INTEGRATING BEHAVIORAL HEALTH AND PRIMARY CARE FOR CHILDREN AND YOUTH

Concepts and Strategies



Samhsa-Hrsa Center for Integrated Health Solutions





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EXECUTIVE SUMMARY

Behavioral health conditions^a among children and youth today occur at a disturbing rate, impacting their overall growth and development and leading to higher mortality rates as they reach adulthood. In fact, studies have shown that adults with mental illness who are served in the public mental health system have a shortened life expectancy of 11 to 25 years on average when compared to the general population.¹ Key to disrupting this phenomenon is the development of preventive and early identification strategies, including integrating care systems for children with behavioral health conditions^b that address the primary care, behavioral health, specialty care, and social support needs of children and youth with behavioral health issues in a manner that is continuous and family-centered. This paper outlines different models for organizing the delivery of services, describes five core competencies of the integrated care systems for children with behavioral health issues,^c and describes financing mechanisms that can be used to support the approach of integrated care systems for children with behavioral health conditions.

An Unmet Need: Behavioral Health Supports for Children & Youth

Today's behavioral health landscape for children and youth is grim, with rising rates of youth and adolescent depression and illicit drug use. The rates of mental illness and substance use rise as youth move into young adulthood, while studies show that people with serious mental illnesses and substance use disorders die earlier than the general population, in large part due to unmanaged physical health conditions.²

To close the early mortality gap, there must be a shift in focus from treatment of chronic disorders to prevention, and greater emphasis on identifying early onset of behavioral health concerns among children and youth. Many factors point to the need for prevention and early identification strategies by primary care clinicians (PCC) in integrated care systems.^d

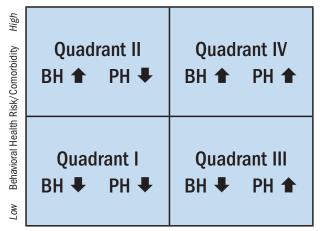
Choosing a Service Delivery Structure

In addition to adopting the core competencies that will be outlined in the next section, organizations serving as integrated care systems need to engage in planning for sub-populations with varying levels of medical and behavioral health complexity, and choose a form and level of integration that works for their organization.

In the Four Quadrant Clinical Integration Model, each quadrant considers the behavioral and physical health risks and complexity of the population and suggests major system elements that would meet the needs of the population subset.³ Since it should not be assumed that a child will remain in one quadrant, organizations need to engage in comprehensive planning that responds to varying needs if they intend to serve as an integrated care system for children with behavioral health conditions.

Organizationally, integrated care systems can choose to facilitate, colocate, or integrate. Given strong interagency and intra-agency communication, any of the following models can work to support integrated care.

Figure 1: The Four Quadrant Clinical Integration Model



Low Physical Health Risk/Complexity High National Council for Behavioral Health

- FACILITATED REFERRAL MODEL. The integrated care system does not provide both physical and behavioral healthcare; rather, if a screening uncovers an issue, a referral is made to an outside provider who then becomes a part of a virtual team.
- CO-LOCATED MODEL. Behavioral health and primary care clinicians work separately from each other but in the same building. Co-location facilitates communication through hallway consults and/or shared charts.
- IN-HOUSE MODEL. Primary and behavioral health services are incorporated into the clinic workflow, using brief interventions and consultations.

Core Competencies of Integrated Care Systems for Children with Behavioral Health Conditions

There are core competencies that should be developed by any organization that means to serve as an integrated care system for a child with behavioral health issues. Derived from the Chronic Care Model and the System of Care approach, these competencies are necessary regardless of the integration model that is ultimately adopted.

- FAMILY AND YOUTH-GUIDED TEAMS WITH CARE COORDINATION CAPABILITY. A coordinator is designated to communicate, network, and educate. The individual designated as the coordinator depends on the needs and strengths of the family, members of the child/youth's multidisciplinary team, and the complexity and intensity of care coordination needed. Family members and youths are considered important participants and advisors throughout the process.
- 2. INDIVIDUALIZED AND COORDINATED CARE PLANS. Care plans are individualized: they are guided by family and youth input, and account for differences among children and children's families; including their values, preferences, and available resources. Care plans are also coordinated: they address the whole health of the youth or child. Behavioral and physical health conditions are considered simultaneously and are incorporated into a comprehensive approach. To accomplish this, the planning process requires team input.
- 3. USE OF EVIDENCE-BASED GUIDELINES. Practitioners use evidence-based screening and assessment tools, and follow the guidance of the Bright Futures initiative of the American Academy of Pediatrics for well child visits until the age of 21. Integrated care systems for children with behavioral health conditions assure that youths receive the full complement of well child visits and screenings, including those for non-behavioral health conditions.
- 4. ESTABLISHED AND ACCOUNTABLE RELATIONSHIPS WITH OTHER ENTITIES. Organizations establish relationships with outside entities that, to the greatest extent possible and practicable, include formal agreements on topics such as communication standards, wait times, or responsibility for development of care plans.
- 5. **DATA-INFORMED PLANNING.** Organizations have clinical information systems that support proactive planning and informed decision making on both individual and population levels.

Financing Integrated Care Systems for Children & Youth

The future of children's integrated care systems rests on both clinical and fiscal sustainability. A variety of sources and methodologies can be used to fund integrated care systems and the associated care coordination services, many of which center on public financing by Medicaid and state Children's Health Insurance Programs (CHIP). In addition, those funds can be combined with funding from other systems, such as child welfare funding, SAMHSA System of Care and other federal discretionary grants, local funds, and even employer purchased insurance.⁴

Conclusion

To close the early mortality gap for individuals with behavioral health disorders, there must be a dedicated focus from early on in children and youths' lives to identify and effectively treat emerging health conditions. Integrated care systems of tomorrow are a critical part of that focus, and represent an approach to delivering care that comprehensively addresses the primary care, specialty care, and social support needs of children and youth in a continuous and family-centered manner.

Organizations that implement individualized and integrated care plans, use evidence-based guidelines, create accountable relationships with outside organizations, engage in data-informed planning, and are family and youth-guided with care coordination capability, will be best positioned to impact the behavioral health of children, youth, their families, and their communities.

INTRODUCTION AND PURPOSE

Behavioral health conditions^e among children and youth today occur at a disturbing rate, impacting their overall growth and development. Meanwhile, evidence shows that adults with behavioral health conditions have higher mortality rates than the general population. Early intervention and effective treatment of co-occurring behavioral health and physical health conditions could have a major role in reducing premature mortality. This puts the children's health and social service system and its challenges squarely at the intersection of the problems facing practitioners and policymakers trying to advance integrated care systems that address the whole health of children and youth

The purpose of this paper is to provide healthcare providers and stakeholders with a practical, organizational framework for developing integrated care systems where the behavioral health needs of children and youth are identified and treated effectively in the context of their whole health. Using the principles and philosophies of the System of Care approach for children with behavioral health conditions and the Chronic Care Model of organizing services for people with chronic health conditions, this paper describes five core competencies of integrated care systems for children with behavioral health issues. In addition, using the National Council for Community Behavioral Healthcare's Four Quadrant Clinical Integration Model—originally developed for adults, but here adapted for children and youth—the paper outlines different approaches for organizing the delivery of services, and major design elements to consider while serving children with varying degrees of behavioral and medical complexities. The paper concludes by describing financing mechanisms that can be used to support the integrated care systems approach.

SECTION 1. AN UNMET NEED: BEHAVIORAL HEALTH SUPPORTS FOR CHILDREN & YOUTH

Human and Financial Costs of Business as Usual

The National Survey on Drug Use and Health found that 8 percent of youths—totaling 1.9 million 12 to 17 year olds—had experienced a major depressive episode in 2010. These same youths, when compared to their counterparts who had not experienced major depression, were more than twice as likely to have engaged in illicit drug use.⁵ The same study found that illicit drug use among youth ages 12 through 17 was at 10.1 percent and had risen in recent years.⁶

The rates of mental illness and drug use rise as youth move into young adulthood. Among adults, individuals ages 18–25 comprised the subgroup of adults with the highest rate of mental illness, with nearly 30% having experienced mental illness in the previous year. The rate of illicit drug use also jumped as the individuals aged, from 10.1% among youth ages 12–17, to 21.5% among young adults ages 18–25. The rates are similarly high for alcohol consumption; heavy and binge drinking were reported by a full 22.1% of individuals ages 12–20.9

The consequences for people with behavioral health disorders are severe. Adults with serious mental illnesses and substance use disorders die earlier than the general population, in large part due to unmanaged physical health conditions.¹⁰ In addition, an estimated 8.7 million Americans had serious thoughts of suicide in the past year, with 1.1 million having attempted suicide.¹¹ Among teens and young adults, suicide is the third leading cause of death.¹²

Several chronic physical health conditions are found tightly linked with behavioral health issues among youth, and treating the underlying behavioral health conditions is necessary to effectively manage the physical health condition. Asthma, for example, has been repeatedly linked as a comorbidity with depression, anxiety, and learning disabilities, especially among children with more severe asthma.¹³ While no directly causal relationships have been identified between the onset of asthma and specific behavioral health disorders, psychological stress (in either children or their caregivers) can worsen the course of asthma,^{14, 15} while interventions that address family functioning, stress, and behavioral changes have been shown to improve the outcomes for children with asthma.¹⁶ Management of sickle cell disease, a blood disorder affecting 1 in 2,000–2,500 newborns nationwide, is exacerbated for children with mental health disorders.^{17, 18} One study among patients ages 5–18 found that eight percent of patients admitted to a hospital for sickle cell disease had a mental health disorder.¹⁹ The paper concluded that pediatric patients with sickle cell disease and a history of mental health disorders have a longer length of stay and higher admission rates for sickle cell-related pain, and mental health issues "pose a challenge to the management of sickle cell pain."²⁰

Financially, too, there is reason to pursue earlier interventions. In 2009, the Institute of Medicine published a report on the prevention of mental, emotional, and behavioral disorders among young people. While there is generally a limited body of research, the Institute of Medicine concluded, "Of those few intervention evaluations that have included some economic analysis, most have presented cost-benefit findings and demonstrate that intervention benefits exceed costs, often by substantial amounts."²¹

To close the early mortality gap, there must be a shift in focus from treatment of disorders to prevention, and greater emphasis on identifying early onset of behavioral health concerns among children and youth.

Bridging the Gap between Primary Care and Behavioral Health

Recognition of the need to treat conditions early is not new, and neither is the awareness that children and youth are not getting the behavioral health services they need. The 1999 Surgeon General's report on mental health notes that "70 percent of children and adolescents in need of treatment do not receive mental health services," and subsequent research has confirmed that trend.²²

Fully 21% of children and adolescents in the United States meet diagnostic criteria for a mental health disorder with impaired functioning,²³ and the prevalence of children who do not meet criteria for a DSM-IV disorder but who have "clinically significant impairment" or "problems" is estimated to be twice the prevalence of children with officially diagnosed severe emotional disorders.²⁴ Most children and youth with mental health conditions that result in functional problems are more likely to be seen in their primary care setting than in the specialty mental health system. In addition, children with chronic medical conditions have more than two times the likelihood of having a mental health disorder. More than fifty percent of adults in the U.S. who have mental health disorders had symptoms by age 14, and three-fourths by age 24.²⁵ All of these factors point to the need for preventive and early identification strategies in the integrated care system by a primary care clinician (PCC).⁸

In a 2009 policy statement on mental health competencies in pediatric primary care, the American Academy of Pediatrics (AAP) articulated several strengths and opportunities inherent in the primary care setting on which clinicians in medical homes could build their competencies:

- Ma longitudinal, trusting, and empowering therapeutic relationship with children and family members
- The family-centeredness of the medical home
- Unique opportunities to prevent future mental health problems through promoting healthy lifestyles, anticipatory guidance, and timely intervention for common behavioral, emotional, and social problems encountered in the typical course of infancy, childhood, and adolescence.
- >> Understanding of common social, emotional, and educational problems in the context of a child's development and environment
- Experience working with specialists in the care of children with special health care needs and serving as coordinator and case manager through the medical home
- Familiarity with chronic care principles and practice-improvement methods."26

Lending additional credence to the first and second advantages listed above is a 2009 study that interviewed parents of children with complex chronic health conditions and found that consistent relationships between children and service providers, shared information, and meaningful and effective communication across healthcare settings were all perceived as integral to the care of their children.²⁷ This consistency allows providers to "anticipate and deal with behavioral challenges more effectively," and allows "children to feel safe and comfortable in clinical settings."²⁸ In addition, the "repeated personal contact results in heightened sensitivity to physiological and functional changes that might be clinically relevant, but incorrectly attributed to individual variability or normal developmental effects."²⁹

There are multiple advantages to building the capacity of PCCs to serve a more central role in integrated care systems for children with behavioral health conditions, but it is not the case that all PCCs could readily step into that role today. As has been articulated by the AAP, "Achievement of the competencies [requisite for providing mental health and substance abuse services in pediatric primary care settings]... is a goal, not a current expectation."³⁰ Not all PCCs currently have the capacity or the individual skill set to serve as the lead on a case with a child who has a moderate or severe emotional disorder. That, however, does not negate the responsibility of an organization acting as an integrated care setting for children with behavioral health disorders to begin formulating the organizational competencies to serve those children.

Integrated Care Systems, Health Homes, and Other Terminology

Multiple terms have evolved over the past several decades to represent comprehensive, holistic, and coordinated healthcare services for people across the age span. The term "medical home" has been in use for decades, and grew out of the pediatric field's development of a healthcare model meant to address the complex health needs of children with multiple medical conditions. The AAP has defined the medical home as "a model of primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective. Over time, and with its adoption by the larger healthcare field, the medical home has come to signify a care model in which the patient has a designated primary care provider who operates as part of a care team with responsibility for coordinating the patient's overall healthcare needs.

More recently, the term "patient-centered medical home" has surfaced, with the intent of underlining key elements that make a medical home model responsive to an individual's needs, and activating patients to participate in their healthcare, as in patient-centered care planning. This model has been the basis for numerous efforts, including TransforMED and the Patient-Centered Primary Care Collaborative. 33,34 In 2007, the American Academy of Family Physicians, AAP, American College of Physicians, and American Osteopathic Association issued a joint statement on the patient-centered medical home's core principles. It is also the term and model that the National Committee for Quality Assurance (NCQA) used in developing its medical home standards.

As "patient-centered medical home" became commonly used, the National Council for Community Behavioral Healthcare (National Council) advocated changing the term (and the model) to "person-centered healthcare home." The National Council argued that the term better conveyed the critical role of behavioral health and self-management in effective, comprehensive primary care.

The Patient Protection and Affordable Care Act used the term "person-centered health home" to convey the need to create a comprehensive coordinated care model for those with chronic health conditions that ensures quality and efficiency. Authors of the Affordable Care

Act wanted to build on the concept of medical homes, and to be explicit about the critical role of referrals for needed social services and behavioral health and community supports.^{37, 38}

This paper uses the term "integrated care system" for discussion of the approach and model of delivering care that comprehensively addresses the primary care, behavioral health, specialty care, and social support needs of children and youth with behavioral health issues in a manner that is continuous and family-centered. "Patient-centered medical home" is used when the work being addressed uses that term to refer to the specific model, as in the American College of Physicians and NCQA's work. "Medical home" is used as a generic term referring to the range of models previously implemented. "Health home" is used when referring to the Medicaid State Plan option for care coordination services.

SECTION 2. CHOOSING A SERVICE DELIVERY STRUCTURE

Whether planning for changes to an existing practice or thinking of creating a new one, organizations serving as integrated care systems need to:

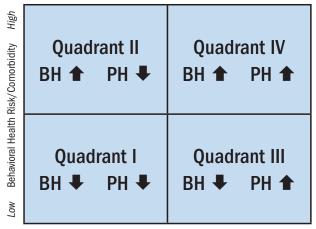
- >> Engage in planning for specialized populations with varying levels of medical and behavioral health complexity.
- Choose a form and level of integration that works for their organization.

Clinical Integration: The Four Quadrant Clinical Integration Model

Integrated care systems for children with behavioral health conditions must plan to address the needs of different populations with different levels of medical and behavioral health conditions. The National Council for Community Behavioral Healthcare's Four Quadrant Clinical Integration Model focuses on these different populations. Each quadrant considers the behavioral and physical health risks and complexity of the population and suggests major system elements that would meet the needs of the population subset.³⁹

The Four Quadrant model serves as a conceptual planning tool for local systems; it is not meant to be prescriptive about individual organizational practices nor treatment provided to individual children and youths. Child and family needs and preferences can change with time and circumstances, and the clinical practices of the designated integrated care system may change to accommodate more or less intensive needs. It should not be assumed that

Figure 3: The Four Quadrant Clinical Integration Model



Low Physical Health Risk/Complexity High
The National Council for Community Behavioral Healthcare

a child will remain in one quadrant or another, which emphasizes the need for comprehensive planning on the part of the organization serving as an integrated care system for children with behavioral health conditions. Care coordination teams should be prepared to assist with children's transitions between quadrants as their health needs change, as well as transitions from the child to adult model of care.

Quadrant I

POPULATION

Low to moderate behavioral health and low to moderate physical health complexity.

PROVIDERS INVOLVED

The team includes the PCC, behavioral healthcare manager (e.g., licensed mental health clinician who can provide short-term treatment and care management), and psychiatric consultant. Access to additional specialists as needed.

SERVICE DELIVERY

The PCC assumes responsibility for ensuring the provision of services for children and youth, including providing and/or arranging for behavioral health services and monitoring progress. Screenings and risk assessments for behavioral health concerns are incorporated into well child visits in accordance with Bright Futures guidelines. Psychiatric consultation services are available as needed for the PCC and/or behavioral healthcare manager. A patient registry/tracking system is used to track progress of the child/youth's treatment and symptoms and, with family input, informs treatment planning.

The behavioral healthcare manager is available for consultation to the primary care provider and to provide brief treatment services as needed. The care manager also provides follow-up coordination as needed, including obtaining reports and recommendations for treatment changes from outside entities. If transitions to higher levels of care are warranted, the behavioral healthcare manager is connected to the specialty behavioral health system and able to support transitions. The behavioral healthcare manager is able to effectively work with other child-serving entities, including schools and child welfare agencies, and is responsible for serving as a liaison for the pediatrician's office when care plan development is being led by another entity.

Quadrant I includes a higher proportion of children and youths than all of the other quadrants combined, and while the need for intense and highly coordinated treatment lies in other quadrants, this quadrant is where prevention and early intervention activities will have the greatest impact on the overall behavioral health of young people in the community.

QUADRANT I IN PRACTICE

- Massachusetts has created a system of regional children's mental health consultation teams designed to help primary care providers meet the needs of children with psychiatric problems, regardless of insurance status. The Massachusetts Child Psychiatry Access Project provides telephone consultation by a psychiatrist, mental health professional, or care coordinator, available to pediatricians within 30 minutes of request. An August 2012 survey of enrolled pediatricians found a 96 percent increase over baseline scores for pediatricians' ability to meet the needs of children with psychiatric problems. (Massachusetts Child Psychiatry Access Project (MCPAP) Primary Care Clinician (PCC) Satisfaction Survey Fiscal Year 2012, MCPAP, August 2012, www.mcpap.com)
- The Pennsylvania Chapter of the Academy of Pediatrics is aggressively promoting the use of "Bright Futures" evidence-based screening tools (birth through adolescence) to identify early developmental, social-emotional, mental health, substance use, and trauma-related evaluation and service needs.
- Children's Hospital of Philadelphia has initiated a program using "School Readiness Counselors" to screen preschool children for behavioral health, social-emotional, autism and other developmental delays. They have established a referral relationship with Early Intervention programs that provide evaluation and referral services and coordinate care with pediatric providers.
- Several primary care practices have hired clinical social workers or clinical nurse specialists to provide brief counseling (about 20 minutes) for parents/children concerning the child's behavioral or social-emotional well-being. Practices have found this to be a cost effective use of "mid-level professionals" in the primary care setting in lieu of using physician time.

(C. O'Brien, Pennsylvania Community Providers Association, October 2012)

Quadrant II

POPULATION

Moderate to high behavioral health issues and low to moderate physical health conditions.

PROVIDERS INVOLVED

The team consists of the PCC, behavioral healthcare manager, and psychiatrist, with involvement and support from family members. Care coordinators assure collaboration with members of the treatment team outside of the organization. Child and family care teams include schools, child welfare, and/or juvenile justice partners as needed. PCC remains engaged in treatment planning and co-monitoring of physical health conditions and their relation to behavioral health.

SERVICE DELIVERY

In addition to the services provided in Quadrant I, an array of specialty behavioral health in-home and community-based services are available, in additional to group wellness programming. Innovative community-based services such as wraparound and therapeutic behavioral services provide additional supports to children and youth to help them be successful.

QUADRANT II IN PRACTICE

- A growing number of Pennsylvania Community Provider Association members have established or are in the process of ramping up collaborative or co-located child-adolescent mental health services in conjunction with primary care practices, pediatric Medical Homes and Federally Qualified Health Centers. Behavioral health services are generally provided by staff not employed by the PCP practice but by a community mental health organization.
- Several Psychiatric Residential Treatment Facilities in Pennsylvania have established on-site pediatric services for the consumers in their care. In these cases the physicians and CRNPs have both an expertise in working with children with emotional and behavioral issues as well as expertise in managing complex health care needs related to mediations and co-occurring health conditions.

(C. O'Brien, Pennsylvania Community Providers Association, October 2012)

Quadrant III

POPULATION

Low to moderate behavioral health conditions and moderate to high physical health conditions.

PROVIDERS INVOLVED

The team includes the PCC, behavioral healthcare manager, psychiatric consultant, and the child/youth's specialty medical/surgical clinicians.

SERVICE DELIVERY

In addition to the services described in Quadrant I, including well child visits and age appropriate screenings, for populations with low to moderate behavioral health issues and moderate to high physical health conditions, the team collaborates with medical/surgical special-ty providers and care managers to manage the physical health concerns of the child. Person-centered approaches such as motivational interviewing and other behavioral change approaches designed to elicit motivation for change are built into the practice.

QUADRANT III IN PRACTICE

- A growing number of pediatric hospitals have psychiatric consultation and liaison services for children seen by physicians through medical-surgical services and emergency departments. Increasingly, these consultation and liaison services include teams of psychiatrists, psychologists, licensed clinical social workers, and certified registered nurse practitioner staff who may or may not follow the patient after discharge. Patients/consumers are most often treated for depression, posttraumatic stress disorder, adjustment reactions, oppositional defiant disorder, obsessive-compulsive disorders, parent-child relationship issues, and eating disorders.
- Non-hospital affiliated mental health professionals and agencies have established specialized capabilities to provide mental health services to children with complex health care needs referred from oncology, hematology, immunology and adolescent medicine services in hospitals and health systems. Patients/consumers are most often treated for depression, post-traumatic stress disorder, adjustment reactions, oppositional defiant disorder, obsessive-compulsive disorders, parent-child relationship issues, and eating disorders.

(C. O'Brien, Pennsylvania Community Providers Association, October 2012)

Quadrant IV

POPULATION

Moderate to high behavioral health conditions and moderate to high physical health conditions.

PROVIDERS INVOLVED

The team includes the psychiatrist, behavioral healthcare manager, PCC, and child/youth's additional behavioral health and medical/surgical specialists.

SERVICE DELIVERY

In addition to the services described in Quadrant II, for populations with moderate to high behavioral health and moderate to high physical health conditions, the pediatrician or family health practitioner collaborates with medical/surgical specialty providers and external care managers to manage the youth's physical health conditions. Specific protocols are adopted that define the methods and frequency of communication among all providers/team members.

QUADRANT IV IN PRACTICE

Pennsylvania has several collaborative practice arrangements where physical health and behavioral health professionals are working together to more effectively meet the needs of neuro-nontypical children with complex physical health and behavioral health service needs related to autism, fetal alcohol spectrum disorder, and traumatic brain injury.

(C. O'Brien, Pennsylvania Community Providers Association, October 2012)

Organizational Integration: Facilitate, Colocate, or Integrate

The collaborative physical-behavioral healthcare aspects of integrated care system responsibilities can be delivered through one of three general types of arrangements: the facilitated referral model, colocated partnership model, or the integrated model.⁴⁰

The arrangements that communities and providers adopt will depend on multiple factors, including:

- Array of and capacity of services in the community—what services are available? Is there access to sufficient amounts of the services needed?⁴¹
- >> Child and family preferences—do they prefer to have their locus of care in a pediatric or specialty behavioral healthcare setting?

 Are there other healthcare providers nearby?
- >> Trained workforce—do current behavioral health and PCC have the right competencies and skills to deliver planned services?
- Organizational support in providing services—do managers provide encouragement and support for collaborative activities? What is the impact of adding new services on operations, documentation, billing, and risk management?
- Reimbursement factors—do payers support collaborative care and make it easy or difficult for the behavioral health and primary care sectors to work together?⁴²

Given internal organizational support and a strong emphasis on interagency and intra-agency communication, any of the following models can work to support integrated care.

FACILITATED REFERRAL MODEL

In the facilitated referral model, the integrated care system does not provide both physical and behavioral healthcare. If, for example, the integrated care system is a specialty behavioral health setting, screenings for physical health problems are completed and children are referred to a PCC for physical health services. If the integrated care system is a primary care setting and screenings uncover a behavioral health issue, then the integrated care system facilitates a referral to an appropriate specialty behavioral health setting.

It is important that each partner have the capacity to accept new referrals and to report back to the designated integrated care system on client progress. The integrated care system remains responsible for tracking progress of treatment and coordination of care between providers. This approach may be more viable for small organizations or those that plan to evolve towards more complex structures in the future.

COLOCATED MODEL

In the colocated partnership model, behavioral health practitioners and PCCs work separately from each other. Clinicians may or may not work for the same organization. Instead, behavioral health professionals work on-site in a separate organization's primary care office, or, pediatricians or other family health practitioners work in the behavioral health specialty setting. The advantages of co-location are facilitated communication—most often hallway consults—and shared charts.

Colocated primary care settings generally serve persons with less serious behavioral health conditions than do specialty mental health settings. These settings often address patients with more serious behavioral health issues by coordinating with an external specialty behavioral health provider.

IN-HOUSE MODEL

In the in-house model, primary and behavioral health services are incorporated into the clinic flow, using brief interventions and consultations. The advantages of the integrated model are the warm handoff, which has been shown to reduce stigma and increase adherence, facilitated communication, and a shared chart.

SECTION 3. CORE COMPETENCIES OF INTEGRATED CARE SYSTEMS FOR CHILDREN WITH BEHAVIORAL HEALTH CONDITIONS

Any organization that means to serve as the integrated care system for a child with behavioral health issues should utilize a series of core competencies. These are necessary regardless of the integration model that is ultimately adopted (as discussed in the previous section). Two frameworks of care are particularly helpful in providing context and background for the core competencies.

The Chronic Care Model is an evidence-based framework that has evolved for providing care to individuals with chronic health conditions; it outlines a series of clinical elements that should be built into the treatment provided to youth with behavioral health conditions in an integrated care system. The System of Care approach is a philosophy for providing a spectrum of effective, community-based services and supports for children with serious emotional disorders and their families; its principles highlight the importance of family and youth engagement as well as collaboration with other child-serving agencies. Examined together, these approaches provide the foundation for organizing and delivering integrated care system services for children with behavioral health issues. This section begins with a description of the principles of both models in order to provide a framework for understanding the core requirements of an integrated care system for children with behavioral health conditions as described later in the section.

The Chronic Care Model

The Chronic Care Model served as the foundation for the patient-centered medical home and collaborative care approaches to the management of common mental disorders in primary care, and is recommended by the AAP as a practice model for children with mental health problems.⁴³ First developed and tested in the 1990s by the MacColl Institute for Healthcare Innovation, the Chronic Care Model identifies the elements necessary for providing high quality care for people with chronic health conditions.⁴⁴ The essential elements of the model have also been adapted for use with children; for example, the National Initiative for Children's Healthcare Quality frames the six essential elements of the model in terms related to pediatric care, as reflected in the elements highlighted below.⁴⁵ While the Chronic Care Model was not specifically designed for children with behavioral health disorders, it has been found effective for the management of physical, developmental,⁴⁶ and behavioral health conditions among children. For this reason, it lays a solid foundation for children's integrated care systems that can treat both physical conditions—such as asthma or obesity—along with behavioral health conditions.

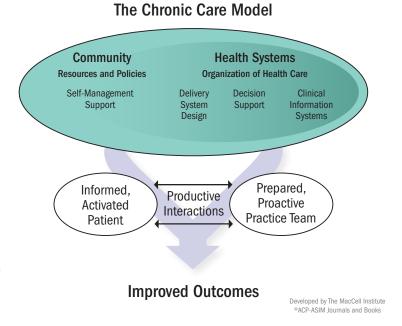
The purpose of the Chronic Care Model was to shift the healthcare system from one that is reactive and focuses only on acute issues—i.e., the immediately presenting condition—to one that is proactive and focuses on early interventions that keep individuals as healthy as possible.⁴⁷ While some are hesitant to use the term "chronic" for children's health conditions in recognition that children and youth are still developing, one definition of chronic is "any condition that requires ongoing adjustments by the affected person and interactions with the health care system."⁴⁸ Thus, this model is well-suited to the care of young people with mild, moderate, or serious behavioral health conditions that require ongoing treatment or monitoring.

The essential elements of the Chronic Care Model include:

- >> Self-management support, including strategies that emphasize the patient and family's central role in managing patient health, and working with patients and their families to set priorities and problem-solve along the way. Depending on the age and maturity of the children and youths involved, these strategies may include parental engagement and motivation or youth-led peer support groups.
- Delivery system design that promotes proactive planning instead of reactive responses, and a team-based approach to care; care management and clear role definition are critical components for patients with complex needs.
- Decision support mechanisms that integrate evidence-based practices into daily treatment and account for patient and family preferences, and include access to specialty expertise.
- Clinical information systems for performance monitoring and tracking changes across populations and sub-populations of children with specific needs; performance indicators and systems are designed to allow for proactive care planning.
- >> Community linkages that build on strengths of organizations and groups outside of the immediate healthcare system to enhance care for children, such as day care, schools, and after-school programs.

Health systems and organizations that create a culture, practice, and mechanisms that promote safe, high quality care.⁴⁹

The foundation of the Chronic Care Model is based on productive interactions between an informed, activated service recipient-or in the case of children, activated parents—and the prepared, proactive practice team.50 Being informed and engaged, the child/youth and/or family is able to participate as a full partner in his/her care. Multidisciplinary staff work together as a team, with the child and his/her parents, to create and define a shared approach to care and treatment. The family and practice team's work is supported by a care delivery system that is supportive in several interdependent areas, including self-management support, delivery system design, decision support, clinical information systems, community linkages, and health systems. See Appendix A for additional information on the Chronic Care Model.



The System of Care Approach

Recognizing the multiple systems that touch youth, especially those involved in the child welfare and juvenile justice systems, there have been dedicated efforts over the past several decades to create, on a local and state level, systems of care for children and youth with serious emotional disorders and their families.⁵¹ In many ways, the System of Care approach and the Chronic Care Model are similar, with the System of Care approach intentionally described in strengths-based, child, family, and developmentally-friendly language. Both a framework and a philosophy, a System of Care is defined as:

A spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs, in order to help them to function better at home, in school, in the community, and throughout life.⁵²

Three core values drive the approach:53

- Family driven and youth-guided, with a strengths-based approach to the needs of the child and family determining the types and mix of services and supports provided.
- >> Community-based, with the locus of services as well as system management resting within a supportive, adaptive infrastructure of structures, processes, and relationships at the community level.
- Culturally and linguistically competent, with agencies, programs, and services that reflect the cultural, racial, ethnic, and linguistic differences of the populations they serve to facilitate access to and utilization of appropriate services and supports and to eliminate disparities in care.

Evaluations of System of Care programs have shown improvement in young child functioning, school attendance, reduced depression levels, improved chronic physical health conditions, and several other positive indicators.⁵⁴ This paper uses these core values as part of the evaluative criteria for establishing the core competencies of children's integrated care systems. Additional information about the System of Care guiding principles can be found in Appendix B.

The Core Competencies

When combined, the Chronic Care Model and the System of Care approach help illustrate the core competencies of an integrated care system for children with behavioral health conditions, regardless of which specialized population of children and youth is being served, the severity of their condition(s), or which clinical integration model is being adopted. The core competencies outlined below are distilled

from the clinical and structural elements of the Chronic Care Model, along with the youth/family engagement and systems-level focus of System of Care. They are:

- Family and youth-guided multidisciplinary teams with care coordination capability
- >> Individualized and integrated care plans
- Use of evidence-based guidelines
- Established and accountable relationships with other entities
- Data-informed planning

CORE COMPETENCY 1: FAMILY AND YOUTH-GUIDED TEAMS WITH CARE COORDINATION CAPABILITY

In 2009 the AAP released a policy statement, Care Coordination in the Medical Home, in which it highlighted the important roles of both PCCs and family members in coordinating care for children and youth with special health care needs. While no universal definition of care coordination exists, the AAP described care coordination as a dynamic process—rather than a defined set of tasks—that involves "needs identification, assessment, prioritizing, and monitoring." "A coordinator," it continues, "is required to communicate, network, and educate as well as advocate for resources." ⁵⁵

RESOURCE

In 2009, the Commonwealth Fund published a framework for care coordination.

In addition to a comprehensive definition and outline of the core functions of care coordination, the report includes recommended outcome measures to ascertain the impact of the care coordination function in the healthcare practice. See "Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework."

IN PRACTICE

CORE COMPETENCY 1: FAMILY AND YOUTH GUIDED TEAMS WITH CARE COORDINATION CAPABILITY

James is a 13-year old boy who lives with his mother and four siblings. The family has a low income and other social challenges. James has a long history of ADHD and severe asthma with poor adherence to the medication regimens prescribed for both conditions. His mother is often unable to get transportation to bring him to medical appointments. In the past two years, his school performance has deteriorated, he has been increasingly defiant in two of his classes, he has begun using marijuana regularly, and he has been in the local emergency department three times in the past six months with severe asthma symptoms.

He was recently evaluated by a clinical social worker. He refuses to see a psychiatrist. The pediatrician, social worker, and mother agree that the family needs multiple services, and they design a team that includes themselves, James, the pediatrician's nurse, a chronic care nurse from the asthma clinic, a psychiatrist, a school counselor, and James' favorite uncle.

The team, facilitated by the social worker, will meet every two weeks at James' home. Not all team members will attend every meeting; the social worker will coordinate communication among all team members. She will also ensure that the mother has the information necessary to make informed decisions about services and that the mother's preferences and decisions are honored.

Different levels of care coordination can be used depending on the complexity and intensity needed.⁵⁶ At a basic level, care coordination may simply be the sharing of information and resources with the family. At a moderate level, a care coordination plan is developed that includes short and long-term goals and related strategies with communication across multiple stakeholders. At the most intensive level, care coordination for children with particularly complex problems/issues is likely to be long-term and involve an ongoing commitment to regular monitoring and planning, including by specialty healthcare and community-based partners. Care coordination at all levels should include oversight and monitoring of transitions across care settings and from one level of care to another, including as individuals move from one quadrant to another (as outlined in greater detail below).⁵⁷

Different levels of care coordination can be used depending on the complexity and intensity needed. At a basic level, care coordination may simply be the sharing of information and resources with the family. At a moderate level, a care coordination plan is developed that includes short and long-term goals and related strategies with communication across multiple stakeholders. At the most intensive level, care coordination for children with particularly complex problems/issues is likely to be long-term and involve an ongoing commitment to regular monitoring and planning, including by specialty healthcare and community-based partners. Care coordination at all levels should include oversight and monitoring of transitions across care settings and from one level of care to another, including as individuals move from one quadrant to another (as outlined in greater detail below).

Family members are important participants and advisors throughout the process, and, with support, are often able to engage with primary care and behavioral health care coordinators in a supportive role. Care coordination is a role that can be played by more than just a care manager—a PCC can play many roles in his/her capacity as a primary care provider, including that of counselor or care coordinator when care coordination needs are not extensive. At a minimum, the team at the integrated care system should include the child's PCC, the child, and his/her family members. Dedicated care coordinators may be added to the team if the child's needs exceed the time available for the PCC, and the healthcare team may expand to include—as either a clinical advisor or as a care coordinator—a nurse, behavioral health professional, or other specialists. Consistent with the Systems of Care principles, the care team may also include members from other child-serving systems with which the youth has contact. This could include school counselors, educators responsible for Individual Education Plans (IEPs), juvenile justice representatives, child welfare workers, or others, depending on the child's need. A critical component of care coordination is the outreach to and maintenance of ongoing relationships with this diverse range of individuals.

The role of behavioral health professionals on a care team may include:

- Part of primary care team
- Immediate triage/response to positive screen
- Behavioral health screening or follow-up with secondary screenings or assessments
- Brief interventions to short or long-term therapy
- >> Self-management counseling for children (and their families) with chronic medical conditions
- Facilitate referrals to and communication with external behavioral health providers
- >> Facilitate transitions across care settings and levels of care
- Communication with teachers or other interested parties

As the child's primary sources of strength and support, family members must be actively engaged even if they are not playing the care coordinator role.⁵⁸ Family members and caregivers are often the one constant in a child's life, making them the most familiar with the child's goals, abilities, and health needs. Integrated care systems should view family members as active partners and should seek to engage them at every opportunity. Actively engaging family members and including children and youths themselves as members of the care team helps to ensure that services are individualized and best aligned to the strengths and needs of the family. Engagement, however, is not just participation in meetings; it results in having families and youth taking ownership of the process. Highlighting the importance of a holistic approach to engaging with families, more than half of care coordination encounters in a primary care setting for children and youth with special healthcare needs may be for non-medical issues such as behavioral health or supportive services.⁵⁹

CORE COMPETENCY 2: INDIVIDUALIZED AND COORDINATED CARE PLANS

Individualized plans must be developed jointly by the care team with input from both primary care and behavioral health providers. Regardless of which organization is leading the development of a care plan, the integrated care system must ensure that each child's care plan is individualized and coordinated.

IN PRACTICE

CORE COMPETENCY 2: INDIVIDUALIZED AND COORDINATED CARE PLANS

The team designs a multi-component treatment plan informed by professional expertise, family preference, family strengths, and community resources. The social worker will provide therapy; James' uncle will provide transportation. A home health nurse will see him regularly regarding his asthma management. James agrees to meet with a psychiatrist if his mother will be there; a neighbor will babysit the siblings to make this possible. The school counselor will work on changing James' curriculum to reduce conflict with two teachers and will talk with a coach about sports opportunities so that James can make some new friends. James and his mother will attend a class for families on substance use. Finally, James agrees to work on improving his grades in exchange for spending more time at his uncle's workplace.

Individualized care plans are guided by the youth's and family's strengths and needs (for example, as determined by a standardized assessment tool such as the CANS⁶⁰ or CASII⁶¹) and are reflective of their goals. They account for differences among children and children's families, including their values, preferences, and available resources. Available resources to be considered include financial resources, insurance and covered services, extended family and family friends, religious and social communities, schools, and other care organizations.

An essential component of creating an individualized care plan is developing cultural and linguistic competency on an individual and organizational level.⁶² Developing these competencies is valuable when engaging youth and families in treatment as well as during the treatment planning phase and the initial identification of potential issues of concern, especially among minority populations. The field of cultural competency is too large and complex to fit in the scope of this paper, but several resources are included in Appendix C, including a link to a cultural competence self-assessment for healthcare practitioners.

Coordinated care plans address the whole health of the child or youth. Behavioral and physical health conditions are considered together and are incorporated into a comprehensive approach. Integrated treatment planning involves asking the question, "How do behavioral health issues affect this medical condition and proposed treatment approach?" or "How do medical issues affect this behavioral health issue and proposed treatment approach?" and making adjustments based on the response. Medications are considered in the same context. Are they impacting other aspects of the child's health and well-being?

To achieve both individualized and coordinated care plans, the planning process requires team input. While one organization may be leading the process of developing a care plan, a team-based approach requires actively soliciting the input of those who will be involved in carrying out the care plan. In Core Competency 4, we address the necessity of establishing relationships with outside entities.

CORE COMPETENCY 3: USE OF EVIDENCE-BASED PRACTICES

For a variety of reasons, behavioral health problems are often undetected or untreated in primary care. ⁶³ Fortunately, several evidence-based screening and risk assessment tools, as well as treatment guidelines, have been developed to assist the integrated care system in working with children with behavioral health concerns. In addition, good screening can identify those at risk for, but not yet displaying,

behavioral health conditions. There are effective preventive strategies that can reduce the development of behavioral health conditions.

Bright Futures, a national health promotion initiative initially launched by the Health Resources and Services Administration's Maternal and Child Health Bureau, develops guidelines and tools for pediatricians to use in the course of well child visits until the age of 21.64 Universal psychosocial/behavioral health assessments are recommended at every well child appointment, starting from the child's newborn visit.65 In Massachusetts, where primary care providers were court ordered in 2008 to offer standardized behavioral health screenings at well child visits, researchers found a threefold increase in the number of children identified as at risk for a behavioral health condition as a result of the increased screenings.66,67 Incorporating drugs and alcohol use items into a pediatrician's surveillance and anticipatory guidance increases the Drug Use and Health found that the extent to which youth believe substances such as alcohol, tobacco and illicit drugs might cause them harm is an important factor influencing whether or not they will use the substances.68

RESOURCE

The Bright Futures Tool and Resource Kit has materials to complement the Bright Futures guidelines for the health supervision of infants, children, and adolescents. The tools and resources include practice management tools, documentation forms, and information for parents and patients to reinforce topics discussed during pediatric visits. Materials are available for download and certain forms can be incorporated into electronic health record systems.

IN PRACTICE

CORE COMPETENCY 3: USE OF EVIDENCE-BASED PRACTICES

Based on her clinical assessment, the social worker has determined that James' depression and defiance originated with a traumatic event two years ago. She provides a structured, brief evidence-based therapy, Trauma-Focused CBT. As he builds his coping skills and comes to understand his experience in a new way, his mood improves, he is more motivated to improve his behavior, and his confidence increases.

The AAP Task Force on Mental Health has produced Addressing Mental Health Concerns in Primary Care: A Clinician's Toolkit, which includes substance use. ⁶⁹ In keeping with Bright Futures, the task force recommends eliciting family concerns at every visit, using routine screening with a common factors approach and motivational interviewing techniques. The role of the PCC is to:

- Fit mental health care into the pace of primary care practice.
- Promote mental health (per Bright Futures guidance).
- Identify risks, intervene to prevent mental health problems (acknowledging strengths).
- Elicit concerns (screening, acute care, chronic care).
- Divercome resistance, stigma, conflict, and other barriers to seeking help.
- Address emerging problems/problems not rising to level of diagnosis.
- Assess/manage mental health problems.
- Refer/co-manage/coordinate.
- Monitor.

Behavioral health organizations that serve as children's integrated care systems should be careful to ensure that:

- PCCs are included as core team members in treatment planning.
- >> Youths continue to receive the full complement of well child visits and screenings including non-behavioral health conditions.

CORE COMPETENCY 4: ESTABLISHED AND ACCOUNTABLE RELATIONSHIPS WITH OTHER ENTITIES

The Chronic Care Model and System of Care principles emphasize the importance of an adaptive infrastructure that includes community linkages and a broad, flexible array of services that enhance care. As described in Core Competency 2, a team-based approach to care is essential to creating individualized and integrated care plans. For children with behavioral health issues, their team is highly likely to include individuals and organizations outside of their integrated care system. Therefore, a core competency of the integrated care system for children and youth with behavioral health conditions is the establishment of relationships with outside entities and, to the greatest extent possible, relationships that are accountable.

Accountable relationships are those in which there are formal agreements between two entities on topics such as communication standards, wait times for patients (possibly with prioritization for certain circumstances, such as emergencies), or responsibility for development of care plans.

Developing relationships with outside groups, such as primary or specialty care providers, might look different depending on the type of organization and the role the outside organization might continue to play in the future. If a primary care practice does not have specialty behavioral health services in-house, it could consider developing a formal relationship with a specialty provider. In Connecticut, the Child Health and Development Institute (CDHI) works with a group of pediatric and behavioral health groups to develop formal protocol for gradually increasing treatment intensity for certain conditions such as depression and ADHD.70 As a result of another integrated care initiative, CDHI recommended that "future partners invest in significant preparation and groundwork to get to know each other as well as possible to design policies and procedures that are compatible with their own office cultures and systems prior to launching their partnerships."71 Appendix C contains resources for developing agreements with outside entities.

When developing a highly structured relationship with an outside group is not viable—such as in the case of some rural areas where

ACCOUNTABLE RELATIONSHIPS IN PRACTICE

One strategy for creating accountable relationships has been advanced by Connecticut's Medicaid program, which designated mental health agencies as enhanced care clinics and gave a higher reimbursement rate if they met certain criteria related to guaranteeing, among other things, timely access to emergency, urgent and routine care, as well as collaborative care agreements with primary care providers.

The collaborative care agreements with primary care practices are formal memoranda of understanding that outline communication and information sharing protocols, seamless referral processes, and "education for primary care providers to increase capacity to address behavioral health needs."

(Integrating Behavioral Health and Primary Care: Making it Work in Four Practices in Connecticut, CHDI, March 2010.)

availability of pediatric behavioral health specialists may be a challenge—integrated care systems should still have internal protocols to govern such relationships. These may include standards for timeliness of communications and identified staff persons who are responsible for facilitating the flow of communication between parties.

IN PRACTICE

CORE COMPETENCY 4: ESTABLISHED AND ACCOUNTABLE RELATIONSHIPS WITH OTHER ENTITIES

After about two months, the mother informs the social worker that James' teachers have not been changed and the school counselor has not returned her calls. The social worker coaches her on advocating for James. The mother contacts the school district's parent advocate, who answers questions about James' educational rights and arranges a meeting with the counselor. The counselor explains that he has been very busy. The mother, supported by the parent advocate, insists on concrete steps: a meeting with the principal or a new counselor. Two weeks later James' school schedule is changed.

When considering which entities to establish relationships with, child and family preferences for who should be involved in their care plan is the first layer that should be considered. Next to be considered are those outside organizations that are actively providing treatment for the child, such as their pediatricians and specialty behavioral health providers. Schools, child welfare, and juvenile justice entities should also be involved depending on the needs of the individual child. Partnerships should be developed on both an individual and organizational level in order to reap the most success from this coordination.

CORE COMPETENCY 5: DATA-INFORMED PLANNING

Integrated care systems must have clinical information systems that support proactive planning and informed decision making. Organized data, in the form of electronic health records or patient registries, facilitates analysis of population-level data as well as maximizing outcomes for individuals.

On an individual level, organized data allows healthcare providers to analyze a child or youth's response to interventions over time by tracking certain indicators (e.g. Body Mass Index or Pediatric Symptom Checklist score). Organized functional outcome measurement data can be used to determine the effectiveness of treatment during and after completion of treatment.⁷² By systematically reviewing this information, individual treatment plans can be adjusted to improve outcomes and track key issues like multiple psychotropic medications or repeated hospitalizations for a particular condition.

IN PRACTICE

CORE COMPETENCY 5: DATA-INFORMED PLANNING

The social worker as team facilitator develops a set of measureable objectives with James, his mother, and other team members. The numbers are reviewed at each team meeting, tracking data points on a "dashboard." Progressed is reinforced, while obstacles are addressed.

- With the support of his mother, James keeps an asthma diary, including daily ratings of asthma symptoms and medication use. The home health nurse tracks peak flows. Frequency of emergency department visits is monitored.
- >> James, his home room teacher, and his mother all complete ADHD rating scales once a week as the psychiatrist makes medication adjustments. James completes a depression rating scale every two weeks.
- The school counselor submits a report on James' academic progress once a month.

Simultaneously, the clinic develops a registry to track all of its patients with asthma, and notices an increase in hospitalization rates among adolescents. The social worker convenes a time-limited support group for parents of adolescents with chronic asthma.

On a population level, organized data allows practices to analyze system-wide trends to identify emerging and unmanaged health conditions among patients (e.g., increasing instance of diabetes among children taking a certain psychotropic medication) or to determine when an organization should establish a formal relationship with an outside entity (e.g., in case of an increasing number of children with autism.) Additionally, organized functional outcome measurement data can be used to determine which types of treatment approaches are most effective for children with particular mental health diagnoses, and thereby identify children who might best be served through an evidence-based practice (e.g. cognitive behavioral therapy for depression or teaching parents evidence-based behavioral interventions for children who have externalizing conditions).⁷³

Health information exchanges being developed in communities and states across the country will facilitate effective communication among primary care and behavioral health providers, pharmacies, hospitals, and other specialty providers. In selecting electronic health records systems, primary care and behavioral health providers should be careful to select products that are compatible with other systems.

SECTION 4. FINANCING INTEGRATED CARE SYSTEMS FOR CHILDREN & YOUTH

A variety of sources and methodologies can be used to fund integrated care systems for children with behavioral health conditions and the associated care coordination services, many of which center on public financing by Medicaid and state Children's Health Insurance Programs (CHIP) set through state and federal policy. Traditional commercial insurance plans have offered limited coverage of specialty behavioral health services, but pending decisions on the scope of essential health benefits for individual and small-group health insurance may change that trend. In addition to Medicaid and CHIP, an array of local, state, and federal funding streams create opportunities for blending or braiding financing to support children's integrated care systems.

AFFORDABLE CARE ACT SECTION 2703 HEALTH HOMES. This new Medicaid health home option was established for Medicaid enrollees with chronic conditions, including mental health and substance use disorders. The goal is to provide a person-centered System of Care that improves clinical outcomes, client experience, and quality of care while achieving cost efficiencies across the covered population.⁷⁴ While health homes cannot be restricted on the basis of age, states—with federal approval—can establish eligibility criteria that include children with behavioral health conditions.

Under this Medicaid state plan option, health homes ensure the provision of primary and acute physical health services, behavioral health services, and long-term community-based services and supports.

Specific services that are covered when delivered by the health home are:

- Comprehensive care management
- Care coordination and health promotion
- >> Comprehensive transitional care from inpatient to other settings, including appropriate follow-up
- Patient and family support
- ▶ Referral to community and social support services.⁷⁵

Seven states have been approved by CMS to provide health home services as of December 2012; Rhode Island is among the states that have an SPA focusing on children and youth with special health care needs.^{76,77} (While states may not formally restrict services by age group, Rhode Island's participating provider requirements are for child-serving providers only.)

Financing consideration of Section 2703 Health Homes through Medicaid is the subject of the Center for Integrated Health Solutions' paper, "Financing and Policy Considerations for Medicaid Health Homes for Individuals with Behavioral Health Conditions." The Human Service Collaborative also published "Customizing Health Homes for Children with Serious Behavioral Health Challenges," which examines specific policy and practice considerations for states when developing Medicaid health homes for this population.

TARGETED CASE MANAGEMENT (TCM) is an optional Medicaid service that covers assistance to help families gain access to needed services and community supports. TCM generally requires the targeting of specialized populations by conditions. Allowable activities include assessment, development of a care plan, referral, monitoring, and follow up.⁷⁸

Massachusetts uses targeted case management to fund intensive care coordination and home and community-based treatment services for youth enrolled in Medicaid and CHIP.

1915(A) VOLUNTARY MANAGED CARE WAIVERS can be used for specific populations, such as children with serious behavioral health conditions. Wraparound Milwaukee, a managed care entity that provides and coordinates services for children identified as at risk for residential or correctional placement or psychiatric hospitalization, is financed through a 1915(a) waiver and blended funding from different agencies. Named as an exemplary program by the President's New Freedom Commission on Mental Health, Wraparound Milwaukee's development was rooted in the principles of the System of Care philosophy.

1115 WAIVERS allow states flexibility in meeting Medicaid requirements in order to demonstrate innovative approaches to service delivery and financing. Arizona is using an 1115 waiver to establish health homes for adults with serious mental illnesses through regional behavioral health authorities. An 1115 waiver could be used to support integrated patient centered teams in the medical home that include mental health professionals.

COORDINATING MEDICAID WITH OTHER FUNDING STREAMS⁸¹ can allow communities to expand the reach of their services beyond Medicaid funded activities only. This strategy for coordinating funding, sometimes called pooling, blending, or braiding funds, can be used with funds from multiple systems, such as child welfare funding, local funds, SAMHSA state block grant funding, and even employer-based insurance.⁸²

- New Jersey uses the Medicaid rehabilitation and targeted case management options, with the mental health and child welfare systems contributing the state match, to fund intensive evidence-based treatment services. The state CHIP plan also participates in the project.
- Through a 1915(a) waiver, Wraparound Milwaukee blends funds through Medicaid capitation, child welfare, juvenile justice, and county mental health revenue to create flexibility and maximize the use of available revenue.⁸³

HRSA FUNDING FOR CHILDREN AND YOUTH WITH SPECIAL HEALTHCARE NEEDS: The Health Resources and Services Administration (HRSA) has engaged in a number of ongoing grant activities through its Division of Services for Children with Special Healthcare Needs.^h These include "State Implementation Grants for Systems of Services for Children and Youth with Special Health Care Needs (CYSHCN)."⁸⁴ This grant program improves access to a quality, comprehensive, coordinated, community-based system of services for CYSHCN and their families that is family-centered and culturally competent. The initiative supports grants to assist State Title V Children with Special Health Care Needs (CSHCN) programs, family organizations, providers, and other partners to implement the six core outcomes of a system of services based on evidence-based practices for CYSHCN. These six core outcomes are as follows:

- Families partner in decision making and are satisfied with the services they receive.
- >> CYSHCN receive coordinated ongoing comprehensive care within a medical home.
- >> Families of CYSHCN have adequate private and/or public insurance and financing to pay for the services they need.
- Children are screened early and continuously for special health care needs.
- Community-based service systems are organized so families can use them easily.
- Youth with special health care needs receive the services necessary to make transition to adult life, including adult health care, work, and independence.⁸⁵

The future of integrated care systems for children and youth with behavioral health conditions rests on both clinical and fiscal sustainability. Untangling the complex financial, regulatory, and organizational components that impact service delivery is an endeavor that likely means integrated care systems will develop in fits and starts over the years to come. With Medicaid policy tied so closely to state level decision making, we should expect to see growth of children's integrated care systems in states that have already begun dismantling barriers to behavioral health and primary care integration.

CONCLUSION

To close the early mortality and morbidity gap for individuals with behavioral health disorders, there must be a dedicated focus from early on in children and youth's lives to identify and effectively treat emerging behavioral health conditions. Integrated care systems for children with behavioral health conditions are a critical part of that focus, and represent an approach to delivering care that comprehensively addresses the primary care, specialty care, behavioral health, and social support needs of children and youth in a continuous and family-centered manner.

Organizations that are family and youth-guided with care coordination capability targeted to the intensity of the youth's behavioral and physical healthcare needs, utilize individualized and coordinated care plans that include both behavioral and primary health care, use evidence-based guidelines, create accountable relationships with outside organizations, and engage in data-informed planning will be best positioned to impact the behavioral health of children and youth in their communities.

APPENDIX A. CHRONIC CARE MODEL

The Chronic Care Model served as the foundation for the patient-centered medical home and collaborative care approaches to the management of common mental disorders in primary care. First developed and tested in the 1990s by the MacColl Institute for Health-care Innovation, the Chronic Care Model identifies the elements necessary for providing high quality care for people with chronic health conditions. The model grew out of the awareness that primary care tends to be organized to provide acute care, but conditions such as asthma and depression require a system that can provide ongoing treatment and support.

The elements of the Chronic Care Model, as excerpted from the Improving Chronic Illness Care website (www.improvingchroniccare.org), include:

HEALTH SYSTEM: Create a culture, organization, and mechanisms that promote safe, high quality care.

- >> Visibly support improvement at all levels of the organization beginning with the senior leader.
- Promote effective improvement strategies aimed at comprehensive system change.
- >> Encourage open and systematic handling of errors and quality problems to improve care (2003 update).
- Provide incentives based on quality of care.
- Develop agreements that facilitate care coordination within and across organizations (2003 update).

DELIVERY SYSTEM DESIGN: Ensure the delivery of effective, efficient clinical care and self-management support.

- Define roles and distribute tasks among team members.
- Use planned interactions to support evidence-based care.
- Provide clinical case management services for complex patients (2003 update).
- Ensure regular follow-up by the care team.
- ightharpoonup Give care that patients understand and that fits with their cultural background (2003 update).

DECISION SUPPORT: Promote clinical care that is consistent with scientific evidence and patient preferences.

- ▶ Embed evidence-based guidelines into daily clinical practice.
- >> Share evidence-based guidelines and information with patients to encourage their participation.
- Use proven provider education methods.
- Integrate specialist expertise and primary care.

CLINICAL INFORMATION SYSTEMS: Organize patient and population data to facilitate efficient and effective care.

- Provide timely reminders for providers and patients.
- Identify relevant subpopulations for proactive care.
- >> Facilitate individual patient care planning.
- Share information with patients and providers to coordinate care (2003 update).
- Monitor performance of practice team and care system.

SELF-MANAGEMENT SUPPORT: Empower and prepare patients to manage their health and healthcare.

Emphasize the patient's central role in managing their health.

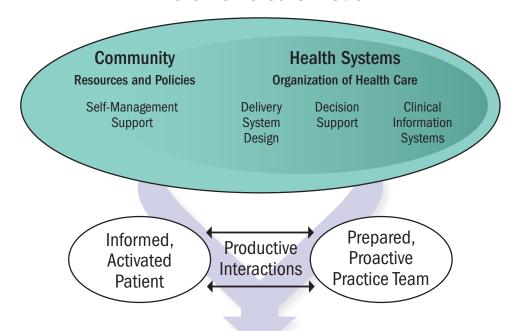
Use effective self-management support strategies that include assessment, goal-setting, action planning, problem-solving and follow-up.

Organize internal and community resources to provide ongoing self-management support to patients.

THE COMMUNITY: Mobilize community resources to meet the needs of patients.

- Encourage patients to participate in effective community programs.
- >> Form partnerships with community organizations to support and develop interventions that fill gaps in needed services.
- Advocate for policies to improve patient care (2003 update).

The Chronic Care Model



Improved Outcomes

Developed by The MacCell Institute
®ACP-ASIM Journals and Books

APPENDIX B. SYSTEM OF CARE CONCEPT AND PHILOSOPHY

The System of Care concept was first published in 1986, and it outlined a framework and philosophy for meeting the needs of children and adolescents with mental health challenges and their families. In 2011, 25 years later, the framework was updated to account for new insights and research.⁸⁷ The following definition, core values, and guiding principles are from the National Technical Assistance Center for Children's Mental Health Issue Brief, "Updating the System of Care Concept and Philosophy."

DEFINITION

A System of Care is:

A spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs in order to help them to function better at home, in school, in the community, and throughout life.

CORE VALUES

Systems of Care are:

- Family driven and youth-guided, with the strengths and needs of the child and family determining the types and mix of services and supports provided.
- >> Community-based, with the locus of services as well as system management resting within a supportive, adaptive infrastructure of structures, processes, and relationships at the community level.
- Culturally and linguistically competent with agencies, programs, and services that reflect the cultural, racial, ethnic, and linguistic differences of the populations they serve to facilitate access to and utilization of appropriate services and supports and to eliminate disparities in care.

GUIDING PRINCIPLES

Systems of Care are designed to:

- ▶ Ensure availability and access to a broad, flexible array of effective, community-based services and supports for children and their families that address their emotional, social, educational, and physical needs, including traditional and nontraditional services as well as natural and informal supports.
- Provide individualized services in accordance with the unique potentials and needs of each child and family, guided by a strengths-based, wraparound service planning process and an individualized service plan developed in true partnership with the child and family.
- Ensure that services and supports include evidence-informed and promising practices, as well as interventions supported by practice-based evidence, to ensure the effectiveness of services and improve outcomes for children and their families.
- >> Deliver services and supports within the least restrictive, most normative environments that are clinically appropriate.
- Ensure that families, other caregivers, and youths are full partners in all aspects of the planning and delivery of their own services and in the policies and procedures that govern care for all children and youth in their community, state, territory, tribe, and nation.
- ▶ Ensure that services are integrated at the system level, with linkages between child-serving agencies and programs across administrative and funding boundaries and mechanisms for system-level management, coordination, and integrated care management.
- Provide care management or similar mechanisms at the practice level to ensure that multiple services are delivered in a coordinated and therapeutic manner, and that children and their families can move through the system of services in accordance with their changing needs.
- Provide developmentally appropriate mental health services and supports that promote optimal social-emotional outcomes for young children and their families in their homes and community settings.

- Provide developmentally appropriate services and supports to facilitate the transition of youth to adulthood and to the adult service system as needed.
- Incorporate or link with mental health promotion, prevention, and early identification and intervention in order to improve long-term outcomes, including mechanisms to identify problems at an earlier stage and mental health promotion and prevention activities directed at all children and adolescents.
- Incorporate continuous accountability and quality improvement mechanisms to track, monitor, and manage the achievement of System of Care goals; fidelity to the System of Care philosophy; and quality, effectiveness, and outcomes at the system level, practice level, and child and family level.
- Protect the rights of children and families and promote effective advocacy efforts.
- Provide services and supports without regard to race, religion, national origin, gender, gender expression, sexual orientation, physical disability, socio-economic status, geography, language, immigration status, or other characteristics, and ensure that services are sensitive and responsive to these differences.

APPENDIX C. ADDITIONAL RESOURCES

Cultural and Linguistic Competency

- Integrating 'Youth Guided' and 'Cultural and Linguistic Competence' Values Into Systems of Care, Technical Assistance Partnership for Child and Family Mental Health (July 2011).
- The Family Experience with Primary Care Physicians and Staff, NAMI (May 2011).
- >> Cultural Competence Health Practitioner Assessment, National Center for Cultural Competence
- Cultural and Linguistic Competence Implementation Guide, Technical Assistance Partnership for Child and Family Mental Health, Martinez and Van Buren (January 2008).
- Cultural and Linguistic Competence Guidelines for Residential Programs, National Building Bridges Initiative Cultural and Linguistic Competence Workgroup. (Developed for residential programs, this resource is also useful for community-based health-care providers.)

Assessment and Screening Tools

- Bright Futures Practice Guides and Other Resources, American Academy of Pediatrics
- >> Early Childhood Materials for Early Identification, Substance Abuse and Mental Health Services Administration
- Pediatric Symptom Checklist (This checklist can be used with children and youth ages 3-16.)

Partnering with Outside Entities

- The Patient-Centered Medical Home Neighbor: The Interface of the Patient-Centered Medical Home with Specialty/Subspecialty Practices, American College of Physicians (2010).
- ▶ Enhancing the Continuum of Care: Integrating Behavioral Health and Primary Care through Affiliations with FQHCs, National Council for Community Behavioral Healthcare
- >> Co-Management Letters and Cost Sharing Agreements
- Partnering with Health homes and Accountable Care Organizations: Considerations for Mental Health and Substance Use Providers, National Council for Community Behavioral Healthcare (January 2011).

Medicaid Health Homes

- Behavioral Health Homes for People with Mental Health & Substance Use Conditions: The Core Clinical Features, Center for Integrated Health Solutions (May 2012). www.integration.samhsa.gov/clinical-practice/CIHS_Health_Homes_Core_Clinical_Features.pdf
- Financing and Policy Considerations for Medicaid Health Homes for Individuals with Behavioral Health Conditions, Center for Integrated Health Solutions.
- >> Customizing Health Homes for Children with Serious Behavioral Health Challenges, Human Service Collaborative (March 2013).

FNDNOTES

- a. In this paper, "behavioral health" is used to encapsulate both mental health and substance use disorders and conditions.
- b. Integrated care systems is used to describe a care delivery model that comprehensively addresses the primary care, behavioral health, specialty care, and social support needs of children and youths with behavioral health issues in a manner that is continuous and family-centered. It is not necessarily a residential center for children.
- c. Information on the system of care approach and chronic care model may be found in Appendices A and B.
- d. In this paper, the term "primary care clinician," or PCC, is meant to refer to all primary care providers who see children: pediatricians, family practice physicians, family nurse practitioners, and physician assistants.
- e. In this paper, behavioral health is a term used to encapsulate both mental health and substance use disorders and conditions.
- f. Information on both the Chronic Care Model and System of Care approach may be found in Appendices A and B, respectively.
- g. In this paper, the term "Primary Care Clinician," or PCC, is meant to refer to all primary care providers who see children: pediatricians, family practice physicians, family nurse practitioners, and physician assistants.
- h. Children and youth with special health care needs (CYSHCN) are defined by HRSA as "...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." (Health Resources and Services Administration, National Survey of Children with Special Health Care Needs: Chartbook 2005-2006," http://mchb.hrsa.gov/cshcn05/)
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