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Improving Access to Children's Mental Health Care:
Lessons from a Study of Eleven States

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The Center for Health and Health Care in Schools (CHHCS) is a nonpartisan policy, resource, and technical assistance center with a 25-year history of developing strategies for better outcomes for children. CHHCS partners with foundations, government health and education agencies, school districts, intermediaries, and providers across the country to advance their school-connected initiatives. Located at the George Washington University School of Public Health and Health Services, CHHCS applies its expertise in children's health and education policy to build and sustain services and programs grounded in evidence of what works.
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About the Series

Improving Access to Children's Mental Health Care: Lessons from a Study of Eleven States is the second in a series of studies that report on strategies to sustain children's mental health services and prevent the onset of problem behaviors. The first paper, *Developing a Business Plan for Sustaining School Mental Health Services*, examines three case studies in which local communities partnered with state agencies to support school-connected services. Future papers will focus on the mechanics and politics of building long-term support for mental health promotion and illness prevention services in schools.

Introduction

Implementation of the Patient Protection and Affordable Care Act (ACA) is well underway, creating long-overdue opportunities for growing the capacity of child and adolescent mental health systems and meeting children's pressing needs. The good news is that as of January 1, 2014, coverage of mental health conditions and substance use disorders will be required as part of the broad Essential Benefits package of services under the ACA. While states will determine specific benefits, it is widely accepted that mental health and substance abuse coverage will substantially increase, though the details remain to be determined.[1] Additionally, as a result of this new law, funding for prevention, early intervention, and treatment services and programs will likely expand.

A challenge to capitalizing on the ACA opportunity, however, is the underdeveloped state of children's mental health services across the United States. Unlike children's physical health services, for which there is a robust private and publicly funded functioning system, management and delivery of mental health services are much less well developed or coherent. From significant disconnects between the multiple institutions that serve children and their families to chronic financial instability, the children's mental health system is fragile and at-risk. Realizing the promise of the ACA for children and adolescents will require acknowledging systemic barriers that often lead to significant disparity and gaps in care.

The following research, conducted by the George Washington University Center for Health and Health Care in Schools (CHHCS), identifies the systemic challenges to ensuring children's access to mental health care common among many states and points to encouraging examples of success. The bright spots can serve as a guide for those responsible for implementing the ACA or developing other policies that strengthen children's mental health supports.
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Children's Mental Health: The Past 20 Years

While the current capacity of children's mental health services remains inconsistent and insufficient, the federal and state governments have made modest progress in addressing the problems over the last two decades. These efforts have focused primarily on linking or integrating the various components of care to improve connectivity and secure better outcomes for children.

These initiatives have typically included one or more of the following elements:

- ***Integrating residential and inpatient care with community-based care.*** These programs connect residential and inpatient care with home-based and community-based care for seriously emotionally disturbed children.[2] The goal of this movement has been to reduce residential treatment, increase family and community care, integrate domains of care, and secure lower per-case costs.

- ***Integrating family priorities into professional care plans.*** Including families in treatment planning for mentally ill children is driven by the belief that parental knowledge and interests should drive care plans for seriously emotionally disturbed kids.

- ***Integrating primary medical and mental health care.*** This strategy emphasizes linking pediatricians and other primary care providers with behavioral health professionals, encouraging cross referrals and comprehensive care management.

- ***Integrating children's mental health services and K – 12 schools.*** An emerging theme of the past 20 years has been recognition that school-community partnerships can fill gaps in the delivery of children's mental health services. These partnerships have been promoted by: (1) those who want school-community mental health collaborations to address the unmet needs of seriously emotionally disturbed children, and (2) those who want to expand school-based preventive and early intervention programs as a way to create emotionally healthy school environments and support early identification of children with behavioral health needs.

Despite these positive trends, the availability of mental health services remains insufficient to help many children who need care.[3,4] Low-income children have been especially underserved. As noted in the National Academies 2009 study, *Preventing Mental, Emotional, and Behavioral (MEB) Disorders,* "early MEB disorders should be considered as commonplace as a fractured limb."[5] A study from the 1990s[6] that continues to be recognized as particularly insightful regarding children's mental health needs reported the following:

Only 20 percent of children with diagnostic disorders saw a mental health specialist

Only 40 percent of children diagnosed with a serious emotional disorder saw a specialty mental health clinician

Fewer than ten percent of children receiving mental health services got them for more than three months

Source: Costello EJ. The Great Smoky Mountains Study: A detailed picture of children's mental health services in western North Carolina. Reprinted in: North Carolina Family Impact Seminar (2006). Douglass N, Owen J, Berlin LJ, eds.

In 2010, it was estimated that the overall prevalence for lifetime disorders among a nationally representative group of young people ages 13 to 18 was 22.2 percent, with many of those disorders appearing during childhood or adolescence.[7]

Efforts to create a children's mental health safety net have met with limited success. The federal government, through the Substance Abuse and Mental Health Services Administration (SAMSHA) and the Department of Education, has supported a variety of pilot and demonstration programs at the community and state levels to expand child and adolescent mental health programming.[8] However, support for children's mental health services is typically not high on the public or political agenda. Moreover, the use of Medicaid carve-outs at the state level that set aside specific funding levels for mental health services have limited the availability of public dollars for low-income children's mental health care.

Of equal concern is the complexity of the relationships among federal and state authorities not only in the ongoing adaptation and development of Medicaid but also in the implementation of the Mental Health Parity and Substance Abuse Equity Act. These issues will continue to challenge those attempting to improve mental health programs and services for children. Some of the strategies described in the following pages suggest different ways of approaching and responding to those challenges and making important progress in improving children's mental health services.

State Policies And Programs That Support Children's Mental Health

In the summer and fall of 2011, researchers at CHHCS undertook a study of how children's mental health services are organized and paid for with the intent of uncovering what is working, and what is not. We conducted one-hour interviews with 47 individuals from 11 states: Arizona, Connecticut, Florida, Georgia, Massachusetts, Minnesota, North Carolina, Oregon, Texas, and West Virginia. States were selected to ensure a variety of population sizes and regions of the country were represented. Interviewees included representatives from governors' offices, state mental health agencies, education and health departments, and child advocacy organizations.

Our conversations focused on children's mental health programming, with questions that dealt specifically with school mental health. We asked whether there had been recent efforts to improve services for children and, if so, were there specific triggers, such as lawsuits or critical incidents that drove policy. From these interviews, themes emerged that are relevant to current discussions about mental health services for children and adolescents.

A goal in sorting through the complexity that characterizes state-level child mental health programs was to identify "bright spots" where mental health policies and programs have worked and children have been served. We sought to understand what interventions or activities states are undertaking that seem to improve services or outcomes for children and adolescents.

As described below, there *are* bright spots within a number of states, as well as serious challenges in all the states we explored. The following summary of our findings suggests both the diversity reflected across the 11 states studied, along with the promising practices and lessons to be learned from these examples.

Key Findings

1. The critical challenge to strengthening children's mental health programs is funding, a result of the low priority assigned to these services. Often this comes as a result of the stigma associated with mental health.

Nearly all of those interviewed for this study agreed that adequate and consistent funding is the major challenge to securing high-quality children's mental health services. While wise use of resources is essential, the consensus is that quality programs and services depend on sufficient and sustained funding.

Securing adequate support for children's mental health services will be aided by implementation of the mental health parity guarantee in the Affordable Care Act. But this will not guarantee full access to services and programs for every child.

Repeatedly, key informants noted the impact of public revenue losses experienced by state governments when the housing market collapsed in 2007 and the economy dropped into a sustained recession. The ongoing stresses on state government revenues were cited as strong deterrents to program improvements for children and youth.

The consequences of the economic downturn are graphically demonstrated in Florida, which experienced the full impact of the housing collapse. Florida ranks 48th among the 50 states in mental health spending and is in the bottom quarter of state per-pupil education spending. Recent cuts in public mental health spending have resulted in the lead state children's mental health agency, the Florida Department of Children and Families, as well as local mental health agencies, reducing the number of their full-time equivalent positions by 50 percent.

Privately insured children also face access-to-care constraints due to funding cuts. In 2011, Florida Blue Cross/Blue Shield canceled its contracts with mental health providers. The "Blues" will only accept (and therefore reimburse) providers who are willing to offer services at 50 percent below the previous fee-for-service rate.

In addition to the decline in the pool of state general revenues for services such as children's mental health, several of those interviewed suggested that the stigma associated with mental health appears to limit discussion and legislative action on children's mental health needs. It remains easier to rally support for treating children's disabling *medical* conditions than it does for addressing *mental* disorders, even though they similarly threaten a child's well-being.

The absence of public discussion on the mental health risks for children results in a profound lack of knowledge about unmet needs, what agency or agencies are responsible for addressing problems, and how provision of care is compensated. By the time experts step up to provide the details on how the child mental health system works, a profound sense of MEGO (My Eyes Glaze Over) sets in among both policy makers and voters. The problems seem too complex to address and no action is taken.

2. Services for seriously emotionally disturbed children and adolescents remain the primary focus of effort and funding by state governments.

As one interviewee said, "We do what we are required to do; there's not much money available for anything else." State legislatures typically act to provide services only when there is a deep, compelling awareness among voters or a particularly powerful advocate urging that these services are essential, and often as the result of a newsworthy incident or tragedy. Because funding tends to follow mandated services, it becomes difficult for even well-intentioned state agency leaders to secure dollars to invest in upstream prevention programs and services and broaden their focus beyond crisis services.

Informants from several states commented that the competition for limited mental health dollars is not only affected by the compelling need of those requiring hospitalization or residential treatment, but also by the political power of the residential treatment providers. Institutional providers frequently are more proactive in lobbying state agencies or legislators than community-based organizations.

3. The complexity of child mental health service delivery systems and funding streams hampers integration and expansion of services.

A number of states have no single agency in charge of children's mental health. In Georgia, for example, public funding for children's mental health care is associated with three distinct government systems. The Department of Behavioral Health and Developmental Disabilities supports mental health services for kids receiving Supplemental Security Income (federal payments for disabled children) and for children in foster care. The Georgia Medicaid and CHIP offices, located in the Department of Community Health, serve their beneficiaries through a separate network of carved-out, for-profit managed mental health providers. The school systems, another component of the care delivery system, are responsible for seriously emotionally disturbed children who qualify for special education services under the Individuals with Disabilities Education Act (IDEA).

Similar to Georgia, New Mexico also has no single mental health authority. In 2004, the state established a Behavioral Health Collaborative with 20 members, including representatives of 17 state agencies. This approach was intended to take all state mental health dollars and pool them in a single mental health funding stream. Since that single stream is managed by the 20 members of the Collaborative, the challenge of coordination remains. Public education was the only agency that did not add funds to the pot. Initially, the State Department of Education used a federal SAMHSA grant to fund a position focusing on behavioral health services and representing the education sector on the Collaborative. When the grant ended, the position went away and the education sector was no longer represented on the Collaborative.

Mental health care for kids in Minnesota is also fragmented among several departments. As kids move from one system to another, there is a lack of communication and care coordination. One interviewee shared the story of a teen diagnosed with a bipolar disorder and identified as a danger to himself and others. He was discharged from a residential treatment center. While awaiting placement in another program, with no medication and no supervision, he shot several people. No one took ownership of this teen -- a chronic and all too frequent problem as children move among systems or services. It is not always about the money. Sometimes it is about communication, coordination, and continuity of care.

The complicated service delivery *and* payment arrangements found in numerous states confound families and providers alike and tend to discourage focus on how to improve services. It can simply seem too heavy a lift.

4. Court actions have varying impacts on children's access to mental health services.

In 2006, the Massachusetts Supreme Court held in *Rosie D v Romney* that the state Medicaid program had failed to provide seriously emotionally disturbed children with the care required by the Medicaid Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program[9] and that the state programs had failed to organize community care in such a way that seriously emotionally disturbed children could be cared for at home. As a result of this court action, the quest to bring state-supported programs into compliance with the court ruling has dominated discussions and funding decisions about children's mental health in Massachusetts for the past six years. A key to forward movement has been the development of an overarching framework that articulates a statewide vision.[10]

A 2001 Arizona court decision (*JK v Eden*), however, suggests there are limits to the impact of judicial rulings. In this case, the court upheld the plaintiffs' complaint that Arizona mental health agencies had failed to provide timely services for children as required under the Medicaid EPSDT program. Despite this ruling, there have been limited changes in state policies and programs over the past decade. While government representatives have not taken issue with the ruling, they describe their challenge as figuring out how to sustain or expand services with decreasing revenues.

5. State action expanding insurance coverage for low-income children and families can lead directly to increased service access.

Under its health care reform initiative (MassHealth), Massachusetts has redirected its health care spending from reimbursing health providers for uncompensated care to purchasing insurance coverage for those not covered by the private market. As a result, fewer than four percent of children in Massachusetts are uninsured.

While the state continues to focus its mental health efforts on the seriously emotionally disturbed child and adult populations, the state is also increasing early problem identification efforts through expanded screenings during well-child and primary care visits. The Children's Behavioral Health Initiative, a component of MassHealth, requires primary care providers to offer standardized behavioral health screens at well-child visits. With state funding, pediatricians identified eight screening tools that could be used to identify problems. Community physicians also have been trained in their use. These changes were implemented in December 2008. Currently 70 percent of MassHealth kids are being screened. Unknown, however, is the percent of those identified as needing follow-up services who have actually received them.

6. While legislative and judicial actions to improve children's mental health care have been encouraged by community and family advocates, professional associations and clinical providers have also pressed for change.

As is often the case in successful endeavors to address systematic change, building allies from different sectors can lead to positive action. In North Carolina, for example, collaborations across professional sectors have led to expansions of the mental health workforce and increases in access to screenings for mental health issues among children.

About 10 years ago, the North Carolina chapter of the American Academy of Pediatrics, together with colleagues in psychology, social work, and child psychiatry, worked with the state Division of Medical Assistance (Medicaid) to assess how they could safely and securely share data among the various clinical disciplines that sometimes care for the same children. Several years of negotiation resulted in an expanded number of licensed mental health professionals eligible to bill Medicaid directly. Additionally, primary

care providers were authorized by the Medicaid agency to provide up to 26 pediatric mental health visits. For up to six visits providers can assess children without needing a diagnosis to be paid. These efforts that blend private sector practice with public sector payment policies were supported by federal SAMHSA grants that funded the North Carolina initiatives to strengthen systems of mental health care.

7. While most states have prioritized services to support seriously emotionally disabled children, at least one state has implemented a comprehensive approach that links prevention and early intervention services to deep-end care.

In West Virginia, school-located services are an entry point to a full range of mental health services for children. The West Virginia strategy views expanded school mental health programs not simply as a tweak to existing services, but as a foundational strategy for building a comprehensive children's mental health program.

Over the past several years, West Virginia has developed an Expanded School Mental Health Initiative that funds three tiers of mental health services: prevention, early intervention, and treatment services. On the prevention end of the continuum, many West Virginia schools provide character education, a term that typically includes values-focused curricula that promotes violence prevention, self-esteem building, and empathy. Some schools go beyond this and implement evidence-based programming around universal prevention strategies. The middle tier of mental health programming, early intervention and targeted intervention, is the least developed mainly due to uncertainty about which agency is responsible for its organization and funding. The third tier, treatment services, includes therapy, evaluations, psychiatry, medication, and similar functions that are handled by highly trained mental health professionals. Services at this end of the continuum are less likely to be school-based.

The comprehensive program serves all students in seven communities across the state. In these communities a combination of funding from the state departments of health and mental health, together with several federal grants, supports school-based programming. The schools provide primary prevention programs using their staff members. Schools and mental health agencies collaborate to offer universal, early, and targeted interventions. Mental health agencies deliver therapeutic, evaluative, and psychiatric services in schools or at school-connected sites. The state initiative builds on an expansive network of school-based health centers that hire mental health professionals. Currently 68 school-based health centers serve 82 schools that enroll a total of approximately 45,000 students. Important financial support for West Virginia's school-based services have come from the Sisters of St. Joseph Health and Wellness Fund, created in 2001 by a congregation of Catholic nuns who sold their hospital at the beginning of the decade. The sisters have committed their resources to funding the school-based health initiative and child advocacy centers.

A policy change that supports the Expanded School Mental Health program is a new approach to school discipline taken by the State Board of Education. In fall 2011, the West Virginia State Board of Education changed its previous zero-tolerance policy. Now the first chapter of the State Board's guidance on student conduct describes social-emotional learning standards that must be followed in all schools. The School Board guidance outlines a process for schools to use that supports development of a positive school climate. This policy was approved in fall 2011 and takes effect during the current 2012-2013 school year.

A significant barrier to school-based mental health care in West Virginia, also common in other states, has been restrictions on taking students out of class for services during reading and math blocks.

Mental health professionals frequently must operate within a block-scheduling framework and try not to pull children out of a class they are failing. Other challenges include securing adequate space, keeping the program staffed, and meeting documentation requirements for public and private insurance.

Finally, West Virginia's most intractable problem is reported to be persistent workforce shortages. Staffing challenges are chronic because professionals leave public employment for the private sector or leave the state altogether. In rural areas there are rarely enough qualified behavioral health providers. And with highly trained professionals in short supply, West Virginia has to balance filling positions versus filling positions with a professional who will meet requirements for reimbursement.

8. Locally-controlled school policies and priorities may complicate implementation of state funded, school-located child mental and behavioral health programs.

Depending on the state, the authority of state officials to mandate policies for individual school districts will vary considerably both by law and tradition. For example, when the Connecticut legislature passed a bill intended to reduce use of school suspensions to punish student violations of school policy, local districts responded both positively and negatively. To encourage reductions in school suspensions, Connecticut state government together with several private foundations funded local projects to reduce the number of children and adolescents arrested in schools. However, the state *must* be invited in by the school district and not all districts were welcoming. In a related effort, the state supports an emergency mobile psychiatric service (EMPS) for children with behavioral problems. These initiatives not only provide an alternative to calling police for urgent matters occurring in local districts and individual schools but these particular services also help link youth to ongoing services. In both instances, state initiatives intended to encourage school districts to handle students' behavioral problems through less punitive approaches have been embraced by some, but rejected by others.

9. While underfunding has limited the capacity of child mental health services across the nation, additional promising practices can be found in a number of states.

Here are three current examples:

Telemedicine and tele-psychiatry: Workforce shortages in some communities and travel times in rural and frontier areas limit access to highly trained mental health specialists. In Minnesota, the state is exploring investments in telemedicine and tele-psychiatry. In 2012, the Minnesota Department of Human Services entered into a two-year contract with the Mayo Clinic to provide expert guidance to pediatricians and other primary care providers who prescribe psychotropic medications for children.

Teacher accreditation and mental health training: Also in Minnesota, as part of their 5-year re-accreditation process, educators must now have some mental health training to meet the continuing education requirement.

Classroom-based social-emotional learning and positive behavioral instructional supports: There is increasing interest in problem-prevention initiatives. While they go by many names, classroom-based strategies and practices that build respectful, positive school communities and teach children social and emotional competencies are being promoted in a number of states. Interviewees in nearly half the states -- Minnesota, New Mexico, North Carolina, Oregon, and Texas – pointed specifically to these initiatives, which can help students at every point along the spectrum of social, emotional, and mental well-being.

What Moves The Children's Mental Health Agenda And How Can We Improve Access To Care

The underdeveloped state of children's mental health services in the United States has been well documented. The interviews confirmed that little has changed for children despite, perhaps, greater recognition of the price paid by both individuals and communities of inadequate mental health service systems. The hopeful news is that even in states that did not demonstrate significant investments in children's mental health, there was broad interest in improving services. Five of the eleven states offered particular bright spots of positive state strategies that can inform future work:

- Connecticut has demonstrated the value of making emergency psychiatric services available to schools.
- Massachusetts expanded children's access to mental health screenings through statewide health care reform.
- Minnesota is working to overcome professional shortages in rural areas through tele-psychiatry.
- North Carolina has demonstrated the power of partnerships between mental health professionals and physical health providers.
- West Virginia has implemented a child mental health system that moves prevention and early intervention to the forefront by creating a statewide school-based initiative.

While none of these states has resolved all or even the most important challenges in their communities, their stories remind us that there are promising opportunities to make progress. Capitalizing on these opportunities requires that each state undertake its own self-assessment, exploring where progress has been made, what partners have moved the children's agenda forward, which alliances are proving enduring and effective, and what confluence of events or interests can lead to success.

The 11 states that participated in this study not only offer encouraging examples of incremental improvements in children's mental health services but also suggest hopeful directions for future improvements.

Endnotes:

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