



WRITTEN TESTIMONY OF  
GILLETTE CHILDREN'S SPECIALTY HEALTHCARE  
PRESENTED BY STEVEN KOOP, M.D. MEDICAL DIRECTOR  
U.S. HOUSE OF REPRESENTATIVES COMMITTEE ON ENERGY AND COMMERCE  
HEALTH SUBCOMMITTEE HEARING  
"EXAMINING THE ADVANCING CARE FOR EXCEPTIONAL KIDS ACT"  
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Good morning Chairman Pitts, Ranking Member Green, and members of the Subcommittee. My name is Dr. Steven Koop and I serve as the Medical Director at Gillette Children's Specialty Healthcare (Gillette), an independent specialty care children's hospital based in Saint Paul, Minnesota. Thank you for inviting me here today to testify on behalf of Gillette and the children we serve, and to discuss how to improve Medicaid for children who have medically complex conditions. We are grateful for Congress's attention to this very important issue facing children and families and those who care for them. We thank Chairman Pitts and Ranking Member Green for calling this hearing, as well as Chairman Upton and Ranking Member Pallone for their work.

**Background**

In addition to serving as Medical Director, I have been a pediatric orthopedic surgeon at Gillette for 30 years. In my dual role as hospital administrator and practicing physician, I have gained valuable insight into the needs of medically complex children and their families. By sharing

background on Gillette and the children we serve, I hope to highlight the unique needs and abilities of the children you strive to help, the importance of protecting patient access to the most appropriate providers for their conditions, and the benefit of specialty hospitals to children who have significant medical needs.

Gillette was established in 1897 as the first state-funded hospital in the United States dedicated to treating children who have disabilities. We have been an independent, nonprofit since 1988. While the patients we serve, the conditions we treat, and many other factors have changed over that time, our mission has remained focused on this vulnerable population of children.

Our experience has taught us that children who have complex, often multiple, medical conditions require more coordination of care across multiple specialized providers than the average pediatric patient. Therefore, rather than expanding to provide care for all pediatric conditions, we have made the conscious decision to build our integrated care model on delivering high quality and effective treatments to a narrow segment of the pediatric population. Even as we have grown and expanded through the years, any new program offered is one we have identified as an unmet need for our distinct patient population.

Gillette's mission has guided our specialists to develop a coordinated care model that designs the optimal care plan for each patient. These plans are not created in isolation, but are the result of ongoing relationships with each patient and their family or support unit, and guided by the latest in evidence-based medicine. Our care teams facilitate coordination with primary care

(community) providers in our patients' home communities to ensure that primary care providers remain informed and involved in the specialty care their patients are receiving.

Gillette patients include some of the most medically fragile children, who require lifelong care coordination and multiple medical interventions in order to thrive and reach their full potential. A significant percentage of our patients with medically complex conditions are eligible for or are covered under Medicaid.

### **Children and Families at the Center**

It is paramount that any effort seeking to change the way that Medicaid services are delivered to medically complex children be data driven and put improving the lives of these children and their families at the center. Congressional action should be evaluated by whether it ensures that children with medical complexity, and their families, are able to work in partnership with a care team that specializes in the child's unique condition in order to maximize the life and health of the patient in alignment with the families' goals for their child. Although children with medically complex conditions will likely have significant interactions with health care providers throughout their lives, it is the family that truly becomes expert in their child's unique condition.

One of the many patients who stand to be impacted by the proposed legislation is 11-year-old Javier, a resident of Shoreview, Minnesota, and Soldotna, Alaska. Javier was born with spastic quadriplegia cerebral palsy (the most severe form of the condition), and developed epilepsy and neuromuscular scoliosis. Javier sees more than ten Gillette specialists who manage his complex,

interrelated conditions, and Gillette works to coordinate his care between providers in Alaska and Minnesota.

Until recently, Javier's spinal curvature was nearing 90 degrees. It was compromising his organs, breathing, and causing him pain. Javier's spine surgeon suggested he could benefit from new technology called magnetically-driven growing rods—metal rods that straighten the spine without the need for frequent invasive surgeries. The result for Javier is improved quality of life and engagement with the community, including a recent trip to Washington, DC, with his mom to advocate for Gillette and children like him.

Another patient, Brandon, began coming to Gillette when he was 3 years old. He had been diagnosed with cerebral palsy and hydrocephalus. Brandon began seeing a multitude of pediatric specialists and receiving services important to his care on a regular basis. As Brandon grew older, his shunt (a device that drains fluid from his brain) began to fail – a common result as children grow. At age 7, he received a cranial expansion procedure, literally giving his brain more space.

In addition to his shunt-replacement procedures, Brandon has received three orthopedic surgeries—at ages 8, 15 and 16—to correct issues caused by his cerebral palsy. Today he is 20 years old and pursuing a college degree. He also competes in Special Olympics and other athletic events, where he excels at running. Brandon aspires to be a journalist.

Javier, Brandon, and thousands of children and their families who are the experts in their care are who we are talking about today, and why we are paying such close attention to the Advancing Care for Exceptional Kids Act (ACE Kids Act).

### **How Children Who Have Medically Complex Conditions Are Served by Medicaid Today**

With patients like Javier and Brandon and their families at the center, we would like to share our perspective with respect to how children with medically complex conditions are currently being served by the Medicaid program. Medicaid, jointly funded by the federal government and states, and state-administered, is most commonly known for its role in providing health care coverage for those who cannot afford health care and do not have insurance. However, for children with medical complexity and their families, Medicaid also plays an important role in helping to cover medical expenses. Nearly nine million people qualify for Medicaid as a result of their disability, of which approximately three million are children. For these families, Medicaid becomes a critical support to the family and for some, helps to ensure the medical expenses do not force the family into bankruptcy.

When a child is born with a medically complex condition or experiences a traumatic injury, a family's world is changed forever. At this moment, the care team at Gillette has the role of helping the family redefine what is possible for their child and family. Part of that conversation inevitably crosses over to a discussion about the impact on the family finances. Many of these families rely on Medicaid exclusively, while for others Medicaid can also coexist with a family's private insurance. In these cases, Medicaid acts as secondary coverage— assisting when primary

insurance limits are reached and helping with services not covered by primary insurance, such as hygiene equipment, personal care services, and medical transportation. As an attachment to this testimony, we have included a flowchart depicting how families in Minnesota get on Medicaid as a result of their child's complex medical condition. It shows a long process with multiple steps that requires families to apply based on income (a means-tested pathway). This can result in weeks or months of waiting for approved enrollment based on disability, causing hardships for families working within a process that lacks an express-lane pathway based on disability or medically complex conditions – the reason for which families are applying.

### **Patients & Specialty Needs**

There are challenges in the current system in that children who have complex medical conditions – like Brandon and Javier – often need care that requires them to cross state lines. This may occur because the care they need is not found close to home, or because their providers at home recommend they obtain care from a subspecialist located out of state. To better understand this, it is important to know that children who are on Medicaid as a result of a medical condition are patients on the extreme end of the bell curve of acuity, with significant disabilities that are often chronic, complex, and/or statistically uncommon. These children may have co-occurring conditions, creating an even greater need for highly coordinated care in diagnosis and treatment. Gillette treats more than 25,000 of these unique patients each year. Below are some examples of conditions we treat that children on Medicaid may face due to their medical complexity:

- **Cerebral Palsy:** Gillette is known around the world for its care programs for children with cerebral palsy, seeing over 3,500 cerebral palsy patients in each of the past five years. Today, according to the Centers for Disease Control and Prevention, 1 in 323 children have cerebral palsy. Children with cerebral palsy are a diverse group best characterized by the Gross Motor Function Classification System (GMFCS), and all need a spectrum of care, with complexity increasing with GMFCS III, IV, and V. For many of these children, they also have a secondary diagnosis, making their condition that much more complex. For example, in children with cerebral palsy, 41 percent have co-occurring epilepsy and nearly seven percent have co-occurring autism spectrum disorders.<sup>1</sup> An example may be a patient who develops cerebral palsy due to being born prematurely. Over the course of childhood, this one patient will likely need to see a team from neurosciences for brain shunts and treatment of seizures, pediatric orthopedic surgeons for spinal deformities, physical medicine and rehabilitation treatment as a result of cerebral palsy, physical therapy and occupational therapy, as well as lifelong service from assistive technology devices to help them with their daily life.
- **Epilepsy:** More than 450,000 children have epilepsy in the United States.<sup>2</sup> For the majority of patients, epilepsy can be readily and effectively controlled with medication. However, for a fraction of patients who have what is called medically refractory epilepsy, drug-resistant epilepsy or medically intractable epilepsy,<sup>3</sup> families may work for years

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<sup>1</sup> Data and Statistics for Cerebral Palsy: Centers for Disease Control and Prevention Web site. <http://www.cdc.gov/ncbddd/cp/data.html> Published May 2, 2016. Accessed June 30, 2016.

<sup>2</sup> Epilepsy in Children: Centers for Disease Control and Prevention Web site. <http://www.cdc.gov/Features/epilepsy-in-children/index.html> Published September 23, 2015. Accessed June 30, 2016.

<sup>3</sup> Refractory Epilepsy: Epilepsy Foundation Web site. <http://www.epilepsy.com/learn/refractory-epilepsy> Published March 2014. Accessed June 30, 2016.

with specialists to find the right combination of medication to treat or minimize the effects of their child's condition. Many of Gillette's patients who have epilepsy also have complex associated conditions, such as cerebral palsy, developmental delays or traumatic brain injuries, and require a large team of specialists and extensive support services built around the child's condition.

- **Muscular Dystrophy:** Muscular dystrophies refers to a group of diseases that cause muscle weakness, usually presenting in childhood. It is statistically uncommon. For example, about 15 out of 100,000 males between 5 to 24 years of age were affected with Duchenne Muscular Dystrophy in 2007.<sup>45</sup> At Gillette, integrated care teams from neurology, rehabilitative medicine, cardiology, pulmonology, genetics, and orthopedics work together to make a diagnosis, follow the latest advances in care, and provide interventions to help children maximize function, increase independence, and improve the quality of life for the child. This neuromuscular program also provides care to an equally challenging group of children who have conditions such as spinal muscular atrophy, hereditary motor and sensory neuropathies, and primary myopathy.
- **Scoliosis:** Scoliosis is a disorder that, although it may be known widely (literature suggests as many as five percent of children have scoliosis), has varying levels of severity.<sup>6</sup> For children with medical complexity, like those treated by subspecialist providers, the curves may be so profound that they warrant surgical intervention.

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<sup>4</sup> Facts about Muscular Dystrophy: Centers for Disease Control and Prevention Web site. <http://www.cdc.gov/ncbddd/muscular dystrophy/facts.html> Published April 7, 2016. Accessed July 1, 2016.

<sup>5</sup> Emery AEH. The muscular dystrophies. *The Lancet*. 2002 Feb 23 2002;359(9307):687-695.

<sup>6</sup> Konieczny MR, Senyurt H, Krauspe R. Epidemiology of adolescent idiopathic scoliosis. *Journal of Children's Orthopedics*. 2013;7(1):3-9. doi:10.1007/s11832-012-0457-4.



However, only a fraction of children in the U.S. will develop scoliotic curves this extreme. Scoliosis can also be a co-occurring condition, with an estimated 20 percent of children with cerebral palsy and 90 percent of children with Duchenne muscular dystrophy developing neuromuscular scoliosis.<sup>7</sup> For those children and teens with scoliosis that appears early, becomes severe, and who have co-occurring conditions, the disorder can be very difficult to manage, and have many negative consequences. A team of specialists may include neurology, orthopedics, orthotics, pulmonology and respiratory care, rehabilitation therapies, and assistive technology devices. These children may require surgeries such as a spinal fusion surgery or vertical expandable prosthetic titanium rib surgery.

- **Spina bifida:** Spina bifida, another condition we specialize in at Gillette, treating over 450 patients with spina bifida in 2015, is a neural tube defect that occurs when an embryo's spinal cord, surrounding nerves and/or spinal column fail to develop normally. More than 1,500 babies are born with spina bifida in the United States each year.<sup>8</sup> The severity of the spina bifida can range from no symptoms to significant lifelong effects. In the more severe cases, like Myelomeningocele where a sac containing an abnormally formed spinal cord protrudes from an opening in the spinal column of a newborn's back, children can experience a wide range of associated medical complications. These complications may require: extensive, interdisciplinary teams of highly-trained providers to provide surgical repair (typically required within 24 to 48 hours of birth); medical and surgical care from neurosurgeons who manage hydrocephalus and release tethered spinal

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<sup>7</sup> Neuromuscular Scoliosis: Medscape Web site. <http://emedicine.medscape.com/article/1266097-overview#a6> Accessed June 30, 2016.

<sup>8</sup> Spina Bifida Data and Statistics: Centers for Disease Control and Prevention. <http://www.cdc.gov/ncbddd/spinabifida/data.html> Published December 31, 2015. Accessed June 30, 2016.

cords; orthopedic surgeons; and possibly urologists, neurologists, rehabilitation medicine specialists, sleep specialists, dieticians and many other providers.

- **Osteogenesis imperfecta:** Osteogenesis imperfecta, also known as Brittle Bone Disease, is one example of a rare genetic condition treated at Gillette. It is characterized by bones that break easily, often from little or no apparent cause. The National Institutes of Health estimates that between 25,000 and 50,000 people in the U.S. are living with some form of osteogenesis imperfecta.<sup>9</sup> Children with osteogenesis imperfecta require teams of specialists to provide medication, physical therapy and occupational therapy, and orthopedic treatments. Gillette uses an interdisciplinary approach to manage osteogenesis imperfecta focused on increasing bone density and muscle mass, minimizing fractures, maintaining or restoring bone alignment, maximizing musculoskeletal function, and maintaining optimal growth and well-being.

When children with complex, chronic and statistically uncommon conditions need diagnosis, treatment or coordination of their care, a highly trained and experienced team of providers across multiple subspecialties is required for a complete diagnosis and to develop a long-term treatment plan. Often, the care team trained to care for the child's unique needs is located in another state. In these cases, patients may require an approval from their state Medicaid program to seek care outside of the state in which they reside.

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<sup>9</sup> Osteoporosis and Related Bone Diseases National Resource Center – Osteogenesis Imperfecta Overview: National Institutes of Health Osteoporosis and Related Bone Diseases National Resource Center. [http://www.niams.nih.gov/health\\_info/bone/osteogenesis\\_imperfecta/overview.asp#a](http://www.niams.nih.gov/health_info/bone/osteogenesis_imperfecta/overview.asp#a) Published December 31, 2015. Accessed June 30, 2016.

Patients come to Gillette from across the United States for treatment options that may not be available closer to home as the result of a referral from a local provider who recognizes our expertise, or to seek a second opinion on the best course of treatment for their condition. One of our patients, Owen, illustrates this point. Owen, now age 7, was born prematurely. He developed bleeding in his brain and hydrocephalus, a dangerous buildup of fluid around the brain at birth. Owen received treatment at a children's hospital near his family's Iowa home, but as Owen grew, it became increasingly clear that he needed a care team with significant experience in his specific, complex and co-occurring conditions. A local provider referred Owen to Gillette where he received a series of procedures, including replacement of a malfunctioning shunt and a reconstruction of his skull.

Owen also has cerebral palsy and as a result, last summer, underwent a selective dorsal rhizotomy surgery. This procedure treats muscle spasticity caused by damage to the brain that controls voluntary movements. The selective dorsal rhizotomy surgery is followed by weeks of intense, condition-specific inpatient rehabilitation. The surgery permanently reduced debilitating muscle tightness in Owen's arms and legs, making it easier for Owen to walk, run and even play baseball. The result has been increased quality of life not just for Owen, but for his entire family.

### **Medicaid across State Lines**

Over the past five years, patients from all 50 states, plus the District of Columbia, Puerto Rico, and more than 20 countries, have come to Gillette for care. And in recent years Gillette's inpatient unit (not including outpatient clinic visits) served patients who are on Medicaid or

Medicaid eligible from 18 states. This includes Medicaid and Medicaid eligible patients from states represented by Subcommittee members including Florida, Illinois, Kentucky, Michigan, Missouri, Texas, and Virginia. Gillette's Medicaid and Medicaid eligible patients made up 59 percent of our inpatient stays and 62 percent of our inpatient days in 2015.

Gillette and other hospitals, which develop expertise in condition-based groups, provide care for a relatively small number of medically complex conditions. The need for subspecialty trained physicians across multiple disciplines and the relatively small number of patients results in limited programs of this type across the country. Because of this, hospitals like Gillette hear from our patients who live in multiple states and the social workers who assist them about the struggles families face when attempting to obtain approval and ultimately access care across state lines.

To ease the burden on families and improve care, we must work together collectively – the federal government, states, providers, and patients and their families – to streamline the process. Specifically, we need to facilitate access to the appropriate providers to care for the specific medical needs of a Medicaid child who has medical complexity. We need to simplify the process to gain Medicaid coverage for children who qualify for Medicaid because of their medical complexity. Efforts to improve care and enhance access should be developed in a way that does not disrupt established patient/provider relationships that are working well or impede access to expertise in a child's unique medical complexity.

### **Federal Legislation on Medicaid Children with Medically Complex Conditions**

As Congress works to develop federal legislation to improve access to specialized services for medically complex children, it is important that, as a threshold matter, we fully understand the scope and nature of the problem. Although we know our patients' stories anecdotally, there is a dearth of national and statewide data related to children on Medicaid who have medical complexity. In crafting policy aimed at positively impacting the lives of these children and their families, we must first understand the conditions these children experience, the system that currently serves them, and the panoply of issues that affect their access to care. We also need to understand models that have been built in various states that are working well to support these children and families, and to identify ways to replicate them across the country. In order to encourage their adoption, proposed changes should be developed that are attractive to states.

We are grateful that the Subcommittee has put forth language that prioritizes a data-based solution and sharing of the learnings. We need to know the number of children enrolled in Medicaid who would be affected by any proposed changes and the number and types of providers currently serving these children. We also need to learn what factors currently impact a provider's ability to refer patients across state lines, obstacles to payers paying out-of-state providers, a family's ability to get a child in the care of the most appropriate specialist, and trends or themes in where and how gaps in access affect families.

In addition, we also must protect patient access to specialized providers. Children with complex medical conditions need to be able to access care from providers who have trained to treat their conditions specifically, and facilities that have developed refined programs to care for their

disabilities, regardless of geographic boundaries or network limitations. Any policy change should protect patient access to specialty providers and support referral and care coordination relationships between providers across geographies.

Lastly, federal legislation must ensure access to demonstrated quality and competencies through outcomes we achieve for our patients in both treating the specialty needs of patients and coordination of care. There is a basic business principle that you cannot excel at everything, and we should not emphasize facility size or volume over expertise. As such, it is important for patients and their families to have access to the care they need and not be confined to specific hospitals or networks. Medicaid children with medical complexity might need care across multiple systems and providers, for example a primary care provider in their home community and a specialist at a specialty care hospital. Excellence should be fostered when it exists or develops, and the best impetus for excellence is a close relationship between those who need care and those who dedicate themselves to providing that care.

## **ACE Kids Act**

*H.R. 546 as introduced January 2015*

With respect to H.R.546, the as-introduced version of the ACE Kids Act, we would like to again thank the original sponsors, especially Congressman Barton and Congresswoman Castor, for their leadership on this bipartisan effort to improve Medicaid for medically complex kids. We support the legislation's goals of improving care coordination, making it easier for patients to

access treatment, and collecting important data to advance care for children who have medically complex conditions.

While we are gratified by the attention these Members and this Subcommittee are paying to issues facing children on Medicaid as a result of their medical complexity, we do have a number of concerns with the legislation as introduced. In April 2016, the leadership of Gillette Children's Specialty Healthcare sent a letter to the Energy and Commerce Committee of the House of Representatives to share these concerns. This letter is attached.

In sum, our letter explains that we believe that the ACE Kids Act, as introduced in January 2015, puts the hospital at the center of care, rather than the child and family. As described above, we believe that it is critical that Congress ensure that the child and family are at the center by protecting access to providers.

#### *Updated ACE Kids Act*

Overall, we are pleased and encouraged with the discussion draft that is the subject of today's hearing. Though early in our review, we believe it moves the ACE Kids Act in a positive, child- and family- focused direction. Gillette appreciates that the proposed data-driven revisions to the ACE Kids Act would focus on gathering information and statistics, learning more about the population of children being served by Medicaid who have disabilities, and highlighting best practices. This new approach makes improving Medicaid for families struggling to access care

for their children who have complex medical conditions a priority, but helps to ensure we obtain data first to work towards a shared goal, not to disrupt patient care while improving Medicaid.

To that end, we believe that the data provision requiring the Medicaid and CHIP Payment and Access Commission (MACPAC) to do a study on children with medical complexity and report back to Congress would be beneficial. Careful analysis of all available data is needed to improve care coordination for children on Medicaid as a result of complex medical conditions and this data must be collected as a first step, providing a baseline to inform future innovations aimed at improving outcomes and saving costs. At a high level, we recommend data collection be related to the number of children enrolled in Medicaid as a result of a medically complex condition, provide an estimate of the number of health care providers (and a reasonable description of provider types) serving children on Medicaid as a result of a medically complex condition (with estimates on shortages of pediatric specialists and subspecialists), and provide data and recommendations on how to promote care coordination and ease the burden on families by standardizing the process of enrollment on Medicaid, approval for care, and coordination across state lines. Another key provision in the discussion draft that we strongly support, and our patients and their families will likely view as essential, is the Rule of Construction with Respect to Freedom of Choice in Section 3.

We generally support the concept of a federal agency like the Centers for Medicare and Medicaid Services issuing guidance to State Medicaid Directors regarding best practices for providing care to children who have medical complexity. The best way to introduce a new system and create successful models that improve access to care for children with medically



complex conditions on Medicaid would be to identify transferrable and replicable ideas, such as identifying which states are leading successful innovations, and build upon those successful models. The guidance would provide an important opportunity for a sharing of best practices.

We support a state option to provide coordinated care through a health home for children who have complex medical conditions. The health home model focuses on providing patient-centered care and engaging patients and families. This is important for all patients, but extremely important for children with complex medical conditions who are often navigating multiple providers. Existing health homes are improving quality for the patients they serve by transforming the way in which care is delivered. Expanding the option for states, and including an education requirement, is key to achieving the goals of the ACE Kids Act. The detailed state reporting requirements are essential as this data does not currently exist, and without it we cannot fully understand children who have medical complexity and how we serve them. The health home model allows for care to be coordinated closer to the child's home in a wide variety of settings, while promoting community engagement and partnerships for when that care may not be as easily accessible. Like any innovative health care delivery reforms, newly proposed options for states must be attractive enough to encourage them to exercise their option to participate. Providing appropriate incentives to states to exercise their option seems to be consistent with the ongoing effort of Congress and the administration to transform the health care delivery system.

In putting forth a health home model for children who have complex medical conditions, we ask Congress to consider the importance of ensuring that these health homes accurately reflect the needs of these children who are often predominantly and primarily seen by specialty providers.

Any new model must ensure that specialty and subspecialty providers have the ability to be certified as a health home in order to best meet the needs of each individual patient. Health homes for children with complex medical conditions should not follow a one-size-fits-all approach, and the structure should reflect and be flexible enough to accommodate the needs of each individual patient. Patients and families need assistance in navigating the system and deserve the benefits of effective care coordination, while preserving access to the provider that is best suited to care for that individual patient.

Finally, we present a few specific points about the proposed health homes for the Committee to consider as it moves forward with the new discussion draft. We recommend the Committee ensure that patients and their families be allowed to select the designated providers and health homes rather than have one selected for them, keeping the language consistent with the language in section 2703 of the Affordable Care Act. Second, rather than listing specific disorders to define ‘chronic conditions,’ we recommend listing conditions in groups such as by clinical needs of those who have physical disabilities, developmental disabilities, statistically uncommon and/or complex or chronic medical conditions. The current listings include both groupings and specific diagnoses, and specific diagnoses could change over time. For example, listing muscular dystrophy rather than neuromuscular conditions could exclude patients who have spinal muscular atrophy and other dystrophies. As we work to study the system that serves children who have medically complex conditions and improve services, we recommend that data collection efforts like section 5, the MACPAC Report, include inpatient and outpatient procedural needs, including pharmaceutical and therapeutic needs of patients, and aim to

quantify total resources used in relation to specific groups of patients over time and not based solely on episodes of care.

## **Closing**

Thank you again, Chairman Pitts, Ranking Member Green and members of the Subcommittee, for your attention to Medicaid children who have medically complex conditions. We care deeply about these patients and their families. They are among the most vulnerable populations and they rely on those here today, clinical teams back at home at our institutions, and state and federal governments—including members of Congress—to be their advocates. Thank you for your commitment and efforts to ensure that we collectively put children first. We believe the ACE Kids Act discussion draft is an important step in the right direction for the Health Subcommittee's work.