

Summary: Advancing Care for Exceptional Kids Act (Public Law No. 116-16)

On April 18, the ACE Kids Act was signed into law as part of a package of Medicaid bills, the Medicaid Services Investment and Accountability Act of 2019 (P.L. 116-16). Lead congressional co-sponsors include Sens. Charles Grassley, R-Iowa, and Michael Bennet, D-Colo., and Reps. Kathy Castor, D-Fla., Gus Bilirakis, R-Fla., Anna Eshoo, D-Calif., and Jaime Herrera Beutler, R-Wash. The ACE Kids Act is designed to improve care for children with medically complex conditions in Medicaid. This new law addresses existing challenges—identified by families and physicians—facing children with medically complex conditions by expanding access to patient-centered, pediatric-focused coordinated care models tailored for these children across multiple providers and services, and by easing access to out-of-state care.

New State Option: Provide Coordinated Care through Health Homes for Children with Complex Medical Conditions

- The legislation builds off of current law to establish specially designed health homes for children with medically complex conditions beginning on Oct. 1, 2022. Participation is voluntary for children and their families, providers and states. States that opt to create these health homes will receive a higher federal matching rate (15 percent above regular matching rate for the state, not to exceed 90 percent) for six months. The bill also provides \$5 million for state planning grants.
- Eligible children include those with at least one chronic condition—cumulatively affecting three or more organ systems and severely reducing cognitive or physical functioning—who also require medication, durable medical equipment, therapy, surgery or other treatments. Children with one life-limiting illness or rare pediatric disease—as defined in the Food, Drug, and Cosmetic Act—are also eligible. The law allows the Secretary of U.S. Department of Health and Human Services (Secretary) discretion to operationalize the definition.
- To qualify as a health home, providers and health teams must demonstrate the ability to coordinate prompt care for children with medically complex conditions, develop an individualized comprehensive pediatric family-centered care plan, coordinate access to subspecialized care, and coordinate appropriate care with out-of-state providers. The Secretary must establish standards for qualification as a health home, including those outlined above.

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- States must develop a plan to educate providers on the availability of health home services for children with medically complex conditions, including the process by which such providers can refer these children to a health home. States must also develop a plan to educate families with children eligible to receive health home services about the availability of these services through family-to-family entities and other family outreach organizations.
- States have flexibility to develop their own methodology for determining payment, including the use of alternative payment models.

Guidance, Monitoring, Data Collection, and Reporting

- By Oct. 1, 2020, the legislation requires the Secretary to issue guidance to state Medicaid directors on best practices for ensuring this population receives prompt care from out-of-state providers when medically necessary.
- Participating states must develop a methodology for tracking reductions in inpatient days and reductions in total cost of care resulting from improved care coordination and management, a proposal for the use of health information technology in providing health homes services and a methodology for tracking prompt and timely access to medically necessary care from out-of-state providers.
- Participating states must collect and share with CMS:
 - Data on the number of children with medically complex conditions who are enrolled in a health home
 - The nature, number and prevalence of chronic conditions, illnesses, disabilities and rare conditions that the children have
 - The type of delivery systems and payment models used
 - The number and characteristics of providers and health professionals designated as health homes under this legislation
 - The extent to which the children receive health care services from out-of-state providers (including whether provided on an emergency or non-emergency basis)
 - Quality measures developed specifically with respect to health care items and services provided to this population of children