

# Statement for the Record

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

Submitted to the Subcommittee on Health,  
House Committee on Energy and Commerce  
July 7, 2016

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The Children’s Hospital Association represents 220 hospitals nationwide dedicated to the health and well-being of our nation’s children. On behalf of our member institutions and the patients and families they serve, we wish to offer our strong support for H.R. 546, the Advancing Care for Exceptional Kids Act (also known as the ACE Kids Act).

We are extremely grateful to Rep. Barton and Rep. Castor, for their leadership on behalf of children as the original cosponsors of this legislation, and to the more than 200 additional House members who have joined as cosponsors. 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. With the release of a recent discussion draft outlining potential revisions to H.R. 546, the Committee has embarked on a process to bring stakeholders together to collaborate in support of the shared goal of improving care for children with medical complexity. We are excited at the prospect of action in Committee on the bill this year, and look forward to working with the bill’s many champions and committee staff to further refine and strengthen this bill and move it towards enactment this year.

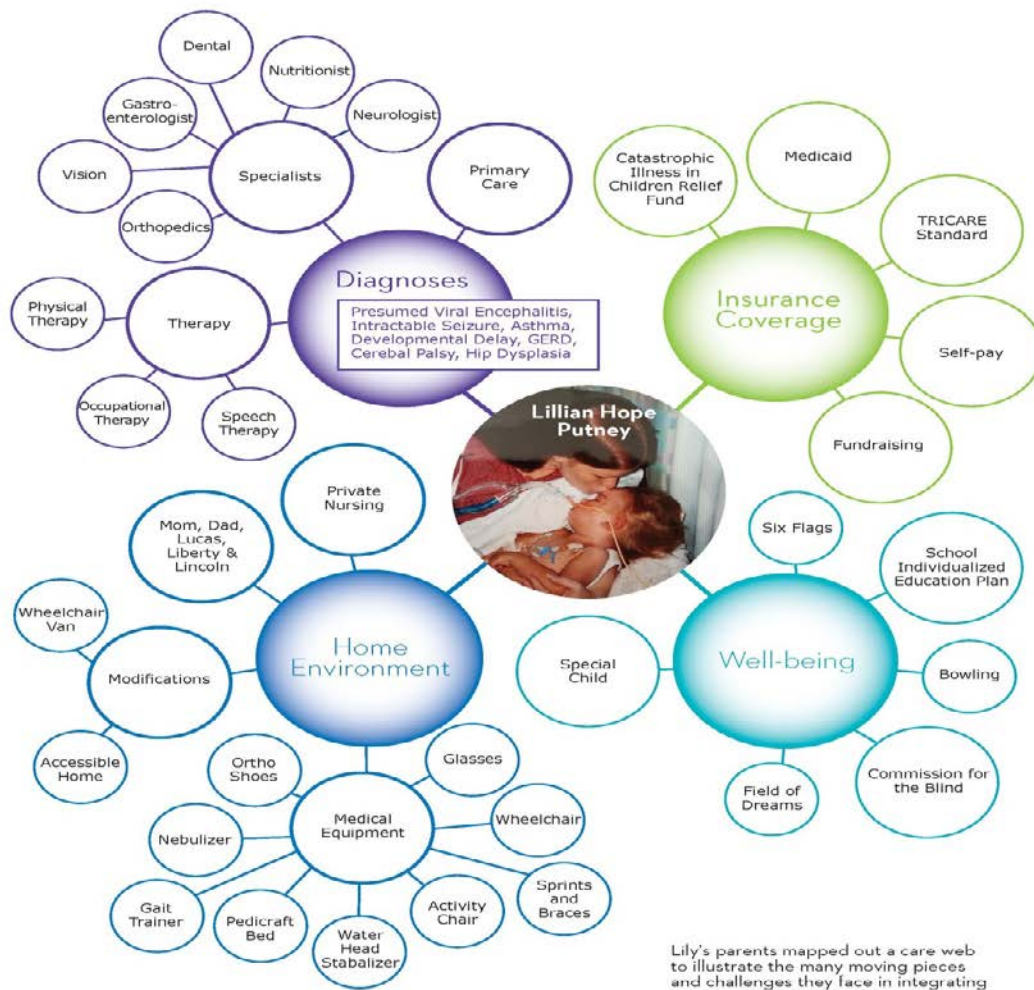
The ACE Kids Act is about fundamentally improving care for the approximately 2 million children with medical complexity in the Medicaid program. The ACE Kids Act builds upon Medicaid’s strengths and creates a flexible framework that focuses on care coordination for this population and will drive further improvement in our ability to care for these children.

Children with medical complexity comprise approximately 6 percent of children on Medicaid. While these children represent a distinct subgroup within Medicaid, they 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 additional services from within and outside of the health care system. These children and their families face real challenges in managing the large number of providers and services their children require on a daily basis, including very often coordinating out-of-state care.

It is important to understand that while we talk about statistics, national issues or the challenges faced by this small but unique population, behind each of these data points is a family who struggle with how to coordinate their care for their own child. To cite one example: Lily Putney of New Jersey. Her family has shared their story publicly numerous times, including with lawmakers during a Capitol Hill briefing, in one-on-one meetings with members of Congress, and even to *Health Affairs*<sup>1</sup> What is important to note is that children like Lily are not facing a healthcare condition; they are facing multiple, life-long, complex, chronic health issues. Below is Lily’s “care map” which shows the challenges she and her family face coordinating care with so many physicians, specialists, therapists and other support services.

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<sup>1</sup> Anthony P. Putney, “Across State Lines, A Family Navigates Medical Complexity and Medicaid Hurdles,” *Health Affairs* 34:7 (July 2015), <http://content.healthaffairs.org/content/34/7/1241.full>.



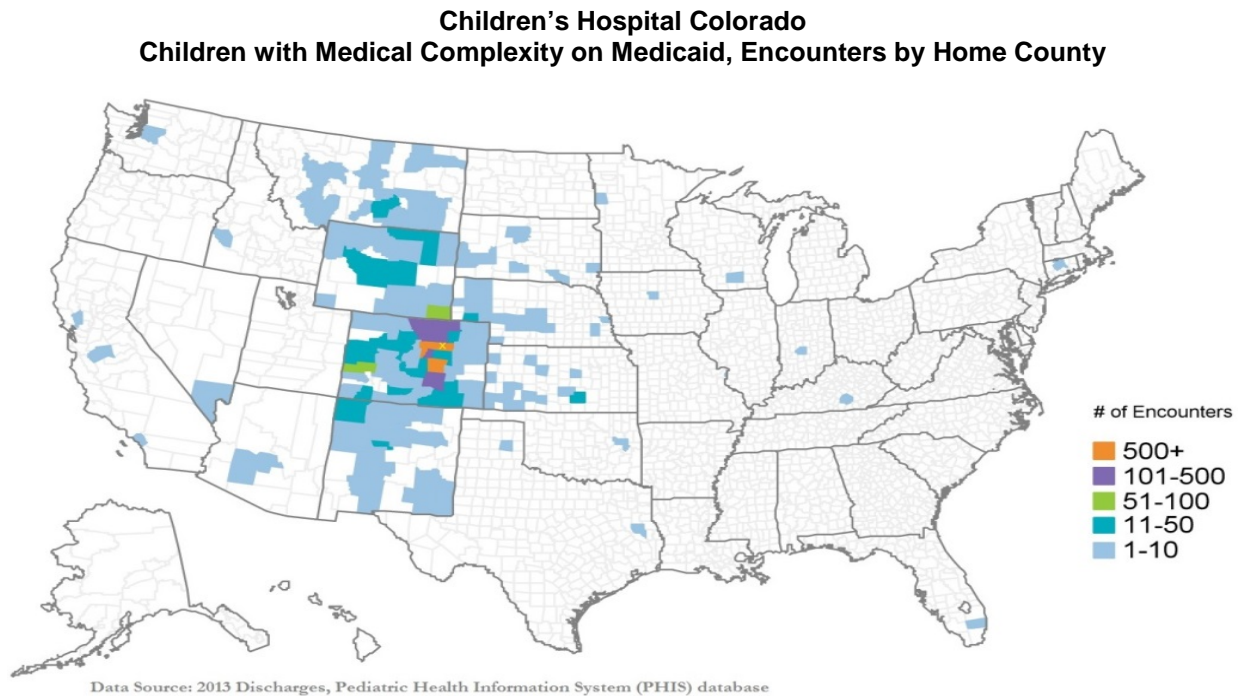
Lily's parents mapped out a care web to illustrate the many moving pieces and challenges they face in integrating coordination of her health care into everyday life.

The ACE Kids Act can help families like Lily's in very real, tangible ways. 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.

To improve care, it is key to advance elements of a national framework that will 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. Legislation will support 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 with a goal of creating easier access to needed, lifelong services, including 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. For example, children's hospitals typically serve larger geographic regions than their adult counterparts, often

covering several states. Furthermore, due to national shortages of pediatric specialists, many children, particularly those with complex medical conditions, travel long distances to access appropriate specialty care, often across state lines. The map below shows, as an example, the states of origin for those children with complex medical conditions covered by Medicaid served by Children's Hospital Colorado.



Children's hospitals, working with physicians and local communities, have long served as key coordination centers in addressing the needs of medically complex children in the face of substantial challenges such as a lack of definitions, data or interstate access. The formalized coordination pilot programs that exist today are in place because there is a need for better coordination among and between the large numbers of specialized providers necessary to care for a child with medical complexity. These programs have been supported by children's hospitals because no other entities have come forward and invested their expertise and resources to better coordinate and support care in the community, home and hospital, or demonstrated a commitment to share their results and improve practice more broadly. These programs have increased the quality of care for children enrolled and family satisfaction.

The ACE Kids Act works within the existing structure of states' Medicaid programs, including those with Medicaid managed care, to better coordinate care for very sick children. The legislation is envisioned as a way for states, health plans, 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. Furthermore, the legislation is completely voluntary for states, children and families, and health care providers.

A strength of the Medicaid program is, as a state-federal partnership, it provides flexibility for individual states to develop unique and innovative solutions. However, this same flexibility has proven to not be conducive to the development of consistent national standards capable of supporting quality improvement and cost reduction efforts. A key to driving improvement in care is building a framework to enable the creation of consistent data supporting development and sharing of best practices and informing clinical standards and quality measures specifically designed for children. 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. In short, there is no national data available today to inform our policies for children with medical complexity.

The recent Committee discussion draft is a strong positive step forward for the ACE Kids Act. As the Committee and cosponsors continue to refine the bill, the more specific the legislation can be with regard to definitions of the population, identification of the specialized pediatric resources essential to the health home, and definition of the quality measures assessing their health, the stronger and more effective the bill will become in better serving these children and saving money.

The ACE Kids Act is also about using existing Medicaid resources more efficiently. Children with medical complexity represent about 6 percent of the children on Medicaid, but this small group accounts for 40 percent of the Medicaid costs for children. Numerous published studies show positive cost savings for children with medical complexity when they are enrolled in a coordinated care program. From the outset, under the ACE Kids Act, savings would come through increased efficiencies, including reducing unnecessary hospitalizations and emergency room visits.

Finally, 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.

We are thankful that so many members of Congress have joined in embracing the goal of driving improvement in care for this population of vulnerable children. The ACE Kids Act is the only proposal enabling the national improvement necessary to impact millions of children and save billions of dollars. Children's hospitals and their patient families look forward to working with champions for children's health to further refine and strengthen the legislation and pass the ACE Kids Act this year.

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The Children's Hospital Association (CHA) advances child health through innovation in the quality, cost and delivery of care. Representing 220 children's hospitals, CHA is the voice of children's hospitals nationally. CHA champions public policies that enable hospitals to better serve children and is the premier resource for pediatric data and analytics, driving improved clinical and operational performance of member hospitals. CHA has offices in Washington, DC, and Overland Park, KS.