

Executive Summary

- Mr. Merrill is speaking in support of H.R. 3325, “The Advancing Care for Exceptional Kids Act (ACE Kids Act) of 2017” as President and CEO of Cook Children’s Health Care System in Fort Worth, Texas and Chair of the Children’s Hospital Association (CHA) Board of Trustees.
- The goals of the ACE Kid Act are improving care for children with medical complexity in Medicaid, driving improvements in quality, and reducing program spending.
- The ACE Kids Act will give states the option to implement health homes specifically serving children with complex medical conditions.
- The pediatric health homes established under the ACE Kids Act will implement a specific care plan for the medically complex child, coordinating care from multiple highly specialized providers such as physicians, children’s hospitals, specialized hospitals, non-physician professionals, home health and behavioral health — all with a goal of creating easier access to needed services.
- The bill creates incentives for states to establish these models by providing a higher Medicaid federal match for care coordination services provided by the new pediatric health homes.
- Participation will be completely voluntary for children, families and health care providers, and the pediatric health homes will work within the existing structure of a state’s Medicaid program — including those states with Medicaid managed care.
- A growing body of research shows that the coordination of care for people with chronic conditions can save money through reductions in inpatient hospital stays and emergency room visits, improved medication management, better compliance on preventive care, and a guarantee that care is provided as close to a child’s home and community as possible. Potential cost savings from the ACE Kids Act have been demonstrated through projects supported by the Center for Medicare and Medicaid Innovation (CMMI).
- The ACE Kids Act will also create a data and quality framework to drive improvement in quality of care and further reduce costs. There is currently no consistent national data available to inform our policies for children with medical complexity.
- Finally, the ACE Kids Act lays the groundwork for additional future advances in care by sharing best practices across state Medicaid programs.

Statement for the Record

Rick W. Merrill, Chair, Children's Hospital Association Board of Trustees
and President and CEO, Cook Children's Health Care System

In support of H.R. 3325,
“The Advancing Care for
Exceptional Kids Act (ACE Kids Act)”

Submitted to the Subcommittee on Health,
House Committee on Energy and Commerce
September 5, 2018

Chairman Burgess, Ranking Member Green, and members of the Subcommittee, thank you for the opportunity to speak in support of H.R. 3325, “The Advancing Care for Exceptional Kids Act (ACE Kids Act).” I am Rick Merrill, president and CEO of Cook Children’s Health Care System in Fort Worth, Texas and Chair of the Children’s Hospital Association (CHA) Board of Trustees.

Last year, Cook Children’s treated children from more than 35 states, recorded nearly a half million child visits to our 60 pediatric specialty clinics, 230,000 visits to our Emergency Department and Urgent Care Centers, and registered over 11,200 inpatient admissions. With over 1.5 million patient encounters a year, Cook Children’s provides comprehensive and coordinated care across our fully integrated system, including Home Health services and a Health Plan, which enrolls over 138,000 children who rely on Medicaid, many of whom have serious disabilities.

CHA represents 220 hospitals nationwide dedicated to the health and well-being of our nation’s children. These hospitals vary widely in size and specialty, but they all exist to put our children’s health first. On behalf of my own hospital system, our CHA member institutions and the patients and families we serve, I wish to offer our strong support for H.R. 3325, the Advancing Care for Exceptional Kids (ACE Kids) Act.

We are extremely grateful to Reps. Barton and Castor for their leadership on behalf of children as the original co-sponsors of this legislation, and to the more than 90 additional House members who have joined as co-sponsors. We also wish to thank the leadership of the Energy and Commerce Committee and the Health Subcommittee for devoting considerable time and resources to working towards solutions in this important area. In addition, we want to recognize the leadership of Chairman Burgess and Ranking Member Green on important issues affecting

children's health, including extending funding for the Children's Health Insurance Program (CHIP) and the recent reauthorization of the Children's Hospitals Graduate Medical Education program (CHGME).

Medicaid covers over 37 million children. A small percentage of these kids have complex medical conditions requiring ongoing and specialized care. These children have diagnoses that are multiple and varied, from cerebral palsy to cystic fibrosis, and that impact multiple body systems at once. They typically are under the continuous care of multiple pediatric specialists — often seeing a dozen or more physicians — and require access to specialized care and additional services from within and outside of their state. Additionally, their care accounts for a drastically disproportionate percentage of Medicaid spending on children.

The ACE Kids Act is about fundamentally improving care for children with medical complexity in Medicaid, driving improvements in quality, and reducing program spending — all further strengthening the Medicaid program. The bill will do this by expanding access to patient-centered, pediatric-focused coordinated care models tailored to the unique needs of these children.

To date, a number of children's hospitals, working with physicians and local communities, have supported pilot programs that coordinate care among and between the large numbers of providers necessary to care for a child with medical complexity. These programs have a track record of improving the quality of care for the children enrolled, increasing family satisfaction and reducing costs. However, the acceleration and spread of innovative care coordination cannot be achieved on a piecemeal basis. Creating the greatest benefit for the greatest number of children requires a national approach.

The ACE Kids Act will fill this need by advancing elements of a national framework to drive the creation of systems of care coordination informed by shared data and quality standards. It will also provide state and local flexibility in tailoring care for this very complex population. To achieve this, the ACE Kids Act will modify Medicaid's existing health home option. Currently, states may choose to establish a health home to coordinate care for Medicaid beneficiaries who have chronic conditions, but this option was not designed for this unique population of children. The ACE Kids Act will give states the option to implement health homes specifically serving children with complex medical conditions to improve their care.

The data supporting the ACE Kids Act is convincing, yet it is crucial to remember that behind the statistics are real children and families. The ACE Kids Act was developed in response to the experiences of these families and the clinicians serving them — families like the Beckwiths. Alex and Maddy Beckwith of Keller, Texas are the kindest 14 and 4-year-old you could hope to meet, but they also both suffer from mitochondrial disease along with other health issues. This disease is a serious, complex condition without a cure, which requires lifelong medication and therapy. Due to their conditions, Alex and Maddy's care is very complex and ongoing — so much so that they have become like family members to the staff at Cook Children's. They see 15 specialists between them and require major interventions to remain stable.

Such families are an inspiration every day, teaching us about hope, resilience and unconditional love. We urge you to watch this short video about Alex Beckwith, which captures why the ACE Kids Act and your support is enormously important to children and families who are enduring complex medical conditions:

<https://youtu.be/jXeHXeGqZ-4>

The new pediatric health homes created by this legislation will be required to follow national guidelines in providing and better organizing pediatric-specific care and care coordination services appropriate for the needs of this population, kids like Alex and Maddy. This will help families manage the heavy responsibility and logistical challenges associated with their children's care. The pediatric health homes established under the ACE Kids Act will implement a specific care plan for the medically complex child, coordinating care from multiple highly specialized providers such as physicians, children's hospitals, specialized hospitals, non-physician professionals, home health and behavioral health — all with a goal of creating easier access to needed services.

Enabling children to access more of their care in their own communities is critical to improving patient experience as well as realizing program savings. But the nearby health homes will also play an important role when required care is only available out-of-state. Helping to better facilitate out-of-state care is critically important, as pediatric medicine — particularly for children with medical complexity — is more regional in nature than adult care. In fact, even Alex and Maddy have needed to travel to Ohio and Maryland for treatments despite living so close to Cook Children's.

The bill creates incentives for states to establish these models by providing a higher Medicaid federal match for care coordination services provided by the new pediatric health homes. Participation will be completely voluntary for children, families and health care providers, and the pediatric health homes will work within the existing structure of a state's Medicaid program, including those states with Medicaid managed care. The legislation envisions payment models that will align reimbursement with the best outcomes for these children to reduce costs and support the highest quality of care. States will determine which alternative payment methodologies could be used for the health

homes. Moving to these performance-based systems will further encourage improvements in utilization and costs, similar to what has been supported under the Medicare program for adults.

The ACE Kids Act is also about using existing Medicaid resources more efficiently. As noted, children with medical complexity account for a disproportionately large share of the Medicaid costs for children. A large and growing body of research shows that the coordination of care for people with chronic conditions can save money through reductions in inpatient hospital stays and emergency room visits, improved medication management, better compliance on preventive care, and a guarantee that care is provided as close to a child's home and community as possible.

Potential cost savings have been demonstrated through projects supported by the Center for Medicare and Medicaid Innovation (CMMI). CMMI's Coordinating All Resources Effectively (CARE) Award — involving 10 children's hospitals, including my own Cook Children's, with eight different state Medicaid programs, including DC — implemented care coordination programs serving 8,000 children with medical complexity. Collectively, these programs reduced emergency department visits by 26 percent and reduced inpatient days by 32 percent. In the first full year of operations coordinating care for these children, CARE ultimately reduced overall Medicaid costs by 2.6 percent while improving patient experience for 8,000 children. The CARE award results were made possible by effective collaboration between different providers, including children's hospitals and more than 40 separate pediatric practices. The ACE Kids Act will enable these innovations to spread nationally. An analysis of the ACE Kids Act introduced in the 114th Congress conducted by the American Action Forum showed billions in potential savings to the Medicaid program over 10 years.¹

¹ <https://www.americanactionforum.org/research/14241/>

Very importantly, the ACE Kids Act will also create a data and quality framework to drive improvement in quality of care and further reduce costs. The creation and collection of consistent data supporting development and sharing of best practices while informing clinical standards, including quality measures specifically designed for children, are key to achieving these improvements. Unfortunately, this information and sharing does not exist under Medicaid today; there is currently no consistent national data available to inform our policies for children with medical complexity.

The ACE Kids Act outlines a definition of children with medically complex conditions who will be eligible to participate in the program and includes standardized data-reporting requirements related to the care of children in the enhanced pediatric health homes. By supporting the development of consistent national definitions and standards, the ACE Kids Act will represent an important step forward to improving the knowledge base necessary to truly advance care for this most vulnerable population. Finally, the ACE Kids Act lays the groundwork for additional future advances in care by sharing best practices across state Medicaid programs to ensure this population receives prompt care from out-of-state providers when medically necessary, and by requiring the Medicaid and CHIP Payment and Access Commission to submit a report to Congress and the Secretary of Health and Human Services on the characteristics of children eligible for health homes and the effectiveness of the program overall.

Since its original introduction in the 113th Congress, the ACE Kids Act concept has continued to evolve based on extensive stakeholder feedback. The current language reflects the results of this collaborative process and we thank the bill's champions and Committee staff for their continued efforts. **The current focus of the bill is on how providers can best collaborate with the family to provide the highest quality of care to these kids.** This will look different depending on the state, community and needs of the child and family. The current version of the bill

is about organizing and coordinating services that the child needs, not about guaranteeing one provider or another a special place in that delivery system.

The evolved legislation has received support from many additional organizations dedicated to children's health. The ACE Kids Act is envisioned as a way for states, families and providers to work in partnership to ensure that the unique health care needs of this population are met and was designed with state flexibility in mind. We are thankful that so many members of Congress have joined together in embracing the goal of improving care for this population of vulnerable children.

The ACE Kids Act will enable the national improvement necessary to provide better care for children with medical complexity and reduce Medicaid spending. We ask lawmakers to prioritize kids' health by passing the ACE Kids Act this year.