

Children's Memorial Hospital Attachment A 7-1-11

Almost 78% of the fees that Illinois Medicaid pays to CMH are for children with Complex Chronic Conditions (or CCCs, using the definition developed by Feudtner, 2002). **37% of the State's 2009 total costs for all Illinois recipients under age 19 are for CCC children**

These include children with neuromuscular conditions, cardiac conditions, malignancies and many other highly complex medical conditions. As CMH considers HFS's move to a coordinated care model, our chief concern is that these children and adolescents have excellent health outcomes and continue to have access to the highly specialized services that help produce those outcomes.

Research shows that children with special health care needs may benefit from improved outcomes when their care is coordinated in a medical home setting (Kaye and Takach, 2009). This concept originated in 1960s in the field of pediatrics as an answer to the needs of children with highly complex needs, but it has rarely been realized. Hence, the research literature examining its strengths and weaknesses is sparse. An important recent study suggests that care coordination for such children could potentially produce cost savings for Illinois (Casey, et al., 2011; Sloyer, 2009).

The desire to create a risk-based provider system that spans fully comprehensive care raises some concerns:

(1) There is no incentive in risk-based systems for health insurers or providers to enroll children with CCCs. Rather, most risk-based incentives encourage insurers to enroll healthy children who have minimal health needs. For example, when such a system was attempted in Los Angeles County, no insurer was willing to accept the risk for covering the services for children with CCCs. The California Department of Health Care Service is instead developing an entirely separate payment system for these youth.

(2) The medical home models for children with Complex Chronic Conditions developed for Medicaid programs in other states have not required care coordination organizations to be financially responsible for the delivery of comprehensive care, but instead merely to coordinate this care in typically a primary care setting. This means that we have very little information about how to financially and contractually structure a viable integrated care system, Accountable Care Organization or Managed Care Organization for children with complex chronic needs.

Given these realities, the experiences of other states and our own experience managing the care of children with Complex Chronic Conditions provide insights that can guide us as we develop a coordinated care system for these youth.

What would a medical home for children with CCCs look like?

- States focusing on complex chronic conditions establish separate fees or whole systems for children and adults with complex conditions. For example, Massachusetts established a three-tiered primary care coordination system in which individuals are placed in tiers depending on a number of factors (e.g., the ratio of ED visits to primary care visits) (Institute for Health Care Improvement, 2011). The intensity of care coordination, and fees paid by Medicaid, varies by tier. Individuals who are not able to coordinate their care effectively enough to avoid ED visits for ambulatory care sensitive

conditions, for example, are candidates for the most intensive coordination support. Other states that have experience developing care coordination systems for children with special health care needs include Wisconsin, Minnesota, and Washington. None of these states has yet released an analysis that demonstrates cost savings.

- Disease management is not enough (Kaye and Tacach, 2009). Most states that have implemented disease management systems, typically through a disease management provider who was not integrated with primary care, have moved away from these systems towards more integrated and comprehensive care coordination. For example, in its attempt to restrain costs of its disabled population, Washington State first attempted a traditional disease management model. This did not restrain costs because the clients had far more complex health needs than a traditional disease management model could address. The state evolved its system into a Chronic Care Management program (2009). Medicaid recipients are determined to be eligible for this program as a result of predictive modeling that assigns risk to individuals based on past claims and diagnostic information.
- The chronic care management model for children with complex medical needs, which is now being developed in various form by Medicaid programs in Washington, Minnesota, Massachusetts and Wisconsin, is defined as having six essential elements (RWJF, 2009): (1) care occurs in a *system* that includes hospital, specialist and primary care, (2) the system is designed to assure the delivery of efficient clinical care and self-management, (3) the system promotes best practices,(4) the system employs integrated clinical information systems, (5) the system empowers patients to manage care independently, and (6) the system optimizes the use of community resources on behalf of patients.

Quality issues

- All Medicaid care coordination systems have minimal standards for primary care case managers (Kaye and Takach, 2009). The requirements for Massachusetts include 24/7 phone availability, a minimal number of office hours outside of the 9-5 work day, the engagement of the care coordinator during hospitalization, and meaningful urgent care capacity. Many states have appointed statewide committees, including providers, state agency experts, and family members, to develop medical home and care coordination standards for children and adults with special health care needs.
- Studies examining outcomes for patients served by medical homes are able to report only process improvements and quality improvements in the delivery of services (e.g., Colby, 2009). Studies have not yet shown improvements in health outcomes; the lack of outcome findings is likely the result of the fact that these systems are new and have not had the opportunity to be fully evaluated.
- There is concern in the research literature successful medical home/care coordination models will increase costs. It is generally held that children with CCCs are currently underserved. One study suggests that care coordination will increase costs of caring for these children because care coordination will do a better job of making sure children get the care that is optimal (Feudtner, et al., 2010).

Cost issues

- Very few studies examine cost savings of medical homes for children with CCCs. A small hospital-based medical home pilot in Arkansas for children with complex health needs produced substantial savings (Casey, et al., 2011). This short-term analysis focused on inpatient, outpatient, pharmacy and emergency department costs 12 months prior to and 12 months after enrollment in a medical home and, indeed, was able to achieve substantial savings. It did not consider home health, long-term care or other costs.
- It is expected that successful medical home models will see costs of primary and out of hospital care increasing, while the costs of hospital care decreases. Medicaid systems that focus on the disabled or chronic illness population offer an elevated monthly care coordination payment for clients with chronic or disabling conditions. These range up to \$30 per month per client (Kaye and Takach, 2009). In addition to the monthly care coordination fee, some states offer an enhanced visit rate when the client has a complex chronic condition and/or a performance-based bonus for quality improvements (such as the very effective bonus provided to Illinois primary care providers for conducting developmental screenings). For example, Oklahoma offers all three - a \$30 monthly fee, an enhanced visit rate, and performance incentives - to care for individuals with chronic conditions.

Balancing primary and specialty care for children with CCCs

- One of the challenges of implementing a medical home for children with CCCs is developing methods to balance primary care and specialty care. For example, a number of children who are served by CMH for highly complex conditions receive intense care over a long period through CMH specialists. Many of these children receive primary care from their CMH specialty providers. But many children will require a CCC medical home more episodically. The American College of Physicians offers a similar model, in which the primary care/specialist partnership is balanced differently during spells of highly complex need (ACP, 2010). In Washington State, the Chronic Care Management program is intended to enroll recipients during spells of high care use. When the spell of high use ends, recipients are returned to a lower level of care coordination.

CHILDREN'S MEMORIAL HOSPITAL - ATTACHMENT B MENTAL HEALTH AND COORDIANATED CARE

The document indicates that, to meet the definition of coordinated care, an entity must provide for a "majority of care," including behavioral health services (p. 2). It does not necessarily mean that the "coordinated care" entity must provide for 50% of all mental health care needs. Rather, it must provide for a majority of the total package of medical and mental health care.

To appreciate the implications of this requirement with regard to behavioral health, one must consider the strengths and weaknesses of behavioral health care as provided by health care specialists, primarily physicians and nurses.

It is possible to categorize the mental health services provided by medical specialists (primary care doctors and nurses) into 4 categories: 1) identifying behavioral, emotional, and developmental problems; 2) providing appropriate referrals for identified problems; 3) providing medication management for behavioral health problems; 4) providing counseling or psychotherapy for such problems. Ideally, decisions about what services can and should be provided in a coordinated care setting will be based upon empirical support.

With regard to #1: identifying behavioral, emotional, and developmental problems. Presently two carefully done studies by CMH faculty (Lavigne in Illinois, Costello and Dulcan in Pittsburgh) show that pediatricians are not effective in identifying child emotional and behavioral problems. A large number of children with problems are not identified, resulting in a substantial "hidden morbidity." This is a significant problem since early identification and treatment is likely to be more effective than treatment initiated when problems are more entrenched. These studies also show that children identified by pediatricians as having behavioral or emotional problems are incorrectly identified (about 50%). To improve the screening and diagnostic activities a coordinated care center will require: 1) incorporating appropriate screening instruments into primary care; 2) training physicians to interpret these instruments; 3) finding ways to reduce the burden of scoring such measures so that they can be used by providers.

With regard to #2: providing appropriate referrals for identified problems. Here primary care physicians can play an important role. Our research with young children indicates that a physician recommendation to the parent that their child receive a psychological evaluation was a good predictor of parents actually seeking such an evaluation.

With regard to #3: providing medication management for behavioral health problems. ADHD is a psychiatric disorder with significant educational and behavioral sequelae. The single best treatment for ADHD involves medication (usually a stimulant medication). Primary care physicians treat many more children with those medications than do child psychiatrists and neurologists. Nonetheless, there are many studies indicating that

treatment in primary care is not optimal and does not fit with expert recommendations for standards of care. Physicians need training in how to provide optimal care. We have developed a computer-assisted approach to providing optimal care that is available on-line at the CMH website. With the proper training, primary care physicians are well-suited to provide this care in a coordinated care setting. Especially in rural areas, primary care physicians may be called upon to treat children for anxiety and depression. For these conditions, they are not well trained. To provide such care in the primary care setting will require careful coordination with child psychiatrists and, since there is a shortage of such individuals, innovative approaches (telepsychiatry, other forms of collaboration, etc.) will be needed to provide such services in coordinated care settings.

With regard to #4: providing counseling or psychotherapy for such problems. There are virtually no studies to support the notion that physicians and nurses can effectively provide counseling or psychotherapy services for children and adolescents in the primary care environment. We (Lavigne, et al.) published one of the very few such studies showing that properly trained nurses can effectively provide care for young children with symptoms of oppositional defiant disorder, but there are virtually no other studies showing that primary care medical staff can effectively provide such services for other pediatric behavioral health problems. Coordinated care centers thus must either incorporate mental health specialists into those settings or establish appropriate referral networks. Incorporating mental health specialists into such settings, however, hardly guarantees that empirically-supported treatments will be employed. Doing so will require training of those personnel and ways of monitoring treatment fidelity and outcomes. It is also likely that some centralized service will be needed to initiate and monitor such services, perhaps following procedures employed in Hawaii to address these problems.

Outcome measures. We (Lavigne et al.) recently surveyed existing outcome measures for mental health services for children. Appropriate outcome measures must be easy to administer and score, take little time for parents to complete, address a wide range of ages, and be applicable to a wide range of clinical problems to avoid needing different outcome measures for different clinical problems. We developed an instrument meeting these needs, the CASI-TM-P (Child and Adolescent Symptom Inventory-Treatment Monitor-Parent form). There is also a parallel form for teachers to complete. Another option would be the outcome scales developed by the Ohio Mental Health Consumer Outcomes Initiative.

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