

# Evolving Federal and State Health Care Policy: Toward a More Integrated and Comprehensive Care-Delivery System for Children With Medical Complexity

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abstract

Irrespective of any future changes in federal health policy, the momentum to shift from fee-for-service to value-based payment systems is likely to persist. Public and private payers continue to move toward alternative payment models that promote novel care-delivery systems and greater accountability for health outcomes. With a focus on population health, patient-centered medical homes, and care coordination, alternative payment models hold the potential to promote care-delivery systems that address the unique needs of children with medical complexity (CMC), including nonmedical needs and the social determinants of health. Notwithstanding, the implementation of care systems with meaningful quality measures for CMC poses unique and substantive challenges. Stakeholders must view policy options for CMC in the context of transformation within the overall health system to understand how broader health system changes impact care delivery for CMC.

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*The moral test of government is how that government treats those who are in the dawn of life, the children; those who are in the twilight of life, the elderly; and those who are in the shadows of life, the sick, the needy, and the handicapped.*

Hubert Humphrey

Although the implications for continued payment and delivery system reform remain to be seen in the wake of the 2016 presidential election, a strong impetus to innovate and advance toward a value-based system of care persists. Payment for health services in the United States has historically been based on a complex set of fees charged for services provided by physicians, hospitals, and other health professionals and paid for by both patients and an equally complex network of insurance providers. Under that payment model, the United States has seen unprecedented growth in the services available for the treatment of previously untreatable diseases, such as leukemia and meningitis, while sustaining a growth in medical cost far in excess of that seen in other Western countries.<sup>1</sup> With the passage of the Patient Protection and Affordable Care Act (ACA) in 2010<sup>2</sup> and the Medicare Access and Children's Health Insurance Program Reauthorization Act (MACRA) in 2015, Congress has embodied in law a commitment to move Medicare payments from a fee-for-service (FFS) model to a payment methodology that is based on alternative payment models (APMs) and aimed at reining in the costs of chronic-disease management among the elderly.<sup>3</sup> Although Medicare provides coverage for few children, it is likely that this change in Medicare policy will be reflected in similar changes within Medicaid, affecting the care provided to the 43 million children covered by Medicaid and the Children's Health Insurance Program (CHIP) across the country. Unlike Medicare, policy changes within Medicaid roll out with tremendous

variation across the country, reflecting the variation in the state-federal partnership that creates each state Medicaid program. For example, whereas federal standards entitle all children <21 years of age to a comprehensive set of health care services known as Early and Periodic Screening, Diagnostic, and Treatment, each state has developed its own plan for implementing that standard with some variation.<sup>4</sup> Of particular interest is the impact of APMs on the care of children with medical complexity (CMC), a subset of the general pediatric population that requires collaborative services across multiple sectors (eg, health, social services, and education) to optimize their health outcomes. Payment models designed to improve outcomes for adults with a fragile status will need careful scrutiny to ensure that they meet the needs of CMC.

### THE ROLE OF THE PRIMARY CARE MEDICAL HOME

Children and youth with special health care needs require care from multiple providers to meet those needs. To be most efficient in the allocation of resources, the care of these children and youth is optimized in care models that are integrated. Care integration has been defined by Singer et al<sup>5</sup> as "care that is coordinated across professionals, facilities and support systems; continuous over time and between visits; tailored to the patients' needs and preferences; and based on shared responsibility between patient and caregivers for optimizing health." Although this definition is foundationally sound for child health care delivery, it is important to emphasize the fundamental dependence of child health outcomes on additional factors (including family functioning) and the provision of both medical and nonmedical services (such as education, home care, and family support) across

the care continuum. For children, integration results from coordinating the efforts of all providers, irrespective of institutional, agency, or community-based organizational boundaries.<sup>6</sup>

An analysis of a commercially insured, pediatric population receiving care at a pediatric subspecialty hospital in Boston revealed that 0.5% of the patients are responsible for 20% of the health care expenditures.<sup>7</sup> These patients typically have significant neurodevelopmental and psychiatric needs and include patients who are technology dependent. Another 20% of the population account for 55% of the overall medical expenses and primarily consist of children and youth with single or multiple chronic conditions but who are not particularly complex. Often, CMC have Medicaid as a primary or secondary insurance, and consequently, the percentage of CMC with Medicaid is even higher than those who are commercially insured.

Although having a medical home is essential for all children and youth,<sup>8</sup> understanding the needs of this population of CMC is critical when designing care models that can effectively meet their needs. Evidence to date reveals that for patients with complexity, the primary care-based medical home is not sufficient to meet all the care needs in a cost-efficient manner.<sup>9</sup> Based on the broad and diverse subspecialty care needs of CMC, the care model must support significant engagement among pediatric subspecialty providers. This may be most effectively achieved by measurably integrating care between primary care practitioners and subspecialists, enabling a high-performing family- and/or patient-centered medical home.<sup>6</sup> In some cases, these needs may be met by a subspecialty-based family- and/or patient-centered medical home. This latter model must be appropriately resourced to serve all

the care needs of the CMC, including a single point of access, care coordination, care planning, tracking, and cultural effectiveness, and be held accountable to the same care outcomes as the primary care-based, integrated model.

Financing mechanisms based on FFS are limited in their ability to support care integration because the only way to generate revenue to sustain the care model has typically been through face-to-face visits. The transformation of the payment model in the ACA enables a shift toward value-based payments. These new payment models will support care management loci within delivery systems in the primary care and subspecialty care settings.

Currently, there are significant barriers in caring for CMC, regardless of whether they are insured by public or private payers. The ability of CMC to receive insurance coverage for out-of-state care is challenging, necessitating that care models develop within state borders regardless of whether those models have sufficient capacity to care for the most complex cases among these CMC. Some states are beginning to move toward more integrated systems of care by taking advantage of the health homes provision, Section 2703 of the ACA.<sup>10</sup> The need to implement frameworks of care coordination and integration across sectors (eg, medical, behavioral, social) becomes even more critical. Indeed, health home models have the potential to provide services for some of the most complex and vulnerable populations of children and adults in the United States. To be successful in meeting the needs of these populations, it will be essential to train the workforce of care providers, including primary and subspecialty care providers, nursing, social workers, and anyone serving in the capacity as care coordinator. Beyond the training, measures of care coordination and care integration

will be essential elements of these new care models.

Care or case management has traditionally been a function of payers, especially for those payers providing services such as Medicaid managed care organizations. There has been much debate over the setting in which care management services should be based and/or reimbursed (in the managed care organization versus in the delivery system). Health care systems need to promote the use of care integration process and outcome measures that are aligned with all the domains of the Triple Aim (ie, quality, cost, experience)<sup>11</sup> so that current debates center on who is best qualified to perform these functions to achieve the highest value.

### APMS

More than 43 million children, including half of all low-income children in the United States, receive health coverage through the Medicaid and CHIP programs.<sup>12</sup> Specifically, as of the first 9 months of 2015, public insurance covered 41.8% of children and private insurance covered 55.1% of children between the ages of 0 and 17 years.<sup>13</sup> Under the Early and Periodic Screening, Diagnostic, and Treatment component, states are required to provide enrolled children <21 years of age all Medicaid-coverable services to “correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services,” including preventive, dental, vision, mental health, developmental, and specialty services.<sup>14</sup> Although the CHIP also offers a comprehensive set of benefits for children, states have flexibility with program design such that CHIP benefits may not include all the services required under Medicaid. The ACA provided additional coverage options for individuals and families purchasing health plans (known as qualified

**TABLE 1** The 10 Essential Health Benefits Required Under the ACA

Ambulatory patient services
Emergency services
Hospitalization
Maternity and newborn care
Mental health and substance use disorder services, including behavioral health treatment
Prescription drugs
Rehabilitative and habilitative services and devices (to help people with injuries, disabilities, or chronic conditions gain or recover mental and physical skills)
Laboratory services
Preventive services and chronic disease management
Pediatric services, including oral and vision care

Centers for Medicaid and Medicaid Services. Essential health benefits standards: ensuring quality, affordable coverage. Available at: <https://www.cms.gov/CCIIO/Resources/Fact-Sheets-and-FAQs/ehb-2-20-2013.html>. Accessed November 11, 2016.

health plans) through the health insurance marketplace (also called health insurance exchanges). Health plans offered in exchanges and in the individual and small-group markets must cover 10 essential health benefits under the ACA (Table 1).

As a result of both Medicaid and/or the CHIP and the ACA, the rate of uninsured children dropped to a record low, decreasing from 13.9% in 1997 (when the CHIP was established) to 4.5% in the first 9 months of 2015 in children 0 to 17 years of age.

Building on the delivery-system reform actuated by the ACA, both public and private payers have begun focusing on novel payment and care-delivery models to promote value-based, high-quality, affordable care. Under FFS systems, provider reimbursement usually incented volume of services delivered with little accountability for value or health outcomes. Such FFS payment methodologies often resulted in fragmented, poorly coordinated services with a focus on acute, episodic care. In contrast, the goal of APMS is to achieve better outcomes at a lower cost through

**TABLE 2** Characteristics of FFS Versus APMs

FFS Payments	APMs
Payment for volume	Payment for value and health outcomes
Emphasis on acute, episodic encounters	Patient-centered care
Fragmented care	Care management
Poor coordination of care	Care coordination
Lack of focus on population health	Population-based analysis and reporting
Poor management of chronic disease	Clinic system integration
Poor integration with behavioral health or long-term services and supports	Incentives to integrate with behavioral health and community-based organizations
Little incentive to address social determinants of health	Recognition of the social determinants of health
Access issues	Enhanced access to care
Inadequate data	Improved data sharing
Lack of transparency	Shared decision-making
Slow dissemination of evidence-based practices	Patient self-management support
Workforce capacity and/or workforce development issues	Multidisciplinary team

performance-based payment models that promote patient-centered, population-based, high-quality, coordinated, accessible, and effective care (Table 2).

Multiple payment models exist across Medicare, state Medicaid programs, and commercial payers, but the following highlight common payment systems.

### Patient-Centered Medical Home

The patient-centered medical home (PCMH), which is typically based at the primary care site, is used to organize care that is patient centered, comprehensive, team based, coordinated, accessible, and focused on quality and safety.<sup>15</sup> PCMHs are accountable for the full range of patients' health care needs, including prevention and wellness, acute care, and chronic care. Requirements include the coordination of care with specialists and, frequently, integration of medical and behavioral health care. Reimbursement to PCMHs may include global budgets or traditional FFS payments augmented by medical home activity payments (payments are often based on a per-member, per-month formula for services [such as care coordination] that are not usually billable under traditional FFS). With either method, the PCMH might also have the opportunity for shared savings.

### Accountable Care Organization

Accountable care organizations (ACOs) are groups of doctors, hospitals, and other health care providers who come together voluntarily to give coordinated, high-quality care to the patients they serve. Coordinated care helps ensure that patients, especially the chronically ill, get the right care at the right time, with the goal of avoiding the unnecessary duplication of services and preventing medical errors.<sup>16</sup> ACOs typically receive a risk-adjusted, global budget to manage the total cost of care for a defined population. These payments are often accompanied by upside and/or downside risk-sharing arrangements. PCMHs are considered to be foundational to a successful ACO.

### Bundled or Episodic Payment

A bundled payment establishes a single payment for health care services on the basis of the expected cost provided during a clinical episode of care over a specified time. The bundle may encompass services or procedures rendered over time by multiple providers across multiple care settings. The provider typically assumes the financial risk for the episode of care (including costs resulting from preventable complications) as well as

the accountability for performance. For example, a bundled payment for pediatric high-risk asthma might encompass comprehensive medical services as well as nontraditional services, such as home inspections, community health worker visits, and air purifiers, for which the provider might not have been reimbursed under a traditional FFS system.

Virtually all the APM designs provide incentives to reward high-quality health care, often linking payment to quality metrics that represent a mix of process, outcome, and patient experience measures.

Quality-incentive payments may take different forms, such as a bonus in addition to base payments, payment modification (quality performance modifiers), or a quality gate (minimal thresholds must be met to trigger quality payments and, sometimes, shared savings payments). Quality measure sets continue to evolve to capture impactful, evidence-based measures that promote quality improvement, better value, and improved health outcomes.

APMs advance the PCMH and, if designed well, provide primary care providers with the flexibility to meet the unique needs of CMC. Through medical home activity payments or global payments, APMs enable providers to invest in the infrastructure and services that are often nonbillable under FFS payment models, such as care coordination, care management, peer and/or parent support, telemedicine, community health worker visits, and more. The emphasis on population-based improvements in quality, cost, and efficiency have the potential to incentivize a greater coordination of care with other providers and with community-based organizations. APMs also afford providers with greater flexibility to address the social determinants of health (for example, covering a home inspection by appropriately trained staff and the provision of an air filter for a

child with asthma). In addition to quality measures, APMs may also spur the adoption of medical home elements through payer contractual obligations (eg, a mandate to staff the practice with a care coordinator) and/or certification requirements (eg, the PCMH and ACO).

APMs are in their infancy and continue to evolve. As providers assume greater financial risk, they also have the opportunity to provide input to the design of these new payment and care-delivery models and to influence systems of care for CMC.

Incorporating CMC into current efforts in payment and delivery reform is challenging because many of the fundamental assumptions driving APMs for adults<sup>17</sup> do not hold for pediatric patients. In payment, as in measurement and delivery system design, children are developing into adulthood while always living in dependent family relationships. They differ in the epidemiology of their disease processes, inhabit a different demographic, and use different services, often across sectors that include education, social services, and juvenile justice.<sup>18,19</sup> APMs often focus on common chronic diseases, such as hypertension and diabetes, as markers of quality care, with measures of blood pressure or glucose control, respectively, being used to assess health outcomes at the practice level. Often, an individual practitioner will have enough patients with a condition to support reliable measurement. In contrast, CMC represent diverse conditions, and primary care providers of CMC confirmed in a recently published survey that this heterogeneity of rare and unfamiliar diagnoses make caring for this population challenging. As a result, CMC typically lack common measures of optimal outcomes similar to those used in the adult chronic disease model.<sup>20,21</sup> The natural history of many CMC derives from the complications of premature

birth, including chronic lung disease, developmental delay, and cerebral palsy. In many cases, those children are initially high users of medical services but over time become high users of social and educational services.<sup>22</sup> These outcomes are important to families and society but have a less direct impact on health care costs in the short-term. Moreover, the ability of the health care system to alter outcomes in this population must take into account the impact of poverty on health. Poverty has an adverse impact on a family's ability to coordinate care across systems and address the social determinants of health. APMs should include incentives for cross-system collaborations that address these social needs of families as well as the medical needs of CMC.<sup>23</sup> Finally, the impact of unmet behavioral health needs for both children and families must be recognized and addressed within APMs developed around child health.<sup>24</sup>

### EXAMPLES OF CURRENTLY IMPLEMENTED APMs

Policy options for improving care and reducing costs for CMC are dynamic. The ACO is 1 example in which a network of providers is responsible for care outcomes and assumes financial risk for a defined patient population to incentivize increased health care value. The oldest pediatric ACO, Partners for Kids, was established in 2008 and covers >330 000 Medicaid pediatric patients across 34 counties in Ohio. The provider network includes >300 primary care physicians and nearly 700 specialists anchored at a children's hospital.<sup>25</sup> An evaluation of this ACO revealed that health care spending grew at a lower rate than comparable FFS models, with improvement in 5 quality-of-care indices.<sup>26</sup> Aligning care improvement with cost containment is promising, but further disruption in the form of community engagement (for

example, putting resources into evidence-based programs delivered in the community or via mobile technology to reduce rather than treat premature birth) is needed.<sup>27</sup>

California provides a different model of care for CMC. Founded in 1927 and funded partly by Title V of the Social Security Act, California Children's Services (CCS) provides public insurance coverage, care coordination, and a regionalized system of pediatric specialty care facilities for ~180 000 CMC.<sup>28</sup> Unlike that of Ohio, the California model focuses solely on CMC and specialty care. CCS increases the percent of pediatric patients cared for by pediatric specialists, including those in pediatric cardiology and oncology,<sup>29</sup> although variation in such access exists.<sup>30,31</sup>

A significant challenge to establishing a pediatric regionalized system of care is accessing the appropriate level of specialty care required because complex pediatric care is concentrated in pediatric specialty care centers that are not located in all states or regions. New proposed federal legislation would allow states to opt in to a system of coordinated care for CMC, enabling families to receive coverage of care across state lines as needed.<sup>32</sup>

### POLICY OPTIONS

The epidemiology of pediatric illness is the inverse of that of adults; unlike elderly adults, children overall are healthy, and CMC are rare. Those in a sustainable system of care for CMC might argue for services provided in regionalized centers, where a sufficient volume of patients with relatively rare conditions can be sustained in practices providing pediatric subspecialty care, thereby driving quality improvement and outcomes. Although quality care for CMC has unique characteristics, viable policy options for CMC care systems cannot stand in

isolation from policy options for the overall health care system. Major stakeholders developing policy focused on cost, access, and quality for the general population and adults with chronic conditions often are unable to focus on the nuances of care systems for CMC, especially when there is a negligible impact on larger care issues. For example, California has a \$94 billion Medicaid budget covering 13.5 million people, of which CCS is ~\$2 billion, or only 2% covering 180 000 children.

In 2015, a bill entitled Advancing Care for Exceptional Kids Act was introduced in Congress. Under this proposed legislation, states would have the option of providing services to children with medically complex conditions under the Medicaid and CHIP programs through a Medicaid Children's Care Coordination program. Eligible children would be enrolled in a Medicaid Children's Care Coordination program within a nationally designated children's hospital network with the aim of better coordination of care, improved health outcomes, and lowered costs. It is anticipated that this bill will be reintroduced in an upcoming session of Congress.

Although challenging, there are opportunities for policy successes for CMC. However, pediatricians

and children's advocates cannot operate in isolation. It is critical to understand the implications of CMC policy proposals for overall health care policy and align CMC policy accordingly. Understanding how pediatric goals speak to a larger context around which constituencies could coalesce creates broader support that is necessary for success. Active engagement in mainstream, nonpediatric health advocacy organizations and with broader constituencies, such as labor, business, and education, can further promote shared goals. Finally, the fact that total pediatric spending is relatively small can also be a strength; cost-containment drivers that are central to the debate of adult health care reform need not be in play for CMC.

Advanced APMs were created as 1 of 2 delivery system reform tracks in the nearly unanimous and bipartisan MACRA of 2015. The Centers for Medicare and Medicaid Services estimate that nearly 360 000 clinicians serving >12.3 Medicare and/or Medicaid beneficiaries will participate in APMs in 2017. Although the MACRA is largely independent of the ACA, it is impossible to know if APMs and other mechanisms to control spending will be impacted by the

efforts to repeal and/or replace the ACA.<sup>33</sup> Notwithstanding any uncertainty regarding the new administration's impact on the health care environment, strong bipartisan support for the MACRA indicates policy agreement for a movement toward value-based models of care. Pediatricians and children's advocates need to understand how broader health system transformations will change the delivery of care for CMC and their families.

#### ABBREVIATIONS

ACA:	Patient Protection and Affordable Care Act
ACO:	accountable care organization
APM:	alternative payment model
CCS:	California Children's Services
CHIP:	Children's Health Insurance Program
CMC:	children with medical complexity
FFS:	fee for service
MACRA:	Medicare Access and Children's Health Insurance Program Reauthorization Act
PCMH:	patient-centered medical home

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