Section-by-Section Summary of S. 428
Advancing Care for Exceptional Kids Act of 2017

SECTION 1: Title – Advancing Care for Exceptional Kids Act of 2017 (or ACE Kids Act of 2017)

SECTION 2: State Option to Provide Coordinated Care to Children with Complex Medical Conditions through Enhanced Pediatric Health Homes

- Allows states the option to provide coordinated care through enhanced pediatric health homes (EPHH) for children with complex medical conditions, beginning Jan. 1, 2018.

Definitions

- A child with complex medical conditions is a child under 21 years of age who is enrolled in Medicaid or CHIP; and
  - Has a chronic medical condition or serious injury that affects two or more body systems, affects cognitive or physical functioning; AND
    - Requires intensive health care interventions and intensive care coordination to optimize health and avoid hospitalizations or ER visits; OR
    - Meets the criteria for medical complexity under existing risk adjustment methodologies using a recognized, publicly available pediatric grouping system selected by the Secretary.

- An EPHH is a provider-sponsored entity qualified to care for children with medically complex conditions that:
  - Meets the requirements in the legislation (below),
  - Enters into an EPHH program agreement with a state; and
  - Provides and arranges for the provision of EPHH services to children with medically complex conditions.

- To be a EPHH for children with medically complex conditions, an entity must:
  - Demonstrate expertise in providing, integrating and coordinating prompt care for children with complex medical conditions, including pediatric emergency services;
  - Design child-specific comprehensive family-centered care plans;
  - Work closely with families to meet ongoing needs in the home, hospital and community;
  - Include families in delivery of care and development, operation and evaluation of EPHH services;
  - Interact with families in a culturally and linguistically appropriate manner;
  - Provide integration and access to sub-specialized pediatric services and programs, including the most intensive diagnostic, treatment and critical care levels as medically necessary, including appropriate out-of-state care;
  - Coordinate and integrate the full range of pediatric medical, surgical and behavioral specialists and subspecialists needed;
  - Coordinate the provision of outpatient care needs, including durable medical equipment, medical supplies and medical foods;
  - Arrange and coordinate care from out-of-state providers;
  - Coordinate and collect payments from liable third parties; and
  - Collect and report on appropriate pediatric quality measures for children with medically complex conditions.
• EPHH services are timely, high-quality pediatric services provided to children with complex medical conditions by an EPHH, including all services for which medical assistance is available under the state plan. The health home specific services include:
  o Comprehensive pediatric care management;
  o Care coordination and health promotion;
  o Comprehensive transitional care;
  o Patient and family support;
  o Referral to community and social supports;
  o Use of health information technology; and
  o Coordinating access to the full range of pediatric specialty and subspecialty medical services, including those located outside the state, as medically necessary.

• An EPHH program agreement would be established between the state and the EPHH to participate in the program and enroll children with complex medical conditions.

Family Preference for an EHPP
• Each child with complex medical conditions who is eligible to receive EPHH services has the option of requesting to enroll with an EPHH of the child’s choice.

• An EPHH is required to enroll any child with complex medical conditions who requests enrollment unless the EPHH program agreement allows the EPHH to decline on the basis of pre-established criteria.

Outreach and Education
• Each state is required to conduct outreach and enrollment activities to raise awareness with children and families of the option to enroll in an EPHH. These activities may include the use of family-to-family information centers, family navigators, non-profit organizations and faith-based organizations.

Option to Withdraw from Program
• A child enrolled in an EPHH is allowed to disenroll. Disenrollment shall take effect no later than 30 days after the child or family notifies the EPHH.

Transition Assistance
• If a child withdraws from an EPHH for any reason, the EPHH is required to continue to provide EPHH services to the child during a transitional period.

Coordinating Care from Out-of-state Providers
• No later than two years after enactment, the Secretary of Health and Human Services (the Secretary) must issue guidance to state Medicaid Directors on best practices for ensuring that children with complex medical conditions receive prompt care from out-of-state providers when medically necessary. This guidance must address:
  o Arranging access to and providing payment for care provided outside the state;
  o Reducing barriers for this care;
  o Screening and enrollment of out-of-state providers;
  o How best to streamline these processes;
  o Payment for out-of-state providers in emergency and non-emergency situations; and
  o How this guidance interacts with current out-of-state requirements outlined in regulation (Code of Federal Regulations, Title 42, §431.52).

• The Secretary shall seek input in developing this guidance from states, patient and family advocates, children’s health groups, providers, managed care plans and other relevant stakeholders.
Out-of-state Policies for EPHH

- Participating states are required to provide information to EPHHs regarding state policies and procedures for accessing care for children with complex medical conditions for out-of-state providers, including how out-of-state providers can receive payment from the state.

- Participating states should consider adopting best practices for providing access to out-of-state providers for children with complex medical conditions consistent with the guidance provided by the Secretary.

Payments to EPHHs

- The federal Medicaid matching rate for health home services provided to children enrolled in an EPHH that has a program agreement with the state will be 90 percent for the first eight quarters the EPHH program agreement is in effect. The services that qualify for the 90 percent FMAP are:
  
  o Comprehensive care management;
  o Care coordination and health promotion;
  o Comprehensive transitional care, including appropriate follow-up, from inpatient to other settings;
  o Patient and family support (including authorized representatives);
  o Referral to community and social support services, if relevant; and
  o Use of health information technology to link services, as feasible and appropriate.

- Each state Medicaid program will determine an alternative payment methodology for EPHHs, informed by Centers for Medicare and Medicaid Services (CMS) guidance (see below) and considers current data to maximum extent possible.
  
  o Payment methodologies must include a risk adjustment method, re-insurance system or risk corridor procedure to account for variations in acuity; and
  o An alternative payment model, which may include a shared savings or performance-based approach, such as bundled payment or risk-reward payment model.

- By Jan. 1, 2018, CMS will provide guidance describing best practices for states to employ in designing and establishing alternative payment model methodologies, including guidance on risk adjusted shared savings and performance based payment models, that are risk adjusted for the population enrolled in the EPHH programs and may include guidance on other alternative payment models, including global and bundled payments. The Secretary will solicit stakeholder input and analyze data collected through the program to inform this guidance.

Data and Quality Assurance

- The EPHH, in collaboration with the state and the child’s health plan if appropriate, must collect and submit claims data for children who are provided services. After review and approval by the state, the data will be reported in a standardized manner and made publicly available for purpose of establishing a national claims database.

- The state must submit reports to the Secretary to monitor operation, cost and effectiveness of the services provided by the EPHH.
Development of Standards and Measures

- The Secretary must, in consultation with states and EPHHs:
  - Establish a national set of quality assurance and improvement protocols and procedures to apply to EPHH programs;
  - Develop quality measures tailored to this population of children;
  - Create accessibility standards for access by children to EPHH services; and
  - Develop criteria for national pediatric focused care coordination for children with complex medical conditions.

- In this work, existing pediatric quality measures will be considered and pediatric groups will be consulted.

- The Secretary will work with EPHHs to obtain consistent and verifiable Medicaid Analytic Extract data or a comparable data set, and will establish data-sharing agreements to further support collaborative planning and care coordination for children with complex medical conditions.

- An independent third party will be commissioned to perform claims analysis to determine utilization of services and overall effectiveness of EPHH programs.

- The Secretary must submit a report to Congress on the data analysis activities.

Application under CHIP

- EPHH program provisions apply to the Children’s Health Insurance Program (CHIP) as they do under the Medicaid program.

SECTION 3: MACPAC Report

- No later than two years after enactment, the Medicaid and CHIP Payment and Access Commission (MACPAC) must submit a report to Congress and the Secretary on children with complex conditions, including characteristics of this population of children, number of children with complex conditions, the types of chronic conditions/illnesses/injuries/diseases, the number of children receiving services under the EPHH program and the type of payment model, the extent children are receiving care coordination, the pediatric providers caring for the children, the extent to which children with complex conditions receive or are denied services from out-of-state providers, and any barriers to receiving care in a timely manner.

SECTION 4: Report to Congress

No later than five years after enactment, the Secretary must submit to Congress, and make publicly available on the CMS website, a report evaluating and assessing the EPHH program established in the legislation to determine if the program could be improved or expanded to include additional pediatric populations.