

Advancing Care for Exceptional (ACE) Kids Act Policy Brief

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INTRODUCTION

The federal Advancing Care for Exceptional (ACE) Kids Act became law in 2019 and aims to provide access to a high quality, well-coordinated system of care for children with medical complexity (CMC) and their families. This policy brief focuses on patient-centered health home models of care coordination with a comprehensive care plan that addresses all service needs. Care integration is achieved by providers working together across specialties and locations including facilitating out-of-state care. State Medicaid agencies have the option to adopt this program after the effective date of October 1, 2022. This paper describes the background on the need for the ACE Kids legislation and outlines three benefits for states that choose to implement it.

BACKGROUND

Children with medical complexity are a subset of children and youth with special health care needs (CYSHCN) who have “family-identified service needs, severe chronic clinical conditions, functional limitations, and high utilization of health resources” (Cohen et al., 2011). Despite comprising only a small pediatric subgroup, the intensive health needs of CMC require greater attention and coordination. According to the National Survey of Children’s Health, only 19.2% of children ages 0-11 years old with complex needs receive care in a well-functioning system of care, and these numbers continue to drop to 4.5% for children ages 12-17 with more complex care needs (CAMHI, 2019/20). More specifically, a 2014 study on health care access found that CMC were more than twice as likely as the broader CYSHCN population to have at least one unmet need (Kuo, 2014).

One significant barrier to health care access for CMC is the fractured system of pediatric specialty care and the silos that exist between providers. This lack of horizontally integrated care produces conditions that force families of CMC to rely on numerous uncoordinated care entities (Simon et al., 2012). To compound the issue, CMC typically transition frequently between care settings and systems (Cohen, 2011). Navigating health care providers becomes even more difficult when out-of-state health care is needed. In order to meet the specific and varied needs of CMC and their families, coordinated linkage between community-based primary care, specialty care, other community social services, and payers is necessary.

Health care disparities caused by a fractured system of care for CMC have a direct impact on health outcomes for CMC, family quality of life, and financial challenges, among others (Kuo, et al., 2011). As a result of these outcomes, the cost of care for CMC accounts for up to thirty-three percent of all pediatric health care spending, equating to ten billion dollars annually (Berry et al., 2014). A leading cause of these costs, and a target area for improved quality of life for CMC and families, is unnecessary inpatient hospitalization. Medicaid inpatient hospital spending on CMC

equals \$5,903 per child per year (Berry et al., 2014), a very large amount of which can be reduced through a more effective system of care. Though Medicaid enrolled children have a right to necessary preventative care under Medicaid's Early and Periodic Screening, Diagnostic and Treatment (EPSDT), barriers to access translate to low utilization rates and higher need for emergency hospital care (Berry et al., 2014).

The ACE Kids Act aims to alleviate the national absence of a comprehensive and coordinated system of care for CMC through Medicaid, with a goal of improving health outcomes and quality of life for their families. The focus on Medicaid is intentional, as approximately two-thirds of children with medical complexity's health care coverage is concentrated in the Medicaid program (CHA, 2013). This paper will outline three of the most noteworthy benefits for state uptake of this policy.

BENEFIT #1 – Federal Policy Supporting a System of Care for CMC

The ACE Kids Act singles out CMC as a population that needs a unified system of care and then identifies essential elements for building it. This affirmative public policy highlights CMC as a high need group meriting uniquely designed comprehensive systems of care. ACE Kids directly addresses the challenge to get the focused attention of the Medicaid program with its huge general enrollment and coverage of many high need subpopulations.

Virtually all state Medicaid programs rely on broad structures to assure access to services and coordinated care. The most common approach is to contract with HMOs as organizers and coordinators of care for their assigned population. The difficulty is that each HMO's enrollment typically is a relatively average cross-section and this leads to general methods of care coordination with very low staff to population ratios (i.e., low staff, high population) and almost always distant from the providers of direct care. Other structures, like primary care case management (PCCM) programs, exhibit the same issues.

Historically, Medicaid waiver programs have been the mechanism to address needs unmet by Medicaid's standard covered services for special subpopulations. Special programs for CMC (usually of the 1915(c) waiver or TEFRA SPA variety) are often limited to those who meet an institutional level of care, a very narrowly defined group. Not only are waiver populations usually limited, but waivers by definition only add certain specified services, albeit very helpful. In sum, waivers provide extra services for some individuals. They do not build a system of care for an entire population, like CMC.

ACE Kids builds the systems of care that waivers do not. It makes the health home the system anchor and accountable party for the comprehensive plan of care. It goes on to mandate that services be effectively coordinated to assure the connected delivery of pediatric primary care, emergency services, palliative care, behavioral health services, pediatric specialty and subspecialty services, and linkage with out-of-state providers when appropriate. The Act also mandates identification, monitoring, quality measurement, appropriate IT support for communication, and reporting: the elements of a well-organized system. The developing health homes for CMC and their families are resourced with a team of professionals, embedded care coordinators, high staffing ratios, and direct access to pediatric subspecialists. This is an exciting

model system of care that strives to identify all CMC and then provides them with comprehensive, coordinated, high quality services.

This policy is encouraged by federal incentives for both planning and an initial service period. Planning grants are matched at the services rate, a higher percentage than the standard 50% for most states, and there is an enhanced federal matching rate for health home services as explained below under financing. ACE Kids is policy that benefits state government and providers, but most profoundly, CMC and their families.

BENEFIT #2 - A Roadmap for Collaboration and Coordination

As affirmative policy for a system of care designed for CMC, the ACE Kids Act explicitly requires collaboration and coordination between the many parties with significant roles, both direct caregivers and the functions that support them. While this starts with the family and the health home's comprehensive care planning function, it includes all of the medical and community service providers as well as payers. By longstanding statutory obligations, this extends to government agencies with responsibility for policy and systems development, Title V CYSHCN, and Medicaid. While these functions and relationships are common attributes of excellence, ACE Kids is unique in enunciating them as aspirational for an encompassing system of care for all members of this special pediatric subpopulation.

The broad responsibility for systems of care for statewide populations (in this case CMC and their families) starts with government agencies. ACE Kids provides a policy, health service delivery, and financial structure for Medicaid to support a system of care for CMC and their families. While this federal policy is optional for states, and Medicaid agencies are preoccupied with a multitude of demands and priorities, ACE Kids calls for special attention to this population. It is instructive that Medicaid regulations specifically call for "cooperative and collaborative relationships" between Medicaid and "Crippled Children's Services". This out-of-date language makes the point that this is a longstanding requirement for Medicaid state plans. It follows that Title V CYSHCN agencies (the current terminology for the prior "Crippled Children's Services") have an obvious role with ACE Kids and building systems of care for CMC, a role that they have performed historically but has appeared to atrophy in recent times. This policy collaboration is vital for each state to develop overarching systems of care that are effective for all CMC and their families.

An intensive level of care coordination among providers is vital. This should always start with the child and family and their interests, environment, and needs. While the health home team fulfills a core role in the development of a comprehensive care plan, ongoing linkage and rapid communication among and between all providers is essential. For CMC, this is very challenging since it often includes an imposing range of providers from quaternary and tertiary hospitals (some out-of-state) and their pediatric subspecialists, many other specialty resources, and primary care and community-based providers. Further, because the health of CMC is often fragile, there is the need to quickly connect with the appropriate provider, often one of the multiple pediatric subspecialists, to address urgent situations that arise in the home. This is key to a desired outcome we have seen in pilot studies, the reduction in inpatient hospital admissions.

ACE Kids provides a great opportunity for a systematic approach to fusing the worlds of medical/healthcare and community-based services that address other family needs. The opportunity emanates from the magnified impact of social determinants of health (SDoH) on the health of the CMC and family. The investment in more intensive care coordination resources on the healthcare side makes the identification of SDoH needs and connection to community services more consistent and systematic. This is yet another area where ACE Kids can act not only to advance services and outcomes for CMC, the prime and appropriate purpose, but also as a forerunner in the broader effort to improve services and outcomes for all populations.

BENEFIT #3 – Financing

As the largest source of public healthcare financing, which occupies a substantial percentage of State budgets, Medicaid program leaders and policymakers are understandably concerned about costs and cost growth. Even with EPSDT as a foundational principle, there is some validity to the assertion that children are put on the backburner, as collectively they are not a high-cost Medicaid group. The ACE Kids Act shines a light on CMC, a fast-growing subpopulation, bringing their very high current and future costs into focus along with their intensive service needs.

ACE Kids relies on health homes as the core organizational structure for CMC care planning, coordination, and services. It is almost instinctual for policymakers to view any “new” service as an added cost. However, the actual cost implications of coordinated care are more optimistic, as most new services impact the utilization of existing covered services and have cost offsets. In this particular case (i.e., health home services for CMC), there is a considerable and growing body of evidence that this new service model reduces inpatient hospital services and, in many cases, results in overall cost savings (ASPE, 2018). It is critical to present ACE Kids as a system of care model that systematically impacts the utilization mix for this vulnerable population.

There is a tendency for healthcare cost studies and debates to be myopic, considering only the near term and limited to the healthcare domain. For CMC, there is the reality of financial impacts on public services outside of the healthcare domain as well as those that project well into the future, both healthcare and otherwise. This is a particularly relevant point for state and local governments where they fund many types of human services. Perhaps the most significant example is education, a major source of services for CMC. Better health outcomes for CMC are likely to affect the depth and breadth of educational supports and their costs. A broader perspective embraces the whole child across the lifespan. An improved system of care for CMC affects both the longer term and larger public system, both qualitatively and financially.

ACE Kids provides a special federal financial incentive for health homes. This is in the form of an increase in the federal Medicaid services matching rate (commonly referred to as FMAP) of +15% for six months for health home services. For states with the average matching rate of roughly 57%, this would translate to 72% for health home services for the six-month start-up. Since there is the opportunity to implement these services incrementally by state geographic region, this can be done in phases. The bottom line is that ACE Kids provides a federal financial cushion for the start-up period where any kinks get worked out. This advantage, combined with

the evidence for decreased inpatient hospital admissions and lengths of stay, results in a very credible case for cost effectiveness.

The ACE Kids Act provides for alternative payment models (APM) and states that “T(t)he methodology for determining payment for provision of health home services under this section shall not be limited to a per member per-month basis.” While this is an apparent reference to HMO enrolled CMC, it makes the point that there should be special attention to reimbursement methods for CMC, particularly in an evolving system of care. More generally, providers for high-cost populations such as CMC are often fearful of any payment methodology that deviates from fee-for-service with special angst for those involving even minimal levels of risk. While there is a legitimate concern of a “race to the bottom” and withholding and/or underpaying for services, well designed APMs offer great opportunities to align comprehensive quality care and financial incentives. APMs usually focus on the total cost of care and this is advantageous, as previously mentioned, in showing how utilization shifts from acute episodes to increases in ambulatory services based on a more preventive plan of care. Given the potential advantages to both payers and providers, the reimbursement methodology negotiation can be collaborative with goals and incentives starting modestly and then growing over time. This is a potential win-win proposition when one also considers the positive service and life impact on CMC and their families.

CONCLUSION

The ACE Kids Act offers a significant opportunity to improve the lives of CMC and their families through enlightened public policy that advances the work of those providing direct services. It deserves attention and support.

REFERENCES

Assistant Secretary for Planning and Evaluation, US Department of Health and Human Services. May, 2018. *Report to Congress on the Medicaid Health Home State Plan Option*. Retrieved 5.27.22 from <https://www.medicaid.gov/state-resource-center/medicaid-state-technical-assistance/health-home-information-resource-center/downloads/medicaidhomehealthstateplanoptionrtc.pdf>

Berry, J.G., Hall, M., Neff, J., Goodman, D., Cohen, E., Agrawal, R., Kuo, D., Feudtner, C. (2014). *Children With Medical Complexity and Medicaid: Spending and Cost Savings*. Health Affairs, 33(12), 2199-2206. doi:10.1377/hlthaff.2014.0828

Child and Adolescent Health Measurement Initiative (CAHMI). 2019-2020 National Survey of Children’s Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved 3.2.22 from <https://www.childhealthdata.org/browse/survey/results?q=8671&r=1&g=922> and <https://www.childhealthdata.org/browse/survey/results?q=8672&r=1&g=922>

Children’s Hospital Association. (2013). *Optimizing Health Care for Children with Medical Complexity*. Retrieved from https://www.childrenshospitals.org/-/media/Files/CHA/Main/Issues_and_Advocacy/Key_Issues/Children_With_Medical_Complexit

y/Issue-Briefs-and-Reports/OptimizingHealthCareReport_10152013.pdf

Cohen, E., Kuo, D., Agrawal, R., Bhagat, S., Simon, T. and Srivastava, R. (2011). *Children With Medical Complexity: An Emerging Population for Clinical and Research Initiatives*. *Pediatrics*. 2011 Mar; 127(3): 529–538. doi: 10.1542/peds.2010-09101

Glader, L., Plews-Ogan, J., & Agrawal, R. (2016). *Children with medical complexity: creating a framework for care based on the International Classification of Functioning, Disability and Health*. *Developmental Medicine & Child Neurology*, 58(11), 1116-1123. doi:10.1111/dmcn.13201

Kuo, D.Z. (2011). *A National Profile of Caregiver Challenges Among More Medically Complex Children with Special Health Care Needs*. *Archives of Pediatrics & Adolescent Medicine*, 165(11), 1020. doi:10.1001/archpediatrics.2011.172

Kuo D.Z., Goudie A., Cohen E., Houtrow A., Agrawal R., Carle A.C., Wells N. (2014). *Inequities in health care needs for children with medical complexity*. *Health Affairs (Millwood)*. 33(12):2190-8. doi: 10.1377/hlthaff.2014.0273.

Simon, Tamara D., MD, MSPH, Mahant, Sanjay, MD, MSc, FRCP, & Cohen, Eyal, MD, MSc, FRCP. (2012). Pediatric Hospital Medicine and Children with Medical Complexity: Past, Present, and Future. *Current Problems in Pediatric and Adolescent Health Care*, 42(5), 113–119. <https://doi.org/10.1016/j.cppeds.2012.01.002>

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