

Statement for the Record

In support of

H.R. 546, The Advancing Care for Exceptional Kids Act (“ACE Kids Act”)

Submitted by

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One Page Summary of Testimony

Children's hospitals applaud the bill's sponsors and the Committee for working to advance the shared goals of improving quality of care for the millions of children with medical complexity in Medicaid. The recently revised discussion draft of ACE Kids provides a framework for collaborative efforts to achieve these aims. We look forward to working with the committee and bill's sponsors to further refine and strengthen the bill.

It is clear the current system, working within the limitations of a state-by-state approach, lacks the necessary organization and integration of care essential to best serve this unique population of children and their families. To improve care, it is key that legislation create intensive, pediatric-focused systems of care coordination informed by shared data and quality standards, while also providing state and local flexibility. The ACE Kids Act legislation is designed to work within the existing structure of states' Medicaid programs and is completely voluntary for states, children and families, and health care providers.

Ensuring access to the necessary range of pediatric providers needed to implement a care plan for the medically complex child, such as physicians, children's hospitals, specialized hospitals, non-physician professionals, pediatric home health, and behavioral health will result in easier access to needed, lifelong services and will help children and families more easily access care.

By improving coordinated care for this population, we can reduce spending, potentially by billions of dollars over a multi-year period, by decreasing unnecessary utilization of costly services. Numerous published studies show cost savings for children with medical complexity when they are enrolled in a coordinated care program. Furthermore, the bill aligns with national trends moving away from fee-for-service structures and supports care coordination systems aligned with performance-based financial models.

To best advance care for children with medical complexity, Children's Hospital recommend including strong, pediatric-specific definitions with respect to providers of care and the services offered to patients, as well as consistent, uniform quality measures and data elements. We believe that this will further strengthen the bill for children.

On behalf of Cook Children's Health System and children's hospitals nationwide, we wish to offer our strong support for the Advancing Care for Exceptional Kids Act of 2015, or "The ACE Kids Act", (H.R. 546).

We wish to thank the original cosponsors of the ACE Kids Act, Reps. Joe Barton and Kathy Castor. Their leadership has galvanized strong bipartisan support for the bill from over 200 of their House colleagues. We would also like to thank Energy and Commerce Committee Chairman Fred Upton and Ranking Member Frank Pallone, and Health Subcommittee Chairman Joe Pitts and Ranking Member Gene Green for holding this hearing on improving care for children with very serious and complex medical conditions. Finally, we would also like to express our appreciation to Rep. Michael Burgess and more than a dozen additional members of the Subcommittee for their support of the bill.

We applaud the bill's sponsors and the Committee for working together to advance the shared goals of improving quality of care for the millions of children with medical complexity in Medicaid. The recently revised discussion draft of ACE Kids provides a framework for collaborative efforts to achieve these aims. We look forward to working with the committee and bill's sponsors to further refine and strengthen the bill.

Cook Children's Health System in Fort Worth, Texas, is a not-for-profit, integrated pediatric health care system. With over 1.3 million patient encounters a year, Cook Children's cares for patients from all of Texas and more than 30 states. Last year, Cook Children's recorded nearly a half million child visits to our 60 pediatric specialty clinics, 240,000 visits to our Emergency Department and Urgent Care Centers, and registered over 11,000 inpatient admissions. As a fully integrated health care system, Cook Children's is able to provide comprehensive and coordinated care to our pediatric patients. As part of our integrated system of care, Cook Children's operates a Home Health company and a Health Plan, with over 100,000 Medicaid children enrolled, many of whom have serious disabilities.

For a long time now, we have taken care of some very sick kids, and we've done a good job of it in our part of Texas. But we could and we should do better. As a nation, we have an obligation

to improve care for our sickest, most vulnerable children who have complex medical conditions and who largely depend on Medicaid for their health care.

Working together we can achieve the delivery reform required to strengthen Medicaid for these children. Passing the ACE Kids Act is key to this effort. The ACE Kids Act builds upon Medicaid's strengths and creates a framework that focuses on care coordination for this population and drives further improvement in our ability to care for these children. Not just in one state, but for the nation.

Although the number of children with medical complexity is very small overall, perhaps 6 percent of the children on Medicaid, the group accounts for 40 percent of Medicaid's current spend on kids. These children have diagnoses that are multiple and varied, from cerebral palsy to cystic fibrosis to congenital heart defects and childhood cancers. They typically are under the continuous care of multiple pediatric specialists, often seeing a dozen or more physicians. They require access to specialized care and require additional services from within and outside of the health care system.

Each year the number of children with multiple life-threatening disabilities grows. Over the coming decade, the 2 million children with medical complexity in Medicaid will greatly increase in numbers at the current growth rate of 5 percent or more, and the \$30-40 billion dollars we incur yearly in Medicaid costs for this population will increase even more rapidly given medical inflation rates.

We do our best today, working closely with our state Medicaid program, but we can do better, much better. The ACE Kids Act was developed in direct response to the experiences of these families and the clinicians serving them from across the country. It is clear the current system, working within the limitations of a state-by-state approach, lacks the necessary organization and integration of care essential to best serve this unique population of children and their families.

While Medicaid is state-based, the children we serve are not necessarily locally based. Many of our patients travel great distances for our specialized care. We have no national data to accelerate best practice and quality improvement work, and no national quality standards to assess if we're doing a better job. These essential elements of improvement in service and care cannot be achieved without changes to Medicaid.

Another result, although unintended, of our current Medicaid system is the burden parents of children with medical complexity experience when trying to coordinate care for their kids. It's simply not structured to meet the intensive, high-cost needs of a small population of children who often travel far from home and across state lines for care.

To improve care, it is key that legislation create intensive, pediatric-focused systems of care coordination informed by shared data and quality standards, while also providing state and local flexibility in tailoring care for this very complex population. Ensuring access to the necessary range of providers needed to implement a care plan for the medically complex child, such as physicians, children's hospitals, specialized hospitals, non-physician professionals, home health, and behavioral health will result in easier access to needed, lifelong services and will help children and families more easily access care quickly when needed.

As mentioned previously, we are missing critical opportunities to improve care for this population because we lack, at the most basic level, standard definitions for children with medical complexity. As a consequence we have no consistent data across states on the care of these children – from utilization to costs – and we have no shared national quality measures tailored to their unique needs.

Thankfully, we've seen great strides in improvement of care in the Medicare population that's possible through national data and national standards, informing best practices and better care. Don't we want the same for children with serious health care needs?

A key to driving improvements in care is building a framework to enable the creation of consistent data supporting development and sharing of best practices. This information and sharing does not exist under Medicaid today on either the state or health plan level, and cannot

be readily established without federal legislation. There is no national data available today to inform our policies for children with medical complexity. The ACE Kids Act can help fill this gap.

While promoting elements of a national framework, the ACE Kids Act legislation is designed to work within the existing structure of states' Medicaid programs and is completely voluntary for states, children and families, and health care providers. The ACE Kids Act will be implemented locally around the needs of the families, state Medicaid, the managed care plans and health care providers. We have these kinds of partnerships in place in several communities across the country, including Fort Worth, and they are achieving great results for children locally. For example, at Cook Children's we are increasingly able to keep children out of expensive care settings like our intensive care unit and emergency room through better coordination with primary care, home health and families to deliver anticipatory and effective care in alternative care settings.

Additionally, the ACE Kids Act is about using existing Medicaid resources more efficiently. By improving coordinated care for this population, we can reduce spending, potentially by billions of dollars over a multi-year period, by decreasing unnecessary utilization of costly services. Numerous published studies show positive cost savings for children with medical complexity when they are enrolled in a coordinated care program.

Furthermore, the legislation envisions payment models that would align reimbursement with the best outcomes for these children to reduce costs and support the highest quality of care. The bill aligns with national trends moving away from fee-for-service structures and support care coordination systems aligned with risk-based financial models. Moving to these performance-based systems will further encourage improvements in utilization and costs.

Together we can change the experience of these children and families from episodic, fragmented care to coordinated and efficient care that seamlessly crosses Medicaid's state lines. With a national framework in place, states, health plans, families and providers can work together to improve care for our nation's sickest and most vulnerable children.

As noted, we think the discussion draft is a strong positive step forward for the ACE Kids Act. To best advance care for children with medical complexity, children's hospitals recommend that as the committee and cosponsors continue to refine the bill they consider including strong, pediatric-specific definitions with respect to providers of care and the services offered to patients, as well as consistent, uniform quality measures and data elements. We believe that this will further strengthen the bill for children.

We look forward to continuing our work with the bill's champions in Congress to advance solutions that improve care for these kids. On behalf of children's hospitals and the thousands of children and families served by Cook Children's, thank you for the opportunity to share this testimony with the Subcommittee.