MACPAC | Medicaid and CHIP Payment and Access Commission

August 1, 2016

Comments on Advancing Care for Exceptional Kids Act Discussion Draft

Staff of the House Committee on Energy and Commerce Health Subcommittee have asked for MACPAC's feedback on the Advancing Care for Exceptional Kids (ACE) discussion draft (dated June 29, 2016). This legislation would establish a new Medicaid state plan option to create health homes for children with medically complex conditions. Below we present several comments for the Committee's consideration.

Important changes from earlier draft

The Commission applauds the Committee's attention to improving the quality of care for children with complex medical conditions and its focus on care coordination and team-based care. The approach described in the discussion draft represents a substantial improvement from the approach taken in prior versions of ACE Kids legislation (H.R. 546 and S. 298). These earlier versions would have created a new type of comprehensive risk-based organization in Medicaid to serve children with medically complex conditions.These risk-based organizations, nationally designated children's hospital networks, would have been responsible for providing enrolled children with comprehensive services, including care coordination, and access to a full complement of providers. However, these networks would have been exempt from many Medicaid managed care rules and protections that apply to other risk-based, closed-network delivery systems serving Medicaid-enrolled children. For example, the legislation would have exempted the new networks from licensure requirements, beneficiary protections (e.g., format and timing of enrollment information, service authorization timeframes, grievance and appeals policies), and network adequacy and quality assurance requirements (e.g., assuring coverage of emergency services, demonstration of adequate capacity).

Building on prior success of the model

The new ACE Kids discussion draft creates a new Medicaid state plan health home option to provide coordinated care for children with complex medical conditions, integrating primary, acute, and behavioral health care, as well as long-term services and supports and social and family supports. This option is in many ways similar to the health home state plan option created by Section 2703 of the Patient Protection and Affordable Care Act (ACA, P.L. 111-148, as amended). This approach has been widely adopted; as of December 2015, 20 states and the District of Columbia were operating a total of 27 approved Medicaid health home models, serving over 1 million enrollees.

States have been able to adapt the model to the unique needs of different subpopulations and delivery system design, including primary care case management and comprehensive risk-based managed care, within their states. Some early data from states suggest positive health outcomes and savings from health home initiatives. For example, one state's health home has been reported to have decreased blood

pressure, low-density lipoprotein cholesterol levels, and hemoglobin A1C levels (an indicator of diabetes risk) among enrollees and has been shown to reduce hospitalizations, emergency room visits, and total spending. More information should be available in the forthcoming the final evaluation of Section 2703 health homes, anticipated in January 2017.

The ACE Kids Act differs from the Section 2703 model in that it focuses exclusively on children with specific types of health care conditions and needs, and includes provisions that would promote and facilitate care from out-of-state providers, which has been identified as a concern for children in need of care from pediatric subspecialists.

Importance of flexibility in program design

Unlike some of the populations enrolled in health homes, most Medicaid-enrolled children with complex medical conditions are already enrolled in managed care. Thus the Commission notes that the new option should build on and coordinate with states' existing health care delivery systems, such as primary care case management and comprehensive risk-based managed care models, rather than create a separate delivery system for medically complex children.

The existing health homes model has been implemented under several models that recognize the varying degrees of managed care penetration across states. These include models in which:

- managed care plans administer or serve as the health home programs, contracting out for services important to the population of interest to the extent these are not otherwise available for other plan enrollees;
- plans receive and disburse payments to health home partners; and
- plans may support health homes contractually (for example, through data sharing) but are not the lead entities, most commonly in states without a significant managed care presence.

Although the Centers for Medicare & Medicaid Services (CMS) has facilitated varying degrees of managed care integration in the existing health homes program and provides technical assistance to states in implementing these models, the Committee may wish to include language in the draft to ensure the new option similarly builds on existing state efforts to manage care, whether through comprehensive risk-based care or primary care case management approaches.

Definition of children with medically complex conditions

The discussion draft defines children with medically complex conditions as those having: two chronic conditions, one chronic condition that affects two or more body systems and reduces cognitive or physical functioning, or one life-threatening illness or rare disease. The definition of chronic conditions includes, at a minimum: cerebral palsy, cystic fibrosis, HIV/AIDS, a congenital heart condition, blood problems (e.g., anemia, sickle cell disease), muscular dystrophy, spina bifida, epilepsy, severe autism spectrum disorder, and severe emotional disturbance or serious mental health condition. This definition addresses concerns

about the existing health home model in that it focuses on complex conditions experienced by children and youth.

The Commission notes that to the extent that the legislation is intended to target children with particularly high health costs, including frequent hospitalizations, the definition in the discussion draft may be effective in focusing efforts on a relatively narrow group. On the other hand, other children with significant health concerns and functional deficits might also benefit from the intensive care coordination model envisioned in the draft. Thus the Committee might want to consider giving more explicit authority to the Secretary of the U.S. Department of Health and Human Services to define additional groups that could be the focus of such health homes, or provide authority to the states to do so within parameters determined by the Secretary.

Coordination of services across systems

The list of health home services in the discussion draft is identical to that in the existing health homes model. The Committee may wish to consider adding additional services that are important to children and youth, including coordination with schools, juvenile justice, and child welfare authorities.

Data collection

The discussion draft's requirements for data collection and reporting on the use of and quality of children's health home services and the characteristics of children with medically complex conditions could provide valuable information for understanding their care experience. Currently little data are collected and reported specific to this population. Such information will be important to evaluating the success of the new model and to making comparisons across states.

MACPAC report

The discussion draft would require MACPAC to issue a report to Congress and the Secretary on the characteristics of children with medically complex conditions, the numbers of such children enrolled in Medicaid, their diagnoses, the number of such children in different delivery systems, extent to which such children receive care coordination, providers serving these children, and extent to which they receive services from out-of-state providers and barriers to those services. The report would be due 18 months from the date of enactment.

MACPAC welcomes the opportunity to do significant work on this issue, given its importance and its consistency with the Commission's statutory authority. The normal caveats about the completeness and timeliness of Medicaid administrative apply here (for example, data on care coordination services may be not be available from managed care plans). It is also worth noting that the requested analyses are complex and will require a significant commitment of resources in terms of staff time and data analysis;[i] we are hopeful that Committee staff will be helpful in ensuring that MACPAC has sufficient resources to devote to these tasks.

[i] For example the methodologies for the data analyses are likely to require use of a diagnostic classification/risk adjustment system to identify children with medically complex conditions. Staff would need to assess whether the completeness of the data systems is consistent across all the states, and if it is not, what additional steps would be required. Additionally, identifying provider characteristics (e.g., specialty, group practice) requires linking Medicaid data to other provider taxonomy datasets such as the National Plan and Provider Enumeration System, and this link may be incomplete depending on the availability and completeness in states' reporting of National Provider Identifier (NPI) numbers in MSIS or T-MSIS.