorder (ADHD)**

ADHD is one of the most common and studied of mental disorders in childhood. Almost 7% of children aged six to eleven years old have been diagnosed with ADHD, which generally is recognized in the preschool or early childhood years. The disorder is characterized by difficulties in paying attention and controlling behavior, and is more common in boys. Prevention and treatment of ADHD continues to be a subject of debate, with concerns about using medication to control behavior, especially in very young children.<sup>93</sup> As noted above, classroom management has been found to be effective with ADHD.

NIMH has sponsored an ongoing, multi-site cooperative agreement treatment study of young school-aged children with ADHD entitled *The Multimodal Treatment Study of Children with Attention Deficit Hyperactivity Disorder*. The findings, published beginning in 1999, indicated that long-term treatments combining psychosocial/behavioral therapies and medication, as well as medication-management alone, were superior to intensive behavioral treatment and to routine community treatment. The combined treatments were consistently superior for some specific symptom areas, and also required lower dosages compared with the medication-only group.<sup>94</sup> The success of the medication management treatment over routine community treatment appeared to have been due to the more careful management practices utilized in the study.<sup>95</sup> Recently published 10 month follow-up studies indicated an overall diminished effect for medication in part due to changes in use of medication.<sup>96,97</sup> Continuing effectiveness for those children maintaining medication management was documented, but also continuing mild growth suppression. The NIMH also is sponsoring an ongoing multi-site study, "Preschool ADHD Treatment Study" (PATS).<sup>98</sup>

Recent studies have identified a number of areas for improvement in primary care practice related to ADHD. Diagnosis is one area, with many practitioners failing to use DSM criteria or to obtain data from schools. Dosing, follow-up and counseling also have been identified as areas for improvement.<sup>99</sup> NICHQ worked with the AAP and with the support of McNeil Pharmaceuticals to produce a web-based ADHD Practitioners Toolkit. The toolkit is grounded in AAP guidelines published in 2001.<sup>100</sup>

### **Depression**

It is only in the past few decades that depression has been

recognized as a serious problem in children.<sup>101</sup> As many as 8% of children and adolescents 11 to 18 years old meet criteria for depression.<sup>102</sup> Increased recognition has been followed in the past several years by a dramatic increase in use of selective Serotonin reuptake inhibitors (SSRIs) with children and adolescents. There is some research showing that this increase has coincided with a significant decrease in suicide rates for this age group, but it is not known if SSRIs are directly responsible for this improvement. SSRIs have been shown to be of benefit in adults. However, most SSRIs are not approved for use with children, and so are prescribed "off label." Among these antidepressants, only Prozac (fluoxetine) is approved for the treatment of pediatric major depressive disorder.<sup>103</sup>

In October and November, 2004, the Food and Drug Administration (FDA) asked manufacturers of all antidepressant drugs to include in their labeling a boxed warning and expanded warning statements that alert health care providers to an increased risk of suicidality (suicidal thinking and behavior) in children and adolescents being treated with these agents, and additional information about the results of pediatric studies.<sup>104</sup>

Some forms of psychotherapy have proven useful for adolescents with depression. Cognitive-behavioral therapy has the most research support, but interpersonal therapy also has documented benefits.<sup>105</sup> NIMH is conducting research on antidepressants, and on how medications compare with psychotherapy in treating adolescent depression. In the late 1990s, NIMH funded a multi-site controlled clinical trial, the Treatment for Adolescents with Depression Study (TADS), to directly compare the efficacy of Prozac (fluoxetine), cognitive-behavioral therapy, and a combination of the two. Results are pending.<sup>106</sup>

As with ADHD, there are identified concerns with aspects of primary care practice in relation to child and adolescent depression. Work is underway to develop guidelines and tools for diagnosis of depression in youth in primary care settings.<sup>107</sup>

## ENDNOTES

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## SELECTED RESOURCES FOR FURTHER INFORMATION

The following list is by no means exhaustive. Many of these sites provide extensive linkages to additional resources on children's mental health. Furthermore, a more detailed list of links to national resources on children's mental health is available on NIHCM Foundation's web site at: <http://www.NIHCM.org/linksmentalhealth.htm>

FEDERAL AGENCIES	WEBSITE
Centers for Disease Control and Prevention – Division of Adolescent and School Health	<a href="http://www.cdc.gov/healthyyouth">www.cdc.gov/healthyyouth</a>
Centers for Medicare and Medicaid Services – New Freedom Initiative	<a href="http://www.cms.hhs.gov/newfreedom">www.cms.hhs.gov/newfreedom</a>
Center for Mental Health Services, Substance Abuse and Mental Health Services Administration (SAMHSA), U.S. Department of Health and Human Services	<a href="http://www.mentalhealth.samhsa.gov">www.mentalhealth.samhsa.gov</a>
Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA)	<a href="http://www.mchb.hrsa.gov">www.mchb.hrsa.gov</a>
National Institute of Mental Health – Information on Child and Adolescent Mental Health	<a href="http://www.nimh.nih.gov/healthinformation/childmenu.cfm">www.nimh.nih.gov/healthinformation/childmenu.cfm</a>
National Mental Health Information Center – Programs for Child and Adolescent Mental Health	<a href="http://www.mentalhealth.org/child/childhealth.asp">www.mentalhealth.org/child/childhealth.asp</a>
President's New Freedom Commission on Mental Health	<a href="http://www.mentalhealthcommission.gov">www.mentalhealthcommission.gov</a>
"Take A Stand. Lend A Hand. Stop Bullying Now!"	<a href="http://www.stopbullyingnow.hrsa.gov">www.stopbullyingnow.hrsa.gov</a> , or call 1-888-ASK-HRSA
US Food and Drug Administration, Question and Answer on Anti-Depressant Use in Children, Adolescents and Adults	<a href="http://www.fda.gov/cder/drug/antidepressants/Q&amp;A_antidepressants.htm">www.fda.gov/cder/drug/antidepressants/Q&amp;A_antidepressants.htm</a>

PROFESSIONAL ORGANIZATIONS	WEBSITE	DESCRIPTION
The American Academy of Child and Adolescent Psychiatry	<a href="http://www.aacap.org">www.aacap.org</a> <a href="http://www.aacap.org/clinical/parameters/index.htm">www.aacap.org/clinical/parameters/index.htm</a>	provides information on child and adolescent psychiatry, fact sheets for parents and caregivers, current research, practice guidelines, and managed care information
The American Academy of Pediatrics	<a href="http://www.aap.org">www.aap.org</a>	has extensive education, advocacy and clinical and policy resources
The National Association of School Nurses	<a href="http://www.nasn.org">www.nasn.org</a>	has resources that include a recent position statement and issue paper on mental health
The National Association of School Psychologists	<a href="http://www.nasponline.org">www.nasponline.org</a>	represents and supports school psychology through leadership to enhance the mental health and educational competence of all children.
The Society for Adolescent Medicine	<a href="http://www.adolescenthealth.org">www.adolescenthealth.org</a>	has issued position papers on topics that include eating disorders
QUALITY MEASUREMENT AND IMPROVEMENT	WEBSITE	DESCRIPTION
Bright Futures	<a href="http://www.brightfutures.org">www.brightfutures.org</a> <a href="http://www.brightfutures.aap.org">www.brightfutures.aap.org</a>	is a national health promotion initiative for infants, children, and adolescents offering practice guides, distance education and training tools, including a practice guide on mental health
The Center for Health Care Strategies	<a href="http://www.chcs.org">www.chcs.org</a>	provides training and technical assistance to help states, health plans, and consumer organizations effectively use managed care to improve the quality of services for beneficiaries, reduce racial and ethnic health disparities, and increase community options for people with disabilities
Child and Adolescent Health Measurement Initiative (CAHMI)	<a href="http://www.cahmi.org">www.cahmi.org</a>	tools and resources
National Initiative for Children's Health Care Quality (NICHQ)	<a href="http://www.nichq.org">www.nichq.org</a>	tools and resources

TECHNICAL ASSISTANCE CENTERS	WEBSITE	DESCRIPTION
Mental Health in Schools Program	<a href="http://www.smhp.psych.ucla.edu">www.smhp.psych.ucla.edu</a> <a href="http://www.csmha.umaryland.edu">www.csmha.umaryland.edu</a>	<p>Developed in 1995, with support from the MCHB, HRSA, the Federal Mental Health in Schools Program focuses on increasing capacity of policy makers, administrators, school personnel, primary care health providers, mental health specialists, agency staff, consumers, and other stakeholders to enhance how schools and their communities address psychosocial and mental health concerns. SAMHSA's Center for Mental Health Services joined MCHB in 2000 in braiding resources to co-support two centers. These centers are the Center for Mental Health in Schools at UCLA and the Center for School Mental Health Assistance at the University of Maryland, Baltimore.</p>
National Technical Assistance Center for Children's Mental Health	<a href="http://www.gucchd.georgetown.edu/cassp.html">www.gucchd.georgetown.edu/cassp.html</a>	<p>Based at the Georgetown University Center for Child and Human Development, the Center assists states to build systems of care for children and adolescents who have or who are at risk for mental health problems.</p>
Research and Training Center for Children's Mental Health	<a href="http://www.rtckids.fmhi.usf.edu">www.rtckids.fmhi.usf.edu</a>	<p>Based at the at University of South Florida's Louis de la Parte Florida Mental Health Institute, the Research and Training Center was initiated in 1984 to address the need for improved services and outcomes for children with serious emotional/behavioral disabilities and their families.</p>
The Promising Approaches Series	<a href="http://www.fmhi.usf.edu/cfs/stateandlocal/hctrking/hctmain.htm">www.fmhi.usf.edu/cfs/stateandlocal/hctrking/hctmain.htm</a>	<p>Since 1995, the Health Care Reform Tracking Project (HCRTP) has been tracking publicly-financed managed care initiatives and their impact on children with mental health and substance abuse (i.e., behavioral health) disorders and their families. Drawing on the findings to date, a series of papers, Promising Approaches for Behavioral Health Services to Children and Adolescents and Their Families in Managed Care Systems, highlights relevant issues and approaches that have surfaced through the HCRTP's all-state surveys and in-depth impact analyses in a smaller sample of 18 states.</p>
OTHER NATIONAL ORGANIZATIONS AND RESOURCES	WEBSITE	DESCRIPTION
Annie E. Casey Foundation	<a href="http://www.aecf.org">www.aecf.org</a>	<p>fosters public policies, human service reforms, and community supports that more effectively meet the needs of today's vulnerable children and families</p>
The Association of Maternal and Child Health Programs	<a href="http://www.amchp.org">www.amchp.org</a>	<p>has resources on prevention as well as children with special health care needs, including a fact sheet on children's mental health</p>



OTHER NATIONAL ORGANIZATIONS AND RESOURCES (continued)	WEBSITE	DESCRIPTION
The Association of State and Territorial Health Officials	<a href="http://www.astho.org">www.astho.org</a>	has a project on maternal and child health that produced a resource guide on child and adolescent mental health
The Bazelon Center for Mental Health Law	<a href="http://www.bazelon.org">www.bazelon.org</a>	promotes the rights of people with mental disabilities and offers a range of resources and information on children's mental health
Center for Health and Healthcare in Schools	<a href="http://www.healthinschools.org">www.healthinschools.org</a>	provides numerous resources on mental health in schools
The Center for Health Services, Research and Policy	<a href="http://www.gwhealthpolicy.org">www.gwhealthpolicy.org</a>	located at The George Washington University, it provides numerous resources on Medicaid, SCHIP and overall health care access, quality, and financing
Children and Adults with Attention-Deficit Hyperactivity Disorder	<a href="http://www.chadd.org">www.chadd.org</a>	a national non-profit organization providing education, advocacy, and support to children and adults with ADHD.
Children's Defense Fund	<a href="http://www.childrensdefense.org">www.childrensdefense.org</a>	resources include a kit on children's mental health
The Commonwealth Fund	<a href="http://www.cmwf.org">www.cmwf.org</a>	supports initiatives and provides resources on improving quality of health care generally and early childhood development specifically
The Federation of Families for Children's Mental Health	<a href="http://www.ffcmh.org">www.ffcmh.org</a>	a national family-run organization dedicated exclusively to helping children with mental health needs and their families achieve a better quality of life
National Academy for State Health Policy	<a href="http://www.nashp.org">www.nashp.org</a>	includes resources and information on the Assuring Better Child Health and Development (ABCD) Initiative

OTHER NATIONAL ORGANIZATIONS AND RESOURCES (continued)	WEBSITE	DESCRIPTION
The National Adolescent Health Information Center	<a href="http://youth.ucsf.edu/nahic">youth.ucsf.edu/nahic</a>	offers extensive resources on all aspects of adolescent health, including topics such as suicide and violence
The National Assembly on School Based Health Care	<a href="http://www.nasbhc.org">www.nasbhc.org</a>	a not-for-profit membership association whose mission is to nurture interdisciplinary school-based health care.
The National Association of State Mental Health Program Directors	<a href="http://www.nasmhpd.org">www.nasmhpd.org</a>	represents the directors of state mental health authorities
The National Center for Children in Poverty	<a href="http://www.nccp.org">www.nccp.org</a>	provides a range of resources on children's issues, including mental health
The National Center for Education in Maternal and Child Health	<a href="http://www.ncemch.org">www.ncemch.org</a>	maintains a number of resources, including a library and MCH projects database
National Conference of State Legislatures	<a href="http://www.ncsl.org">www.ncsl.org</a>	includes information on a range of policy issues of interest to state legislatures and resources on states' mental health parity initiatives
The National Governors Association	<a href="http://www.nga.org">www.nga.org</a>	provides policy analysis and resources to the nation's governors and their staff
The National Mental Health Association	<a href="http://www.nmha.org">www.nmha.org</a>	a national advocacy organization dedicated to improving the mental health of all Americans
Robert Wood Johnson Foundation	<a href="http://www.rwjf.org">www.rwjf.org</a>	a non-profit dedicated to improving the health and health care of all Americans

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