

EXAMINING THE ADVANCING CARE FOR EXCEPTIONAL KIDS ACT

HEARING BEFORE THE SUBCOMMITTEE ON HEALTH OF THE COMMITTEE ON ENERGY AND COMMERCE HOUSE OF REPRESENTATIVES ONE HUNDRED FOURTEENTH CONGRESS SECOND SESSION

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EXAMINING THE ADVANCING CARE FOR EXCEPTIONAL KIDS ACT

THURSDAY, JULY 7, 2016

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON HEALTH,
COMMITTEE ON ENERGY AND COMMERCE,
Washington, DC.

The subcommittee met, pursuant to call, at 10:15 a.m., in room 2322 Rayburn House Office Building, Hon. Joe Pitts (chairman of the subcommittee) presiding.

Members present: Representatives Pitts, Guthrie, Barton, Murphy, Burgess, Lance, Griffith, Bilirakis, Long, Brooks, Collins, Upton (ex officio), Green, Engel, Schakowsky, Castor, Matsui, Schrader, Kennedy, and Pallone (ex officio).

Staff present: Rebecca Card, Assistant Press Secretary; Paul Edattel, Chief Counsel, Health; Graham Pittman, Legislative Clerk, Health; Michelle Rosenberg, Detailee, Health; Jennifer Sherman, Press Secretary; Heidi Stirrup, Policy Coordinator, Health; Sophie Trainor, Policy Coordinator, Health; Josh Trent, Deputy Chief Health Counsel; Tiffany Guarascio, Minority Deputy Staff Director and Chief Health Advisor; Rachel Pryor, Minority Health Policy Advisor; Samantha Satchell, Minority Policy Analyst; and Andrew Souvall, Minority Director of Communications, Outreach and Member Services.

OPENING STATEMENT OF HON. JOSEPH R. PITTS, A REPRESENTATIVE IN CONGRESS FROM THE COMMONWEALTH OF PENNSYLVANIA

Mr. PITTS. The subcommittee will come to order. The chair will recognize himself for an opening statement.

Today's subcommittee hearing will examine a new discussion draft of the Advancing Care for Exceptional Kids—the ACE Kids Act, legislation championed by Mr. Barton and Ms. Castor.

The goals of the ACE Kids Act are laudable—to improve the delivery of, access to, healthcare for children with complex medical conditions served by Medicaid and who all share the goals and want to prioritize the needs of these children.

The committee received robust feedback from stakeholders on the introduced bill. Many expressed concerns with the bill's ritual scope, approach and cost. So I applaud the co-sponsors for working through the committee to address serious stakeholder concerns by taking a new approach in the draft we are discussing today.

Today, we will hear from witnesses representing a diverse mix of Medicaid stakeholders representing parents, clinicians, research-

ers, providers and Medicaid directors. Every child is unique and every state program is a little different.

So we want to listen and learn about the ways in which children with complex medical needs are served by the Medicaid program currently. Medicaid already provides a critical safety net for providing care for some of our youngest and most vulnerable patients. Yet, when a child is born with a rare disease or has medically complex conditions there can be unique challenges.

In many ways, state Medicaid programs are already successfully leveraging the expertise of providers and plans to provide needed care for medically complex children. Yet, we know challenges exist and the status quo can be improved.

So today we look forward to hearing from witnesses about ways we can increase options, reduce barriers, enhance analysis, and better align incentives to care for these children.

Finally, let me just note that the discussion draft before us represents one approach but, clearly, does not exhaust all the good ideas others may have.

So moving forward, the committee welcomes feedback on how we can improve care for children with medical complexity without disrupting the successful approaches already in place.

[The prepared statement of Mr. Pitts follows:]

PREPARED STATEMENT OF HON. JOSEPH R. PITTS

The Subcommittee will come to order.

The Chairman will recognize himself for an opening statement.

Today's Subcommittee hearing will examine a new discussion draft of The Advancing Care for Exceptional ("ACE") Kids Act—legislation championed by Mr. Barton and Ms. Castor.

The goals of the ACE Kids Act are laudable—to improve the delivery of, and access to, health care for children with complex medical conditions served by Medicaid. I know we all share the goals and want to prioritize the needs of these children.

The Committee received robust feedback from stakeholders on the introduced bill. Many expressed concerns with the bill's original scope, approach, and cost. So I applaud the cosponsors for working through the committee to address serious stakeholder concerns by taking a new approach in the draft we are discussing today.

Today we will hear from witnesses representing a diverse mix of Medicaid stakeholders—representing parents, clinicians, researchers, providers, and Medicaid directors. Every child is unique. And every state program is a little different. So we want to listen and learn about the ways in which children with complex medical needs are served by the Medicaid program currently.

Medicaid already provides a critical safety net for providing care for some of our youngest and most vulnerable patients. Yet, when a child is born with a rare disease or has medically complex conditions, there can be unique challenges.

In many ways, State Medicaid programs are already successfully leveraging the expertise of providers and plans to provide needed care for medically complex children.

Yet, we know challenges exist and the status quo can be improved. So, today we look forward to hearing from witnesses about ways we can increase options, reduce barriers, enhance analysis, and better align incentives to care for these children.

Finally, let me just note that the discussion draft before us represents one approach, but clearly does not exhaust all the good ideas others may have. So, moving forward, the committee welcomes feedback on how we can improve care for children with medical complexity without disrupting the successful approaches already in place.

I yield the balance of my time to the Chairman Emeritus, Mr. Barton.

Mr. PITTS. I will yield the balance of my time to the chair emeritus, Mr. Barton.

Mr. BARTON. Well, thank you, Mr. Chairman, and I want to applaud you and the ranking member, Mr. Green, and Mr. Upton and Mr. Pallone for agreeing to this hearing.

We have a bill that we have been working on for 4 years. Some of you in the room have been working on it a lot longer than that. I think, Mr. Chairman, you can tell there's a lot of energy in the room, a lot of positive energy, and we want to build on that.

We have changed the focus of our bill. We have gone from a facility-centric bill to a family-centric bill and that's because we are open minded and we want to listen.

Today, we are going to hear from six witnesses. Unusually for me, I actually read your testimony. I don't normally do that, and it's all good. I want to applaud our witnesses.

Some of the testimony is very moving, Ms. West's testimony about her daughter especially and all that they have gone through. Mr. Koop, Mr. Merrill, who represents Cook Children's Hospital in my district, I am especially pleased that you are here, sir.

We want to have an open hearing, Mr. Chairman. We want to put all the issues on the table. We want the American people to see Congress at its best where we agree on a premise and then we work together to find a solution.

I can't say enough about Kathy Castor and her efforts, Gene Green and his efforts, Cathy McMorris Rodgers on my side of the aisle and Congresswoman Beutler, who just had a brand new baby boy who is totally healthy. But her first daughter would qualify for this program if they were Medicaid eligible.

So we have 30 co-sponsors of the committee. Thirty members of our committee are co-sponsors of our original bill. We have almost 218 House members. We have over 30 senators on a bipartisan basis.

So, Mr. Chairman, if we listen to these witnesses and then work together we can have a markup in this Congress. We can pass a bill through the House in this Congress. We can work with our friends in the Senate and try to get this if not as a standalone bill as part of a larger package that goes to the president and we can do something for our kids working together.

So with that, Mr. Chairman, I yield back.

Mr. PITTS. The Chair thanks the gentleman, and now I will recognize the ranking member, Mr. Green, 5 minutes for opening statements.

**OPENING STATEMENT OF HON. GENE GREEN, A
REPRESENTATIVE IN CONGRESS FROM THE STATE OF TEXAS**

Mr. GREEN. Thank you, Mr. Chairman, and I apologize for being late. I was giving a statement in one of our sister committees downstairs.

I'm an original co-sponsor of H.R. 546, the Advancing Care for Exceptional Kids, or ACE Kids Act. I'm grateful to Representative Barton and Castor for their commitment to children with complex medical needs and their quest to improve the system of care provided to these children.

I want to thank the chairman for having this hearing today and our witnesses for their time and passion. The ACE Kids Act aims to improve the delivery of care for children with complex medical

conditions served by Medicaid. It presents a great opportunity for us to implement better care delivery and payment models to support children and their families.

The bill seeks to improve coordination of care for children, address problems or fragmented access, especially when the care they need is available out of state and gather national data to help researchers improve services and treatments for children with complex medical conditions in the Medicaid program.

The discussion draft we were examining attempts to address the goals of the introduced bill in a manner that incorporates and builds upon the diverse range of stakeholder feedback.

I want to thank the stakeholders, Texas Children's Hospital in particular in our district area in Houston. My colleagues are moving this important legislation forward.

Children with medical complexity require a lot of healthcare and generate significant costs. According to one study, there are 2 million of these children on Medicaid, 6 percent of the total Medicaid population, and they account for 40 percent of the Medicaid spending on children.

While that data is compelling, it's important not to reduce these children and their families to statistics. We must do a better job and ensure that all of those exceptional kids get the care they need.

I had the pleasure to meet a remarkable young lady named Adrianna, who was born with her heart outside her chest. Thanks to the excellent care she received at Texas Children's Hospital, she is a happy and thriving toddler. Her survival would not be possible without the premier care she received and this legislation will help more and make sure every child regardless of where they are born has the same opportunity.

Like Adrianna, children with medical complexity have multiple illnesses, disabilities, and often see six or more specialists and a dozen more physicians and require the kind of care that takes them across state lines.

Under the current system, parents of kids with complex conditions struggle to coordinate the intricate multistate care of their children. We need this legislation to make this care more coordinated and seamless for the families.

This discussion draft is an important step forward. We must ensure that the final legislation is robust and meaningful to accomplish our shared goals in improving care and removing barriers for children with complex needs.

I am happy to hear that we now have 218 co-sponsors to the ACE Kids Act. It proves that the health care of our children is an issue that is above partisanship and brings us all together.

I look forward to working with my colleagues to move this legislation forward to give our children the bright futures they deserve and I thank the chairman for calling the hearing and our witnesses today and I yield the remainder of my time to my colleague, the lead sponsor, Congresswoman Castor.

Ms. CASTOR. Well, thank you, Congressman Green, and thank you, Congressman Pitts, for calling the hearing today and I am also appreciative to Chairman Upton and to Ranking Member Pallone for all of their great staff work and their attention.

I really want to thank by colleague, Congressman Joe Barton. Joe, you have been a tiger for these kids and families. Joe Barton, you have taught me how to be a better legislator because you just never give up and you never give in. And this truly is a committee effort, and with the help of Congresswoman Jaime Herrera Beutler.

Over 200 bipartisan co-sponsors in this fractious Congress including Eliot Engel on this committee, Jan Schakowsky, thank you—Doris Matsui, thank you—Joe Kennedy, Tony Cardenas, my good friend, Brett Guthrie, Congressman Whitfield—

Mr. BARTON. We are about to get Billy Long. He doesn't know it yet.

Ms. CASTOR. Good. I would think so. I would think so. Cathy McMorris Rodgers, Congressman Lance, thank you. Congressman Bilirakis, my good friend from Tampa Bay, Congresswoman Ellmers and Susan Brooks, thank you, Susan, very much.

I became an advocate for these families after meeting of families and health professionals at St. Joseph's Children's Hospital in Tampa including Tish and Bill West, who are here today, and their daughter, Caroline.

They explained to me what they had gone through early with fragmented uncoordinated care and how meaningful it was to have a medical home where they could save time, save money but most importantly get the best care for Caroline and that is what we want to replicate all across the country for these families.

So I am grateful to everyone that has participated today and over the past few years and I look forward to bringing this bill to fruition and thanks again to Congressman Barton and to Congressman Upton—Chairman Upton and Frank Pallone as well and I will yield back.

Mr. PITTS. The chair thanks the gentlelady. I will now recognize the chair of the full committee, Mr. Upton, 5 minutes for an opening statement.

OPENING STATEMENT OF HON. FRED UPTON, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF MICHIGAN

Mr. UPTON. Well, thank you, Mr. Chairman, and all of our colleagues on both sides of the aisle.

We know that the Medicaid program is a very important safety net that provides the needed medical care to millions of kids to communities across the country and in 2013 roughly half of all Medicaid enrollees were children.

Many of the kids are healthy, well and primarily just rely on the program for routine medical care—preventive screening and other treatment.

But we know that some of the kids served by Medicaid face very serious debilitating, even life-threatening conditions that make it so difficult for them to perform the activities of their daily life.

The kids are often referred to as children with medical complexity because they may face any number of rare diseases and conditions which can force them to rely on very specialized care.

We all want to ensure that the Medicaid program does right by these kids and their families that depend on the program for care, particularly the most vulnerable.

So today we are discussing another bipartisan bill introduced by very good members of the committee. There's no really bad members on the committee. They're all good members of the committee.

But the ACE Kids Act, led by Barton and Castor, seek to improve care for these kids. We first discussed the bill as part of 21st Century Cures Initiative a few years ago and since we have received a lot of feedback from our colleagues and stakeholders, many of which I know are in this standing room only room.

I am glad to see such strong interest in working together to get the bill right and better serve the patients in need of help.

So in that spirit of cooperation and collaboration I want to stress we all agree on the goals. There is no question about that—improving care coordination within a state, ensuring access to care across state lines and ensuring that we are leveraging the data to target interventions.

But each of us also wants to ensure that any targeted improvements actually fix what is broken by building on what is working without disrupting proven successful models of care that help kids within the program today. I want to do everything that we can to ensure that we enhance care and protect choices within the program.

So that is why we have the witnesses today. We need your feedback and we also want to hear from folks not on the panel. Whether it's managed care plans, individual Medicaid directors, physicians, nurses, the whole ball of wax.

We invite them to continue to share their insights so that we can better understand what is working and how we might be able to move forward. And I don't know if other members on my side want any of my time, any of the co-sponsors? Susan, anybody else. I know, you did a great—I yield back the balance of my time.

[The prepared statement of Mr. Upton follows:]

PREPARED STATEMENT OF HON. FRED UPTON

Today, the Medicaid program is an important safety net that provides needed medical care to millions of children in communities across the nation. In FY2013, roughly half of all Medicaid enrollees were children.

Many of these children are healthy, well and primarily just rely on the program for routine medical care, preventative screenings, and other treatments.

However, some of the children served by Medicaid face very serious, debilitating, even life-threatening conditions that make it very difficult for them to perform the activities of daily life. These children are often referred to as “children with medical complexity,” because they may face any number of rare diseases and conditions, which can force them to rely on very specialized care.

I know we all want to ensure that the Medicaid program does right by these kids and the families that depend on the program for care—especially the most vulnerable. So today we are discussing another bipartisan bill introduced by members of this committee. The ACE Kids Act, led by Chairman Emeritus Barton and Ms. Castor, seeks to improve care for these children.

We first discussed this bill as part of the 21st Century Cures initiative. Since then, we've received a lot of feedback from my colleagues, and stakeholders—many of which are in this very room. I'm glad to see such strong interest in working together to get this bill right and better serve the patients in need of our help.

So, in that spirit of cooperation and collaboration, I want to stress we all agree on the goals of the ACE Kids Act—improving care coordination within a state, ensuring access to care across state lines, and ensuring we are leveraging data to target interventions. But each of us also wants to ensure that any targeted improvements actually fix what is broken by building on what is working—without disrupting proven, successful models of care that help kids within the program today.

We want to do everything we can to ensure we enhance care, and protect choices within the program.

That's why we have our witnesses before us today. We need their feedback and insights to better understand the challenges this population of children faces within the Medicaid program today.

We also want to hear from folks not on the panel. Whether it's managed care plans, individual Medicaid directors, physicians, nurses, children's health advocates, or others—we invite them to continue to share their insights and ideas about how we can tailor solutions to improve care for children.

We want to better understand what's working and also what opportunities exist for bipartisan improvements to give beneficiaries, states, plans, and providers more tools to design solutions that best serve these kids.

I yield the balance of my time to the Vice Chairman of the full committee, Ms. Blackburn.

Mr. PITTS. The chair thanks the gentleman and now recognize the ranking member of the full committee, Mr. Pallone, for an opening statement.

OPENING STATEMENT OF HON. FRANK PALLONE, JR., A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY

Mr. PALLONE. Thank you, Mr. Chairman, and thanks to our witnesses for being here today. Few programs are as critical to the wellbeing of our nation's citizens as Medicaid.

For over 50 years, the Medicaid program has provided comprehensive health care coverage to America's most vulnerable populations and while our hearing today is specifically about medically complex children in Medicaid, I urge my colleagues not to forget the important role that Medicaid plays broadly for children in this country. Medicaid finances more than 50 percent of all births in this country and provides more than one in three children with the chance at a healthy start in life.

In 2015, the Medicaid and CHIP programs together covered more than 45 million children, and children with complex medical needs includes a very special subset of children in the Medicaid program.

These children typically have chronic multi-system diseases and demand intensive care and that is why Medicaid is particularly crucial for their families under the Medicaid and CHIP.

Children with complex medical conditions receive a broad set of services that in many instances private insurance won't cover. It's not an overstatement to say that Medicaid is lifesaving to these children and provides a financial lifeline for their families that struggle with insurmountable medical expenses.

However, families and stakeholders agree that there are several issues related to treatment for this population that must be addressed. For example, many children with complex medical conditions travel nationwide for care and report significant difficulty coordinating care across state lines and across many state Medicaid programs.

They need care that is family centered and is based on comprehensive quality data that is simply not available nationally for this specialized population of Medicaid.

H.R. 546, the Advancing Care for Exception Kids Act, known as the ACE Kids Act, aims to address these shortfalls, to revise discussions that are being examined today tries to incorporate some of the feedback we have received to date from stakeholder.

The new draft gives states the option to establish health homes geared towards the treatment of children with complex medical conditions and includes two years of enhanced payments to states to help with implementation.

The draft also requires increased quality reporting, transparency regarding payment across state lines and guidance from the Centers for Medicare and Medicaid Services to states on best practices for payments across state lines.

So I want to thank my colleagues, Representatives Castro and Barton, for championing this legislation for many Congresses and building extensive bipartisan support for such an important issue.

The discussion draft under consideration is just that, a draft for discussion. But I look forward to comments from stakeholders including our witnesses today and I hope that we can continue working in a bipartisan fashion, moving forward to take a positive step forward for medically complex kids in the Medicaid program.

And most importantly, I'm glad we share the common goal of ensuring that these children receive the best possible treatment. I yield back.

Mr. PITTS. Chair thanks the gentleman.

As usual, all members' written opening statements will be made a part of the record. That concludes our opening statements.

We will now go to our panel of witnesses. We have one panel with six witnesses today and I will introduce them in the order of their presentations.

First, Dr. Jay Berry, M.D., MPH, Assistant Professor for Pediatrics, Harvard Medical School, and Mr. Matt Salo, Executive Director, National Association of Medicaid Directors.

Then Ms. Maria Isabel Frangenberg, Project Coordinator, Family Voices. Then Ms. Tish West, parent of a child with medically complex conditions. Then Dr. Steven Koop, M.D., Medical Director, Gillette Children's Specialty Health Care, and finally Mr. Rick Merrill, President and Chief Executive Officer of Cook Children's Health System.

Thank you for coming today. Your written testimony will be made a part of the record. You will each be given 5 minutes to summarize your testimony. There is a system of lights on your table.

I think after four minutes the yellow should come and then finally after 5 minutes the red. So we ask if you would respect that, and we thank you for coming today.

We, at this point, will recognize Dr. Jay Berry for your opening summary—5 minutes.

STATEMENTS OF JAY G. BERRY, M.D., M.P.H., ASSISTANT PROFESSOR OF PEDIATRICS, HARVARD MEDICAL SCHOOL; MATT SALO, EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF MEDICAID DIRECTORS; MARIA ISABEL FRANGENBERG, PROJECT COORDINATOR, FAMILY VOICES; TISH WEST, PARENT OF A CHILD WITH MEDICALLY COMPLEX CONDITIONS; STEVEN KOOP, M.D., MEDICAL DIRECTOR, GILLETTE CHILDREN'S SPECIALTY HEALTHCARE; RICK W. MERRILL, PRESIDENT AND CHIEF EXECUTIVE OFFICER, COOK CHILDREN'S HEALTH SYSTEM

STATEMENT OF JAY G. BERRY, M.D., M.P.H.

Dr. BERRY. Thank you, Mr. Chairman, Mr. Barton, Ms. Castor, committee members and staff for prioritizing today's discussion on children with medical complexity for giving us here the opportunity to share our experiences and perceptions caring for these children and for taking a step far with legislation to optimize a system of care for them. It is a dream come true to be talking with you guys about these children today.

I am a general pediatrician. I have a decade of experience working a clinic and a hospital-based team dedicated exclusively to caring for children with medical complexity.

I am also a health services researcher who has been trained to use health administrative claims data to identify this population of children and to assess their health care resource use and their outcomes.

When I think of children with medical complexity, I think of children that have a lifelong chronic condition that most often is incurable it's so severe that it affects multiple organ systems of the body.

It also significantly impairs the functioning of the children, their ability to eat, to drink, to digest food, to breathe, to walk and talk independently.

These children have a variety of health care needs. It's not uncommon for them to be on dozens of medications, lots of durable medical equipment and to have 20 or more providers taking care of them across continuum from primary care, specialty care, social workers, surgeons, home nurses, school nurses, et cetera.

The prevalence of this population of children is small. At most, they account for a few percent of all children. But their impact on the system is quite large where they account for 30 or 40 percent of total spending, especially in Medicaid.

The balance of their health care spending is also interesting, where about half of it, we think, is going to hospital care but a vast minority of it, 2 to 3 percent or so, is going to primary care, community care and home care.

For the current state of health affairs for these children, too many of them have unmet health care needs. Many of them can't find local pediatricians and other clinicians who are willing to help them, especially with urgent care matters.

Often, many of them have to travel great distances for specialty care even outside of their state and some are stuck without a provider truly owning their care.

This impacts the children. They are getting sick too often and they are relying on the emergency department in the hospital too much for their health crises. Their parents have limited support in their home.

Many parents are running many hospitals in their home, trying to care for their children and they are experiencing immense caregiving time and effort which can result in loss of employment, marital and family discord, and emotional distress.

It's just hard to take care of these kids. It's time consuming. It takes a lot of people to do it. No one clinician or one clinic can do it all.

It takes a lot of brain power. It's emotionally taxing, especially just riding along with the families as they are experiencing unbelievably dire health circumstances.

It's often not financially attractive. The providers for these children, as we've talked about, are geographically dispersed. It's hard sometimes to hold them accountable for what they are doing and the health data are just not forthcoming enough to really identify best practices for these children.

So I couldn't be more excited about federal legislation in health care policy that can help these kids. Anything that could help redirect and stabilize health care spending for them into the primary community and home care world that could institute accountability and governance across all the providers caring for them that could improve their accessibility of care especially across state lines and could optimize the Medicaid data that we have, making it more reliable, standardized and useful to measure the quality of care for these children and identify best practices.

Thank you so much for having me here today. I will be happy to answer any questions for you after the other testimonies. Thank you so much.

[The prepared statement of Jay G. Berry follows:]

Children with Medical Complexity

Written Testimony

U.S. House Committee on Energy and Commerce, Subcommittee on Health

"Examining the Advancing Care for Exceptional Kids Act" Hearing

July 7, 2016

Jay G. Berry, M.D., M.P.H.

Complex Care Service, Division of General Pediatrics, Department of Medicine, Boston

Children's Hospital, Harvard Medical School

Testimony Summary

- Children with medical complexity (CMC) represent a small, vulnerable population that has a large impact on the pediatric health care system; CMC are the “sickest of the sick” children.
- Most healthcare spending for CMC goes to hospital care. Small amounts of spending go to primary and home care. Large proportions of care provided to CMC are not reimbursed.
- The main goal of caring for CMC is to continuously strive to give the children the best life possible, under the unfortunate circumstance that their health will always be limited to a certain degree because of their chronic health problems.
- Very rarely is one provider or one clinic able to achieve this goal. Rather, this goal is more often achieved by all providers working in large geographic catchment areas (often across state lines) as a team.
- Major areas of deficiencies in care for CMC include (1) underfunded and understaffed primary and home care; (2) insufficient accountability and governance of the healthcare professionals involved in their care; (3) lack of access to high quality urgent care; (4) insufficient integration of care across the continuum; and (5) inadequate healthcare data (e.g., Medicaid claims) available to measure their quality of care and identify best practices.
- These deficiencies negatively affect the health and wellbeing of CMC, causing the children to have unmet healthcare needs, to get sick more often than they should, to require emergency and hospital care too frequently, and to have parents/family members struggle (emotionally, physically, and financially) to care for them.
- There are wonderful opportunities for healthcare policy and legislation to help CMC receive the quality of healthcare that they deserve. In my opinion, opportunities best positioned to help are those that (1) redirect healthcare spending and resources to primary and home care; (2) create accountability and governance across the children's healthcare providers; (3) make it easier for CMC to receive out-of-state care when they need it; and (4) bolster the availability and integrity of Medicaid claims data.

Thank you to the Committee members and staff for making time to discuss legislation intended to better the health and lives of children with medical complexity (CMC). I offer this testimony to convey my perceptions and experiences of caring for these children.

A. My Clinical And Research Background On Children With Medical Complexity

I am a general pediatrician and hospitalist with a decade of experience providing healthcare and conducting research in the inpatient, outpatient, home, and rehabilitation settings exclusively for CMC. Clinically, I work for a clinical service (i.e., the Complex Care Service at Boston Children's Hospital) that is dedicated entirely to serving CMC throughout the greater New England area and beyond. Through my research, I have linked together healthcare providers across the U.S. of all types, practicing in a variety of settings to assess the prevalence, health services, and outcomes of CMC using large administrative health datasets, including those available from hospitals and state Medicaid programs.

B. Definition of Children with Medical Complexity

My colleagues and I think of the following clinical attributes when defining children with medical complexity (CMC):

1. A lifelong, often incurable, chronic disease that is so severe that it causes multiple organ systems of the body to function improperly.
2. Significant impairment in the ability to perform basic bodily functions, including - but not limited to - the ability to independently eat, drink, breathe, walk, talk, etc.
3. The need for myriad healthcare providers (e.g., specialists, therapists, home nurses, etc.) and treatments (e.g., multiple medications, durable medical equipment, etc.) to maintain health.
4. High health resource use, through numerous outpatient clinic visits, medication prescription fills, recurrent hospitalizations, and emergency department visits.

Although these attributes may seem non-specific, children's hospitals and other healthcare entities throughout the U.S. use themes and variations of the attributes to successfully identify and enroll CMC into clinical programs to optimize their health.

C. Example of a Child with Medical Complexity

Suzanne is a 14-year-old female with cerebral palsy that was caused by lack of oxygen to her brain during her birth. Cerebral palsy is Suzanne's underlying, lifelong chronic condition. Her organ systems affected by the cerebral palsy include:

Neuro/brain: she has seizures due directly to her brain injury, which require multiple medications to control.

Urinary: she can't adequately empty her bladder, which causes her to have multiple urinary tract and kidney infections.

Bones: her muscles in her back and abdomen are so tight that they have twisted and curved her spine, which causes chronic pain and impedes her ability to sit up in a straight position.

Lungs/airway: she sometimes is unable to protect her airway from saliva getting into it. When saliva gets into her airway and lungs, she develops pneumonia and lung damage.

Digestive: she is unable to drink and eat enough by mouth to stay hydrated and nourished; she requires a feeding tube (gastrostomy) in her stomach to receive water and formula.

Endocrine: her brain is unable to keep her sodium levels normal in her bloodstream and cells; major increases and decreases in her sodium levels require urgent care and hospitalization if not promptly treated.

Suzanne has 15 healthcare providers actively involved in her care, not including hospital and emergency care providers who are needed on an episodic basis. Her family thinks of her

durable medical equipment vendor

as a "provider," because Suzanne

relies heavily on medical equipment to maintain her health.

Suzanne recurrently engages the healthcare system on a monthly –

and sometimes weekly or daily – basis.

Throughout her life, she's experienced

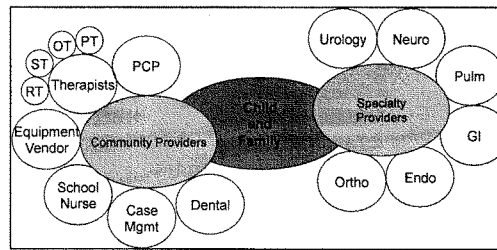
multiple hospitalizations and emergency department visits.

Her most frequent healthcare encounter

occurs by phone, mostly from her parents

calling her providers for questions, advice, and for help meeting a healthcare need.

Suzanne's Healthcare Providers



Suzanne's Health Services Use

Health Service	N
Chronic medications	8
Elective surgeries	10
Acute hospitalizations	15
Emergency department visits	45
Outpatient clinic visits	150
Telephone calls to the clinic	600

D. Goals of Caring for Children with Medical Complexity

The main goal of caring for CMC is to continuously strive to give the children the best life possible, under the unfortunate circumstance that their health will always be limited to a certain degree because of their chronic health problems. Very rarely is one provider or one clinic able to achieve this goal. Rather, this goal is more often achieved by all providers working as a team.

E. Key Concepts of Care Activities for Children with Medical Complexity

Provided below are key concepts of care activities of CMC that influence the children's health and quality of life (taken from Berry JG et. al, Children with Medical Complexity and Medicaid: Spending and Cost Savings; *Health Affairs* 2015)

Understanding the Child's Health
Managing Health Information
Creating Care Plans
Providing Urgent Care
Empowering Families

Through recurrent communication with the child, their family, and care team, it is important that clinicians in care management achieve an on-going understanding of the child's acute and chronic health problems, healthcare needs, issues that could modify the child's health for better or worse, important physical examination findings, health trajectory, well-being, and quality of life.

CMC can accumulate a very large amount of health information. It is important to organize, update, validate, and share the child's health records as well as help the family and other health care team keep track of and actively use the child's health records when making treatment decisions.

Care managers can help coordinate care with the child's healthcare team to create proactive care plans that will help 1) treat acute illnesses, 2) avoid chronic illness exacerbations, 3) meet all of the child's healthcare needs; 4) manage the roles and responsibilities of the child's health care team, and 5) optimize the child's well-being and quality of life.

Through rapid response in the outpatient, community, and home settings, care managers can help make possible the ability to deliver high quality urgent care to the children by executing care plans, mitigating the illness severity of urgent health problems, and shortening acute illness duration.

Care managers can help assess family values and perceptions, teach caregiving skills, assist with home caregiving activities, support physical and emotional health, address financial and social issues, and encourage shared medical-decision making.

These care management activities help to:

- 1) Optimize the health of CMC who are at high risk for poor health outcomes and excessive healthcare utilization;
- 2) Prevent altogether or address early-on health problems that otherwise would require the need for expensive health services;
- 3) Rapidly and effectively respond to changes in patients' conditions to avoid use of unnecessary use of health services; and
- 4) Ensure efficient and successful transitions of hospitalized CMC at admission and hospital discharge

F. Example Approaches to Conduct Care Management Activities for Children with Medical Complexity

Community Case Management	Primary Care Clinic	Complex Care Clinic
<p>Example of care management services provided in the community, independent of a clinical practice:</p> <p>Medicaid contracts with community care management personnel (e.g., nurse or social worker) working independently of an outpatient or community clinic to integrate with the children's existing healthcare providers, school, hospitals, etc. to perform various care management activities. The nurses make home visits, attend clinic visits, and interact directly with hospital personnel when the children are admitted.</p>	<p>Example of enhancing care management for CMC in a primary care pediatric practice:</p> <p>Within a practice, CMC are distinguished to receive special care characterized by access to a designated pediatric nurse practitioner (8 hours per week), consultation from a local parent, modifications of office routines, implementation of an individualized health plan, regularly scheduled continuing medical and nursing education, and expedited referrals and communication with specialists and hospital-based personnel.</p> <p>Systems are developed to streamline the ordering of medications and supplies as well as coordinating patient appointments so that family burden was minimized. Care plans are created and maintained in Word and faxed to specialists, emergency departments, hospitals, etc.</p>	<p>Example of care management in a consultative, outpatient clinic dedicated entirely to CMC:</p> <p>Nurse care managers (NCM) serve as a single point of contact for patients and families, PCPs, and community resources. They prepare a plan of care, facilitate communication among specialists and PCPs, attend appointments, work with community agencies and insurers to make sure that the children had all needed services. They sometimes spend up to 20 hours per patient per month.</p> <p>Physicians are available 24 hours / 7 days a week. They perform detailed H&Ps, reviewed the medical record, and synthesize the child's many problems in a comprehensive summary provided to the family, PCP, and specialists. The physicians frequently arbitrate among competing diagnoses and therapies. They see patients electively in the clinic, urgently in the ED, and occasionally at home or in the PCPs' office. They facilitate admissions and coordinated care during the hospital stay.</p>

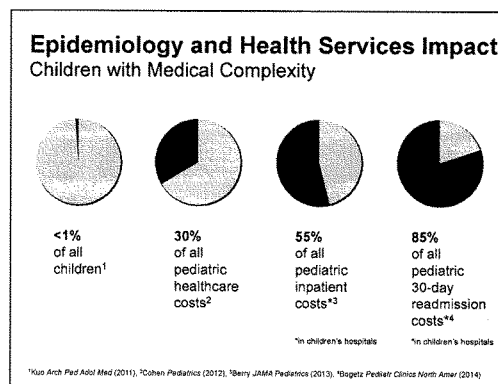
(taken from Berry JG et. al, Children with Medical Complexity and Medicaid: Spending and Cost Savings, *Health Affairs* 2015)

G. Distinguishing CMC For Policy, Research, And Clinical Initiatives

It is possible to distinguish CMC from populations of children. My research group has accomplished this through the use of both proprietary and open-source diagnosis classification systems that rely on ICD-9-CM diagnosis codes for use with health administrative data. My clinical service has distinguished CMC using "subjective" attributes that are not disease specific. The service continuously receives new referrals every week to enroll new CMC into our service based on the attributes.

H. CMC Prevalence and Impact on the Pediatric U.S. Healthcare System

The estimated prevalence of CMC ranges from <1% to 5% depending on the strictness of the definition used. My personal belief is that the true prevalence of these children resides on the lower side of that range. It is estimated that CMC account for as much as 30% of all healthcare spending on children.



Their impact is felt tremendously in children's hospitals, where they account for over 50% of hospital costs and the vast majority of hospital readmission costs.

I. Healthcare Spending and Health Resource Use for CMC

From analyzing state Medicaid data, we have learned that hospital care accounts for a large percentage (i.e., nearly one-half) of healthcare spending for CMC. Conversely, primary care and home nursing care accounts for a small percentage (i.e., 2%) of healthcare spending for CMC. Many providers caring for CMC believe these percentages are imbalanced; they reflect

one of the biggest problems of the system: CMC are using the hospital too much and primary/community/home care too little.

J. Reimbursement for Care Management Activities for CMC

Outpatient and community healthcare providers often receive the same reimbursement for an office visit for a CMC as they do for a generally healthy child with an acute illness that takes much less time and effort to treat. Care management activities that involve extended time for an office visit, lots of telephone correspondence, lengthy review of medical records, large amounts of paperwork, multidisciplinary team meetings etc. are insufficiently reimbursed to cover the cost of the clinic personnel doing them, especially when the activities are not associated with an in-person patient encounter. This, in part, explains why many hospital-based clinics serving CMC are not financially self-sufficient. Some programs following ~250 CMC report annual deficits as large as ~\$400,000. Often, these clinics depend on philanthropy and hospital subsidies to operate. As long as reimbursement of care management services for CMC is insufficient or absent, providers may be reluctant to offer them. Absent adequate reimbursement, care management activities for CMC will continue to be viewed, in many practice settings, as peripheral - rather than a core - clinical activities that occur sporadically when time permits [e.g., during a lunch break or when another patient "no shows"].

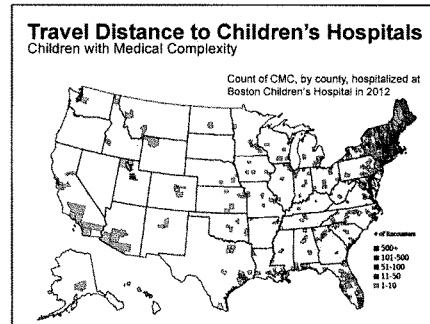
K. Dispersion of Healthcare Providers for CMC

From analyzing children's hospital data, we've learned that healthcare for many CMC is dispersed across large geographic areas. CMC often rely on a children's hospital for their specialty, surgical, and inpatient care. This is largely because children's hospitals employ most of the clinical workforce who is proficient to care for CMC. Children's hospitals are largely inaccessible to most CMC and their primary, community, and home care providers who do not

reside near the children's hospital. This is especially true for CMC and their providers who reside in rural / underserved medical areas or out-of-state from the children's hospital.

L. Experiences with Care Coordination for CMC

The term care coordination is used frequently when discussing optimal care delivery for CMC. Implied in the spirit of care coordination is that everyone involved in the children's care (i.e., the child's care team) should function together in an organized way, dividing and sharing responsibility. Care coordination for CMC works best when the coordination duties are explicitly articulated and agreed upon among the child's care team. That process can ensure that someone on the team takes ownership and accountability for each piece of the child's care, even if certain pieces are co-managed between two or more providers. Understanding who is on the team and knowing who is responsible for each aspect of care and care coordination will greatly benefit the team leader for each child, making it easier to monitor care and assure optimal outcomes. Throughout this process, the child and family should remain the focus. Family-centeredness will ensure that they are always a part of critical discussions, decisions, and planning as well as full partners in all care processes. Care coordination should not be limited to medical decisions at hand (e.g., a primary care physician, pulmonologist, and home nurse working together to treat pneumonia in a child with cerebral palsy and a tracheostomy). Rather, care coordination should involve the child's care team consistently thinking forward to create and execute plans that will (1) fulfill the child's healthcare needs; and (2) manage and treat future health problems that the child could experience.



From my position in my clinical program for CMC, I have had a vantage point of care coordination the entire care continuum. This point exists because my colleagues and I are recurrently communicating with, collaborating with, and relying on with healthcare professionals practicing in the children's communities and homes to help CMC. For example, we're constantly on the phone with (a) *primary care physicians* trying to help them decide what to do to help a CMC that shows up in their office for an acute health problem or healthcare need; (b) *home nurses* troubleshooting issues in the children's homes, (c) *durable medical equipment vendors* attempting to deliver and maintain medical treatments (e.g., home ventilator, feeding tube supplies, etc.) that are critical to maintain the children's health, (d) *specialists* trying to manage a particular comorbidity; (e) *surgeons* needing assistance to keep the children safe during and after an operation; (f) *community case managers* assigned to a CMC who are stuck trying to meet a healthcare need (e.g., obtain a referral, adjudicate differing opinions in a treatment plan); and (g) *emergency department clinicians* unfamiliar with a CMC trying to determine the best way to promptly treat the child's critical, urgent health problem. Of course, communication lines are constantly open with CMC and their families when helping with these situations.

M. Experiences with Primary, Community, and Home Care for CMC

Unfortunately, many CMC and their families report a non-optimal experience with primary, community, and home nursing care. They report that their primary care clinicians do not (1) take the time to understand and take charge of their child's health problems; (2) help CMC when they are facing urgent health problems; or (3) sufficiently coordinate care with the children's specialty physicians and therapists. This may explain why a large proportion (up to 40%) of CMC do not visit annually with their primary care physician. Regarding home nursing care, many families of CMC report that they are unable to obtain a sufficient amount of home care; that is they are unable to fill the number of home nursing hours that are approved to their

children by Medicaid. Families of CMC feel that the insufficient supply of pediatric trained home nurses is largely responsible for this.

Primary, community, and home care clinicians also report non-optimal experiences caring for CMC. Primary care clinicians report that Medicaid does not sufficiently reimburse them for the lengthy office visits (e.g., 1 hour or longer), multiple phone calls, administrative paper work (e.g., letters of medical necessity to obtain Medicaid approval for durable medical equipment), and other domains of care that are needed to keep CMC healthy. As a result, they are reluctant to provide care to CMC; rather, they are incentivized to take care of healthier children (e.g., a healthy child with an ear infection) in a shorter amount of time and with better reimbursement. Similarly, home nursing companies report that Medicaid reimbursement for their pediatric home nurses is insufficient to recruit and maintain high quality personnel. These companies often rely on financial margins (when they exist) generated from adult patients to underwrite the financial losses accrued from payment for their pediatric patients.

N. Overall Challenges of Caring for Children with Medical Complexity

In my experience, caring for CMC is very difficult and time consuming. Lengthy office visits (sometimes lasting an hour or longer) are required to meet the children's healthcare needs. Often, lots more work with follow-up phone calls, emails, paperwork, etc., is required after a visit when trying to communicate and coordinate care with all of the children's healthcare providers. It's often a laborious process to meet some of the children's health care needs (e.g., obtain insurance approval for more home nursing hours). During this process, it's common to rely on other healthcare providers for help, which can be tricky depending on how willing they are to engage.

Providing urgent care, in particular, to CMC is very hard. The health of many CMC is so tenuous that minor delays in assessment and treatment can lead to major effects. In the setting of pneumonia in a child with cerebral palsy, for example, minute to hour delays in administration of respiratory therapies (e.g., nebulized medications, suctioning, oxygen, chest physical therapy, positioning, etc.) can lead to substantial, protracted worsening in respiratory function that may require hospital admission and may take days or weeks to resolve. Failure to provide adequate attention to the child's routine needs (e.g., punctual administration of anti-epileptic and gastrointestinal motility drugs) while addressing new, acute illness may inadvertently induce exacerbations of existing, chronic conditions. It is imperative, then, that CMC have - as best as possible - immediate access to a site of urgent care that is equipped with clinicians, medical supplies, etc., that can rapidly assess, accommodate, and treat them. Unfortunately, many CMC do not have such access to high quality urgent care.

I believe that the main challenges that emerge when caring for CMC include:

- 1) Empowering primary, community, and home care providers to engage in their care
- 2) Empowering specialty and hospital providers to integrate with primary, community, and home care providers – especially those providers practicing in distant locations.
- 3) Incentivizing providers to work on the children during non in-person healthcare encounters for which they are not typically reimbursed
- 4) Incentivizing providers to deliver high quality urgent care to CMC
- 5) Convincing providers to be accountable for the care they provide to CMC
- 6) Making care accessible for CMC who need to cross state lines to get it

I can affirm that these challenges are not exclusive to my local area of clinical practice; they are present throughout the U.S.

O. Illustrative Cases of Substandard Care for CMC

Described below are three real world cases that, in my opinion, indicate substandard care delivery to CMC.

- A primary care provider declines to help a CMC with an urgent health problem because it's easier for the provider to send the child to the emergency department for help. In the emergency department, it's easier for the clinicians there to admit the child to the hospital rather than watch and wait to see if the child's health improves. Once in the hospital, it's easier for the hospital providers to discharge the child back to the primary care physician without substantive communication rather than to work with and help the physician improve their urgent care capability and responsibility to the child.
- A child travels out of state to undergo a highly specialized surgery to better align their hips and spine in the hopes that the surgery will improve their mobility. Intensive rehabilitation, including physical therapy, is recommended to make sure that the surgery has long-lasting effects. The child's home state Medicaid program does not approve the frequency of therapy prescribed by the surgical team. There is no inpatient option for rehabilitation in the child's state. A rehabilitation facility outside of the child's state is available to help the child, but the child's home-state Medicaid program denies approval to receive care from the out-of-state rehab facility. The child does not receive the needed rehabilitation and physical therapy, which significantly impedes the affect of the surgery.
- Healthcare providers in some states are advising families of CMC to move to a different state because the Medicaid funding for and the supply of home nurses are insufficient in the child's home state; without sufficient home nursing, it is anticipated that the health of the child will decline and recurrent emergency and hospital care will be required. In these same states,

some hospitals have blocked investment of clinical resources and personnel to help CMC because their state legislators are proposing substantial cuts to the Medicaid budget that threaten the hospitals' capability, in general, to provide care for children in Medicaid.

P. Illustrative Cases of Optimized Care for CMC

It is important for the Committee members and staff to understand that not all is dire regarding healthcare for CMC. Described below are additional real world cases of state Medicaid programs instituting novel initiatives to optimize care delivery for CMC. I believe that standardization of these initiatives, and others like them, across states could have a profound impact on the health and wellbeing of CMC.

- Some state Medicaid programs are reimbursing outpatient, community, and home care providers of CMC for non in-person healthcare encounters with the children and families. That is, they are reimbursing providers directly when coordinating care by phone and email, and when holding multi-disciplinary team meetings, etc. As a result, providers are expanding the amount of time to care for CMC by billing for these activities.
- Some state Medicaid programs are embedding case managers directly into primary care practices to help coordinate care for CMC. There are some phenomenal success stories of how these case managers have optimized the health and well being of the children. On-site and in-person, the care managers assist the primary care providers with activities that, in particular, involve interaction with insurance personnel (e.g., prior authorizations for medications, approval for durable medical equipment, etc.). The care managers facilitate treatment adherence by accessing Medicaid claims data for medication refills. They make home visits to educate families and ensure the safety and stability of the children's home environment. They help communicate with the children's subspecialty providers who may be

distant from the child's home. Such efforts can increase the use, capacity, and value of primary care for CMC.

Q. Healthcare Policy and Legislation That Could Help Children with Medical Complexity

I truly believe that healthcare policy and legislation can help optimize care delivery for children with medical complexity and improve health for these vulnerable children. To me, policy and legislation that affects the following attributes will have the highest likelihood of success.

- Healthcare spending: redirect it toward primary, community, and home care; use financial incentives to bolster and engage this clinical workforce
- Accountability and governance: make all providers on the hook for care quality; call them out explicitly as part of a formal team (e.g., "health home" or "care network")
- Accessibility: make it easier for patients to get the care they need cross state lines
- Medicaid data: make it reliable and standardized across states; make it usable to distinguish best practices of care delivery for CMC across states

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S. Suggested References for Additional Information Related to CMC

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Mr. PITTS. The chair thanks the gentleman. No one has their mic switch on, do they.

So staff is working on it and I apologize for the VA system. At this point, I'll recognize Mr. Matt Salo for 5 minutes for your summary.

STATEMENT OF MATT SALO

Mr. SALO. Thank you, Mr. Chairman.

Chairman Pitts, Ranking Member Green, members of the committee. My name is Matt Salo and I'm the executive director of the National Association of Medicaid Directors and I too appreciate the opportunity to testify before you today about our efforts and our collective efforts to improve the health care delivery system for all Medicaid patients but especially the system for children with medically complex conditions and we very much appreciate your hard work and your leadership to help us help the children and the families who rely on Medicaid.

And so on behalf of the Medicaid administrators and all 56 of the states and territories, we support the primary goals of H.R. 546 of improving the coordination of care for kids to address problems with fragmentation and uncoordinated care, to think about how these issues work across state lines and very much to relook and to examine the data on quality issues, on clinical issues underlying how the health care system treats or fails to adequately treat these populations.

Now, I am not a doctor but I have spent 22 years working on behalf of state Medicaid agencies and governors in the Medicaid space and so what I do know is that while the Medicaid programs across the country do look very different from one another. The commonality or the common theme and thread amongst the Medicaid directors is a deep commitment and passion for trying to improve the health care system, trying to improve the quality and efficiency of services that we provide and improving the overall patient experiences for all of the 72 million beneficiaries who rely on Medicaid.

And I can report that every state is aggressively working on multiple efforts to redesign the fragmented delivery silos and to reorient the misplaced financial incentives that are legion throughout the rest of the U.S. healthcare system.

These efforts take many forms, and I'm happy to go into some of the details later. But suffice to say that we are looking to try to do this on behalf of kids with medically complex conditions, on behalf of adults with physical disabilities, on behalf of frail seniors who are duly eligible for Medicare and for Medicaid, and that each of these efforts is undertaken in close partnership with patients, with providers, with family members and, of course, with our partners at the Centers for Medicaid and CHIP services.

And as Mr. Pallone said, I think it's important to note, that many of the kids with medical complex conditions in Medicaid are there not because they are poor, not because they are on Medicaid, but let's face it, because the broader U.S. health care system has failed to adequately address their needs and they have ended up on Medicaid because of the cost or the failure of the broader system and that is what we are really trying to fix.

Now, clearly, challenges remain and I appreciate that that's what we are trying to do here is to talk about how do we effectively overcome some of those challenges and, again, this is the beginning of a discussion.

We very much want to be part of this discussion and we want to see something happen that can actually improve the care and the coordination of that care in the field.

One important point I would make, though, is that the key to long-term lasting success in this area and other areas is that we ensure that we have a broad alignment of purpose, organization and implementation of these reforms.

The core components of the failed health care system that we are moving away from includes fragmentation, delivery silos and financial incentives that simply do not reward improved health outcomes.

And again, while the patient populations that we serve in Medicaid may look very different from one another, it is critical to our long-term efforts that we avoid defaulting back into fragmentation.

And I appreciate Chairman Barton talked about wanting to move away from a facility-based view of the world and more towards a family and community-based view. So the components here I think are really important, looking at a health home model as an option for states.

This is a logical and sensible step for many states. This is an approach that is known to us. It is known to providers.

It is known to stakeholders and I think the availability of the enhanced match can go a long way towards providing the right incentives to take this up but also really to provide the adequate infrastructure that's needed to make these things sustainable.

And then, finally, and I'm happy to talk much more about this later. But the idea of creating, compiling, and sharing best practices is critically important.

There is no currency in Medicaid quite like the fact that something has succeeded in a state and the ability of one state to say, we have done this and we have made this work in Medicaid is an enormously compelling statement for their colleagues and so we want to work with that.

And so I probably have much more to say but I will stop there because I am over my time.

Thank you.

[The prepared statement of Matt Salo follows:]



Testimony of
Matt Salo
Executive Director
National Association of Medicaid Directors

Before the
United States House of Representatives Committee on Energy
and Commerce; Subcommittee on Health
on
“Examining the Advancing Care for Exceptional Kids Act”

July 7, 2016

Chairman Upton and Ranking Member Pallone:

My name is Matt Salo, and I am the Executive Director of the National Association of Medicaid Directors (NAMD). Thank you for the opportunity today to testify about helping state Medicaid programs improve the health care delivery system for medically complex children. We appreciate your leadership and hard work to improve the quality of care available for the low-income, vulnerable children and their families who rely on Medicaid.

On behalf of the nation's state Medicaid Directors, we support the three primary goals of H.R. 546, the Advancing Care for Exceptional Kids Act of 2015: to improve coordination of care for children; to address problems with fragmented or uncoordinated care for children, especially challenges accessing care across state lines; and gathering data on conditions to help researchers improve services and treatments for children with complex medical conditions who are covered by Medicaid.

NAMD

NAMD is a bi-partisan, non-profit association representing Medicaid Directors in all 50 states, the District of Columbia, and the territories. Our members drive major innovations in health care while overseeing Medicaid, the nation's predominant health care safety net program, which covers more than 72 million Americans. State Medicaid programs, together with the Children's Health Insurance Program (CHIP), serve more than 1 in 3 children in the United States. Federal statute requires that states provide comprehensive

services and furnish all Medicaid coverable, appropriate, and medically necessary services needed to correct and ameliorate health conditions, based on certain federal guidelines.

Medicaid Reform Background

Medicaid programs across the country vary considerably in many ways, ranging from eligibility policy to the take up of optional benefits, payment policies, and service delivery structure. Despite these differences, Medicaid Directors are deeply committed to improving the quality and efficiency of services as well as the overall patient experience for all beneficiaries, especially those with medically complex conditions. Every state in the country is aggressively working to redesign the fragmented delivery silos and reorient misplaced financial incentives that have challenged the US health care system for many years.

These efforts take many forms, including better aligning Medicare and Medicaid for those eligible for both programs, integrating behavioral health services into the overall health care delivery system, and creating patient centered medical homes for a variety of special needs populations. There are many parallel efforts to move Medicaid towards paying more for value than for volume. These can be done through traditional managed care approaches, through Accountable Care Organizations, and even in traditional fee for service models that allow for shared savings.

Each of these efforts is undertaken with close partnership with key stakeholders, including providers, patients and their family members and/or caregivers, and of course the Center for Medicaid and CHIP Services (CMCS). It is important to note that these efforts must

take into close consideration the health care landscape in each state, in order to maximize effective implementation.

NAMD Support for Improved Care for Children with Medically Complex Conditions

NAMD members support the overarching intentions and specific policy recommendations of the newly revised and improved ACE Kids bill, which is aimed at improving the quality of care and care coordination for children with medically complex conditions. These children represent some of the most vulnerable Medicaid beneficiaries, and Medicaid programs across the country have been and continue to be developing programs and strategies to optimally address their needs. We understand that the legislative proposal is only the beginning of this important conversation, and remain eager to work with you and other key stakeholders to continue to improve the legislation and to address the challenges that states are facing in their current efforts to improve the care experience for these children and their families.

The key to the long term success of many of the Medicaid delivery system and payment reforms that are underway is to ensure broad alignment of purpose, organization and implementation. The core components of the failed system we are moving away from include fragmentation, delivery silos, and financial incentives that don't reward improved outcomes. While the patient populations we serve may look very different from one another, it is critical to the long term viability of our broad reform efforts that we avoid defaulting back into fragmentation or setting up new silos that inhibit integrated care.

ACE Kids

The newly revised legislation contains three main components, a Medicaid health home option for children with medically complex conditions; promulgation of best practices and lessons learned; and more research into the health care needs of and how the health care system is currently working for these vulnerable populations.

Health Homes

Similar to an approach in the President's budget, but more targeted at children with exceptional needs, the idea of an option for states to develop health homes for this population is a logical and sensible step in our efforts to improve care coordination and service integration for this population. The health home process is known to states and increasingly understood and appreciated by providers and other stakeholders. A new option of this type could empower states to improve the investment in the infrastructure that supports children with medically complex conditions in ways that parallel similar efforts for other populations and contribute to the broader efforts to reform the entire health care system.

We wanted to also acknowledge the question about assigning a higher federal match rate for the development of these health homes. It is clearly an important incentive for states looking to embrace the option, and would contribute significantly towards increasing the ability of states to build the infrastructure needed.

Best Practices

One of the key functions of our organization is the focus on sharing lessons learned and successful practices among our members. No idea or proposal can carry the same weight as one that has actually succeeded in a Medicaid context. While the solutions that work in a New York or a Texas may not seem to hold much relevance for a Vermont or an Idaho, the unique structure and requirements of Medicaid are so critical to success that the currency of successful innovations is significant.

We stand ready to work with our federal partners at CMCS to help identify and promote best practices in this area, and assist states in helping to improve the health care system so that it is more responsive to the needs of children with medically complex conditions.

MACPAC

Despite the work currently underway in many states, there are clearly many hurdles that still stand in the way. There can be a role for MACPAC to provide additional research on a wide variety of issues related to the care for this population. We would argue that this could also include more about health outcomes, access to care (particularly in out-of-state hospitals); quality of care, and patient/family satisfaction; so that future efforts can be informed by identifying problems in the delivery system.

We believe there can be value in the idea of a “Center of Excellence” designation as a way to help states figure out which out-of-state entities to contract with for particular services, and to encourage some price competition between hospitals for Medicaid services. This effort might also facilitate improved quality measurement and reporting. We hope that this is an idea that MACPAC or other entities can explore.

Conclusion

Thank you again for the opportunity to testify and for your leadership in this vital area. NAMD supports the three primary goals of H.R. 546, the Advancing Care for Exceptional Kids Act of 2015: to improve coordination of care for children; to address problems with fragmented or uncoordinated care for children, especially challenges accessing care across state lines; and gathering data on conditions to help researchers improve services and treatments for children with complex medical conditions who are covered by Medicaid.

Our members are committed to helping inform your efforts ensure the proposals achieve these goals within the context of running effective and efficient state Medicaid programs.

Mr. PITTS. Chair thanks the gentleman and now recognized Ms. Frangenberg 5 minutes for your summary.

STATEMENT OF MARIA ISABEL FRANGENBERG

Ms. FRANGENBERG. Thank you, Mr. Chairman, Mr. Ranking Member and members of the committee. Thank you very much for allowing me to testify today.

My name is Maria Isabel Frangenberg, and I am a Project Coordinator for Family Voices, which is a national nonprofit organization of and for families of children and youth with special health care needs.

Prior to working with Family Voices, I served as a Latino community liaison for the Virginia Family to Family Health Information Center.

Family to Family Health Information Center, or F to F, are the statewide federally funded centers that help parents of children with special health care needs to navigate the health care system.

As we know, one in five families with children have at least one child with special health care needs and children, as you have mentioned before, children with complex medical conditions are a subset of children with special health care needs.

These children may see multiple providers on a regular basis and therefore care coordination is of the essence. In addition, many of these children, as you have mentioned, need highly specialized care from several different providers across state lines.

Medicaid doesn't always provide the necessary care coordination and access to out-of-state is often very difficult. The ACE Kids Act addresses some of these barriers and we at Family Voices fully support its goals.

So through my work many families from diverse backgrounds have told me their stories about their need to get medically necessary and culturally and linguistically competent and appropriate care for their children.

Medicaid can be a lifesaver for children and families both literally and figuratively. So let me tell you Cindy's story. Cindy is a mother from Indiana and she told us that her family went from two incomes to one when she left work to care for her newborn daughter, Rebecca, who was born with multiple disabilities and health care conditions.

Even with private insurance they were paying over \$12,000 per year in pharmaceutical, medical equipment, expenses, deductibles, specialists, out of pocket travel expenses and other noncovered items.

However, since Rebecca has been on Medicaid their lives have changed. They have paid off medical debt and are even saving for college for their own two children. They have peace of mind knowing that they won't have to go into debt to provide for Rebecca's complex medical needs.

So Cindy's story is, clearly, a Medicaid success story and the reason that we are here today committed to building on that success and improving access to its critical supports for families.

However, access to Medicaid services is not always that smooth and a complication for some families is the failure of Medicaid

agencies to provide written and oral communications in the language of the child's family when that language is not English.

Rosa from Massachusetts, whose son has Down Syndrome, told me that she must wait weeks for Medicaid correspondence to be translated into her language and days to speak to an agency representative in Spanish.

Another example of barriers to accessing Medicaid services came from Beth, a mother from North Dakota. Beth is a widow who is raising two children with a rare and extremely painful and incurable pancreatic condition, the same disease from which her husband died.

Because of their extreme pain and the medications used to treat it, the children have severe behavioral side effects. The children's mental health providers and the medical providers don't talk to each other. So there is no care coordination, and Beth is left to connect all the dots on her own.

What is worse, her son's medical providers have accused her of child neglect when Beth withheld pain medication following the advice of her son's mental health provider.

Adding to her worries, Beth's full time salary is not enough to cover all of her children's expenses. In a strange twist of fate, her daughter lost her Medicaid waiver for lack of use, really a reason that has Beth befuddled. Her son has not qualified for Medicaid because of the income that he receives from his father's death benefits.

But Beth is hopeful that some of these system issues will be resolved to improve the coordination of care for her children and reduce her financial and emotional burdens.

The ACE Kids Act would help to address such problems with care coordination as well as barriers to getting care out of state. Our written testimony provides several recommendations that would improve the bill.

Among these we recommend that the administrator of CMS be required to establish clear standards to ensure the quality of health home services for children with complex medical conditions.

We also believe that it is critical that the administrator, the states and health home providers meaningfully engage families in the development and implementation of health home services.

And here I wish to acknowledge the outstanding work of the Maternal and Child Health Bureau for their long-time commitment to engage in the diverse constituents that they serve as full partners at all levels of health care.

Very active engagement has had a profound impact on appropriately meeting the needs of families and their communities. Let me get back to Beth really quickly, the mom from North Dakota.

When we were finishing our conversation she paused and she said, you know, I'm really grateful that somebody is listening to me. That was truly humbling.

So I think that we can agree that we can work harder to give families like Beth's better reasons to be grateful.

[The prepared statement of Maria Isabel Frangenberg follows:]



TESTIMONY

on

Examining the Advancing Care for Exceptional Kids Act

before the

Health Subcommittee

House Committee on Energy & Commerce

July 7, 2016



Summary of Testimony
Examining the Advancing Care for Exceptional Kids Act
July 7, 2016

Medicaid provides critical support to children with complex medical conditions and their families, but there are some serious barriers to care. The ACE Kids Act (discussion draft) addresses some of these barriers, including access to out-of-state care and the lack of adequate coordination among multiple health care providers. Family Voices fully supports the goals of the ACE Kids Act and many of its specific provisions, particularly the requirement that the Administrator of the Centers for Medicare and Medicaid Services (CMS) develop best practices to assure access to specialized out-of-state care. Nevertheless, we respectfully recommend several additions and modifications to the bill. Among our recommendations, we suggest that the bill –

- require the Administrator of CMS to develop qualification standards for health homes that are specific to the needs of pediatric enrollees;
- require health homes to coordinate with their state Family-to-Family Health Information Centers;
- require that family leaders associated with family organizations be engaged in the development of the qualification standards for health homes, the health-home State Plan Amendment, and the policies and procedures of individual health homes; and
- require that states adopt the best practices developed by the CMS Administrator regarding access to out-of-state care.

We also urge that the Subcommittee examine the “medical home” model and consider broadening the definition of “child with medically complex conditions.”



Good morning Mr. Chairman, Mr. Ranking Member, and Members of the Subcommittee.

My name is Maria Isabel Frangenberg and I am a Project Coordinator for Family Voices.

Family Voices is a national nonprofit organization of and for families of children and youth with special health care needs (CYSHCN) -- those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.¹ Children and youth with special health care needs may have physical, developmental, or intellectual disabilities (e.g., cerebral palsy or autism), chronic health conditions (e.g., diabetes or epilepsy), serious illnesses (e.g., cancer), rare genetic diseases (e.g., mitochondrial disorders), severe injuries (e.g., traumatic brain injury), mental health conditions, or other conditions requiring frequent health care services.

Family Voices is entering its 24th year as the national, cross-disability, family-led organization dedicated to "*keeping families at the center of children's health care.*" Through our national grassroots network of families and family organizations, we provide families with resources and support to make informed decisions, advocate for improved public and private policies, build partnerships among families and professionals, and serve as a trusted resource on health care.

¹ This is the definition used by the Health Resources and Services Administration. From: McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B. A new definition of children with special health care needs. *Pediatrics*, 102(1):137-140, 1998.

Prior to working for Family Voices, I served as the Latino Community Liaison for the Family-to-Family Health Information Center in Virginia. Family-to-Family Health Information Centers (F2Fs) are state-wide, federally funded centers that provide individual assistance and connection to resources to help parents of children with special health care needs to navigate the health care system and work effectively as partners with their children's health care providers. In that and my current position, I have heard from many families about their challenges in getting timely and appropriate care for their children with complex medical needs on Medicaid.

MEDICAID SERVICES FOR CHILDREN WITH MEDICALLY COMPLEX CONDITIONS

Background

The most recent (2009/10) National Survey of Children with Special Health Care Needs found that there were over 11 million children with special health care needs under age 18 in the United States. A subset of these children have "medically complex conditions," although there is no clear definition of that population. These children may need care from multiple pediatric subspecialists (e.g., pediatric cardiologists or neurologists) to treat different body systems. Some of these children have rare conditions in which only a handful of providers, or even a single provider, in the country have expertise. Some of these children need multiple surgeries and hospitalizations, significant physical, occupational, and/or speech therapy, multiple medications, transplants, prostheses, medical foods, and/or special medical supplies or equipment. Some depend on ventilators or other medical technology to survive and may need 24-hour per day monitoring. Today there are more such children than there were in the past, given new medical

techniques and technologies that allow them to survive prematurity or problems at birth, or to live longer with chronic conditions than they might have lived a generation ago.

It is estimated that there are about three million children with medically complex conditions in the US, of which about two-third are enrolled in Medicaid.² These two million children – approximately six percent of the total number of children on Medicaid – account for about 40 percent of Medicaid spending for children’s coverage.³ For some children, Medicaid is their only source of insurance; for others Medicaid serves as the secondary payer, supplementing a family’s private insurance and covering services that private insurance typically does not cover, such as private duty nursing, transportation or respite care.

The critical role of Medicaid for children with medically complex conditions

For children with medically complex conditions and their families, Medicaid can be a life-saver, both literally and figuratively.

An Indiana mother recounted last year: “My family went from a dual-income family with minimal medical expenses to a single-income family with significant medical expenses when my daughter with disabilities was born. Even with private insurance ... we were paying upward of \$12,000 per year for her medical, pharmaceutical, and equipment expenses including high-tiered medications, out-of-network costs for several specialists, and of course deductibles and copays-- to say nothing of the out-of-pocket travel expenses and other non-covered items (prescribed over-the-counter medicines, therapy beyond annual limits, incontinence supplies, Pediasure,

² Many families whose children have medically complex conditions or special health care needs could benefit greatly from Medicaid coverage, but their children are not eligible due to family income or years-long waiting lists for waiver services. This testimony does not address the problems related to eligibility for Medicaid.

³ Information from the Children’s Hospital Association website at <https://www.childrenshospitals.org/Issues-and-Advocacy/Children-With-Medical-Complexity/Issue-Briefs-and-Reports/Optimizing-Health-Care-for-Children-With-Medical-Complexity> and <https://www.childrenshospitals.org/Issues-and-Advocacy/Children-With-Medical-Complexity/Fact-Sheets/Defining-Children-With-Medical-Complexities>.

specialized eyeglass frames and lenses, dental work, and more). Since my daughter began qualifying for Medicaid Disability last year...we have made good headway toward paying off medical debt and even saving for college for our other two children. Beyond the very tangible benefits, I have more peace of mind knowing that we will never again have to go into debt to provide for my daughter's complex medical and therapy needs.”

A few years ago, another Indiana mother told us about her daughter, Grace Susan Akers. Grace was born with two rare genetic syndromes, and was in the hospital for four months after her birth. Although the family had private insurance, they quickly approached their policy's lifetime cap. The private insurance stopped paying for home nursing, and did not cover the specialized nutrition Grace needed, so the family's out-of-pocket costs were “staggering.” Without the Medicaid assistance the family received, Grace's medical expenses, even with private insurance, would have escalated beyond her parents' actual income. Although Grace passed away in 2015, she was able to live at home with her loving parents during the 17 years of her life.

Carissa Malley, from New Jersey, is an example of a child who needs highly specialized treatment for a rare condition, as well as treatment for many less serious health problems. Born with Down syndrome, Carissa had heart surgery as a baby, needs special bi-focal glasses, hearing aids, a bi-pap machine for sleep apnea, and night nursing to monitor her breathing. In addition, Carissa has a rare, life-threatening condition called Pulmonary Hypertension (PH). She receives care from the Pulmonary Hypertension Center at New York-Presbyterian Morgan Stanley Children's Hospital, where the pediatric cardiologists are at the forefront of treatment for this condition. Medicaid has allowed Carissa to get treatment in NY and participate in drug trials

when necessary. If she were covered only by traditional private health insurance, it is unlikely that her team of specialists would all be in one network.

Obstacles to timely and appropriate treatment for children on Medicaid with medically complex conditions

Carissa's story is an example of Medicaid working to help children get the extensive and highly specialized care they need, even across state lines. Unfortunately, there are many families who face multiple barriers in getting timely and appropriate Medicaid services for their children with complex medical needs. As identified recently by family leaders from Family Voices state affiliates around the country, some of the more common problems for medically complex children on Medicaid are:

- a scarcity of subspecialty providers (especially in rural areas), or those who take Medicaid, resulting in the need to travel long distances and/or wait long times for an appointment;
- problems with managed care -- an inadequate network of providers; lack of continuity of care due to changing provider networks; and lack of plan experience in dealing with this population;⁴
- lack of or ineffective care coordination (with effective care coordination, all of a child's providers would be well-informed, the "whole child" would be treated, and families would know about all of the resources available to them);
- failure to cover or slow approval for out-of-state or out-of-network care;

⁴ From the National Academy for State Health Policy: "The first wave of Medicaid managed care in the 1990s saw many states carving out services for children and adults with special needs through fee-for-service arrangements. However, these trends have changed dramatically since that time. Recent CMS data and a 2010 Kaiser Family Foundation survey indicate that 32 states mandatorily enroll at least some children and youth with special health care needs (CYSHCN) in managed care, 20 states enroll CYSHCN in managed care on a voluntary basis, and about half of states mandate managed care for at least some children who receive Supplemental Security Income (SSI)." (Source: <http://www.nashp.org/early-highlights-of-what-the-final-managed-care-rule-for-medicaid/>)

- long-waiting lists for and incomplete information about Medicaid waivers;
- failure to translate written communications from the Medicaid agency and lack of interpreters during medical appointments for families who are not proficient in English;
- lack of “cultural competence” on the part of health care providers and the Medicaid agency;
- inadequate coverage of medications, medical equipment, medical supplies, hearing aids, medical foods, and other necessities;
- inadequate coverage of nursing services, therapeutic services (e.g., and occupational, physical and speech therapies), and non-medical services (e.g., transportation, respite, home or vehicle modifications, family lodging for out-of-area care);
- failure to integrate mental health and medical services and lack of provider expertise in treating children with co-occurring diagnoses;
- insufficient access to home and community-based care (forcing children into nursing homes rather than allowing them to be cared for at home); and
- inadequate preparation for transition to adult-care services when a child ages out of coverage for Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services.

In addition, family leaders, family members who work for and are trained by family organizations, find that some state Medicaid agencies, managed care organizations, and health care facilities do not meaningfully engage or consider the input of families and family organizations in the development, implementation and evaluation of their organizational policies, procedures, programs, and practices. As a result, they are missing opportunities to address some

of the issues mentioned above, and thus improve patient care and family satisfaction. The topic of family engagement is discussed further in our comments about the discussion draft, below.

Following are some accounts from families about the struggles they have had getting Medicaid services for their children with complex medical conditions:

In North Dakota, a widow is raising two children with a rare, extremely painful, and incurable pancreatic condition, Hereditary Pancreatitis (PRSS1), from which her husband died. She has had trouble with Medicaid eligibility for her children, but, even when they were receiving Medicaid benefits, there were significant barriers to getting needed care. There was only one pediatric gastroenterologist in the state, and that doctor was not familiar with her children's rare condition or the follow-up care they needed after their highly specialized surgery at the University of Minnesota Children's Hospital. At one point, the children's primary care pediatrician told the Medicaid agency that he could not responsibly treat the children without assistance from specialists, but even then it was difficult to get state approval for specialty treatment out of state.

A case from Colorado illustrates some of the problems with Medicaid denials of service and poor communication between Medicaid-waiver administrators and families. Stacy lives with her 7-year-old son, Noah, who suffered oxygen deprivation at birth, resulting in Spastic Quadriplegia Cerebral Palsy. He cannot sit, stand, walk, talk or self-feed, so requires 24-hour assistance. In addition, he needs wheelchairs, adaptive clothing because of his severe sensory processing disorder, home modifications, and more. Noah is covered by Medicaid, but Stacy had to appeal denials of service almost every time she submitted a request for coverage. Even after a judge found a denial to be inappropriate, the state still withhold services under an "exception to initial decision," which cannot be reviewed by a judge again. Noah is also eligible to receive

services under a waiver administered by the Community Centered Boards (CCB), but the process for reimbursement is very opaque and has appeared to be arbitrary or inappropriate. (See [this Denver Post article about the CCB's handling of funds.](#))

Care coordination

One of the more common problems for families of children with complex medical conditions is a lack of care coordination among their child's many health care providers – one of the major issues that the ACE Kids Act seeks to address.

In a 2012 survey, families of children with special health care needs (CSHCN) identified care coordination as their top priority.⁵ As noted by the [Catalyst Center](#): “At its best, care coordination is a covered service...that addresses the interrelated medical, social, developmental, behavioral, educational, and financial needs of children and their families. But there is great confusion over who is responsible for providing care coordination services, who should pay for them, and how to get reimbursed for such services.”

As a result of this confusion, families of children with complex medical conditions sometimes fail to get any care-coordination services at all, and sometimes get it from too many sources, such as hospitals, insurance companies, and public agencies. Thus, they may end up “coordinating the coordinators.” Families of children with complex medical conditions often find that their child's multiple physicians and other providers are not communicating, or not doing so effectively, leading to gaps in care, inappropriate treatment, or duplicative appointments, assessments and tests (which needlessly cause stress for the child and cost time and money for parents).

⁵ Catalyst Center webpage introducing the publication *[The Care Coordination Conundrum and Children and Youth with Special Health Care Needs](#)*.

Although some Medicaid agencies and managed care organizations claim to provide care coordination, families may not really be receiving it, or the services they get are inadequate. For example, some care coordinators are not well-trained, do not have the capacity to help families with limited English proficiency, and/or lack knowledge about community services, Medicaid waiver programs, specialty clinics, or other resources that could improve a child's treatment or be useful to families.⁶ Although pediatricians, children's hospitals and other providers may be willing to coordinate care, they generally are not reimbursed for the staff time required so are limited in their capacity to do so.

That said, there are some effective care coordination programs. In Rhode Island, a partnership of state agencies, the state's chapter of the American Academy of Pediatrics, the Rhode Island Parent Information Network/Family Voices, and the Neighborhood Health Plan of Rhode Island developed the Pediatric Practice Enhancement Project (PPEP), through which parents of children with special health care needs are employed to help patients' families at primary- and specialty-care sites. Like Family-to-Family Health Information Centers, the PPEP model is based on the concept that parents who have faced the challenges of raising children with special needs are best equipped to help other families of CYSHCN. The parent coordinators help families access and coordinate specialty services, link to other community resources, navigate the complicated health care system, and overcome barriers to care. Placing parent consultants directly in the offices of practitioners also assists the physicians and their staff by identifying resources and support services that will help patients and their families. PPEP promotes a

⁶ Family-to-Family Health Information Centers (F2Fs) help families to get this type of information, and help them develop skills to enhance communication with their children's health care providers and coordinate their care.

“medical-home” model of care, where the primary care or other provider serves as the hub for coordinating the child’s care. The PPEP model has also been used in Delaware.⁷

Some resources about other care-coordination models and medical homes are listed at the end of this testimony.

COMMENTS ON THE DISCUSSION DRAFT

As illustrated above, there are serious obstacles to getting necessary care for children with medically complex conditions in the Medicaid program. Therefore, Family Voices wholeheartedly supports the goals of the ACE Kids Act, including better coordination of care for children with complex medical conditions, and improved access to the full range of medical and support services they need, including services in other states.

The committee discussion draft would give states the option to provide “health home services” to children with complex medical conditions. “Health home services” are defined as “comprehensive and timely, high quality services” provided by a “designated provider or a team of health care professionals, that include, at a minimum: comprehensive care management; care coordination and health promotion; comprehensive transitional care, including appropriate follow-up, from inpatient to other settings; patient and family support; connection to community and social support services; use of health information technology to link services, as feasible and appropriate; and coordinating access to the full range of pediatric specialty and subspecialty medical services, including services from out-of-State providers, as medically necessary.”

Medicaid payment for the health home services described in the bill would go a long way toward addressing some of the obstacles to appropriate and timely care that are discussed above. Care management, care coordination, and transitional care would help to ensure that children get

⁷ The Commonwealth Fund published a [case study of the PPEP](#) in 2009.

the services they need while avoiding redundancy. Patient and family support, with referral to community and social support services, would help to ensure that families get important non-medical services and supports. The use of health information technology to link services could help to improve communication among a child's multiple health care providers. And coordinating access to the full range of medically necessary pediatric specialty and subspecialty medical services, including services from out-of-state providers, would help to ensure that children receive the most appropriate services, even if the providers are out-of-state.

Since access to out-of-state care has posed a significant problem for some children, we are very pleased that the discussion draft would require the Administrator of the Centers for Medicare and Medicaid Services (CMS) to develop best practices for using out-of-state providers in both emergency and non-emergency situations. We also appreciate the requirement that the Administrator issue a Request for Information to obtain stakeholder input in developing these guidelines.

Although we think the discussion draft provides a good start in addressing some of the Medicaid obstacles discussed above, we would like to offer the following comments and suggestions that we think could enhance the positive impact of the legislation. We would welcome the opportunity to work with the committee staff to develop specific language related to these issues.

Recommendations

Qualification standards for health homes. The health homes provision of the Affordable Care Act (ACA), §1945 of the Social Security Act, from which much of the language of proposed §1947 is based, requires the Secretary of Health and Human Services to establish standards for

qualification as a health home. The discussion draft, however, does not include a parallel provision. The draft bill (pp. 10-11) would require only that a “designated provider” “be determined by the state to be qualified ... on the basis of documentation evidencing that the [provider] has the systems and infrastructure in place to provide health home services.”

Some of the problems with care coordination in Medicaid arise from the fact that the individuals and organizations responsible for providing coordination services are not always well-trained, knowledgeable about community resources available, or equipped to provide translation services or work with effectively with families from other cultures. We believe that Medicaid funds would be better spent if health homes were required to meet clear standards with respect to training of personnel, record-keeping, communication procedures, linguistic and cultural competence, and other aspects of the “systems and infrastructure” needed to provide quality health home services. *Therefore, we recommend that the ACE Kids Act require the Secretary or the CMS Administrator to develop qualification standards for health home providers. These standards should include a requirement that the health home have pediatric expertise. Further, these standards should be developed through the issuance of a Request for Information to ensure appropriate stakeholder input.*

Coordination with state Family-to-Family Health Information Centers. The staff of Family-to-Family Health Information Centers (F2Fs) are familiar with community resources available to families whose children have medically complex conditions. As parents of CYSHCN, F2F staff can also offer important peer support to families seeking their help. Coordination between health homes and F2Fs would enhance services for families and promote efficient use of federal

resources. *Therefore, we recommend that health homes be required to work with their state's federally funded Family-to-Family Health Information Center.*⁸

Family Engagement. Families have critical insights about how institutions and systems can best serve their children, and do so more efficiently. Family Voices believes that there should be “nothing for families without families.”⁹ *Therefore, we also recommend that states, in developing their health home State Plan Amendments, and individual health homes, as they develop and implement their policies and procedures, be required to seek meaningful engagement of families of children with complex medical conditions, youth with complex medical conditions, and organizations that represent these families and youth.*

Hospital referrals and education about availability of health home services. The draft bill (pp. 4-5) requires states to include in their health-home State Plan Amendment a description of the state's process for educating providers about the availability of health homes for children with medically complex conditions, including the process by which such providers can refer children to designated health home providers. *We agree with this requirement, but recommend that states also be required to describe a process by which they will educate families, in a linguistically and culturally competent manner, and appropriate social service agencies about the availability of health home services. In addition, states should be required to educate*

⁸ We also recommend that Congress extend funding for Family-to-Family Health Information Centers (F2Fs) beyond FY 2017.

⁹ One of Family Voices' main missions is the promotion of family engagement, with the aim of improving institutional and government policies affecting CYSHCN and their families. Through a series of cooperative agreements with the Maternal and Child Health Bureau, Family Voices has run the National Center for Family/Professional Partnerships (NCFPP) for 17 years. The NCFPP, among other things, provides technical assistance and training to the nation's 51 Family-to-Family Health Information Centers (F2Fs). The NCFPP and the F2Fs train parents and professionals to become more effective partners in the treatment of CYSHCN, and train parents and youth of diverse backgrounds to meaningfully engage with policymakers at the individual, community, state and federal levels. (Please see the relevant attachments.)

providers and families of children with medically complex conditions about the state's Family-to-Family Health Information Center.

Adoption of best practices for access to out-of-state services. The draft bill (p. 5) provides that states taking up the health home option “consider” adopting best practices for providing access to out-of-state providers for children with medically complex conditions. *We recommend that states taking up the health home option be required to adopt the best practices developed by the Administrator for providing access to out-of-state providers. (In fact, we recommend that all states be required to adopt these best practices, and that they be applicable to all Medicaid beneficiaries, so that no Medicaid beneficiaries are denied access to medically necessary out-of-state care.)*

Data collection. The draft (p. 6) requires designated health home providers to report quality measures to the state in accordance with guidance provided by the Administrator. *We recommend that the Administrator be required to seek stakeholder input in developing these quality measures through the issuance of a Request for Information.*

Definition of “Child with Medically Complex Condition” (p. 7-9)

We are concerned that the definition of a child with a medically complex condition may be too narrow, particularly since a state can further narrow it. The proposed definition would not include children with a **single** but very serious or complex condition, such as severe epilepsy, mental illness, or a traumatic brain injury, that does not also affect two body systems or impede physical or cognitive function. *We recommend that the committee consult with stakeholders to consider whether this definition should be broadened.*

Freedom of provider choice. The draft bill (p. 12) seeks to protect beneficiary choice of Medicaid providers. We strongly agree with this provision, given the importance of having a

continuous relationship with appropriate subspecialists who are familiar with a child's (often rare or unique) condition, and have relationships with the child and child's family. ***We recommend that language be added to this or another appropriate section to make it clear that a child may not be assigned to or be required to select a health home.***

General comment

As we interpret the discussion draft, a health home would not necessarily be providing any health services to the child. Nor would it be required to have any pediatric expertise. In fact, unless there are a number of health homes to choose from, a child seeking health home services might need to get them from a type of provider totally unrelated to his or her condition. For example, a family whose child has spina bifida might be receiving health home services from a community mental health center. Although such a situation would not necessarily pose a problem, we urge the committee to give further thought to the relationship between a child's health home and health care providers. The committee might want to consider ways that the Medicaid program can be used to support the "**medical home**" model. As defined on the website of the National Center for Medical Home Implementation, a "medical home is an approach to providing comprehensive primary care that facilitates partnerships between patients, clinicians, medical staff, and families. It extends beyond the four walls of a clinical practice to include specialty care, educational services, family support and more." In fact, the US Department of Health and Human Services' Healthy People 2020 goals and objectives state that "all children with special health care needs will receive regular ongoing comprehensive care within a medical home."

On behalf of Family Voices, I would like to thank the Chairman, Ranking Member, and Subcommittee Members for the opportunity to testify about the important issues addressed in the

ACE Kids Act. We would be happy to work with the Committee staff to develop specific language related to any of our recommendations, or to help in any other way we can to ensure that children with complex medical conditions receive timely and appropriate Medicaid services.

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REFERENCES

Medical debt

Payer of Last Resort: Medical Debt and Financial Hardship Among Families Raising Children and Youth with Special Health Care Needs, from the Catalyst Center

Out-of-state care

Interstate Medicaid Billing Problems: Helping Medicaid Beneficiaries Who Get Care Out of State, from Families USA

Care coordination

Care Coordination, from the Catalyst Center (examples of care coordination models funded through the Maternal and Child Health Block Grant and Medicaid)

The Care Coordination Conundrum and Children and Youth with Special Health Care Needs

Care Coordination in a Statewide System of Care: Financing Models and Payment Strategies, from the Catalyst Center

Health homes and Medical Homes

National Center for Medical Home Implementation (MCHB-funded, American Academy of Pediatrics)

Building a Medical Home for Children, from HRSA

Data Resource Center for Child and Adolescent Health Medical Home Portal

Medicaid Health Homes Still a Work in Progress, from the Commonwealth Fund, Washington Health Policy Week in Review, June 27, 2016

What's in a Name? Medical Home vs. Health Home vs. PCMH, from Greenway Health, LLC, blog post of Sept. 5, 2013

The Difference Between Patient-Centered Medical Homes & Medicaid Health Homes (In Plain English), from eCaring, April 29, 2013

Medical Home V. Health Home – Confused?, from Open Minds

ATTACHMENTS

1. Family Voices & Family-to-Family Health Information Centers
2. Family-to-Family Health Information Centers
3. The Importance of Medicaid to Children and Youth with Special Health Care Needs
4. Family Voices Awarded New 3-Year Cooperative Agreement as the National Center for Family/Professional Partnerships



Family Voices & Family-to-Family Health Information Centers

Introduction

Family Voices is entering its 24th year as the national, cross disability, family-led organization dedicated to “*keeping families at the center of children’s health care.*” This includes serving in its 18th year as the National Center for Family Professional Partnerships (NCFPP) (www.fv-ncfpp.org), funded by the Health Resources and Services Administration’s (HRSA’s) Maternal and Child Health Bureau (MCHB). Family Voices, in partnership with HRSA and the Centers for Medicare and Medicaid Services, created and piloted the model for what are now the 51 HRSA-funded Family-to-Family Health Information Centers (F2Fs). Over the last decade, Family Voices has supported the development and strengthening of vital, connected, family leadership in the states, through the network of F2Fs and Family Voices State Affiliate Organizations (SAOs).¹⁰

Over time, Family Voices has also partnered extensively with many professional organizations helping them engage families as partners. In addition to the NCFPP project, Family Voices this year has secured funded projects engaging families as partners with the following:

- American Academy of Pediatrics (AAP),
- Centers for Disease Control,
- Association of Maternal and Child Health Programs,
- Association of University Centers on Disability,
- Patient Centered Outcomes Research Institute (PCORI),
- Child and Adolescent Health Measurement Initiative,
- American Association on Health and Disability,
- National Conference of State Legislatures,
- National Academy for State Health Policy,
- Association for State and Territorial Health Officials, and
- Society of General Internal Medicine.

Each of these projects extends the impact and priorities of HRSA and MCHB. In the new NCFPP project, Family Voices is partnering with the Statewide Parent Advocacy Network (SPAN) of New Jersey, which serves as the statewide F2F and FV SAO, as well as the Parent Training and Information Center, Parent to Parent USA affiliate, and a chapter of the Federation of Families for Children’s Mental Health. SPAN also houses the National Center for Parent Information and Resources and the National Resources for Access, Independence, Self-Advocacy and Employment (RAISE) Transition Technical Assistance Center – projects funded by the US Department of Education.

¹⁰ F2Fs are the federally-funded and designated organizations that are family-staffed/run to provide support to families of CYSHCN across the six MCHB core outcomes. Family Voices SAOs are family-led organizations are designated by Family Voices, Inc. Each SAO’s Board of Directors consists of a majority of parents of CYSHCN (ages birth to 26). The vast majority of F2Fs (80.4%) are also the FV SAO in their state.

Why are F2Fs so important for outcomes?

Parents who advocate effectively on behalf of their child's health care and who have the partnership skills to communicate and work with healthcare providers in meaningful ways report improved health outcomes for their children as a result of that parent involvement. A growing body of evidence demonstrates that parents are more likely to be able to advocate effectively when they are provided with support by peers.

For example, a study of the impact of the *Rhode Island Pediatric Primary Care Enhancement Project*, a pilot funded by HRSA via Rhode Island's D70 project, found that housing trained parents of CYSHCN in pediatric practices reduced the cost of care from 11-15%, improved appropriate utilization of healthcare services including lowering in-patient utilization, and increased both parent and provider knowledge and satisfaction. The project involved housing trained Family Resource Specialists at primary care practices 20 hours/week to provide support to individual families (including families of children with and without special healthcare needs) in navigating across and advocating in multiple systems. These family leaders also worked with primary care providers on partnering more effectively with families and connecting families to available resources and supports. See "Evaluation of Rhode Island's Pediatric Primary Care Enhancement Project," <http://rimed.org/medhealthri/2009-07-253.pdf>.

In a more recent study, a randomized trial revealed that trained Parent Mentors (PMs) are significantly more effective than traditional Medicaid and Children's Health Insurance Program methods in insuring uninsured minority children; obtaining insurance faster; renewing coverage; improving access to primary, dental, and specialty care; reducing unmet needs and out-of-pocket costs; achieving parental satisfaction and care quality; and sustaining long-term coverage. PMs also are inexpensive, costing \$53/child/month, and save \$6,045.22/insured child. The study, led by Medica Research Institute Distinguished Chair in Health Policy Research Glenn Flores, is the first to assess the effectiveness of PMs in insuring uninsured minority children. PMs are a special category of community health workers who have children with particular health conditions and risks. They leverage their relevant experience, along with additional training, to assist, counsel, and support other parents of children with the same health conditions and risks, including assisting families with insurance applications, retaining coverage, medical homes, and social needs, a model that sounds remarkably like that of the F2Fs. See www.medicaresearchinstitute.org/files/2114/5875/8554/Pediatrics_Kids_HELP_RCT_Article_3-17-16_DV.pdf.

F2F staff are parents of CYSHCN who have learned how to effectively navigate multiple systems and who are able to share their knowledge and expertise and work with families to develop their advocacy and partnership skills. Ninety-two percent (92%) of families helped by F2Fs report that they are better able to partner with providers and navigate systems as a result of the assistance received, and 90% report increased confidence in their ability to access the services their child and family need.

How do F2Fs Connect Families to Health Insurance and Healthcare Financing?

F2Fs support families across all six MCHB core outcomes for CYSHCN, including access to adequate healthcare financing such as Medicaid, State Children's Health Insurance Program, and private insurers via the Affordable Care Act (ACA) Marketplace.¹¹ In 2014-2015, F2Fs served 638,713 families on topics

¹¹ F2Fs provided 1-1 assistance and training to 43,607 families on medical home, 79,035 families on navigating community-based systems, 67,997 families on partnering with professionals, 24,120 families on screening, and 27,284 families on transition. When you include information provided via listservs and newsletters, the totals are 626,582 (medical home), 662,010 (navigating systems), 650,972 (partnering with professionals), 607,095 (screening), and 610,259 (transition to adult systems of care).

related to health insurance and other healthcare financing via individual assistance, workshops, and dissemination of resources (55,738 via individual assistance and workshops alone), including information from the FV NCFPP monthly blog/Tip Sheets on the ACA and CYSHCN (www.fv-ncfpp.org/blog/). According to most recent data, 48 F2Fs reported engaging in initiatives focused on Medicaid, Medicaid managed care, Medicaid waivers, and Medicaid buy-in programs. In addition to this HRSA-funded work, many F2Fs have secured additional funds to provide ACA information, training, and enrollment assistance to families. Family Voices wrote grants to help nine F2Fs (*Arizona, Colorado, Indiana, Louisiana, Nevada, N. Dakota, Rhode Island, Texas, and Washington State*), receive funding from the National Disability Navigator Resource Collaborator to support individuals with disabilities to access the ACA. Other F2Fs have received funding to serve as ACA navigators individually (e.g., *Vermont* Family Network) or as members of coalitions (e.g., *Georgia* Parent to Parent), with state or CMS-funded navigator grants, while others have received foundation funding to assist with enrollment (e.g., Statewide Parent Advocacy Network of *NJ*). Some F2Fs have also utilized their expertise to build the capacity of the funded navigators to be able to understand the special healthcare financing issues faced by families of CYSHCN as well as other healthcare financing resources above and beyond the ACA (e.g., State Catastrophic Illness in Children Relief Funds) by providing training to ACA navigators, Federally Qualified Health Center (FQHC) enrollment assisters, and others. Finally, some F2Fs have partnered with health advocacy coalitions to develop and disseminate videos about the ACA for diverse families (for example, www.spanadvocacy.org/content/affordable-care-act-helps-connect-new-jerseyans-health-care).

How do F2Fs Reach and Support the Most Underserved Families?

F2Fs provide direct support through free one-to-one assistance and training. From June 1, 2014, through May 31, 2015, F2Fs assisted and trained 155,950 families (unduplicated) and 74,225 professionals (unduplicated). Almost 40% of the families served by F2Fs reported that they were non-white, while almost 30% were Hispanic/Latina. F2Fs reach families of diverse backgrounds in many ways—hosting support groups and leadership conferences for Spanish-speaking participants, facilitating focus groups to create culturally competent materials, participating in community meetings serving diverse communities, and partnering with community brokers. F2Fs also help develop the leadership skills of diverse families, which is a major focus of the new NCFPP project. F2Fs partner with agencies that serve the most underserved families such as FQHCs. Thirty-seven (37) F2Fs indicated significant involvement with community health/rural health agencies, and 21 F2Fs reported collaboration with FQHCs on specific initiatives in 2014-2015. For example, in *Georgia*, the F2F houses regional coordinators in clinics serving underserved populations. After the family sees the doctor, the regional coordinator connects the family to local resources, matches them to another family for emotional support, and provides them with information. In *NJ*, the F2F facilitated a State Implementation Grant on Innovative Evidence-Based Practices that partnered with three FQHCs in low income, high immigrant communities. Trained Family Resource Specialists provided training to the FQHCs to improve their screening, medical home-ness, and transition to adult life services, and training, leadership development, and support to immigrant, limited English proficient parents served by those FQHCs leading to statistically significant improvements in outcomes. Trained immigrant parent leaders continue to work with the FQHCs to provide ongoing support to families of CYSHCN, and several of the FQHCs continue to facilitate ongoing parent support groups for families of CYSHCN in their practice. In addition, the NJ Primary Care Association is a member of the Statewide Community of Care Consortium for CYSHCN and has invited the F2F to

present at its annual conference several times.

Family Voices supports this work through the NCFPP and with other resources, including funding seven F2Fs as Polly Arango Mentoring Initiative grantees and members of a learning collaborative around preparing and supporting diverse parent leaders (private funds); funding two F2Fs as PCORI grantees around health promotion for diverse families (PCORI funds); identifying exemplary/promising practices in serving diverse families and organizations disseminating information about those practices (NCFPP); and many educational opportunities such as webinars, resource materials and conferences (NCFPP and NCFPP supplement).

How do F2Fs Enhance Quality, Medical Home, Patient/Family-Centered Care, and Impact Delivery System Reform?

In 2014-2015, F2Fs reported active engagement in state initiatives focused on family-centered care (43), medical home (42), and quality improvement (27). For example, the *Utah* F2F developed a Medical Home Portal for families, clinicians, and allied healthcare professionals. The content, tools, and resources were vetted by a team that included parent staff from the F2F, the University of Utah Department of Pediatrics, Title V, and pediatricians (www.medicalhomeportal.org/). In *West Virginia*, the F2F is working with the state to improve the quality of service delivery related to Care Coordination and the Medical Home through redesigning state policies and procedures for CYSHCN, assisting with level of needs assessment, attending home visits, supporting families in clinics, and helping with the assessment and care plan development. NCFPP supported engagement of 14 F2F/professional teams in collaborative quality improvement efforts via its ABCs of Quality Improvement intensive training webinar course, in partnership with the National Institute for Children's Health Quality (NICHQ). (www.fv-ncfpp.org/activities/quality-improvement/). Overall, in 2014-2015, 23 F2Fs reported significant involvement in NICHQ Learning Collaboratives, and 28 reported significant involvement overall with health care quality initiatives or organizations.

Family Voices encourages these initiatives at the state level and also provides many opportunities for family leaders from the states to participate in national systems level partnerships. Examples in the last two years include:

- Development of the Family-Centered Care Assessment tool (FCCA, www.fv-ncfpp.org/activities/fcca/) and participation in its validation study;
- Participation in four Agency for Healthcare Research and Quality measurement development projects around transition, foster care, care coordination, asthma and complex care;
- Participation as liaisons to the AAP Council on Children with Disabilities and the AAP Committee on Quality Improvement;
- Representing families on the National Emergency Medical Services Advisory Council;
- Participation in the development and testing of questions for the National Surveys of Children's Health;
- Assisting the Child and Adolescent Measurement Initiative with the design and development of the Data Resource Center, a public website disseminating information from the surveys;
- Providing input to researchers around Adverse Childhood Experiences (ACEs); and
- Testifying about family needs and experience before government hearings, among others.

Conclusion

Approximately 8.8 million (one in five) families in the US have a least one child under the age of 18 with

a special health care need. Of these, about 3 million families report not being able to easily access community-based services due to eligibility issues, services not available, problems getting appointments, costs of services, lack of information, and other difficulties. F2Fs exist in every state and the District of Columbia to provide assistance to help these families and professionals address these critical issues. F2Fs are staffed by family members who have first-hand knowledge and training in navigating the maze of health care services for CYSHCN. With the support of Family Voices and the NCFPP, F2Fs help families through free one-to-one assistance and training that gives families information and advice, bolsters their confidence, and shares tools that help them more effectively communicate with providers and advocate for their children; disseminate information via fact sheets, manuals, and toolkits, newsletters/e-newsletters, websites, and other social media; and partner at the systems level to improve access to quality of services, by serving as family faculty to healthcare providers, participating on health clinic, hospital, and health maintenance organization advisory boards, working with state agencies on policies to ensure that they effectively meet the needs of diverse families and participating in national level partnership activities to improve policies and systems. Outcomes research provides evidence of the value of such participation at all levels of health care. HRSA's investment in developing strong "family voices" for CYSHCN has already had an impact on other systems and individuals and has enormous potential to contribute to all of HRSA's strategic priorities.



FAMILY-TO-FAMILY HEALTH INFORMATION CENTERS (F2Fs)

- Throughout the US, there are approximately 14.6 million children and youth with special health care needs (CYSHCN), constituting nearly 20 percent of the child population. More than one in five households with children has at least one child with special health care needs. Out of insured CYSHCN, 34.3 percent have families who report their insurance is inadequate to meet their needs.
- It is very difficult for families to figure out how to finance their children's care, given the great expense and complexity of potential funding sources – private insurance, Medicaid, CHIP, state Maternal and Child Health programs, the school system – each with different eligibility and coverage criteria.
- Family-to-Family Health Information Centers (F2Fs) help families of children/youth with special health care needs learn how to navigate the complex health care system and to make informed choices about health care in order to promote good treatment decisions, cost-effectiveness and improved health outcomes.
- There is one F2F in every state and the District of Columbia, each of which receives \$95,700 per year in federal grants. Despite their shoe-string budgets, F2Fs trained and assisted over one million families and 376,000 health professionals in 2013-2014.
- F2Fs also provide leadership and training for health care providers and policymakers to work toward the goal of a family-centered “medical home” for every child.
- F2Fs are staffed by families of CYSHCN who have extensive personal experience and professional training in accessing and financing health care for CYSHCN.
- The F2F grant program, administered by the Maternal and Child Health Bureau, was established with bipartisan support by the Family Opportunity Act, part of the Deficit Reduction Act of 2005, and was directly funded through FY 2009. Through subsequent laws, most recently the Medicare Access and CHIP Reauthorization Act of 2015, the F2F program has been funded through FY 2017 at the level of \$5 million per year. (No appropriations are necessary.)
- A CMS-funded outside evaluation of F2F HICs noted: “The accomplishments of these Grantees are impressive, particularly in light of their modest grant funding,” and “Through their work to promote family-centered, culturally competent, and linguistically appropriate care and medical homes for CYSHCN, [F2Fs] are contributing to improvements in the quality of health care.”
- Said one parent, “Since I now know about Family Voices, my life has changed a lot as far as being strong to make sure my daughter's needs are met. This is a huge change for me.”

For national and state-specific information about F2F HICs, see http://www.fv-ncfpp.org/f2fhic/about_f2fhic/, or contact Janis Guerney (202-546-0558 / jguerney@familyvoices.org) or Brooke Lehmann (202-841-4341 / blehmann@familyvoices.org).



THE IMPORTANCE OF MEDICAID TO CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS OR DISABILITIES

Medicaid is a vital program for children and youth with special health care needs (CYSHCN) – children who have any of a broad range of chronic illnesses and/or disabilities (e.g., *cerebral palsy, epilepsy, diabetes, autism*). Approximately 11.2 million children in the United States – or 15.1 percent of all U.S. children – have special health care needs. Over 44 percent of these children rely in whole or part on Medicaid or CHIP to cover the costs of their care.

Nearly 4 million CYSHCN – 35.9 percent -- rely completely on public insurance to get the services they need. Another 8.2 percent have a combination of private and public insurance. In those cases, Medicaid helps families pay for out-of-pocket costs, and may serve as “wrap-around” coverage to supply services or devices not covered by their private plans. For example, some medical equipment and assistive devices (such as hearing aids) may not be covered under traditional insurance plans but are available through Medicaid.

Accordingly, Medicaid can save families from bankruptcy that might otherwise result from high medical bills. In many cases, it also allows parents to continue working by supplying caretaking services for their children.

In addition, Medicaid helps to prevent or ameliorate disabilities, since children on Medicaid have access to Early and Periodic Screening, Diagnosis and Treatment (EPSDT). Early screening and diagnosis means that developmental or health problems can be identified early in a child’s life, and necessary treatment can be provided before a condition develops or becomes more severe. As a result, some children can avoid the need for special education services.

If not for Medicaid --

- Santana, a 13-year old in Pennsylvania with Rett Syndrome and epilepsy, could lose access to her medication. And, her single mother would probably have to quit her two jobs if Medicaid’s safety net were not there to provide a caretaker for her daughter.
- The family of 8-year old Joshua – whose life-saving liver transplant was paid for by Oregon Medicaid -- would not have the means to pay for the 22 medications he must take every day.
- Jason -- a 3-year-old from Ohio who has developmental delays that leave him unable to speak, walk, or use his hands in a coordinated fashion -- would lose the early intervention, speech, occupational, and physical therapies that will one day allow him to walk, speak and use his hands.

In short, millions of vulnerable children and their families rely on Medicaid to help them obtain and pay for critical medical care and related services.

Mr. PITTS. The chair thanks the gentlelady and now recognizes Ms. West for 5 minutes for her summary.

STATEMENT OF TISH WEST

Ms. WEST. Thank you. My name is Tish West and I am the mother of Caroline West.

On behalf of my daughter and the millions of medically complex children in Florida and across the country I want to thank all of you for devoting your time to discuss how we can better serve the most medically vulnerable children in our country.

I would particularly like to thank Congresswoman Kathy Castor, our longtime champion and original sponsor of the bill. I would also like to thank Congressman Gus Bilirakis, another Tampa Bay member who cares deeply about this issue. Additionally, I'd like to thank Ranking Member Frank Pallone, who travelled to Tampa to see the Chronic Complex Clinic where Caroline and nearly a thousand other children receive lifesaving care at St. Joseph's Children's Hospital. Chairman Upton, Pitts, Ranking Members Green and Pallone and the entire subcommittee, I am deeply honored to be here today.

Our daughter, Caroline, is 19 years of age. She has a rare neurological condition that affects approximately 800 people worldwide. Her condition affects every aspect of her life. She has seizures. She is fed by a tube into her stomach.

She is confined to a wheelchair. She is developmentally delayed. She has cerebral palsy. She has been hospitalized for full spinal fusion, chronic pneumonia and seizures that have lasted as long as 12 hours.

She is currently on seizure meds that she takes three times a day, has physical and speech therapy, is on a specialized diet to control seizures.

Caroline's care is extremely rigorous. She needs my support for every aspect of her life and it takes 29 different specialty care providers to maintain her health and welfare.

Before Caroline was born, I was working in an executive job and was on an advanced promotion career track. As is the case with most parents of medically complex children, I did not have the luxury of continuing to work.

Since we did not have a diagnosis, we were busy visiting doctors, running tests to identify her illness. The first step in treatment is diagnosis.

This diagnostic process took us across the country to hospitals like Boston Children's and Johns Hopkins and others. All of this travel and testing was funded personally. Insurance would not cover our expenses.

During this time, our family was under an enormous amount of stress, both emotionally and financially. I had just left a high-paying job. We were paying out of pocket for travel. We paid out of pocket for expensive medicines that were not covered. Many of her necessary therapies were not covered.

These expensive tests at out of state hospitals were not covered and we had been denied by Florida's Medicaid waiver program. Our family was also in an emotional crisis. We were unprepared for the isolation that having a child with disabilities presents.

Since all of my friends were primarily my past coworkers, I did not have a strong support system. We were navigating uncharted territory alone. A medical home for complex kids is a rarity.

We know firsthand. Caroline's first pediatrician was a highly educated individual that we respected greatly. However, he was not experienced in dealing with kids with chronic and complex illness. We were an unusual sight in his office and did not always feel comfortable visiting the doctor.

Our questions would often go unanswered. We were a puzzle to our doctors. We were visiting many specialty doctors and had a difficult time getting the doctors to consult with each other.

There was an occasion in the diagnostic process where we actually had to be admitted to the hospital just to get our various providers to talk with each other. After years of bouncing around with doctors, we learned about a new clinic, the Chronic Complex Clinic at St. Joseph's Children's Hospital of Tampa.

Moving to this clinic was a lifesaving event for our family. All 800 patients of this clinic are categorized at the highest level of complexity. The clinic is co-located on the campus of St. Joseph's Children's Hospital with every subspecialty on the same floor.

The doctors in the clinic are also hospitalists, which means that if Caroline is admitted into the hospital she will see the exact same doctors that she sees as an in-patient and they in turn will be familiar with her. All the doctors that we see know Caroline and understand her condition. This structure is a true medical home.

This means faster treatment, less time in the hospital and better outcomes. We are the norm at our clinic. We are not outliers. Since coming to the clinic, Caroline's health has improved and her hospitalizations have been reduced.

As you review ways to deliver medicine to children with chronic and complex issues, I would urge you to look closely at this clinic.

The criteria that you put in place for ACE Kids needs ensure that these medical homes are for the most medically complex and that the institutions like St. Joseph's Hospital have all the resources to support this approach to care. Diluting this care to every pediatrician would not accomplish the outcomes that we have experienced through this model.

We were finally approved for the medical waiver program. This allowed us to augment our private insurance with Medicaid. This was a lifesaver for us.

We are hard workers and have always believed in taking care of ourselves and not relying on the welfare of others. We never imagined that we would need a government program to take care of one of our children. However, I am grateful for the program.

Lastly, I am not here testifying just for myself and my daughter. I am here for the thousands of families that are not able to speak for themselves. This legislation is urgently needed.

Thank you.

[The prepared statement of Tish West follows:]

Advancing Care for Exceptional Kids Act of 2015

Energy and Commerce Committee

Subcommittee on Health

Testimony

by

Letitia "Tish" West

Parent of a Medically Complex Child

and Volunteer

Thursday, July 7, 2016

Room 2322 of the Rayburn House Office Building

Washington, DC

Summary Points

Letitia “Tish” West, parent of a medically complex child

*Families are completely unprepared in every way for the enormous task of caring for a child with complex medical problems.

*Most doctor offices are unprepared for advising families and for caring for children with complex medical problems and are not qualified to diagnose rare conditions.

*Parents cannot continue to work and provide for their families when there is a medically complex child in the home.

*I have seen first-hand how beneficial it is to have a clinic that coordinates care for my daughter, other children, and families through the Chronic-Complex Clinic at St. Joseph’s Children’s Hospital of Tampa. It is an exceptional model that should be replicated around the country and used as the standard for providing a medical home for children with complex medical conditions.

Written Testimony

Submitted July 5, 2016

Letitia “Tish” West, parent of a medically complex child and volunteer

The Journey of the Family of Caroline West

My name is Tish West. I am the mother of Caroline West. On behalf of my daughter and the millions of medically complex children in Florida and across the country, I thank you for devoting time to discuss how we can better serve the most medically vulnerable children in our county. I would particularly like to thank Congresswoman Kathy Castor, our long time champion and original sponsor of this bill. I’d also like to thank Congressman Gus Bilirakis, another Tampa Bay member, who cares deeply about this issue. Additionally, I would like to thank Ranking Member Frank Pallone. Congressman Pallone travelled to Tampa to see the Chronic-Complex Clinic, where Caroline and nearly a thousand other children receive life saving care at St. Joseph’s Children’s Hospital. Chairmen Upton, Pitts, Ranking Members Green and Pallone, and the entire subcommittee on Health, I am deeply honored to be here today to testify.

My daughter, Caroline, was born on January 7, 1997. She is 19 years of age. Caroline has a rare neurological condition known as, Alternating Hemiplegia of Childhood. This disease affects approximately 800 people worldwide. Her condition affects every aspect of her life. She has seizures, cannot eat by mouth, is confined to a wheelchair, is developmentally delayed and has cerebral palsy. She has been

hospitalized for full spinal fusion, chronic pneumonia and seizures that have been uncontrolled for as long as 12 hours. She is currently on seizure medicine that she takes three times a day, does breathing treatments twice a day, has physical and speech therapy twice a week, is on a specialized diet to control seizures and attends a specialized school. It takes 29 different specialty care providers to maintain her health and welfare.

In the early part of Caroline's illness she would cry for hours on end. She had uncontrolled seizures and could not eat or participate in outdoor activities. Her sensory system was so delicate that the slightest change in her environment would cause seizures, posturing and pain. Through the advice of many doctors and therapists, and medicine and diet, her condition has improved over the years. Currently, Caroline is a happy child with an infectious smile and a happy disposition. Her improved health over the years is largely due to the wonderful health care that we have received from the doctors and staff at St. Joseph's Children's Hospital of Tampa.

Before Caroline was born I was working in an executive job at Barnett Banks of Florida and was on an advanced promotional track. As is the case of many parents of children with complex illnesses, I did not have the luxury of continuing to work. Her care was extensive and rigorous and required constant monitoring. Further, she did not have a diagnosis at the time so we were very busy visiting doctors and running tests to identify her illness. The first step in treatment is identifying a diagnosis. This diagnostic process took us to Boston Children's Hospital, Miami Children's Hospital, Columbia Medical Center and The University of Chicago Children's Hospital to see various specialists and experts on rare diseases. All this travel and testing was funded personally. Insurance would not cover the expenses at the various hospitals out of our area.

During this time our family was under an enormous amount of stress both emotionally and financially. I had just left a high paying job. We were paying out of pocket for travel. We were paying for expensive medicines that were not covered by insurance. Many of her necessary therapies were not covered by insurance. There were expensive tests at out of state hospitals that were not covered by insurance and we had been denied by Florida's Medicaid Waiver Program. Our family was in an emotional crisis. We were unprepared for the isolation that having a child with disabilities presents. Since all my friends were primarily my past coworkers, I did not have a strong support system. We were navigating uncharted territory alone.

The ACE Kids Act is important in many ways, but one critical component is that it will hopefully establish more medical homes or health homes for this population of children. A medical home for complex kids is a rarity. We know first hand. Our primary pediatrician was a highly educated individual who we respected greatly. However, he was not experienced in dealing with children with chronic and complex illnesses.

We were an unusual site in the doctor's office and did not always feel comfortable visiting the doctor. Our questions would often go unanswered. We were a puzzle to our doctors. We were visiting many specialty doctors and had a difficult time getting the doctors to consult with each other. There was an occasion in the diagnostic process that we had to be admitted to the hospital just to get our various providers to talk with each other. After years of bouncing around with doctors, we learned about a new clinic, the Chronic-Complex Clinic at St. Joseph's Children's Hospital of Tampa. Moving to this Clinic was life changing for Caroline and for our family.

The Chronic-Complex Clinic has been in existence for 14 years. The doctors and nurses are very experienced in treating children with complicated medical problems and severe disabilities. All 800 patients of this Clinic are categorized at the highest levels of complexity. The Clinic is co-located on the campus of St. Joseph's Children's Hospital of Tampa with every sub-specialty on the same floor. The doctors in the Clinic are also Hospitalists, which means that if Caroline is admitted into the hospital she will see the exact same doctors that she sees as an inpatient and they in turn will be familiar with her. This structure is highly efficient and effective and has the benefits of a true medical home. This means faster treatment, less time in the hospital and better outcomes. If specialists are needed during our office visit that appointment is made at the time of her visit or the consult is often accomplished during the same visit. This means less time in between seeing the attending and seeing the specialist which again means faster treatment and better outcomes. This Clinic is one of two of its kind in Florida and only a handful in the county. ACE Kids will hopefully incentivize, through financial reimbursement and outcomes-based reporting, the establishment of more medical homes for kids like Caroline across the county.

We are the "normal" at our Clinic. We are not an outlier. Since coming to the Clinic, Caroline's health has improved and her hospitalizations have been reduced tremendously. Our family feels welcome and embraced at the Clinic. All the nurses and staff know Caroline and our family. There is support through family activities and holiday events. Through the Clinic we have made many friends and have received support in every aspect of our caregiving of Caroline. Our entire family has benefited from this Clinic.

As you review ways to deliver medicine to children with chronic and complex issues I would urge to look closely at the model and structure of this Clinic. Our Clinic works because of the high degree of specialization. The criteria you put into place for ACE Kids needs to ensure that these medical homes are for the most medically complex and the institutions (like St. Joseph's Children's) have all of the clinical and psycho-social resources to support this approach to care. Diluting this care to every pediatrician would not accomplish the outcomes that we have experience through this model.

We were finally approved for the Medicaid Medical Waiver Program which allowed us to augment our private insurance with Medicaid. This was a lifesaver for us. We are hard workers and have always believed in taking care of ourselves and not relying on the welfare of others. We would never have imagined that we would have needed to rely on a government program for the health care of one of our children. However, I am grateful and thankful for the program.

Lastly, I am not here only testifying for myself and for Caroline. I am here for the thousands of families that are not able to speak for themselves. This legislation is urgently needed.

My daughter Carline is approaching adulthood. We had a lot of misfires and missteps along the way. I can only hope that through stories like mine and through the ACE Kids Act that families with young children will have more ease in navigating a health care system not designed for our most medically complex children.

Respectfully,

Letitia "Tish" West

Mr. PITTS. The chair thanks the gentlelady and now recognizes Dr. Koop 5 minutes for your summary.

STATEMENT OF STEVEN KOOP, M.D.

Dr. KOOP. Good morning. I am Steven Koop. I am a pediatric orthopaedic surgeon. I also serve as the medical director at Gillette Children's Specialty Health Care.

Gillette is an independent nonprofit specialty hospital in St. Paul, Minnesota. Thank you for allowing me to testify.

Your efforts to improve Medicaid coverage for the children that you have heard about today is very important to them, to their families and to those who care for them.

Today, I hope to make the following points. First, we appreciate the approach of the new discussion draft of the ACE Kids Act. Second, we believe it is critical to protect patient access to skilled specialty care.

And third, it is important that we work together to gather data and best practices so that we can inform and improve the system that serves these children and their families.

Gillette was established in 1897 to serve children with disabilities. That is still our mission today. In the past 5 years, we have served patients from all 50 states plus the District of Columbia, Puerto Rico and more than 20 countries.

The children we have today, the children we serve, have conditions such as cerebral palsy, spina bifida and a long list of very complex conditions.

Gillette's patients include some of the most medically fragile children, children who require lifelong care coordination and multiple medical and surgical interventions so that they can thrive and reach their full potential.

At Gillette, we have made the conscious decision to build an integrated care model that focuses on delivering high quality and effective care to narrow segment of the population. In doing so, we have learned key elements of serving our patients to the best of our ability.

First and foremost, patients and families must be at the center of our collective work. Why? Because parents and family members become the first experts in their child's unique condition.

As a physician, I have learned to recognize and value this expertise. Moms like Tish West have become my best teachers over my 31 years of work.

When a child is born with a medically complex condition or experiences serious injuries, as you have just heard, the life and finances of a family are transformed. I do not think it's necessary to say more about the challenges of Medicaid and accessing this essential funding for their care.

We are encouraged by the new draft discussion of the ACE Kids Act that is the subject of today's hearing. We believe it moves in a positive direction for the following reasons. It places children and families at the center and builds around them. A state option to provide coordinated care through a health home for children who have complex medical conditions is key to achieving the goals of the ACE Kids Act.

New models should respond to the needs of children and their families, should include data reports that will improve care for children now and in the future, should allow families to make choices amongst providers and it should ensure access to the providers who are most appropriate for that child.

Secondly, it pursues facts and information that will improve our understanding of medically complex children. We believe any effort to improve Medicaid for children with medical complexity must be data driven.

The provision requiring a study of children with medical complexity will increase our knowledge of the children and what they and their families experience, the models of care that serve them well.

Third, it encourages sharing of knowledge that will improve care for all exceptional children. The concept of an agency such as CMS providing guidance to state medical directors regarding best practices provides an opportunity to highlight what works, thereby helping to improve the care that children receive across the entire nation.

Additional and more detailed comments and recommendations with respect to the discussion draft, the story of Gillette Children's and our work and stories of the patients that we serve are included in our written testimony.

I thank the original sponsors of the ACE Kids Act, particularly Congressman Barton and Congresswoman Castor, for their leadership in this bipartisan effort.

Thank you, Chairman Pitts and Ranking Member Green, for allowing me to speak today.

[The prepared statement of Steven Koop, M.D. follows:]



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"
 JULY 7, 2016, 10:15 AM

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.¹ 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.² 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,³ families may work for years

¹ 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.

² 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.

³ 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 2007.⁴⁵ 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.⁶ For children with medical complexity, like those treated by subspecialist providers, the curves may be so profound that they warrant surgical intervention. However, only a fraction of children in the U.S. will develop scoliotic curves this

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

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

⁶ 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.

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.⁷ 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.⁸ 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

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

⁸ 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.⁹ 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.

⁹ 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 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.

Mr. PITTS. Chair thanks the gentleman and now recognizes Mr. Merrill 5 minutes for your summary.

STATEMENT OF RICK W. MERRILL

Mr. MERRILL. Well, good morning. Good morning. I'm Rick Merrill, president and chief executive officer of Cook Children's Health Care System, a not for profit integrated pediatric health care system located in Fort Worth, Texas.

I am very glad to be here with you today representing children's hospitals nationwide to discuss the Advancing Care for Exception Kids Act, H.R. 546 and the discussion draft.

I wish to thank the original co-sponsors of the ACE Kids Act, Chairman Joe Barton and Representative Kathy Castor, whose 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 the Health Subcommittee chairman, Joe Pitts, of course, and Ranking Member Gene Green for holding this hearing on improving care for children with very serious complex medical conditions.

We would also like to express our appreciation to Representative Michael Burgess and more than a dozen additional members of the subcommittee for their support of the bill.

Additionally, it is important to acknowledge the thoughtful input offered on the current bill by other organizations present and we look forward to continuing to work with these groups as the bill moves forward.

Last year, Cook Children's treated children from more than 30 states, recorded nearly a half million child visits in our 60 pediatric subspecialty clinics, 240,000 visits to our emergency department and urgent care centers and registered over 11,000 in-patient admissions.

With over 1.3 million patient encounters in our system, Cook Children's provides comprehensive and coordinated care across this system including home health care services and a health plan which enrolls over 100,000 Medicaid children, many of whom have serious disabilities.

For many years now, we've taken care of some very sick kids and we've done a good job of it in our part of Texas. But I'm here today to tell you we could and 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.

We do our best today working with our Medicaid program but we can do much better. While Medicaid is state-based, the children we serve are not necessarily locally based.

As I mentioned, many of the patients travel great distances across state lines for our specialized care. But right now, 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 in Medicaid. Thankfully, we have seen great strides in the improvement of care in the adult Medicare

population that has been made 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? As it has been stated, the number of these children with medical complexity is a small number, perhaps 6 percent of the children on Medicaid.

The group accounts for 40 percent of the Medicaid's current spend on kids yet 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 billion to \$40 billion we incur yearly in Medicaid costs for this population will increase even more rapidly given medical inflation rates. By strengthening Medicaid to improve coordinated care for this population we can reduce spending potentially by billions of dollars over a multiyear period by decreasing unnecessary utilization of costly services.

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.

Meaningful reform cannot be accomplished by 50 different Medicaid programs working independently. A national approach is needed to create consistent systems of coordinated care across states using common definitions and transparency of data, driving care improvement and reducing Medicaid spending.

The ACE Kids Act would be voluntary for states as well as families and health care providers and can be implemented locally around the needs of the families, state Medicaid managed plans, and health care providers.

We have these kinds of partnerships in place in several communities across the country, mine included, and they are achieving great results for children locally.

With a strong framework in place, states, health plans, families, and providers can work together to improve care for our nation's sickest and most vulnerable children.

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

Thank you.

[The prepared statement of Rick W. Merrill follows:]

Statement for the Record

In support of

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

Submitted by

Rick W. Merrill

President and Chief Executive Officer

Cook Children's Health System

Fort Worth, TX

July 7, 2016

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.

Mr. PITTS. Chair thanks the gentleman. That concludes the opening statements.

I have a UC request. I would like to submit the following documents for the record: statements from the American College of Cardiology, the Cooley's Anemia Foundation, three letters from Medicaid Health Plans of America, a statement from the Seattle Children's Hospital.

Without objection, those will be entered into the record.

[The information appears at the conclusion of the hearing.]

We are going to take a 5-minute break to let the staff reset the mics. They say that way we can get rid of this static and feedback. So, with your indulgence, we will break for 5 minutes.

[Whereupon, the above-mentioned matter recessed at 11:08 a.m. and resumed at 11:17 a.m.]

Mr. PITTS. OK, ladies and gentlemen. If you'll take your seats we'll get started. I apologize for this. That's a little better, I think.

Mr. GREEN. Appreciate help from our friends.

Mr. PITTS. Yes. So thank you very much for your patience. We'll now go to questioning. I will begin the questioning and recognize myself 5 minutes for that purpose and we'll start with you, Dr. Berry.

In your testimony you wrote a bit about your research and some of the challenges with defining the population of children with medical complexity.

Can you explain please the definitional challenges and is it fair to say many definitions risk being simplistic or one size fits all and would you have concerns with Congress mandating a single definition and writing it in federal statute?

Dr. BERRY. Thank you, Mr. Chairman, for that complicated question. So, complexity really is a subject term, right. It's kind of in the eye of the beholder who's trying to make a judgment about it with a patient in front of him.

And, there are very specific ways at going about a definition and then more broad ways. So, for instance, in our clinic and other complex care clinics we have a very general definition.

The kids have to have a chronic condition, it's got to affect multiple organ systems of the body—at least three, we say. They have to have functional limitations and that's about it, and we get referrals every week from providers all over New England sending us kids, with that definition in place.

We have no specific diagnoses. We have no specific medications or anything else they need. It's just that, and the kids are coming.

So I think from the clinical provider standpoint, even a more generic definition like that it actually works for a clinical program to get the kids what they need.

Now, when you're trying to carve out the data I think that's when the definitions become a little bit more challenging but you can definitely do it. Then you're arguing in the fringes about what specific diseases are in or out or a number of chronic conditions and all that kind of stuff.

But, themes and variations on that, no matter how strict you get you're going to be able to identify that core set of kids, I believe, regardless of the specifics. They could really benefit from legislation like this, and over time you may revise it and do things in the

fringes but you really are going to be able to get that core set of kids in there.

Mr. PITTS. OK. Thank you.

Dr. Koop, does Gillette serve children enrolled in Medicaid managed care plans and if so can you discuss how you work with those plans to coordinate care for these children?

Dr. KOOP. We do. Those plans often have individuals who communicate with us about the resources that they have and how we're going to coordinate care. We place a particular emphasis on working with the primary care physicians for our patients. We want them to be connected to the primary care community. We live in a reasonably rural part of the U.S. and many of our patients travel long distances so that constant communication and collaboration is essential.

Mr. PITTS. Thank you.

Mr. Salo, I know one of the concerns Medicaid directors had with the original ACE Kids Act is that it upset the balance of the federal-state nature of the Medicaid and may have given too much authority to CMS instead of states.

How do Medicaid directors feel about this new draft and knowing managed care is an important delivery system to many states like Michigan? Do directors feel like the draft overly incentivizes fee for service?

Mr. SALO. I think, and granted that the draft has only been, I think, on the street for about a week or so so I can't promise that all 56 of my members have looked at it and weighed in it, but I can say with broad confidence that the concepts behind the new draft are very much in keeping with the direction that states are going because, as I alluded to earlier there are a lot—states are very different from one another.

The reforms in Pennsylvania versus the reforms in Texas on one level look very different. So it's important that whatever we do moving forward is able to accommodate that and so by that I mean you do have a number of states who are moving forward in kind of a traditional managed care organization reform model.

But you also have a number of states moving forward with accountable care organizations or in a number of states like Oregon and Colorado and others they even call them other things.

There's RCOs and CCOs and endless acronympalooza there. But this type of approach, the health home approach, is something that can be blended into a more traditional managed care approach.

It can be blended in with the ACOs and it can be used in places like Arkansas where there is no real managed care infrastructure at all.

Mr. PITTS. Thank you. Let me sneak one more question in.

Mr. Merrill, in your testimony you noted we lack national quality measures tailored to the unique needs of children with medical complexity.

Yet, I assume your health care plan, which has more than 100,000 children enrolled reports to the state of Texas on quality measures and as your testimony suggests there are major challenges with accurately defining the diverse population.

So is putting the car before the horse—is it putting the cart before the horse to try to create new quality metrics for this population? Why do you think current metrics are sufficient?

Mr. MERRILL. Great question, Mr. Chairman.

We do have quality measures and a lot of health plans across the nation have quality measures that they are expected to hold to.

But that said, they are quality measures that are specific to our health plan and to our state, and if we want to try and accelerate our opportunity to improve care sooner than later for this patient population and create the budget certainty and potential savings that this bill has or this resolution has in mind, we need a common definition.

We need common standards and that is why we need to get also to a common definition of who these patients are. We need a common denominator and a common language that tethers all of this effort across all of the states together so that we can use that common language to accelerate the improvement in care for these patients and ultimately the budget certainty and savings that this contemplates.

Mr. PITTS. The chair thanks the gentleman. I have gone way over my time. The chair recognizes Ranking Member Mr. Green 5 minutes for questions.

Mr. GREEN. Thank you, Mr. Chairman.

Ms. West, I want to thank you for your incredible moving and illustrative story of what you've shared with us today. No doubt in my mind that the care your daughter has received at St. Joseph's in Florida has been lifesaving and life changing for both your daughter and your family.

What elements of St. Joseph's model do you think are most critical to the success of your child?

Ms. WEST. I think one of the great things is that the clinic itself is adjacent to the hospital. So if additional tests are needed when we go into the clinic we can just go right over to the hospital for x-rays right away or any other kind of testing.

Secondly, I think having the subspecialties co-located with the clinic is really important. We've had situations where we were in our clinic with our primary pediatrician and the doctor was confused about something that was going on with Caroline and they walked over to talk with the GI doctor, consulted and then came back and we made a decision together—the two doctors.

Mr. GREEN. OK. Is Florida in a managed care Medicaid program? Does Florida have—

Ms. WEST. Yes.

Mr. GREEN. And is St. Joseph's Hospital on that managed care?

Ms. WEST. Yes. Don't ask me too many specific details about how the funding works for the hospital.

Mr. GREEN. OK. Well, I'm just wondering because I've had issues for a long time that managed care may only cover certain facilities in certain areas and in Houston, for example, I asked my managed care folks you need to cover a general hospital in a medical center—Texas Children's and MD Anderson, because then you really are a health care provider because you cover those things.

And so that's why I hope that managed care, whether it be in Florida or Texas, would do the same thing.

Dr. Merrill, is Cook on the Texas managed care Medicaid program?

Mr. MERRILL. Yes, Representative Green, we are, and in fact as you may remember or recall or know, the state of Texas is trying to, like many states, find ways to better coordinate care for this population.

We just launched Star Kids, which is similar to ACE Kids. But, again, it's just one solution for the nation. But yes, we do participate with our health plan in Medicaid managed care.

Mr. GREEN. Well, and our next question is is it across state lines? Because I know Cook brings folks from Oklahoma and everywhere else just like Texas Children's in Houston does. That's the main issue we have to deal with, how we can do that, and it's going to take federal rules to do it because Louisiana is so different from Texas and Medicaid just like Oklahoma, I'm sure, is.

But Dr. Berry, one thing that struck me as we were listening to our witnesses here today is how complex is it to coordinate across those lines in Medicaid. People often say you've seen one Medicaid program you've seen them all. But that is just not the case because of the differences. I found that out when we had a lot of our evacuees come into the Houston area—I'm sure in the Dallas area from Louisiana and Katrina.

The Medicaid program in Louisiana was so different from what we were accustomed to in Texas. The same state innovation and flexibility that made Medicaid able to respond to unique needs of populations can have the same characteristics.

But in ped care for kids and complex medical issues I think it's important that we make sure we get it right and move forward.

Dr. Berry, can you please provide an example of variation in care that occurs across state lines for children with medical complexity?

Dr. BERRY. Yes.

Mr. GREEN. Because I assume in the New England area you get them from everywhere.

Dr. BERRY. Yes, we do. We do. It's interesting. One of the major reasons why I went into this field at all and had an affinity for taking care of these children was an experience that I had in medical school back in Alabama.

So they were working with our cardiologist—this is back in the late '90s—they were transferring all of their high-risk congenital heart disease surgery to Boston.

We're talking about some major stuff so kids born with maybe three out of the four ventricles of their heart—big stuff. And that sort of blew my mind as a med student because I'm thinking, why don't you guys just do the surgery here—you're a children's hospital—why don't you take this on.

And they said, well, we've gone all around the country looking at the best outcomes for these children—we want to own them and we want them to undergo surgery in a place that has the lowest mortality rates, lowest complication rates and the highest chance of success.

And so they were doing that, and I found that fascinating that they were bypassing other states and going all the way up to New England to have that done. And to save time—

Mr. GREEN. Did Alabama pay for that care?

Dr. BERRY. We have Alabama Medicaid on board to do that.

Mr. GREEN. OK.

Dr. BERRY. And without a lot of effect locally, right, because, the hospital would probably have enjoyed building a cardiothoracic surgery program around those kids. But they didn't.

Now, understanding that and hearing experiences of children from other surrounding states in the southeast who may not have been offered that opportunity to go and may have been a part of other programs that didn't have as great as an outcome that sort of made me privy to the fact that sort of depending on where you live you might have services offered to you more or less depending on what's going on and certain families may not even know that they're able to travel and find a place with the best outcome.

Mr. GREEN. Thank you, Mr. Chairman. I know I have—it is good to call you Mr. Chairman again.

Mr. BARTON. Temporarily.

Mr. GREEN. Thank you for the time.

Mr. BARTON. This is Mr. Pitts' chair. I'm just substituting for Mr. Pitts. We thank the gentleman from Houston and I would now recognize myself for 5 minutes. Maybe ten or 15.

Mr. GREEN. The authority of the chair.

Mr. BARTON. Yes. No, no. I played by the rules.

I have several statements that I ask unanimous consent to put into the record. We have a statement of support for the ACE Kids legislation from the Children's Hospital Association.

Then we also have a collection of 22 letters from different stakeholders expressing general support for the legislation. Is there objection?

Mr. GREEN. No objection.

Mr. BARTON. Without objection, so ordered.

[The information appears at the conclusion of the hearing.]

Mr. BARTON. Before I ask my questions I want to make another brief statement. I want to commend the committee staff, both the majority and minority. The draft legislation that's before us is obviously quite a bit different than the original ACE Kids Act that was introduced last year.

We had a meeting with Mr. Pallone and Mr. Upton and Mr. Green, Ms. Castor, Congresswoman Cathy McMorris Rodgers about 3 weeks ago in which it was very intense discussion.

But the outcome of that meeting was, for those of us that are proponents of this legislation, that we really wanted to get it right and we weren't hung up on pride of authorship, and the committee staff took that to heart and they have transformed the original legislation.

And Chairman Upton agreed to hold a hearing and that hearing is being held right now, and that's not trivial. We got five weeks of legislative days left before the election, counting tomorrow.

So the outcome of this hearing is real important. If we want to move the bill this year then we're going to have to really listen and then you folks are going to have to interact with us on both the majority and minority side so that Chairman Pitts and Mr. Upton and Mr. Pallone and Mr. Green feel comfortable going to a markup and subcommittee in early September.

So I want to thank the committee staff on both sides for working really hard on this to come up with a transformational draft. That is nontrivial and I appreciate it.

My first question is a general question. The draft as it's currently structured does not have a metric for a quality standard at the federal level and I think most of you in your comments indicated that that was a possible concern and could be something we needed to add.

So I just want to go right down the line. We will start with you, Dr. Berry. Do you think that we should amend the draft and put in a quality standard metric for health homes?

Dr. BERRY. I think you should absolutely consider it and would be happy to collaborate in order to think about what those metrics might be health research utilization wise, measures of the child's health specifically, patient-family experience, all the major domains of quality I think that we would think would be the most important to track progress of this and to show effectiveness.

Mr. BARTON. OK. Mr. Salo.

Mr. SALO. Yes, and I would say that while I think that the quality measurement and reporting component is absolutely critical I would be cautious about putting a specific set of quality components in there because until we are sure what those are and I think it's important to also spend some time looking at the data that we do have and, making sure that we're focusing on a core implementable set of measures that can be done by providers and that we have the infrastructure in place to be able to do that and those are not unimportant things.

But absolutely it is critical to the success of this and many other efforts that we are focussed on the quality metrics.

Mr. BARTON. OK.

Ms. FRANGENBERG. I agree, and I would also add that it is very important that we reach out to families to understand how they are experiencing the system and we need to understand their ease of access on some scale, whether it is for Medicaid or for the systems that they are trying to access.

Mr. BARTON. OK.

Ms. WEST. I agree we do need quality standards. Obviously, that's very important. I would just urge the committee to make sure that we don't build a more bureaucratic system and ease of access for families is super important. So I think that's the main thing I would ask you to think about.

Mr. BARTON. OK.

Dr. KOOP. I too support this. I would put a particular emphasis on the impact of care for the children, what they experienced, how the outcome of that care changed their life and how it influenced the family of their life. The data in that domain is much weaker than other domains and really needs to be accounted for.

Mr. BARTON. OK.

Mr. MERRILL. Yes, I do agree that we should have strong quality standards and not to be lost in all of that is data reporting—not to be used as a stick but to inform best practices so we can accelerate our ability to provide better coordinated care for this patient population.

Mr. BARTON. In your testimony, several of you mentioned—I think Dr. Koop mentioned it and Ms. West mentioned it—that we need to be sure that the decision of whether to enter into a health home was the family's decision.

Is that something that we need to—the draft is ambiguous about that. Is that something that we need to make explicit in a revision? I'll start with, I guess, Ms. West.

Ms. WEST. I think the most important thing is to make it accessible to families and families need to feel comfortable. So like in our situation originally we weren't very comfortable in our pediatrician's office. So we were looking for a place to go. So it was our decision. So I'm going to say yes, I think it should be a decision of the family.

But there are rural communities—I'm lucky enough to live in Tampa, Florida, a big city where we have this fabulous clinic. So if you're in a rural community you might not even know about places to go.

So I think there will some forms of communication that need to be established to communicate with these families.

Mr. BARTON. Dr. Koop.

Dr. KOOP. I think we should be explicit in saying that families should be able to make the choices they think are wisest for their children.

Families today routinely communicate with each other. They're reliable weather vanes about pointing in the direction of quality and we need to make sure that they can follow the quality.

Mr. BARTON. Mr. Salo, to get states to opt into the system, which is voluntary, we have an eight-quarter or 2 year 90 percent federal funding match, which Chairman Upton has indicated that we will fund to pay for. Is that something that you think would help the state Medicaid directors make decisions to become involved?

And I would also ask if that's the right match, too high, too low? Because on the Republican side I can tell you that's going to be one we are going to have a little trouble selling to the most conservative members of my caucus.

We have been down that road with, as Mr. Guthrie pointed out to me in private conversation, some police programs that we established ten years ago and when the federal match ran out then the state legislatures felt like they got left holding the bag.

Mr. SALO. Right. So I don't know whether that's the exact right amount. But I would argue that having an enhanced match there is critically important for two reasons, one of which, states often suffer from what we call opportunity fatigue.

There are so many potential demos or reforms or pilots that are out there. They've got to be able to figure out which ones do

Enhanced match is going to help cut through the clutter and say all right, that's a little bit more enticing and I think the real reason for that is that any of these efforts that we're undertaking and specifically with children with medically complex conditions the infrastructure that you need to build in terms of designing—how do you structure a health home, how do you make sure that you've got interconnected IT systems, how do you think about some of the payments incentives or shared savings to the physicians that might be a part of this.

All of that is going to require a lot of investment in infrastructure and in time and energy, and at least, an eight quarter enhanced match is going to allow for some of that infrastructure investment. And so I think it's really critical, if at the very least for that.

Mr. BARTON. For some reason, my time expired 2 minutes ago. I am going to have to chastise myself.

We want to recognize now one of the original co-sponsors, Kathy Castor, who said nice things about me. Ms. Castor has been indefatigable—it's a big word for a Texan—in her support of this legislation and I think because of her we've got a great chance to get across the finish line.

Ms. CASTOR. Well, thank you, Congressman Barton. I'd also like to recognize former Congressman Jim Davis, who is here in the back of the room making sure we all behave and do the right thing.

He represented Tampa, Florida, the district that I have the privilege of representing, and has always been an advocate for kids and families. So thank you, Jim, for popping in here today.

Ms. West, could you take us back to the real world here and talk about the difference for families without this type of medical home, kind of a before and after and your experience talking with families at the St. Joseph's clinic and what changes in their lives and the lives of their children—this type of coordinated care as well?

Ms. WEST. Well, it's sort of an emotional thing but I'll just take you through—imagine going into a doctor's office where your child is in a wheelchair and has tubes attached to it and everything else and—attached to their chair, not to them but sometimes to the child as well.

And then you go in and there are all these cute little kids running around and families who are staring at you and don't really know what to make of you and I know this sounds like a simplistic thing, but it's very uncomfortable and you don't feel like you're welcome in the doctor's office and people don't know what to do with you. They don't know how to speak with you.

The kids are wondering what's wrong with your child and they're asking their parents. And so, you don't really want to go to the doctor. I'm a strong person, educated, so I'm going to go.

But I think there were people who would not go to the doctor's because they would feel intimidated and uncomfortable. So when you go to the Chronic Complex Clinic, everyone welcomes you.

There's lots of kids who have multiple disabilities. They know how to talk with our children, how to embrace them. The doctors are asking great questions and spending a lot of time not trying to rush us out.

In a regular pediatrician's office you would only be allowed 5 or 10 minutes because they've got more kids that they've got to get through. But at the Chronic Clinic we take as long as we need.

Ms. CASTOR. So at St. Joseph's I've seen team of health professionals and social workers that are there. Dr. Berry, at Boston, talked to us about the typical care management team and in fact in the draft bill we have a reference to the team of health care professionals and we're going to need your input on whether that's the right mix. Talk about the entire team that's necessary to provide good care to these kids.

Dr. BERRY. Right. So at our clinic we have social workers, case managers, heavy on the nursing staff. We have neurodevelopmental-trained pediatricians, general pediatricians working on both the in-patient and out-patient side.

We also collaborate very, very closely with surgeons who we sometimes embed into our clinics, palliative care physicians. So a myriad of folks.

One thing that we hope from legislation, though, is that we can elevate what we've got and really integrate it with the other providers that you just can't mix in to these clinics.

So all the primary care docs throughout New England, home nurses, community case managers, school nurses, even getting the durable medical equipment vendors involved who are in charge of getting all the equipment to the children's home in a timely fashion.

Just thinking about any type of system where all those guys are integrated and functioning as a team would be awesome.

Ms. CASTOR. Yes. What I've seen is, the family is so focused on taking care of their child but there is so much bureaucracy and red tape. There is so much paperwork and for families that are going from doctor to doctor to doctor they're kind of on their own.

But the benefit of having the medical home is you have those caseworkers that know how to fill out the forms and know how to pick up the phone and talk to folks at state Medicaid. Maybe, Tish, you can talk a little bit about that directly.

Ms. WEST. Well, in the beginning of Caroline's life I used to carry around these gigantic notebooks full of all of her medical records and her films and everything else so as we went from doctor to doctor I could explain what was going on with her and what her illnesses were.

And the paperwork was tremendous as well and it would take me 45 minutes to an hour just to explain what was going on with our child to a new doctor.

Now at the clinic they have the medical records that are electronic. Everyone there knows our daughter and also because the subspecialties are right there on the same floor they know our daughter.

They know what's going on with her. It's a real collaborative effort and she is much healthier as a result of that. We don't have to spend hours and hours.

And then we also talk about the Medicaid issue. It took me 7 years just to get approved from the Medicaid waiver program in Florida. There wasn't a clear definition of exactly who got approved.

It was very bureaucratic and there was tons of paperwork. I had to write letters over and over and over again. My doctors had to write letters. It took years for me to get on the program.

Ms. CASTOR. Mr. Merrill—

Mr. BARTON. The gentlelady's time has expired. I hate to—

Ms. CASTOR. Can I ask the witnesses to submit certain documents though?

Mr. BARTON. Yes, ma'am.

Ms. CASTOR. Because one of the outstanding questions is that this is going to be voluntary for states. It's a state option and what's going to happen for kids where their states do not opt in.

So Mr. Merrill and all of you, we really need to you address what Congressman Barton said before, the incentives for states and health professionals to participate, to ensure that the kids across the country are getting the best care.

Thank you.

Mr. BARTON. We thank the gentlelady.

We now recognize the gentleman from the Bluegrass state of Kentucky for 5 minutes.

Mr. GUTHRIE. Thank you very much and first, Ms. West, I want to say thanks for coming in and sharing your stories because it's powerful for us to hear your stories. And I have never thought of the waiting room from your perspective as you just said that and that's an image that's in my mind.

I went through some with my son. He was about 4 or 5 or—about 6 months, when he was 8 we found a problem. Had to spend a lot of time at a pediatric urologist.

Figured it out. He had surgery and there's no implications from it now. But I remember distinctly being in the pediatric urology. So if you're going to a pediatric urologist in a major children's hospital there's a lot of issues with children there and I have specifically a couple in mind.

I remember—he was 8 so I remember specifically a family with a baby and they said does he need to be fed. They're talking to each other and the dad reached over to get the diaper bag out or the bottle bag or whatever and I'm thinking oh, I remember those days when I used to have to do that and he pulls out and pulls her dress up and gives her a syringe through the stomach and it was, like, wow, this is—it just really struck me and it struck me how much families struggle and how much we thought we were struggling and how much families struggle and being able to take those experiences that you have and share them with us helps, and so I appreciate your willingness to do so.

Ms. WEST. Well, thank you very much for having us here. Thank you.

Mr. GUTHRIE. Thanks. But I do have a question. I'm the co-sponsor for the bill and I know you, Mr. Salo, you touched on this a little bit with Mr. Pitts, and he had to go take a vote in another committee so I just want to make sure you touched on it and maybe others can elaborate as well.

But I want to ask you, so the care coordination—Kentucky has moved to managed care Medicaid and so 34 states, I think, do managed care in Medicaid and coordinated care is with complex medical needs through a managed care program. So Medicaid is doing this.

Given this, can you outline or elaborate on the need for the home health model described in the bill? Is this intended for those states that don't have Medicaid managed care?

Mr. SALO. Not necessarily. I think I want to make it clear that I think the home health option is and can be a very attractive option for states that are on a broad spectrum from managed care.

I mean, you can do managed care where you're just—you have a managed care organization and then all they do is pay physicians fee for service.

That's not all that much managing. You could have managed care where the managed care association or organization is employing patients that are in medical homes or other types of intensive care coordination.

So this I would view as a tool that can be attractive for a lot of different states. But I don't want to lead people to think that this will be something that everyone will do because this is not necessarily going to be the option for everyone, which is why I think it's critical that the other components of the proposal, sharing with the best practices and then really investing into the research and the data underlying all of this will help get at some of those other issues for others states.

Mr. GUTHRIE. OK. You're answering my question but I want to just redirect a little bit and then if anybody else wants to add in.

So in May, CMS issued the final rule on Medicaid managed care. The new rule significantly strengthens a number of requirements on managed care plans regarding quality monitoring and oversight.

The new rule also has additional quality requirements specific to pediatric services and although this rigorous quality oversight is for all Medicaid managed care plans there's no comparable for fee for service payment structure.

Considering that most home health models are paid via a fee for service payment structure, are you concerned that the proposed home health model in the discussion bill might put children at risk due to lack of quality oversight?

So anybody can answer that. We're just trying to get to the details.

Mr. SALO. Yes. No, I think what you will see in a health home model and what you're seeing as the trend throughout Medicaid is the gradual movement away from a fee for service only, an uncoordinated fee for service model.

Again, there are different ways of doing this. One of the things that some of the states say is that fee for service—and again, to Ms. Castor's point, fee for service, abbreviated FFS, for kids with medically complex conditions or other people with severe needs the FFS really stands for fend for self and that is not the ideal that we want and that's not where state Medicaid programs are going. They are going there with managed care, they are going there with ACOs, they are going there with patient-centered medical homes.

But the whole point of this is to create an infrastructure, to create a structure where you've got the case managers. You've got the social workers. You've got the community health workers who are bringing all of these fragmented silos of services and it's not just hospitalizations.

It is the primary care. It is the behavioral health, the mental health and it is the long-term services and supports that are critical.

Mr. GUTHRIE. Well, I'm about out of time. That's exactly what we want so I'm glad you're saying that.

Mr. Merrill.

Mr. MERRILL. If I could add to that, Mr. Guthrie. As providers of care and really what ACE Kids is about is—at its core is coordinating the best are possible for these children and since we own our own health plan we have insight into the managed care part of this equation. And the managed care organizations, with all due respect, are focused on claims.

We're focused on care as providers and if we truly want to coordinate care with this population it needs to occur closer to the providers and not so much on the claims side of the equation.

That said, managed care organizations do play a key role in this and all of us have to work together if we truly want to achieve the goals and the aims of ACE Kids.

Mr. GUTHRIE. Thank you very much. I yield back.

Mr. BARTON. The gentleman yields back.

And we weren't able to have the managed care groups testify today but we did ask them for a letter and they have presented the letter and we will put that into the record and they do express some continuing concerns about the legislation.

With that, we recognize the gentlelady from Chicago, the co-chairman of the Czech Caucus with myself, Ms. Jan Schakowsky, for 5 minutes.

Ms. SCHAKOWSKY. Thank you, Mr. Chairman, and I am so proud to be a co-sponsor of the legislation, and I wanted to thank you, Mr. Chairman and Congresswoman Castor, for your great work on this, and I want to thank all the members of the panel who are here today to support the ACE Kids Act and to learn more about the challenges that we face to make the families and health providers able to serve the children with complex medical needs.

I especially want to thank you, Ms. West, for taking the time. I am just so thrilled. I had to walk out during your testimony but read it and just so thrilled to read currently Caroline is a happy child with an infectious smile and a happy disposition due to the care that you were able to, after many struggles, find.

Recently, a Chicago mother came to my office with her child who has complex medical needs, Antoine, and before they were able to find a medical home they really, really struggled.

They finally found it at Advocate's Children's Hospital in the Chicago area where he receives care and coordinated care for children with a medical complexity program. That's what it's called.

The coordination of Antoine's care, as you all know, is no small task and as you can see from his complex care map, I have a map that I can show the witness and the committee. And even with the assistance of Advocate's Children's Hospital, Antoine's mother remains his primary caregiver.

Despite these challenges, Antoine's family is definitely one of the lucky ones that it's able to live close to his health home and has a skilled medical team supporting him at the coordinated care for children with medical complexity program.

So, Ms. West, you mentioned how Medicaid has been in supplementing your family's private insurance to ensure that your daughter Caroline receives the care she needs.

Can you discuss why it's important for families that have children with complex medical needs to have access to both private in-

surance and Medicaid and how Medicaid coverage has helped Caroline to receive the health services she needs?

Ms. WEST. Yes. The insurance programs often do not cover some of the medicines that these kids need. So there were certain seizure meds that weren't covered that were very costly. The insurance programs limit the number of therapies that you can have per year or the types of therapies.

Even though the doctors are writing prescriptions for these things the insurance companies do not allow you to continue to have those therapies.

So Medicaid would pick up anything that our private insurance didn't pick up after our deductible. So, we buy insurance. We meet our deductible and then our insurance picks up and then we have Medicaid pick up the balance.

So many families don't even have the safety net of a private insurance and so they are going to the hospitals, to the emergency rooms particularly, costing the system a lot of money—more money than they would cost if they were going to a really good clinic for care.

Ms. SCHAKOWSKY. Thank you so much.

Some people think that managed care plans within a state's Medicaid program can do this work, coordinating care for some of the most complex and vulnerable kids.

And I'm not saying that a managed care plan doesn't necessarily do some very good care coordination work. But it seems like what I'm hearing today goes far beyond what a remote health plan provides.

Ms. Frangenberg, in your testimony you discuss some of the reasons why managed care plans might struggle to really offer the family-centered care coordination that these families rely on. In fact, in some instances certain claims denial practices or narrow networks just flat out don't work for this population.

So can you explain more about that?

Ms. FRANGENBERG. Sure. Thank you for that important question.

So managed care plans are not normally equipped to handle the highly specialized needs of children with highly complex needs.

So their networks are usually narrow and as we have heard today, many of these children need to cross state lines to get the care that they need and managed care plans are usually not very good at doing this.

Also, this population doesn't usually have the funding—I'm sorry, the managed care plans don't usually have the funding to pay the personnel to do the very complex care coordination that these children need.

So I would say that it's important we consider organizations such as family organizations who already have parents like Ms. West and that know the system, who would be able to provide guidance in that are coordination.

Mr. BARTON. The gentlelady's time has expired.

Ms. SCHAKOWSKY. Thank you.

Mr. BARTON. We now go to Dr. Murphy of Pennsylvania who yesterday passed his mental health reform bill on the House floor 422 to three.

Mr. MURPHY. To two.

Mr. BARTON. To two.

Mr. MURPHY. We convinced—

Mr. BARTON. Who's counting? So congratulations and you are recognized for 5 minutes.

Mr. MURPHY. Thank you, Mr. Chairman, and thank you for this bill.

So you had just said that it's really a landmark mental health bill. It makes a lot of changes and this committee and the Oversight Committee which I chair has done a couple years' worth of hearings on this and everybody on this committee has played a role in trying to help this.

But as part of this we recognize that those children with any medical problem it is an incredible psychological time—financial and emotional strain on the family.

And you know that when you have a chronic illness or an acute condition but certainly chronic, there's a much higher incidence of depression which oftentimes is completely overlooked in the pediatric population but we know is there.

You're also aware, I'm sure, that pharmaceutical costs are high in the extent that they are not followed. People may realize they are expensive. They don't understand. As you know, multiple physicians may prescribe different drugs. That's part of the problem that you need care coordination for.

We know that 72 percent of psychotropic drugs are prescribed by a non-psychiatrist and we know that over 90 percent of psychotropic medication for children is prescribed off label with massive errors.

But then again, we don't have enough child and adolescent psychiatrists. We have 9,000. We need 30,000. Part of what this bill does is create more incentives for child and adolescent psychiatrists, more psychologists and a lot more funding in there to do more pilot programs for tele mental health.

So this gets in a couple issues I want to talk about as we move forward in this. As you know, the people with a medical condition or let's say a psychological condition that's a particularly serious mental illness, 75 percent have at least one co-occurring chronic medical illness. Fifty percent have at least two. Thirty-three percent have at least three.

So along these lines, Dr. Berry, I want to ask you that—and I see you have an undergraduate degree in psychology, which makes you brilliant.

Dr. BERRY. The Harvard part is iffy at that.

Mr. MURPHY. But the extent of children with medical complexity that have serious mental illness and serious emotional disturbance what is the status of coordinating that physical and behavioral health care in dealing with a health care home? Could you address that issue?

Dr. BERRY. I mean, I think those children are the most vulnerable of the vulnerable, right. I mean, to have it on both sides, the emotional health and physical health component interacting is just unbelievably serious.

And we lean on our psychiatry/psychology teams a lot to try to get help coordinating their care. I think the problem is, and hopefully your bill is going to really help address this, is that there is

such an insufficient number of them that the vast majority of the care that they're providing now is acute care for emotional health demise that's occurring when the kids need to come in to the hospital for an acute episode to treat, et cetera.

We don't have that great community infiltration to maintain the emotional health of children after they come out of that.

So, I would hope that in all of this that mental health is hugely recognized as a major co-morbidity if not a primary condition for the children with medical complexity that we're thinking about to be included in these efforts and anything that helps integrate that mental health-physical health continuum would be fantastic.

Mr. MURPHY. I know the Children's Hospital of Pittsburgh has the warm handoff in the pediatrician's office where when they know when they make the referral right away to the family 90 percent compliance plus.

If they say, here's a number, call them back, particularly people on Medicaid, it drops well below 50 percent.

You have some who struggle to get to the office the first place, taking multiple buses and et cetera and now you say come back another day, one of the things this bill changes is to allow the same day doctor rule to be dropped.

But I want to ask, in the context of this how—is there something else we need to do in this bill or other bills to help—allow more if this care home for the medical complex to really coordinate those two issues, and I'll open this up to anybody here.

Dr. BERRY. Specifically for the transportation and sort of getting to the—

Mr. MURPHY. Well, no. Just in terms of what you need for having a good health home and medicine and Medicaid, et cetera, any comments by anybody to strengthen the bill? You don't have to have an answer. If you have one in the future—I want to submit that as a question for all of you.

Mr. SALO. I guess I would just offer that I completely agree with your sentiment about this as being one of the greatest challenges that we do have.

You know, I think the emerging good news is that this exactly is an issue that many, many state Medicaid programs are full on embracing and tackling right now is how do we better integrate.

I talk a lot about silos and physical and long-term care and pharmaceutical and behavioral health are all silos.

One of the things that many, many Medicaid programs are trying to do right now is to better integrate the behavioral health and the acute care within Medicaid and, again, it's within a lot of different contexts—some managed care, some health homes and that's why I think it's important for our approaches when we're looking at a more targeted area like kids with medically complex conditions to make sure that we've got the ability, again, not to just pigeon-hole this as an area that we kind of put off the side over here in a new silo but to allow it to blend in with some of these other efforts that are integrating behavioral health, that are integrating long-term care and those types of things.

So that's just to keep it—my advice to keep it broad so that it accommodates the directions that states are already going in that area.

Mr. MURPHY. Mr. Chairman, I'll submit the questions for the record for the rest of the panel. I hope you can address that because we know this is critically important. I thank you for your time today.

Mr. BARTON. OK. Seeing no other members on the minority side, we now go to the gentleman from Florida, Mr. Bilirakis, who's an original co-sponsor of the bill.

Mr. BILIRAKIS. Thank you, Mr. Chairman, thank you for holding this very important hearing and thanks for being so persistent along with Representative Castor on advancing this very important bill.

In the Tampa area we have St. Joseph's Children Hospital—

Mr. BARTON. We have late breaking news. Dr. Murphy has just co-sponsored the bill.

Mr. BILIRAKIS. Awesome.

Mr. BARTON. Let's give him a round of applause.

Mr. BILIRAKIS. I didn't have anything to do with that.

In the Tampa area, we have St. Joseph's Children's Hospital, which has been successfully running the Chronic Complex Clinic for Children.

I had the opportunity to visit the clinic at least once and it's one example of how to successfully treat children with complex medical conditions. I am pleased that Ms. West is here as well and, her daughter, of course, is a patient at St. Joseph's.

Ms. West, can you talk about how successful or unsuccessful the treatments before you came to St. Joseph's were and what it's like now for your daughter to be a patient at St. Joseph's?

Ms. WEST. Well, she's 19 years of age so we do have a diagnosis and we pretty much are in a routine of managing her care at this point. But earlier in her life we didn't have a diagnosis and so the diagnostic process was pretty crazy, trying to go across state lines and visit doctors who had various expertise.

And I always wondered, who's the case manager and found out that I was the case manager and that was shocking to me because I didn't have the expertise. So I had to quickly get the expertise.

When going to the Chronic Complex Clinic there are social workers there, case managers, people who were educated to help me navigate the health care system, the Medicaid system, and it was huge, not only just for me but now also for Caroline's overall health we were seeing doctors in a more timely fashion.

When we needed to see a gastroenterologist sometimes we could get the appointment the next day through the clinic instead of having to go home, get on the phone, make an appointment, wait a month.

Those kind of issues are really, really important and all of that worked seamlessly through the Complex Clinic.

Mr. BILIRAKIS. What was her medical condition at the time?

Ms. WEST. She has a rare disease called alternating hemiplegia of childhood. You don't need to remember that. It's complicated, but she presented with seizures, low tone cerebral palsy, posturing, nystagmus eyes bouncing all over the place.

It was a mystery because at first they thought she might have seizures and so we hooked her up to EEG and she wasn't having seizures. So then after that test was over we would be dismissed

so then we had to continue to pursue there was something wrong with her.

It's not seizures. It's something else. So eventually we did get a diagnosis of alternating hemiplegia, which is a rare neurological disorder by a spontaneous genetic mutation.

Mr. BILIRAKIS. OK. As a mother of a child with a complex medical condition, how important is it for good care coordination for both the patient and the caregiver?

Ms. WEST. Well, I mentioned earlier in my testimony that at one point before we went to the Chronic Complex Clinic that we actually had to check in to the hospital to get all of our doctors to communicate with each other and that was pretty costly to the system, I think, plus also to our family. Well, that doesn't happen now.

Mr. BILIRAKIS. OK. Question for the panel—is there a standardized definition of a medically complex patient? Who would like to go first?

Dr. BERRY. I think across the country we've pulled together a lot of stakeholders to try to pull that together and I think most agree on that the core attributes are a lifelong chronic condition that affects multiple organ systems to body that leads to significant impairment and even just that in itself really helps articulate and carve out the kids that we really think are complex.

Mr. BILIRAKIS. Anyone else want to—

Ms. WEST. I would just like to urge everyone to please work on a definition that is clear because I would hate to see this get diluted. I think it's important to keep it focused on kids who do have complex illnesses. As I mentioned earlier, going to a typical pediatrician's office was not a really healthy experience for any of my family or for my daughter.

But so going to a clinic where there are lots of kids who have medical complexity is much better. The doctors are more educated. We get things done faster and more efficiently and our daughter is more healthy.

Mr. BILIRAKIS. Anyone else want to elaborate on that?

OK. I know I only have a few seconds, Mr. Chairman. Care coordination is obviously so important, especially for parents with severe conditions. How do we promote greater care coordination in fee for service framework? Who would like to take that first?

Mr. MERRILL. I would say that the intent is to move actually away from fee for service and if you look at the intent of ACE Kids it's actually to move to an at-risk model.

And so if we're able to ramp up through shared data a common definition, quality standards and reporting at the national level that will allow us to accelerate our ability to better coordinate care, reduce waste, the fragmentation of care, the episodic care that occurs with this patient population today and ultimately move to the budget certainty that this bill or this act contemplates.

Mr. BILIRAKIS. Anyone else want to chime in?

Mr. BARTON. The gentleman's time has expired.

Mr. BILIRAKIS. OK. Thank you.

Mr. BARTON. Dr. Berry looked like he was just about to say something so we'll give him—

Dr. BERRY. Well, I will say here is just one anecdotal example. But the Michigan Medicaid program has instituted a policy for re-

imbursing clinicians and their fee for service model for non-face-to-face health care encounters for children with medical complexity—phone calls, paperwork, developing care plans, multi-disciplinary team meeting and just doing that, I think, has incentivized the providers to take on those clinical activities and do them well. It's a Band-Aid but it's working.

Mr. BILIRAKIS. Thank you so much. Appreciate it.

Mr. BARTON. Thank the gentleman. And now Mr. Long, who actually is a sponsor of the bill so we appreciate that.

Mr. LONG. Thank you, Mr. Chairman. I appreciate that and I just want to say for the record how we do ourselves a honor or privilege, I guess, or do ourselves right when we work on legislation like this in a bipartisan fashion that can do so much good for so many people.

And before I get into my question, I'd like to thank Representative Barton on the Republican side and Representative Castor on the Democrat side for all of their bipartisan work and hard work on this legislation and also our great children's hospitals in the state of Missouri and they have been tireless advocates for this legislation. I appreciate that very much.

And our oldest daughter—we have two daughters—our oldest daughter just finished up her first year of residency at the University of Missouri in pediatrics. So this is near and dear to my heart.

Mr. Merrill, in your testimony you referred to a necessary range of providers need to implement a care plan for a medically complex child. Can you expand briefly on what medical specialties this range typically includes and how broad it may need to be in order to properly serve these children?

Mr. MERRILL. Yes, and thank you for the question.

I think as we've heard through the testimony these children with medical complexity require the services and care of multiple pediatric specialists and it's pulmonologists, it's orthopaedic surgeons, it's neuro surgeons. It's cardiologists.

Just go down the line, and what children's hospitals are able to bring to the table is comprehensive services across multiple pediatric service lines to help better care for these patients. And in fact, because of the services that we offer we are the safety net for a lot of these families.

That said, we are not the equation but we are a key part of the equation. We play a key role in coordinating care. But other providers must be part of the equation as well including the specialty hospitals like Gillette, the HMOs, the home health care companies and, of course, as we've heard earlier the mental health services for this patient population.

Mr. LONG. Are you able to touch on some examples of barriers that prevent a medically complex child from receiving care from the appropriate range of providers under the Medicaid system?

Mr. MERRILL. Yes. So as a regional children's hospital not just for Texas but really for all of the southwest, we do receive a number of children from other states and unfortunately the comprehensive services that are offered at full service children's hospital aren't available in every state.

And so I could give you multiple examples and in fact I'd be happy to send your staff and the committee some examples of pa-

tients that come from states like New Mexico and it is an absolute struggle to get these children approved through Medicaid in New Mexico, to get them over to Texas to receive the high-level care, the services that we offer here. The travel, the difficulty of the long distances all come in to play and they create multiple barriers for these families.

Just one very key important point, though, if ACE Kids is passed the idea is to create these networks of care that allow us to push the care back into the community so that these kids can stay in those communities longer.

Mr. LONG. You mean when it's passed, don't you?

Mr. MERRILL. When it's passed. Thank you. Thank you. Thank you for the correction, Mr. Representative.

And so that would include enhancing the care and expertise of the local providers that are there in those communities.

Home monitoring, for example, and then more importantly ACE Kids does create a clear pathway for these children to move across state lines more easily if in fact that care is needed.

Mr. LONG. OK. Thank you. And Mr. Chairman, being an auctioneer I can do 5 minutes in 3 ½ minutes. So I yield back the rest of my time.

Mr. BARTON. All right. We appreciate that.

Seeing no other members present who haven't already had an opportunity to ask questions, we are ready to conclude the hearing.

We would like to give Mr. Green an opportunity for a few closing comments if he wishes.

Mr. GREEN. Mr. Chairman, I want to thank you and both my colleague, Kathy Castor, for bringing this bill up. It's been a work in progress and it still is.

But after we've had a good hearing, I think, today that brought the issues out that, I'll be looking forward to working with both of you all to see we move the bill out of the subcommittee.

Mr. BARTON. OK.

Mr. GREEN. And on to the full committee.

Mr. BARTON. Mr. Engel just walked in. Do you wish to ask questions, Mr. Engel?

Mr. ENGEL. Yes.

Mr. BARTON. All right. You're recognized for 5 minutes starting right now.

Mr. GREEN. And Mr. Chairman, the Missouri fellow said he could do 5 minutes in 3. Congressman Engel is from New York and he always talks faster than any Texan does.

Mr. BARTON. We just met with Mr. Trump this morning. He sends greetings to his fellow New Yorker, Mr. Engel.

Mr. ENGEL. Talking about someone who talks fast, Mr. Trump is certainly in that category.

Thank you, Mr. Chairman, and thank you, Ranking Member Green, for holding today's hearing. You know, it's difficult for members on either side of the aisle sometimes to find common ground.

But I think I speak for everyone here when I say that ensuring that children have access to quality medical care is an issue on which we can all agree and that is why I am a co-sponsor of the ACE Kids Act and I applaud my colleagues—you, Congressman Barton, and Congresswoman Castor for their work on this impor-

tant bill and I thank the witnesses today for their contributions and I hope that today's conversation helps to move this package forward so that we could have better care for children living with complex medical conditions.

Dr. Berry, in your written testimony you describe the key concepts of care activities for children with medical complexity and explain that such activities can help to, and to quote you, "optimize the health of children with medical complexity who are at high risk for poor health outcomes and excessive health care utilization."

Can you elaborate bit on who those high risk children are? I'd like to know who are the particular populations disproportionately affected by complex medical conditions and if that's the case what can we do to address such disparities.

Dr. BERRY. You can think about complex chronic conditions that affect any sentinel organ system and on the severity spectrum all of those kids are at risk. So complex congenital heart disease, neurological disease, urinary disease, digestive, all down the line.

Now, for some of these conditions, for example, cystic fibrosis might be one sometimes the care for those kids may be a little bit better coordinated and organized because the pediatric pulmonary providers are stepping up to the plate to really own the kids and maybe take care of their non-pulmonary problems.

In our experience, we think that the children that have underlying neuromuscular diseases are often the ones that sort of fall through the cracks a bit and don't get as good of care just because they tend to have more co-morbidities and sometimes the neurology workforce is just not equipped to manage all the problems.

Mr. ENGEL. Thank you. Let me ask you a follow-up concerning quality data in order to identify and address these disparities.

We need reliable and comprehensive data regarding children with medical complexity and I believe it's also important that such data is prescribed and collected at the CMS level so that we can have countrywide comparable information on this entire population because obviously without solid information about the issues affecting these children we cannot possibly hope to meet their needs. So let me ask you this, Dr. Berry.

Can you speak to the importance of high-quality national data on children with medical complexity and what data specifically do you feel it would be important to gather?

Dr. BERRY. It's great that right now we do have Medicaid claims data from all of these states, right, that include all their health care encounters across the continuum so that we can see how often these kids are engaging the system, where their spending occurs, et cetera, which is a wonderful base.

There is such variation in the quality and the depth and the organization of those data across states that it sometimes makes it impossible to look at one state and compare the experiences of a kid in the state versus another.

So just knowing on the Medicare side of what they have and they've been able to pull together this nationally clean data set that's readily accessible for use to quickly assess best practices, variation in care and outcomes for their patient population, to elevate what we have now with the Medicaid data and bring it on that trajectory to get to that Medicare side will be phenomenal.

Mr. ENGEL. OK. Thank you. It's 101, Mr. Chairman, so I listened to Mr. Green and became a fast-talking New Yorker.

Mr. BARTON. We thank the gentleman from New York.

I will remind members that they have ten business days to submit questions for the record and if they do I ask our witnesses to respond promptly.

The questions should be submitted by close of business on Thursday, the 21st of this month. Now, my final question to the panel—I am not asking you do you endorse the bill as drafted. But does everybody on the panel support the concept in the bill and encourage us to try to move the bill year?

Mr. Berry.

Dr. BERRY. Unwavering enthusiasm. Can't thank you guys enough for all the background work that led up to this unbelievably excited about the potential law.

Mr. BARTON. So that's a yes?

Dr. BERRY. That's a yes.

Mr. BARTON. Mr. Salo?

Mr. SALO. Yes, we absolutely support the concepts behind the bill and we'd be more than happy to work with you towards fruition.

Mr. BARTON. That's important. Thank you, sir.

Ms. FRANGENBERG. Absolutely, without a doubt.

Mr. BARTON. Thank you.

Ms. WEST. Yes. It's just so exciting to be here after 20 years of going through the medical system kind of alone to see all these people working together to come up with something that's going to be better for all these children and I applaud all of you for doing it. Thank you so much.

Mr. BARTON. Thank you.

Dr. KOOP. Yes. This discussion draft that we went through today is something we would support.

Mr. BARTON. Thank you.

Mr. MERRILL. On behalf of the children's hospitals, yes.

Mr. BARTON. OK.

Is there anybody in the audience that doesn't support it? All those in favor say aye. I mean it. Raise your hands. Let's see it.

Let the record show every hand went up.

The hearing is adjourned.

[Whereupon, at 12:22 p.m., the subcommittee was adjourned.]

[Material submitted for inclusion in the record follows:]



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*ex officio

Chief Executive Officer
Shalom Jacobowitz

*The mission of the American College of
Cardiology and the American College
of Cardiology Foundation is to transform
cardiovascular care and improve heart health.*

April 27, 2015

The Honorable Chuck Grassley
135 Hart Senate Office Building
Washington, D.C. 20510

The Honorable Joe Barton
2107 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Michael Bennet
458 Russell Senate Office Building
Washington, D.C. 20510

The Honorable Kathy Castor
205 Cannon House Office Building
Washington, D.C. 20515

Dear Sen. Grassley, Sen. Bennet, Rep. Barton and Rep. Castor:

On behalf of the American College of Cardiology (ACC), I am pleased to offer our strong support for S. 298/H.R. 546, the *Advancing Care for Exceptional (ACE) Kids Act of 2015*. The ACC is a 47,000-member medical society that is the professional home for the entire cardiovascular care team. The mission of the College is to transform cardiovascular care and to improve heart health. The ACC leads in the formation of health policy, standards and guidelines. The College operates national registries to measure and improve care, provides professional medical education, disseminates cardiovascular research and bestows credentials upon cardiovascular specialists who meet stringent qualifications. The ACC also produces the *Journal of the American College of Cardiology*, ranked number one among cardiovascular journals worldwide for its scientific impact.

S. 298/H.R. 546, the *Advancing Care for Exceptional (ACE) Kids Act of 2015*, would extend medical assistance to payment for items and services furnished under a Medicaid Children's Care Coordination (MCCC) Program. ACE is voluntary for states, providers and families. It would improve care for children with medical complexity by facilitating more seamless care for Medicaid children who see multiple providers across state lines. It would also enable the gathering of national level data on rare, complex conditions to determine best practices and drive continued improvement in care. It would require MCCC programs to coordinate, integrate, and provide a full range of services to enrolled children including pediatric care management, care coordination and health promotion. It would also establish a nationally designated children's hospital network to reduce hospitalizations and emergency room visits. These are laudable goals that would truly advance care for our most vulnerable patients, in complete alignment with the mission of the ACC.

According to the Centers for Disease Control, congenital heart defects (CHDs) are the most common type of birth defect. Access to proper care allows babies born with these conditions to live longer and healthier lives. CHDs affect nearly 1% of—or about 40,000—births per year in the United States.

About 25% of CHD cases are critical and require surgery or other procedures within the first year of life. From 1999–2006, there were 41,494 deaths in the United States that were caused by or directly related to CHDs. Nearly half (48%) of these deaths due to CHDs occurred during infancy (younger than 1 year of age).

The nation has a significant population of medically complex children with exceptional health care needs enrolled in Medicaid. Analysis suggests there are some 2 million of these children in Medicaid representing around 6% of children in the program. Despite their small numbers, this 6% represents 40% of the Medicaid spending on children, presenting both a cost challenge to the nation and an opportunity to address possible quality and cost savings in their care.

The American College of Cardiology would like to commend Senator Portman and Senator Bennet for authoring the budget resolution amendment that encourages Congress to focus on medically complex children. The ACC and its Pediatric Council looks forward to working with you to build support for S. 298/H.R. 546 and see that it moves forward in Congress. For more information on Congenital Heart Disease or ACC's priorities, please contact Nick Morse (nmorse@acc.org) or Charles Cascio (ccascio@acc.org)

Thanks very much for your leadership on this issue.

Sincerely,



Kim Allan Williams Sr., MD, FACC, FAHA, FASNC
President

United States House of Representatives
Committee on Energy and Commerce, Subcommittee on Health

Hearing on

“Examining the Advancing Care for Exceptional Kids Act”

Written testimony submitted by
Craig Butler
National Executive Director
Cooley’s Anemia Foundation

July 6, 2016

Chairman Pitts and Ranking Member Greene,

Thank you for the opportunity to provide written testimony for the hearing entitled, “Examining the Advancing Care for Exceptional Kids Act.” I am writing to you today on behalf of the Cooley’s Anemia Foundation (CAF), which is dedicated to serving people afflicted with various forms of thalassemia, most notably the major form of this chronic, genetic blood disease, Cooley’s Anemia/thalassemia major. Founded over 60 years ago, CAF’s mission is to advance the treatment and cure for this fatal blood disease, to enhance the quality of life of patients and to educate the medical profession, trait carriers and the public about Cooley’s Anemia/thalassemia major.

Thalassemia is the name for a group of blood disorders. There is a wide spectrum of severity for patients with thalassemia, ranging from mild to extremely severe, though many patients must receive regular blood transfusions to make up for the body’s inability to effectively produce hemoglobin. These regular blood transfusions cause a number of health concerns and risks for patients due to the resultant excess of iron in patients, requiring the use of iron chelators to normalize their iron levels. Patients with thalassemia face a number of issues related both to the management of their disease and as a response to the regular blood transfusions which are necessary for many patients.

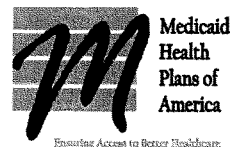
For transfusion-dependent children, many symptoms are the consequence of iron overload, a consequence of their regular blood transfusions. Symptoms of iron overload can include chronic fatigue, liver disease, abdominal pain, heart problems, joint pain, or even early onset osteoporosis. Though the quality and length of life has greatly improved for the thalassemia patient community, many patients will remain dependent on regular blood transfusions and impacted by their condition for the entirety of their lives.

Many thalassemia patients receive care through Medicaid due to the regularity of their healthcare needs and the overwhelming associated costs. As a consequence, the ACE Kids Act has the potential to transform care for these patients in a radical and positive way. As with

many chronic conditions, that which affects a child affects the whole family. Increasing availability of such services as care coordination, comprehensive care management, transitional care and follow up, and patient and family support, will help allow patients and their families to continue to live the healthiest and happiest lives possible while optimizing their access to care.

The Cooley's Anemia Foundation believes that in those states that implement it, the ACE Kids Act will be very beneficial to improving the quality of life for the patients and the families involved. We are proud to support the legislation and hope to see it fully implemented in the states.

Thank you very much for the opportunity to provide testimony regarding this vital and transformative legislation. With any additional questions, please do not hesitate to contact me at cbutler@thalassemia.org.



STATEMENT

MEDICAID HEALTH PLANS OF AMERICA

JULY 7, 2016

ENERGY AND COMMERCE COMMITTEE HEALTH SUBCOMMITTEE HEARING

"EXAMINING THE ADVANCING CARE FOR EXCEPTIONAL (ACE) KIDS ACT"

Medicaid Health Plans of America (MHPA) submits the following comments for the record for the Energy and Commerce Health Subcommittee hearing on "Examining the Advancing Care for Exceptional (ACE) Kids Act" scheduled for July 7, 2016. These comments are specific to HR 546 and the substitute "discussion amendment."

MHPA is the national trade association representing 165 managed Medicaid plans covering over 30 million enrollees in 39 states. Medicaid managed care organizations (MMCOs) provide high quality, coordinated health care services across the continuum of care at a negotiated, predictable, and cost-effective rate. MHPA agrees with the sponsors of HR 546 that children with complex medical needs must be assured access to the highest quality coordinated health care. The original language of HR 546 would make reaching this goal for very sick children significantly less effective, more expensive, and would lead to less accountability. As MHPA has noted in prior communications, most recently in MHPA's July 22, 2016 letter (attached), the current language in HR 546 would turn back the clock on 20 years of progress in achieving better outcomes for these children through fully integrated, at-risk plans.

In some respects, the substitute/discussion amendment is significantly different from the original bill and more clearly focuses on providing specialized coordinated care for children with complex medical needs. MHPA agrees eliminating several highly problematic provisions improves some aspects of the original language of HR 546. Specifically, the financial and structural incentives of the original that strongly favored carve-out specifically to free-standing children's hospitals have been dropped. In addition, the creation of a national network that shifts financial control for these children from states to HHS has also been eliminated. These are important changes that improve the provisions.

July 7, 2016

But MHPA continues to believe the “health home” structure described in the amendment puts children at risk. The language shows clear bias toward providing the care for these medically complex children through a fee-for-service payment model that lacks the rigorous quality monitoring and oversight required of Medicaid managed care plans. Specifically, the amendment 1) implements significantly higher federal matching funds for providing care coordination services (something not necessary with a capitated model), 2) provides a supplemental payment for providing the coordinated service (again unnecessary under a capitated model), and 3) fails to mention options that focus on structured, built-in incentives to achieve both savings and coordinated care.

Additionally, the amendment specifically permits “hospital emergency departments to refer children with medically complex conditions to designated providers.” (p.4) This referral by a hospital emergency room rather than by a child’s care coordination team or primary care provider suggests these “designated providers” operate outside established care coordination programs and existing Medicaid managed care systems. It appears this provision may empower hospital emergency rooms to initiate, or at least contribute to, a carved-out structure resulting in a fragmented care system for these children.

By contrast, federal and state law requires Medicaid managed care plans to adhere to rigorous quality metrics and undergo stringent oversight and monitoring. These mandates, including mandatory external assessments, 1) measure whether Medicaid enrollees receive the care they should, 2) provide a mechanism for state agencies to track plan successes both in patient outcomes and proper processes, 3) identify weaknesses in care provision, and 4) track corrective action. The fee-for-service structure has neither the quality oversight required of managed care plans, nor processes to identify best practices or possible areas of weakness that need to be addressed. MHPA is concerned that the health home structure proposed in the amendment continues to leave children at risk of falling into care systems that lack adequate quality oversight.

Children with complex medical needs are currently enrolled in the Medicaid managed care programs in 34 states and territories and currently receive the benefit of quality care guaranteed by the rigorous quality oversight mentioned above. MHPA suggests that instead of endorsing “one-off” programs that further fragment the system and are not proven to provide optimal care, a better approach is to build on current successful models, such as the managed, capitated, at-risk model that already have a proven track record treating children with complex medical needs. These managed care models encourage the use of best practices in key program areas such as care coordination, data collection, and alternative payment options like value-based purchasing (VBP). Furthermore, many Medicaid managed care plans have implemented medical-social models of care that are holistic in scope and encourage Medicaid MCOs to collaborate with their provider networks to tailor key practices to the individual enrollee.

The language of the amendment allows for reimbursement to health homes using payment structures other than fee-for-service. The fact that the amendment specifically mentions alternative payment methods are permitted suggests in practicality that most, if not all, health homes will operate under a fee-for-service structure.

Regardless, the language is silent on how these structures, no matter which payment methodology is used, would interface with existing care coordination systems such as MMCOs. For example, if a provider directs a child toward one of these health homes (as is allowed and specifically provided for in the amendment), how does the care provided to the child continue to be integrated with the child's MMCO care coordinators? With the child's current health care provider? Again, the amendment appears to exacerbate, rather than mitigate, fragmentation.

MHPA is certainly not opposed to the health home concept, per se. In fact, every enrollee having a functional health home (such as a primary care physician, etc.) is precisely the reason many states have moved to managed care for Medicaid enrollees in the first place and remains a fundamental concept of managed care. But the value of a stand-alone health home structure separate from existing capitated managed care structures, particularly in situations where children with complex medical needs are already enrolled in MMCOs, is questionable. MHPA believes these children would be far better served by a system that integrates all services for the child across the continuum of care. MMCOs are experts at providing high quality coordinated care to numerous populations with special health care needs -- including children with complex medical needs.

Clearly, state Medicaid agencies also see the success of the capitated, risk-based model for nearly all enrollees under their care. In 2015, a PwC analysis showed 70% of all Medicaid enrollees received their care through capitated, risk-based models and that number continues to grow. CMS also recognizes the dominance of Medicaid managed care. In a statement before this Subcommittee a year ago, Vikki Wachino, Director, CMCS, CMS/HHS declared "Medicaid is no longer a fee for service delivery system. Managed care is the delivery system that provides care to the majority of our beneficiaries, and we want to maximize its potential to ensure coordination and quality of care."

Unlike any of the fee-for-service alternatives, Medicaid managed care plans provide an essential quality guarantee and a proven track record for continuing success over time. Children with complex medical needs deserve no less.



Attachment

MHPA's Concerns HR 546 and S298 Advancing Care for Exceptional (ACE) Kids Act

MHPA member plans are full-risk capitated health plans that contract with states to operate a patient-centered, comprehensive and integrated payment and delivery system. Both federal and state regulation require Medicaid managed care plans adhere to stringent quality, program integrity and network adequacy standards, a practice not followed by Medicaid fee-for-service (FFS). In addition, the managed care structure incentivizes at-risk health plans to go above and beyond their contract requirements in order to better serve members, provide more coordinated/integrated care and ensure good stewardship of tax dollars for the states they serve.

MHPA's key concerns with the provisions of HR546 "Advancing Care for Exceptional Kids Act" (ACE) that establishes "Medicaid Children's Care Coordination Programs" (MCCC) are as follows:

Quality of Care and Data

HR 546 creates a new, federally controlled structure that incentivizes states to move an undefined population of children with complex medical needs into a fragmented, uncontrolled FFS structure that lacks quality oversight. While it is true that HR 546 suggests MCCC's should be able to eventually provide coordination, utilization and quality monitoring, HR 546 allows the MCCC's to move forward with only the promise that these functions will be accounted for at some point in the future. We believe it is duplicative at best, and at worst detrimental to high quality care to allow entities like MCCC's to be responsible for providing care to medically complex children while being free of the quality and program integrity oversight currently required of fully functional managed care organizations.

State Medicaid managed care programs (as mandated by law) have always required MCOs adhere to quality monitoring, improvement and data collection (42 CFR Part438 copied below). The excerpted language below illustrates the regulatory emphasis on quality assessment and performance improvement generally, but also focuses on services to special populations (see #4 below). No comparable federal requirements for quality monitoring or improvement exist for services delivered through Medicaid fee-for-service or in the proposed ACE language.

Further, although HR 546, in Section (e) "Quality Assurance" requires the Secretary of HHS to establish QA protocols, develop pediatric quality measures and network

adequacy standards, and "take into account HEDIS measures," implementation of the MCCC's is not contingent on these quality processes being completed, nor is there any recognition or accommodation for the fact that fully validated quality measures take years to complete. The proposed language in HR 546 is silent on how those standards, protocols, etc. will be used in monitoring quality or measuring outcomes and/or applied to value-based payment concepts, etc.

42 CFR 438.240 Quality assessment and performance improvement program.

(a) General rules.

(1) The State must require, through its contracts, that each MCO and PIHP have an ongoing quality assessment and performance improvement program for the services it furnishes to its enrollees.

(2) CMS, in consultation with States and other stakeholders, may specify performance measures and topics for performance improvement projects to be required by States in their contracts with MCOs and PIHPs.

(b) Basic elements of MCO and PIHP quality assessment and performance improvement programs. At a minimum, the State must require that each MCO and PIHP comply with the following requirements:

(1) Conduct performance improvement projects as described in paragraph (d) of this section. These projects must be designed to achieve, through ongoing measurements and intervention, significant improvement, sustained over time, in clinical care and nonclinical care areas that are expected to have a favorable effect on health outcomes and enrollee satisfaction.

(2) Submit performance measurement data as described in paragraph (c) of this section.

(3) Have in effect mechanisms to detect both underutilization and overutilization of services.

(4) Have in effect mechanisms to assess the quality and appropriateness of care furnished to enrollees with special health care needs.

External Review

One notable, long-standing requirement of a quality assessment and performance improvement program is the mandatory External Review.

Federal regulations (see 42 CFR Part 438, subpart E) require Medicaid MCOs to undergo an external quality review (EQR) by an External Quality Review Organization (EQRO) (as defined by 42 CFR 438.354). The process includes a number of mandatory and optional protocols. The mandatory category include:

- Review, within the previous three-year period, to determine Medicaid MCO compliance with state standards for access to care, structure and operations, and quality measurement and improvement;
- Validation of performance measures; and,

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- Validation of performance improvement projects (PIPs)

The EQRO (private accreditation organization review) culminates in several reports and assessments provided to the state that cover

- an assessment of each Medicaid MCO's strengths and weaknesses with respect to quality, timeliness, and access to care;
- recommendations for improving the quality of care provided by the Medicaid MCOs; and,
- an assessment of each Medicaid MCO's response to the quality improvement recommendations made in the previous year's review.

These external reviews provide an independent assessment of the state's Medicaid managed care program, indicate whether any program areas need additional monitoring, and include an assessment of the MCO's response to recommendations. Again, no comparable requirements exist for services provided under the current Medicaid fee-for-service program, nor do they appear to apply to the MCCCs established by the ACE language.

Updated and Significantly Strengthened Regulations

On May 6, 2016, CMS finalized a comprehensive update of Medicaid managed care rules and regulations (doubled in volume) that significantly clarified, updated and strengthened already stringent requirements in a number of key areas (Fed. Reg. Vol. 81, No. 88, May 6th, 2016). In the category of quality reporting and monitoring specific to children's services noteworthy additions included the following (Fed Reg. Vol. 81, No. 88, May 6th, 2016, p. 27658):

- states must ensure children's health care be accounted for under provider and network adequacy, specifically requiring –
 - time and distance standards for pediatric primary care providers and specialists
 - pediatric providers of behavioral health care
 - pediatric providers of dental services

HR 546 by contrast seems to limit networks for MCCCs to only stand-alone children's hospitals and the providers associated with those networks, leaving out a number of children's service providers and other excellent hospitals that have a proven track record and provide additional options that may in many cases be closer to a child's home.

Beneficiary Choice and Protections

As with the Quality Assurance provisions noted above, creating a new pathway for states to force children with complex medical needs be cared for through a fee-for-service model denies these children a number of access and appeals protections required for enrollees

in Medicaid managed care. Again, the ACE language does not replace them with comparable protections.

Patient Protections in Medicaid managed care programs:

Sections 4701, 4704 of the Balanced Budget Act of 1997 (Subtitle H – Medicaid, Chapter 1 – Managed Care) require states ensure that Medicaid managed care plan enrollees have a number of protections including but not limited to: (1) freedom to choose between at least two managed care plans, (2) access to grievance procedures, (3) guaranteed access to emergency services, (4) access standards including capacity and service adequacy, waiting times, travel times, access to specialty providers, etc. (5) compliance with maternity and mental health services requirements, (6) protection against balance billing, etc.

Disruption of Treatment and Lack of Coordination

HR 546 allows the state to prospectively enroll children in an MCCC program by assigning eligible children to a nationally designated children's hospital network for an initial period of up to 90 days. The bill does include an "opt out" provision, but it is weak at best. Although the child can be proactively enrolled in the network by the state (often after being identified by the children's hospital as needing care), opting out requires the child's caregivers to initiate a separate action using a yet to be defined state process. In short, while the assignment of the child to an MCCC is virtually automatic and requires no action on the part of the caregiver, opting out appears undefined and bureaucratic, potentially disrupting treatment and care coordination, and costing the state Medicaid program more money in the process (additional discussion on "cost" included in Financing and Payments below).

Coordination with Mental Health Parity Act of 2008

Since the MCCC program is exempt from Medicaid managed care regulatory requirements, it would also fall outside the requirements of the parity provisions of the Mental Health Parity and Addiction Equity Act (MHPAEA), again leaving children with complex medical needs outside the current protections required of Medicaid managed care plans.

Lack of Program Integrity

Medicaid health plans have a financial incentive to find and prevent improper payments. CMS reported FY 2015 payment error rates for Medicaid fee-for-service were 10.59% and for Medicaid managed care were 0.12% (HHS Financial Report, 2016, p. 193).

<http://www.hhs.gov/sites/default/files/afr/fy-2015-hhs-agency-financial-report.pdf>

Creating a new pathway for states to carve-out populations of enrollees whose care is complex and costly eliminates the inherent incentive present in capitated at-risk models to ensure accountability and appropriate payment for service at all levels.

Financing and Payments

Funding for the MCCC initiative is open-ended, uncontrolled and unpredictable. While the proposal allows for a transition to an "equitable, risk-based payment model" over five years, initial payments must be FFS, even in the 34 states where risk-based payments are already being made to address the needs of children with medically complex conditions.

This type of provider-based model will surely require the infusion of up-front capital to cover, at a minimum, the costs of coordination and care supports, not to mention what it may cost in terms of data collection and quality monitoring/reporting. In fact, the ACE language appears to recognize the need for additional funding making it clear that the hospitals in the MCCC networks will be eligible for additional payments above their fee-for-service payment rates for "per capita care coordination payments" for items and services provided through medical home programs and other care coordination activities.

One additional note -- The Secretary of HHS rather than the individual state makes final determinations concerning the payment methodology. This requirement effectively removes a state's control over managing services for this population and would appear to directly impact the state's traditional control over amount, scope and duration of benefits provided under Title XIX.

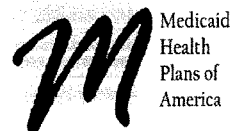
Transparency

HR 546 waives numerous Medicaid statutory requirements related to statewide availability and comparability of services, freedom of choice of providers, and the application of managed care regulatory requirements to entities receiving capitation payments. Although many states in the course of implementing new programs apply for and are granted a variety of waivers by CMS, most are required to obtain public comment and other input from interested parties as part of the waiver process. By waiving these requirements statutorily, the ACE language nullifies important transparency processes.

State Preemption

Any state law or regulation that impedes the ability of an MCCC program to fulfill requirements established for its operation is preempted, giving the Secretary of HHS rather than state regulators supremacy over the regulation of MCCC in states.

Jeff M. Myers
President and CEO



June 22, 2016

The Honorable Joe Pitts
Chairman
Energy and Commerce Health Sub-Committee
U.S. House of Representatives
Rayburn House Office Building
Washington, D.C. 20515

Dear Chairman Pitts:

On behalf of Medicaid Health Plans of America (MHPA), thank you for your commitment to ensuring the Medicaid program remains viable for future generations of those who have no other way to obtain health care for themselves and their families except through safety net programs like Medicaid. In particular, MHPA is grateful for your leadership and support of the Medicaid Task Force. As you know, MHPA has been working closely with Medicaid Task Force members to catalogue critical issues that must be addressed.

In the context of reforming Medicaid to ensure its viability, guarantee quality patient care, and curtail escalating costs, I want to underscore MHPA's serious concerns with the model proposed in HR 546, the "Advancing Care for Exceptional (ACE) Kids Act of 2015." Everyone agrees that poor children with complex medical needs must have access to appropriate medical interventions, and that care coordination is the key to making this work for the patient and their parents. Unfortunately, HR 546 as currently written would make reaching the goal of integrated, coordinated care for very sick children and their families significantly more expensive, less effective, and would ultimately lead to far greater spending in Medicaid with far less accountability. The legislation would "turn back the clock" on the sickest children by placing them in a separate fee-for-service (FFS) system, carved out of Medicaid managed care, reversing 20 years of progress in achieving better outcomes through fully integrated, at-risk plans.

Specifically, HR 546 creates Medicaid Children's Care Coordination (MCCC) entities, a new, federally designed structure that incentivizes states to move an undefined population of children with complex medical needs from coordinated, quality-monitored care provided by Medicaid managed care plans back into the fragmented, FFS payment structure. While it is true that HR 546 states that MCCC's must be able to coordinate, integrate and provide for the "full range of MCCC program services," none of these terms is defined nor are there specified timeframes for compliance. HR 546 allows the MCCC's to move forward with only the promise that these functions will be accounted for at some point in the future. We believe it is detrimental to high quality comprehensive care to allow entities like MCCC's to be responsible for providing care to medically complex

children while remaining free of the quality and program integrity oversight currently required of fully functional managed care organizations.

Medicaid managed care plans are highly regulated, particularly in the area of care management, quality monitoring, data collection, and program improvement. On May 6, 2016, the Centers for Medicare and Medicaid Services (CMS) released the final rule for Medicaid managed care regulation. The rule significantly strengthens many aspects of an already rigorous quality monitoring program. Moving these children back to fee-for-service, with only a vague promise that MCCCs will develop needed safeguards, denies medically complex children the guarantee that the quality of their care will be closely monitored.

Furthermore, using children's hospitals as both anchor and portal to the MCCC makes little sense if the true goal of the legislation is to ensure children with complex health care needs receive the highest quality, coordinated care across the full continuum of health care providers.

These premier specialty hospitals provide wonderful, compassionate, and near miraculous care. But neither their mission nor their expertise is in providing care coordination, or the kinds of administrative, "back-room" support and payment analysis called for in HR 546. This expertise will take years to develop and require significant financial investment. The period of time permitted for having fully developed MCCCs in place and the delay permitted for many features described in HR 546 appears to recognize this shortcoming. What is concerning is there is no guarantee that these systems will ever be developed, or consequences if they are not, leaving children with complex medical needs at risk of not receiving the full range of services they should.

Lastly, the national structure described in HR 546 overly federalizes Medicaid, diminishing the role of governors at a time when states are asking for more autonomy and control over their own programs, not less. HR 546 shifts authority to CMS to determine how care to children with complex medical needs will be provided, but does not diminish any of the state's responsibility to pay for the program. Our analysis shows HR 546 as currently written will significantly increase costs to Medicaid and we urge the Committee to take a close look at this aspect of HR 546 as well. With the cost in mind, I point out that states currently have the authority to create the type of MCCC structure described in HR 546. According to the National Association of Medicaid Directors (NAMC), a few Medicaid agencies have created an MCCC-type structure to focus on individuals with behavioral and other serious health care needs. But it appears states have not chosen to set up an MCCC structure with a children's hospital in the position of control as provided for in HR 546.

We at MHPA and our 165 member plans in 39 states are very proud of our commitment and proven track record providing the best quality care to the 28 million Medicaid enrollees we serve, including children with complex medical needs. We are also fully committed to ensuring verified gaps in care are resolved. But we are resolute in our conviction that the new structure created by HR 546 denies vulnerable children access to

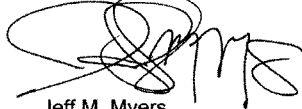
the higher standards of quality, transparency, and accountability required of all Medicaid managed care plans.

Attached for your consideration is a more detailed discussion of MHPA's position.

Again, thank you for your commitment to ensuring the Medicaid program is available for future generations of those who need assistance receiving health care and for your undaunted stewardship of taxpayer resources.

As always, I am available for questions or further discussion. Please feel free to contact me directly at 202-857-5720 or Jeannine M. Bender at jbender@mhp.org.

Sincerely,

A handwritten signature in black ink, appearing to read 'J. Myers', with a large, stylized initial 'J' and 'M'.

Jeff M. Myers
President and CEO
Medicaid Health Plans of America

June 22, 2016

July 6, 2016

The Honorable Cathy McMorris Rodgers
United States House of Representatives
203 Cannon House Office Building
Washington, DC 20515

Dear Representative McMorris Rodgers,

Seattle Children's delivers superior patient care, advances new discoveries and treatments through pediatric research and serves as the pediatric and adolescent academic medical center for Washington, Alaska, Montana and Idaho; the largest region of any children's hospital in the country. In 2015, Children's handled nearly half a million patient visits through specialized inpatient services, a large array of outpatient clinics, outreach visits to local health care organizations, on-call nursing consultations, and telemedicine.

Though our first priority is helping patients, we believe our role on behalf of our patients can also extend beyond the clinical setting and into the relevant policy arena. We were encouraged and grateful to hear that the Committee on Energy and Commerce's Subcommittee on Health would hold a hearing on one of our legislative priorities: the *Advancing Care for Exceptional (ACE) Kids Act*. Tomorrow's hearing is an important milestone that would not have been achieved without your leadership on the Committee. And while we have concerns with the current revised draft, we remain committed to working with you and your colleagues to improve and advance the bill toward final passage.

Specifically, it is important that future versions of this legislation support proven care coordination models and the data management systems required to maximize life-saving efficiency of care. Many Children's patients rely on an extensive team of experts for ongoing care. We, along with other children's hospitals and community physicians in our region, are dedicated to improving coordination of care to reduce the burden on families and improve outcomes and quality of life for children with complex conditions.

As it stands today, barriers to care coordination vary from state to state. A lack of comparative data on treatment approaches and outcomes consistently result in confusion and duplication of effort. This legislation has the potential to ensure that every child on Medicaid has a care coordinator, and that their provider team members in disparate locations are aligned on a plan of care based on evidence of success shown by comparative data from across the country.

This bill would also be strengthened by including more specificity in regards to the definitions of the population, identification of the specialized pediatric resources essential to the health home, and definition of the quality measures assessing health. Doing so would produce a more effective, targeted, and fiscally responsible draft.

We urge the Committee to consider using this legislative opportunity to define and establish adequate networks including highly specialized care for children with complex conditions, create a nationwide outcomes database to guide improved quality of care in the networks over time

and install a timeline for establishing and requiring consistent best practices for care across state lines.

Like you, we feel an urgency to work together and remove impediments to improved care for this very vulnerable population. Children's will always be a resource to hardworking public officials committed to improving the care and quality of life for children with complex medical conditions and their families.

Sincerely,



Jeff Sperring, MD
Chief Executive Officer
Seattle Children's Hospital
P.O. Box 5371
Seattle, WA 98145

DRAFT



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

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).

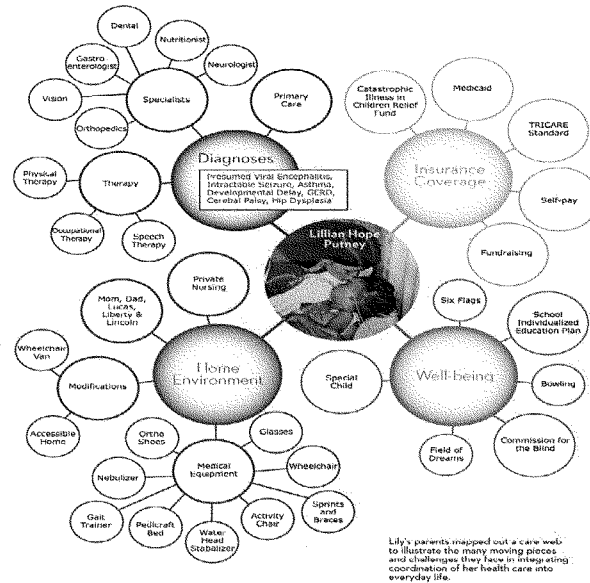
We are extremely grateful to Rep. Barton and Rep. Castor, for their leadership on behalf of children as the original cosponsors of this legislation, and to the more than 200 additional House members who have joined as cosponsors. We also wish to thank the leadership of the Energy and Commerce Committee 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*.¹ 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.

¹ 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>.



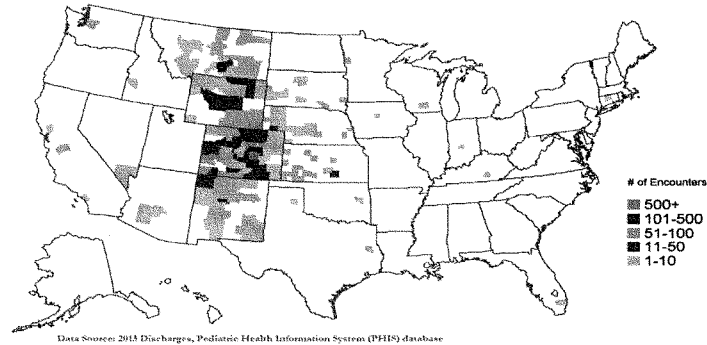
The ACE Kids Act can help families like Lily's in very real, tangible ways. The ACE Kids Act was developed in direct response to the experiences of these families and the clinicians serving them from across the country. It is clear the current system, working within the limitations of a state-by-state 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 Hospital Colorado
Children with Medical Complexity on Medicaid, Encounters by Home County



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.

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.



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ACE Kids Act – Letters of Support

May 20, 2016

Sending Organization	Recipient(s)
Adult Congenital Heart Association American Heart Association Mended <i>Little</i> Hearts Pediatric Congenital Heart Association	Sens. Grassley and Bennet Reps. Barton and Castor
American Academy of Pediatrics	Sens. Grassley and Bennet Reps. Barton and Castor
American Board of Pediatrics	Sens. Grassley and Bennet Reps. Barton and Castor
American College of Cardiology	Sens. Grassley and Bennet Reps. Barton and Castor
American College of Surgeons	Sens. Grassley and Bennet Reps. Barton and Castor
American Psychological Association	Sens. Grassley and Bennet Reps. Barton and Castor
American Society of Echocardiography	Sens. Grassley and Bennet Reps. Barton and Castor
Association of Medical School Pediatric Department Chairs	Sens. Grassley and Bennet Reps. Barton and Castor
ChildServe	Sens. Grassley and Bennet Reps. Barton and Castor
Family Advisory Council at Blank Children's Hospital	Sen. Grassley
Family Voices (with suggested changes)	Children's Hospital Association
Foundation to Eradicate Duchenne	Sens. Grassley and Bennet Reps. Barton and Castor

Page 1 of 2

Champions for Children's Health

Military Child Education Coalition	Sens. Grassley and Bennet Reps. Barton and Castor
Military Officers Association of America	Sens. Grassley and Bennet Reps. Barton and Castor
Military Special Needs Network	Sens. Grassley and Bennet Reps. Barton and Castor
National Association for Children's Behavioral Health	Sens. Grassley and Bennet Reps. Barton and Castor
National Association of Pediatric Nurse Practitioners	Sens. Grassley and Bennet Reps. Barton and Castor
National Down Syndrome Society	Sens. Grassley and Bennet Reps. Barton and Castor
National Military Family Association	Sens. Grassley and Bennet Reps. Barton and Castor
Parent Project Muscular Dystrophy	Sens. Grassley and Bennet Reps. Barton and Castor
Pediatric Congenital Heart Association	Sens. Grassley and Bennet Reps. Barton and Castor
Silicon Valley Leadership Group	Reps. Barton and Eshoo

August 15, 2016

Dr. Jay Berry
Assistant Professor of Pediatrics
Harvard Medical School
25 Shattuck Street
Boston, MA 02115

Dear Dr. Berry:

Thank you for appearing before the Subcommittee on Health on July 7, 2016, to testify at the hearing entitled "Examining the Advancing Care for Exceptional Kids Act."

Pursuant to the Rules of the Committee on Energy and Commerce, the hearing record remains open for ten business days to permit Members to submit additional questions for the record, which are attached. The format of your responses to these questions should be as follows: (1) the name of the Member whose question you are addressing, (2) the complete text of the question you are addressing in bold, and (3) your answer to that question in plain text.

To facilitate the printing of the hearing record, please respond to these questions with a transmittal letter by the close of business on August 29, 2016. Your responses should be mailed to Jay Gulshen, Legislative Clerk, Committee on Energy and Commerce, 2125 Rayburn House Office Building, Washington, DC 20515 and e-mailed in Word format to jay.gulshen@mail.house.gov.

Thank you again for your time and effort preparing and delivering testimony before the Subcommittee.

Sincerely,

Joseph R. Pitts
Chairman
Subcommittee on Health

cc: The Honorable Gene Green, Ranking Member, Subcommittee on Health

Attachment

ACE Kids Act - Responses to Questions

Jay G. Berry, MD MPH

Questions from Chairman Pitts

1. **In your written testimony, you indicated that children with medical complexity are using the hospital too much and primary, community, and home care too little. Why do you think this is and what do you think could be done to change this dynamic and reduce hospital use for these children? It is it fair to say that one smart option is capitation – whether to a high quality managed care plan or a large integrated delivery system?**

Children with medical complexity (CMC) use the hospital too much because they experience acute illnesses that are often not promptly treated fast and effective enough by primary and community care clinicians. Because so many CMC do not visit their primary care physician at all, they often rely on the emergency department as their first place to go for help with an acute illness. Emergency department clinicians – most of the time – recommend admission to the hospital to treat the acute illnesses.

CMC use home care too little because there is insufficient supply of pediatric trained home nurses to take care of the children. One of the biggest reasons for this insufficient supply is substandard payment of home care services by Medicaid. In multiple states, parents are heavily lobbying for increased payment for home services so that (1) more nurses will be incentivized to pursue work in pediatric home care and (2) home care companies will be more likely to engage in pediatric work.

I like the idea of thinking about capitation and/or a high quality managed care plan to help CMC. However, I've yet to observe existing situations with either of these ideas that have made a substantial impact on the health and well-being of CMC. We're currently working closely with a managed care company on a clinical initiative for CMC. The initiative is nice, but the managed care attributes offered by the company are not equipped to provide an integrated, proactive, and accountable health home for the children. I'm hoping that the health home aspect of the legislation might help provide a framework and incentive for existing capitation and managed care programs to "up their game" when caring for CMC.

2. **In your testimony, you noted that policymakers should bolster the availability and integrity of Medicaid claims data. A recent CMS final rule declined to share available, if imperfect, Medicaid claims data with qualified entities. Do you think it would be helpful to have imperfect and incomplete information instead of nothing? Should Congress think about pushing CMS to take a different approach?**

Yes, it will be helpful to have imperfect and incomplete information instead of nothing. However, it's challenging to grasp CMS' position regarding their data. On one hand, CMS has instituted fantastic policies that have optimized the availability and integrity of their Medicare claims data. On the other hand, they are declining opportunities to do the same with Medicaid data. I realize the Medicare and Medicaid data are federally and state nested, respectively. Maybe Congress might have better luck pushing CMS to optimize Medicaid data just for children with medical complexity as a start. These children are probably considered a "small" population in the eyes of CMS with a manageable amount of Medicaid claims.

3. You noted in your testimony that we lack comprehensive national data about some of the particulars about how children with medical complexity are served in Medicaid. It seems like you favor a federal solution. Yet, managed care plans, State Programs, children's hospitals, and others already have a tremendous amount of data and analytic capability to marshal data. If this is as urgent and important as you suggest, I assume committed parties are already participating in some form of public-private partnerships. Could you share with the committee what you and others are doing to leverage existing resources to collaborate on data and analytics?

This is great question. I favor a federal solution to make the data collected in the State Programs and managed care plans the best they can be. One idea for a solution is to establish rules and regulations (i.e., some form of national standards) for the states to institute when collecting, storing, and managing their Medicaid claims. It's really, really great that the data that you mention are out there. Hopefully the legislation will help improve the quality of those data so that they are consistently usable all states. Described below are some of my experiences with the data in their current state.

My colleagues and I have spent years and hundreds of thousands of dollars trying to use the Medicaid Analytic eXtract (MAX) data, which claims to offer useful State Program data for most U.S. states. We are very, very thankful that the MAX data exist. They are a great start! However, in reality, the data are usable from only a small number of states. The substantial up-front work and personnel/analytic costs to use the data from those limited number of states have been incredibly prohibitive. For example, multiple analytic programmers, statisticians, and health services researchers in Boston familiar with administrative healthcare claims data spent nearly two years trying to distinguish hospitals from the data in order to measure readmissions. If the data were in better shape to begin with, then they could be more efficiently analyzed without as much of a need for hefty resources to get into them.

I have collaborated with colleagues who have purchased (from Truven Analytics) Medicaid data from State Programs and managed care programs. Large amounts of those data (including payment and health services data from post-acute and rehabilitation care) are missing. Identifying use certain health services (e.g., primary care) that might seem straightforward has been extremely difficult due to the large amounts of missing and non-specific data. I just don't see those data – in their current state – ready for states to use to help develop and measure the impact of health homes for children with medical complexity.

I have repeatedly marshalled data on hospitalizations for children with medical complexity admitted to children's hospitals throughout the U.S. Although these data are fantastic and helpful, they are limited without health services data on the remainder of the children's health services (e.g., primary care, home care, etc.). I am aware of one public-private partnership seeking to merge children's hospital with state Medicaid data. The partnership was proposed through a federal NIH grant. There are some current CMMI initiatives for CMC that are attempting to pair children's hospitals with state Medicaid data. Maybe there are lessons learned from those initiatives to help inform the approach to bolster Medicaid data in the legislation.

Overall, my impression is that there is sound analytic capacity to marshal data, meaning that many institutions across the U.S. possess the computational hardware and software as well as the analytic personnel to do the job. However, given my experiences described above, the data out there currently to truly help CMC and their families really are insufficient.

Ultimately, I think it will be urgent and important for the health homes caring for CMC to have timely access to high quality Medicaid data so that they can (1) assess the children's health service use and spending across the continuum; and (2) make plans to optimize such use and spending.

Questions from Joe Barton

1. **A majority of witnesses recommended adding quality standards for health homes and providers that are specific to the needs of this pediatric complex population. What specific quality measures do you believe are key for states to use to ensure this population is served well?**

Process Measures. Consider using or adapting some of the quality standards that are currently reported by some states for children and youth with special healthcare needs. These standards are based on the National Survey of Children with Special Healthcare Needs. Texas' reporting: <http://www.childhealthdata.org/browse/data-snapshots/nsch-profiles/performance?geo=45>. I particularly like the process measures on having a usual source of care (especially urgent care), having the children's healthcare needs met, and having high quality care coordination.

Care Integration. Consider use of Gina Browne's Care Integration Measure, which can assess how well the members of a child's health home are working together to optimize the children's health.

Health Service Measures. Consider measuring hospitalization rates and duration (i.e., length of stay), hospital readmissions, and emergency department visit rates. Also, consider measure use of primary care.

Health-Related Quality of Life. More important than the other measures are the child and family's quality of life. We are all striving to optimize their quality of life as much as possible. Several validated tools exist to measure quality of life in children.

Questions from Cathy Castor

1. **You have been doing research on this population of children for a while, what data would you and other researchers find useful to better understand and care for these children?**

High-integrity Medicaid data that - across states - have the same data elements and coding structure with small amounts (or no!) missing values would be amazing. Such data, for the first time, could be used to truly assess best practices in care for children with medical complexity. For example, the data might show that use of home care for children with medical complexity is ten times higher in one state vs. another and that use of home care is associated with decreased use of the hospital and emergency department. States may find this useful when deciding whether to bolster their home care services for children with medical complexity.

- 2. Your testimony touched on the lack of incentives for providers, particularly primary, community, and home care providers, to take care of medically complex children. How could ACE Kids address this issue?**

I believe that the health home component of ACE Kids could help incentivize providers to take care of children with medical complexity, especially if enrollment in the health home is associated with benefits that would enable primary, community, and home care providers to take care of the children. Such benefits might include enhanced payment for office visits or care coordination tasks (e.g., chart review, phone calls, multi-disciplinary team meetings, etc.) that are typically not reimbursed in current fee-for-service payment models. Also, my sense is that most providers will want to be recognized publicly as capable to participate in a health home for the children. Hopefully, a little peer pressure might go a long way as an incentive to get more clinicians involved in the care of the children!

- 3. How would national level data help establish best practices for this population of children?**

In my experience, providers are hungry for health services data on how to best care for children with medical complexity. National data could help provide that. For example, many clinicians want to know how often CMC should visit with their primary care physician. Healthy children visit once a year. Maybe CMC should visit more often. National data would permit an assessment of variation in primary care visits for CMC across states. Maybe CMC from some states are visiting primary care more frequently than CMC from other states. Analyses could be conducted to assess whether increased use of primary care is associated with less use of emergency department and hospital. These analyses and data will help health homes decide how often CMC should visit with primary care. This is just one example of the simple yet very informative knowledge that could be gained with a national Medicaid dataset.

Providers are also seeking data on how to best manage and treat specific healthcare conditions, such as epilepsy, gastroesophageal reflux, respiratory insufficiency, etc. The medication and durable medical equipment billing data on the national level could go a long way to assessing best practices when treating the mentioned conditions.

- 4. Are there ideas we can learn from the current CMMI initiatives that are focused on children with medical complexities or it is too soon?**

Absolutely, there are ideas that we can learn from the current CMMI initiatives. It's not too soon to think about that. I believe that some of the initiatives have made progress attempting to incorporate Medicaid claims data into their initiatives. It would be great to learn about successes and non-successes in that process. There may also be health home-ish components to some of the initiatives. It would be great to know more about how those are working out. Perhaps there is a way to efficiently solicit the leaders of the initiatives for input and ideas.

August 15, 2016

Mr. Matt Salo
Executive Director
National Association of Medicaid Directors
444 North Capitol Street
Washington, DC 20001

Dear Mr. Salo:

Thank you for appearing before the Subcommittee on Health on July 7, 2016, to testify at the hearing entitled "Examining the Advancing Care for Exceptional Kids Act."

Pursuant to the Rules of the Committee on Energy and Commerce, the hearing record remains open for ten business days to permit Members to submit additional questions for the record, which are attached. The format of your responses to these questions should be as follows: (1) the name of the Member whose question you are addressing, (2) the complete text of the question you are addressing in bold, and (3) your answer to that question in plain text.

To facilitate the printing of the hearing record, please respond to these questions with a transmittal letter by the close of business on August 29, 2016. Your responses should be mailed to Jay Gulshen, Legislative Clerk, Committee on Energy and Commerce, 2125 Rayburn House Office Building, Washington, DC 20515 and e-mailed in Word format to jay.gulshen@mail.house.gov.

Thank you again for your time and effort preparing and delivering testimony before the Subcommittee.

Sincerely,

Joseph R. Pitts
Chairman
Subcommittee on Health

cc: The Honorable Gene Green, Ranking Member, Subcommittee on Health

Attachment

Attachment — Additional Questions for the Record**The Honorable Joseph R. Pitts**

1. Can you please discuss state Medicaid programs experiences with health homes? What are the benefits of a health home program and how have existing health homes improved care for beneficiaries?

At least 20 states have implemented one or more Health Home programs under Section 2703 of the Affordable Care Act. The states are in various stages of implementation and analysis of their programs, so that a comprehensive set of conclusions around the impact of the Health Home program is not yet available. An analysis results of the first several years of the Health Home program is due in October, 2016.

The benefits of a Health Home model can be described in two ways: 1. The particular administrative benefits of the language in Section 2703 which allows the states to develop and receive temporary enhanced FMAP for a Health Home; and 2. The benefits of providing a Health Home care coordination model for individuals in Medicaid with complex care needs.

From a state administrative perspective, the Health Home provisions in the ACA offer a number of advantages. First, although there are some designated performance requirements for the Health Home providers, the program is flexible enough so that states may adapt it to their particular programmatic needs. It can be targeted to populations or providers of particular interest to a state Medicaid program to address a perceived quality, access or care coordination deficit. The enhanced FFP in the initial 8 quarters of the program provides benefits to the states in setting up the necessary infrastructure.

From a beneficiary perspective, the Health Home has the potential to fill an important gap in care coordination; a gap that often exists for the most complex and vulnerable Medicaid recipients. The Health Home, when implemented effectively, has the potential to coordinate primary and specialty physical, behavioral and long term care services; and to provide enhanced access to social services important to vulnerable Medicaid populations.

“States implementing the health home program have flexibility in choice of payment system, geographic coverage, conditions targeted, and eligible populations. Although health home designs and implementation contexts are varied, three distinct health home delivery models have emerged. *Medical home-like programs* in Idaho, Iowa, Missouri (primary care program), and Oregon are variations on or extensions of the PCMH. *Specialty provider-based programs* in Missouri (mental health program), Ohio, both Rhode Island programs, and Wisconsin center on entities that traditionally serve special-needs populations but integrate specialized care with primary care. *Care management network programs* in Alabama, Maine, New York, and North Carolina involve consortiums of care coordination entities, direct physical and mental/behavioral health care providers, social services agencies, and other community organizations.”¹

¹ Evaluation of the Medicaid Health Home Option for Beneficiaries with Chronic Conditions: Annual Report – Year 3. 07/01/2015. Urban Institute. <https://aspe.hhs.gov/basic-report/evaluation-medicaid-health-home-option-beneficiaries-chronic-conditions-annual-report-year-three#execsum>

Early evaluation of the Iowa Health Home program showed lower costs, indications of improved self-reported functioning, and improvements in access to care.² In contrast, early evaluation of the Maryland Health Home program did not demonstrate improvements in utilization patterns.³

2. It is my understanding that many state Medicaid programs already have programs in place, either through managed care or other means, to coordinate care for children and others with chronic conditions or medical complexity. Can you discuss some of the existing state care coordination practices or programs?

Existing care coordination programs for children with medical complexity in Medicaid rely on many tools and strategies to improve outcomes and reduce excess costs. Care coordination is often built on the foundation of a person-centered assessment, which identifies the child's needs and goals, as well as an individualized service plan. Further, care coordination takes place by linking children to needed medical services, as well as social supports. In many cases, states use a patient-centered medical home construct to provide this care coordination. In this model, the child's primary provider is responsible for connecting a child to all needed services and supports and collaborating with the care team. The medical home may receive an enhanced fee from the state or managed care plan that is tied to meeting certain practice transformation expectations and may also be able to earn a quality bonus.

For example, Colorado implemented a state-established medical home framework for children through legislation in 2007, and since then, the state has built on this model through its regionally-tailored Accountable Care Collaborative model.⁴ This model leverages partnership between regional entities (Regional Care Collaborative Organizations) and primary care providers to coordinate the medical and non-medical needs of children. Likewise, California is building on its existing California Children's Services program, which serves children with complex conditions. The state is developing the Whole Child Model to better link children to patient-centered medical homes and the full array of health promotion and social supports that they need.

3. In your testimony, you noted that an enhanced federal match would be "an important incentive for states" looking at creating a health home, because it would "contribute significantly towards increasing the ability of states to build the infrastructure needed." To be clear, without an enhanced match, there would already be federal Medicaid matching available.

So other than cutting costs to states, what is the benefit of the enhanced match?

² Summary Report of the Iowa Medicaid Medical Health Home:
http://ppc.uiowa.edu/sites/default/files/hh_summary_report.pdf

³ 2015 Joint Chairman's Report on Health Homes:
[https://mmcp.dhmdh.maryland.gov/SiteAssets/SitePages/Health%20Home%20Program%20Evaluation%20and%20Outcomes/2015%20Joint%20Chairmens%20Report-](https://mmcp.dhmdh.maryland.gov/SiteAssets/SitePages/Health%20Home%20Program%20Evaluation%20and%20Outcomes/2015%20Joint%20Chairmens%20Report-%20Report%20on%20Patient%20Outcomes%20for%20Participants%20in%20Health%20Homes.pdf)

[%20Report%20on%20Patient%20Outcomes%20for%20Participants%20in%20Health%20Homes.pdf](https://mmcp.dhmdh.maryland.gov/SiteAssets/SitePages/Health%20Home%20Program%20Evaluation%20and%20Outcomes/2015%20Joint%20Chairmens%20Report-%20Report%20on%20Patient%20Outcomes%20for%20Participants%20in%20Health%20Homes.pdf)

⁴ Session Laws of Colorado 2007 First Regular Session, 66th General Assembly. Senate Bill 07-130.
http://tornado.state.co.us/gov_dir/leg_dir/olls/sl2007a/sl_346.htm.

What infrastructure would they build?

And wouldn't many states already have that in place from the demonstration programs or existing health home programs?

An enhanced federal match is a key incentive for states in determining their willingness to embrace any new option, even though they could embrace similar efforts with the regular federal matching level. Administering the Medicaid program is complex, time consuming and labor intensive. State administrators are often juggling multiple priorities and numerous efforts to improve the system. Medicaid is a balance between numerous federal mandatory provisions and optional state activities, and states often suffer from what has been described as "opportunity fatigue", where the complexity of taking on more and more options, demos and other programs becomes overwhelming to their fixed budgets and finite staff capacity. Incentives such as increased flexibility or enhanced federal matching funds are often a key factor in getting states to prioritize which new options they choose to pursue.

In fact, the enhanced match is rarely viewed as an opportunity to "cut costs to the state", rather it is an opportunity to spread existing resources even further, to get more impact from the taxpayer dollar.

The types of infrastructure to be built with respect to health homes generally relates to helping providers navigate what is called "practice transformation". Changing how the health care system works generally involves better coordinating fragmented delivery silos, reorienting misplaced financial incentives to focus on volume over value, or both. These concepts may sound simple on paper, but to primary care physicians and other key members of the Medicaid system, they represent significant hurdles and Medicaid can improve their odds of success by providing resources that enable them to change how they staff their practice, research the types of social and economic determinants of health that may be worth investing in, and in building interoperable IT systems (including EHRs but also data analytics capacity) in order to turn the theory into practice.

These investments must be made anew each time they are applied. While there may be economies of scale and lessons learned with the development/creation of IT systems for frail seniors or for adults with severe and persistent mental illness, they will likely need to be mostly (if not wholly) recreated for a system focusing on children with complex medical conditions. Medicaid's complexity does not lend itself to "plug and play" solutions, and "off the shelf" IT solutions/practice transformation guidelines generally do not exist.

4. Some have suggested that it would be beneficial to have a national system of care for children with medical complexity. Yet, variation among states has led to great sources of innovation. Can you discuss your thoughts about the importance of state flexibility in caring for these children?

State flexibility to design care delivery and payment models for children in Medicaid is not only a source of innovation, it is essential to its success. From the frontier states to the urban centers

of the country, there is significant variability in the health care marketplace and the way children access services. There are also significant differences in the populations of children with medical complexity served by state Medicaid programs. By allowing states to design innovations targeted to the needs of children in their state and the health care marketplace, these differences can be accounted for and success can be achieved. For example, a strategy that leverages Medicaid accountable care organizations (ACOs) for children with medical complexity may be appropriate to improve outcomes in certain geographic areas, but in others there may not be sizable provider entities positioned to bear the financial risk that typically accompanies this model. Similarly, states must be able to design models for these children that function within different delivery constructs in Medicaid, such as risk-based managed care or a traditional fee-for-service model.

Likewise, this flexibility allows state Medicaid Directors to partner with families, pediatric providers, and other local stakeholders to design patient- and family-centered innovations. This stakeholder engagement has been critical to the success of existing and new innovations aimed at improving outcomes and delivering value for kids, such as California's Whole Child Model.

Finally, the state flexibility to innovate has allowed states to ensure broad alignment of purpose, organization and implementation in its comprehensive reforms. The core components of the failed system we are moving away from include fragmentation, delivery silos, and financial incentives that do not reward improved outcomes. It is important that state flexibility be retained in innovations for the program's most complex populations, including children, so that further fragmentation is not created in the Medicaid delivery system.

The Honorable Joe Barton

1. What processes do existing networks that serve medically complex children in Medicaid or Medicaid managed care have to coordinate across state lines?

Coordination of care across state lines is carried out on a state-by-state basis. Often out-of-state providers will be enrolled or credentialed on an as-needed basis when the need for out-of-state services arises for a child in the Medicaid program. Managed care organizations may manage this process for states that use a Medicaid Managed Care delivery system.

For states that frequently use an out-of-state provider for services not routinely available in their state, the process may occur smoothly because of the frequency or relatively routine nature of the engagement. Challenges can arise when out-of-state providers are needed infrequently, and the state Medicaid agency or Medicaid Managed Care Organization does not have an ongoing relationship with the out-of-state provider. Both provider enrollment and rate negotiations can be administratively complex and potentially burdensome for both parties.

NAMD members recognize the importance of streamlining this process whenever possible, and are interested in working collaboratively with providers to improve the enrollment as needed.

2. Can you please explain what federal matching rate would be available to states for (1) state expenses for establishing a health home for medically complex children, (2) payments for providing health home services to eligible individuals under ACE Kids model? For example,

under current law would such expenses and payments be reimbursed under the state's matching rate for medical or administrative services?

NAMD reads the July 2016 legislative language as providing states enhanced federal funding (90 percent federal match) for health home services -- as defined in the draft -- for eight quarters following approval. Such services would be reimbursed at the state's regular FMAP after the eight quarters.

We anticipate states could request federal planning funds -- at their medical assistance service match rate -- to support health home program design. This would be consistent with CMS' guidance for the existing Health Home initiative.

3. During the hearing you mentioned the cost associated with infrastructure needed for states to establish a health home for medically complex children. Can you please elaborate on what infrastructure states would need to establish and the associated cost? Would states that already have health homes under current law face the same cost for establishing a health home for medically complex children or do they already have the necessary infrastructure established?

Whenever a state Medicaid agency implements a new program, state agency infrastructure is needed in order to ensure that the program is designed and implemented effectively, that oversight of the provider(s) is conducted, and that program effectiveness is measured and monitored.

In the case of a health home for medically complex children, below are some of the types of agency activities that would require new or re-deployed resources in order to optimally develop and implement such a program:

- Program design and Federal Authority
- Provider outreach and education
- Managed care contracting
- Beneficiary outreach and education
- Provider training
- Quality measurement design, implementation and oversight
- Financial modeling
- Rate setting and payment design
- On-going program management

The number of Full Time Equivalent employees that would be needed for such a program will vary from state to state, depending on whether existing employees have available capacity to add the program, whether the requisite expertise exists at the agency, and the number and types of providers and beneficiaries effected. Program evaluation in particular is an area where states often need to bring on additional staff or contract with outside entities.

A state which already has a Health Home program in place would likely also need to add infrastructure and resources, but there may be some economies of scale depending on the particular circumstances involved.

4. A majority of the witnesses recommended adding quality standards for health homes and providers that are specific to the needs of this pediatric complex population. What specific quality measures do you believe are key for states to use to ensure this population is served well?

The Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA) provided for the identification of a core set of healthcare quality measures for children enrolled in Medicaid and CHIP. The Measures Application Partnership is a public-private partnership that annually reviews the so-called "Child Core Set" and makes recommendations to HHS for strengthening and revising measures. In its 2015 report⁵ the MAP Child Task Force recommended strengthening the measure set with respect to Care Coordination, Home and Community-based Care, Mental Health, Durable Medical Equipment, and Social Services Coordination. Measures in each of these areas would be highly relevant to monitoring quality for children with complex medical needs. The MAP structure appears to be well situated to advise HHS on strengthening the measure set in this area.

The Honorable Kathy Castor

1. Language is included in the discussion draft that says states shall include in its state plan amendment, how it will educate providers about this health home model for children with medical complexities. While I believe the existing health home model for chronic care does not have this educational component, do you know of any successful provider and family education models or recruitment tools to help educate providers and families on this new health home option? Do you have any recommendations that are not currently in use?

NAMD does not currently have access to an inventory of provider-education strategies for Health Homes. In our work with states to understand their provider outreach strategies for delivery system reform more generally, we have learned that states are using the State Innovation Model Test funding in some cases to implement provider education and training programs around quality measurement and care coordination. The National Improvement Partnership Network is an example of an educational model that is focused on improving care for children. "The National Improvement Partnership Network (NIPN) is a network of over 20 states that have developed Improvement Partnerships to advance quality and transform healthcare for children and their families. An Improvement Partnership is a durable state or regional collaboration of public and private partners that uses the science of quality improvement and a systems approach to change healthcare infrastructure and practice."⁶

2. How would national level data help establish best practices for this population of children?

While national level data remains a goal for many researchers and policy makers, it is important not to underestimate how difficult it would be to put that into practice. For example, it is clear that there is no clear consensus on how we would even begin to define children with medically

⁵ Strengthening the Core Set of Healthcare Quality Measures for Children Enrolled in Medicaid and CHIP, 2015. http://www.qualityforum.org/Publications/2015/08/Strengthening_the_Core_Set_of_Healthcare_Quality_Measures_for_Children_Enrolled_in_Medicaid,_2015.aspx

⁶<https://www.uvm.edu/medicine/nipn/>

complex conditions. Similarly, state Medicaid programs have chosen different quality metrics and other requirements relevant to their states, their health care provider and systems infrastructure, and the populations they serve. It is far more important for consensus to develop around core measures that the health care system can effectively adopt and adapt to. There is a tendency for so-called "mission creep" to develop in these areas where the availability of a set of measures or data leads inevitably to desires and demands for expanded measures and such developments often do not consider the lengthy lead time it takes to reprogram or reprocur IT systems, to train providers on the collection, and to fully understand how to interpret the data as it evolves.

None of these challenges should be viewed as de facto barriers to developing best practices, however. Centers of Excellence (however they are defined) exist throughout the health care system (Medicaid, Medicare and commercial). While the vast majority of children with special needs are covered under Medicaid (and not Medicare), the Centers for Medicaid and CHIP Services is well situated to help analyze different approaches to both clinical outcomes as well as processes such as contracting with out of state providers.

3. Are there ideas we can learn from the current CMMI initiatives that are focused on children with medical complexities or is it too soon?

The Center for Medicaid and Medicaid Innovation (CMMI) has a number of initiatives that are focused on children in Medicaid and the Children's Health Insurance Program. In particular, CMMI placed a particular emphasis on pediatric innovations in its second round of Health Care Innovation Awards in 2014 where eight pediatric projects were funded.⁷ Despite the promise of these innovations, it is too early in the process to identify effective strategies and lessons learned, given the time it takes to stand up new payment and delivery system models. As the recent interim evaluation report of these models noted, the models are still in the early stages of implementation and progress has yet to be made on the payment approaches that will support them.⁸ Therefore, additional experience is needed with these models before we consider institutionalizing lessons learned in the Medicaid delivery system through federal legislation.

4. We are still working on the definition for a medically complex child in ACE, do you have any advice on how we should define these kids?

Clarity in the definitions of services and populations has always been an issue for researchers and policy makers in Medicaid. Without clearly articulated, federally driven requirements for definitions of such services as "assisted living", or populations such as frail seniors at risk of institutionalization, state Medicaid programs have developed their own categorization in ways that best meet the needs of their own programs. While this may seem confusing to others who

⁷ Children's Hospital Association. "Children's Hospitals Applaud CMMI for Awarding \$79M in Grant Funding to Children's Health." July 15, 2014. <https://www.childrenshospitals.org/newsroom/press-releases/2014/childrens-hospitals-applaud-cmmi-for-awarding-79m-in-grant-funding-to-childrens-health>.

⁸ Mathematica Policy Research. "Evaluation of the Round Two Health Care Innovation Awards (HCIA R2) First Annual Report." August 2016. <https://downloads.cms.gov/files/cmmi/hcia2-yroneevalrpt.pdf>. Pg. xiii and xiv.

look to compare apples to apples, it has enabled Medicaid programs to evolve and grow in unique ways that push the program forward.

So a strong push to clearly articulate a hard and fast definition of medically complex children may serve to disincite states from pursuing reforms that make sense to their Medicaid programs. State options, like the proposed health home, must remain flexible enough that states can clearly articulate how their adoption can meet their own internal goals and improve their Medicaid programs in concrete ways.

States should be allowed to propose how they might define medically complex children for the purposes of this proposal.

The Honorable Diana DeGette

To be eligible to receive hospice benefits, one must be diagnosed as having no more than six months to live. Parents and medical providers are understandably often hesitant to make a hospice determination for a child. However, increased access to palliative and hospice benefit services from the time of diagnosis can drastically improve the quality of care and outcomes for this population of children. Some states have therefore used 1915(b) and 1915(c) waivers to waive the hospice eligibility requirement for children with life-threatening illnesses.

1. Would the National Association of Medicaid Directors agree that hospice eligibility can be a barrier to care for children with life threatening illnesses?

NAMD has not explored the intersection of hospice care and children with life threatening illnesses, and therefore does not have a position on the issue.

2. What factors should Congress consider creating a state plan option to waive the hospice eligibility requirement of having a life expectancy of six months or less for this vulnerable population?

While we have not done any independent research or analysis on the issue, if Congress is considering a state plan option to waive the hospice eligibility requirement, it should fully explore the experiences of states that have used combo (b) and (c) waivers to get their perspectives on how well (or not) that approach worked. Combining multiple waiver authorities is generally a complex and burdensome endeavor for most states. However, states would want to be comfortable knowing that a comparable effectiveness (of waiving certain statutory provisions) could be achieved with a simple state plan option.

August 15, 2016

Ms. Maria Isabel Frangenberg
Project Coordinator
Family Voices
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Albuquerque, NM 87176

Dear Ms. Frangenberg:

Thank you for appearing before the Subcommittee on Health on July 7, 2016, to testify at the hearing entitled "Examining the Advancing Care for Exceptional Kids Act."

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Thank you again for your time and effort preparing and delivering testimony before the Subcommittee.

Sincerely,

Joseph R. Pitts
Chairman
Subcommittee on Health

cc: The Honorable Gene Green, Ranking Member, Subcommittee on Health

Attachment



August 29, 2016

The Honorable Joseph R. Pitts
Chairman
Subcommittee on Health
Committee on Energy and Commerce
U.S. House of Representatives
2125 Rayburn House Office Building
Washington, DC 20515-6115

Dear Mr. Pitts:

Thank you for the opportunity to answer additional questions for the record of the hearing at which Maria Frangenberg appeared as a witness on behalf of Family Voices. Please find the answers to the questions attached.

If you have any further questions, please do not hesitate to contact me at jguerney@familyvoices.org (or 202-546-0558).

Sincerely,

/s/

Janis Guerney
Public Policy Co-Director
Family Voices

cc: Maria Frangenberg

Attachment

**Responses to Questions for the Record
From Maria Frangenberg of Family Voices
Hearing on the Advancing Care for Exceptional (ACE) Kids Act (July 7, 2016)**

The Honorable Joe Barton

- 1. A majority of the witnesses recommended adding quality standards for health homes and providers that are specific to the needs of this pediatric complex population. What specific quality measures to do you believe are key for states to use to ensure this population is served well?**

Family Voices believes it is critical to have standards, including quality standards, for health homes and providers. Standards regarding quality cannot stand alone; they must be part of a broader set of standards addressing the various aspects of “quality” – clinical care; organizational processes (e.g., record-keeping, responsiveness to enrollee questions); personnel training; access to care (e.g., ability to get a timely appointment); cultural and linguistic competence; patient and family satisfaction; and patient and family engagement. It is also important that health homes and providers be required to submit data about the various standards so that compliance can be evaluated.

We recommend that specific standards be developed by the CMS Administrator or the Secretary through robust consultation with stakeholders (including organizations representing children with special health care needs and their families), via formal (e.g., RFI) and informal (e.g., face-to-face) communications.

We believe that the standards should require that the health home have the qualities of a “medical home,” as identified by HRSA – it should be “accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.” Further, we believe that the health home should be required to demonstrate that it:

- has expertise in providing and/or coordinating care for children with medically complex conditions;
- is familiar with the state’s Medicaid program, including available waivers;
- has the infrastructure, personnel, record-keeping capacity, and other elements needed to provide health home services in accordance with the standards and to make the required reports;
- is capable of providing health home services in a culturally and linguistically competent manner;
- is family-centered, and includes the child’s family in the development of care plans and coordination activities;
- will fully engage families in the development, operation and evaluation of its services; and
- will provide adequate notice and transition assistance to the beneficiaries it serves should the health home cease to serve as a health home.

Some elements of “quality” can be found at the HRSA webpage, *What is a medical home?* <http://www.hrsa.gov/healthit/toolbox/Childrenstoolbox/BuildingMedicalHome/whyimportant.html>. In addition, Family Voices has developed a tool to assess the degree to which a health care provider is “family-centered.” The tool can be found at <http://www.fv-ncfpp.org/activities/fcca/>.

The Honorable Kathy Castor

1. You recommend that states must also outline a process to educate families about health home services. Do you have any recommendations on how this could be done?

We recommend that states contract with and compensate the state Family-to-Family Health Information Centers (F2Fs) to provide outreach and education activities (e.g., culturally and linguistically appropriate publications and events) related to health home services. Family-to-Family Health Information Centers, authorized and funded under section 501 of the Social Security Act, are staffed by families of children and youth with special health care needs (CYSHCN). This grant provides funding for the F2Fs to help diverse families of children and youth with special health care needs to navigate the health care system. Thus, they are perfectly suited to reach and educate the families who should be aware of health home services, including underserved populations. Family-to-Family Health Information Centers work with families of CYSHCN to help them apply for Medicaid and Medicaid waiver programs, and help them resolve problems that may arise in obtaining services. In addition, F2Fs work closely with their state and regional children’s hospitals and other providers of services to CYSHCN, so they are already familiar with most of the entities that might choose to become health homes for children with medically complex conditions. Moreover, the staff of F2Fs are familiar with their own state’s Medicaid benefits, fee-for-service coverage, and Medicaid managed care organizations, so they can help families figure out whether they would benefit from enrolling in a health home.

It is critical, however, that F2Fs be compensated for outreach, education, and assistance regarding health homes for children with medically complex conditions. Currently, each F2F – one in every state and the District of Columbia -- receives a federal grant of less than \$95,000 per year. While some F2Fs have other sources of financial support, they all have insufficient capacity to serve all of the families of CYSHCN in their states. In states that establish health homes for children with medically complex conditions, F2Fs undoubtedly will receive more requests for advice and assistance. To serve families adequately, F2Fs will need continued and increased federal support. Thus, we strongly recommend that the F2F program be reauthorized and funded beyond FY 2017 at an increased level of funding. (Under current law, the F2F program is authorized and funded through FY 2017 at \$5 million per year.)

Additionally, in the development of their outreach and education plans, should be required to fully involve representatives of families of CYSHCN, including staff from the state’s F2F and representatives of community-based organizations representing diverse families of CYSHCN and underserved populations.

All outreach and education activities should be conducted in a culturally and linguistically competent manner, in accordance with the HHS *National CLAS Standards*, at <https://www.thinkculturalhealth.hhs.gov/content/clas.asp>.

Finally, all entities conducting outreach and education, along with all health homes and providers of services to children with medically complex conditions, should be required to coordinate with and provide families with contact information for their state's F2F.

2. How would national level data help establish best practices for this population of children?

National-level data will enable establishment of a baseline for various elements of services to children with medically complex conditions. Once a baseline is established, different aspects of providing care for these children – including cost, clinical care, utilization, coordination of services, access to services (including services in other states), and family engagement – can be compared. For example, if a particular health home's approach to family engagement is shown to reduce costs of care, then other health homes can adopt those practices.

3. Are there ideas we can learn from the current CMMI initiatives that are focused on children with medical complexities or is it too soon?

We do not have an answer to this question at this time. We are reaching out to our state affiliates for information about CMMI initiatives in their states.

4. We are still working on the definition for a medically complex child in ACE, do you have any advice on how we should define these kids?

As noted in our testimony (p. 15), we are concerned that the definition of “child with medically complex condition” in the House discussion draft may be too narrow in some respects, in that it would not include children with a **single** but very serious or complex condition or injury that does not *also* either affect two body systems and reduce cognitive or physical function, or is not life-threatening or a rare “disease.” Examples might include a child with a serious mental illness, or a child with a mild condition and where a co-occurring behavioral condition that exacerbates the primary health problem.

In any case, we caution against listing specific conditions, unless they are clearly used only to provide examples of conditions meeting the definition. Otherwise, a list is likely to be over- or under-inclusive. In addition, regardless of the definition, we recommend that states *not* be permitted to restrict it, in part because the state might then exclude children who could benefit from the services of a health home, and in part because having different definitions in different states would make it impossible to collect standardized national data about these children.

In our testimony, we recommended that the committee further consult with stakeholders about the definition. After further consideration, however, we recommend that the committee set broad parameters, but delegate the crafting of the precise definition to the Secretary, who should consult with experts and stakeholders via formal (Request for Information) and informal (e.g., meetings) processes.

August 15, 2016

Ms. Tish West
4506 West Watrous Avenue
Tampa, FL 33629

Dear Ms. West:

Thank you for appearing before the Subcommittee on Health on July 7, 2016 to testify at the hearing entitled "Examining the Advancing Care for Exceptional Kids Act."

Pursuant to the Rules of the Committee on Energy and Commerce, the hearing record remains open for ten business days to permit Members to submit additional questions for the record, which are attached. The format of your responses to these questions should be as follows: (1) the name of the Member whose question you are addressing, (2) the complete text of the question you are addressing in bold, and (3) your answer to that question in plain text.

To facilitate the printing of the hearing record, please respond to these questions with a transmittal letter by the close of business on August 29, 2016. Your responses should be mailed to Jay Gulshen, Legislative Clerk, Committee on Energy and Commerce, 2125 Rayburn House Office Building, Washington, DC 20515 and e-mailed in Word format to jay.gulshen@mail.house.gov.

Thank you again for your time and effort preparing and delivering testimony before the Subcommittee.

Sincerely,

Joseph R. Pitts
Chairman
Subcommittee on Health

cc: The Honorable Gene Green, Ranking Member, Subcommittee on Health

Attachment

Additional Questions for the Record
Tish West Responding

Honorable Joe Barton

1. A majority of the witnesses recommended adding quality standards for health homes and providers that are specific to the needs of this pediatric complex population. What specific quality measures do you believe are key for states to use to ensure this population is served well?

While medical professionals offer a clinical response to questions regarding quality measures, I offer a parent's perspective. From my view, I am hopeful that the defining qualities we have found in our medical home at the Chronic-Complex Clinic at St. Joseph's Children's Hospital in Tampa, Florida provide a foundation upon which care for all medically complex children can be built. For Caroline, co-location of specialists and the coordination of care have been especially critical. Additionally, it is very important that any standards being considered are specific to medically complex kids, not kids in general or adults. This is a very specialized sub-set of patients that needs very specific standards. The Children's Hospital Association has recommended focusing on several areas important for children with complex medical conditions, including: health and well-being; care management; coordination/integration of care; child and family experience; access to medical care across settings; and cost. My personal experience confirms these components are central to improving care and the quality of life for complex kids and their families.

Honorable Kathy Castor**1. How would national level data help establish best practices for this population of children?**

From my perspective, establishing a national data set will help to identify ways that we can work to improve the quality of care for medically complex children across the country – identifying best practices and helping to establish accountable medical/health homes to provide critically-needed coordination of care for complex kids and their families. Our move to the Chronic-Complex Clinic at St. Joseph’s Children’s Hospital was life-changing for Caroline and our family. Yet far too many complex kids do not have the immense benefit found in having a true medical home; they continue to struggle – as we did – to get the care that they need.

2. Are there ideas we can learn from the current CMMI initiatives that are focused on children with medical complexities or is it too soon?

We’ve begun to see what is possible when we work together, with common definition and purpose, toward better care and quality of life for medically complex children. A couple of strong lessons learned at this point are: the importance of parent involvement in the making choices for health care options; centralized medical records accessible to the families, doctors and the hospital, and developing a strong access plan to educate the communities on the existence and availability of the clinic. I believe strongly that the ACE Kids Act is urgently needed as a next step – to allow thousands of complex kids and their families across our country the ability to experience just how much better life can be when you have a true medical home. The CMMI grant has validated that

this is the right approach. We now need to make that a permanent change.

3. We are still working on the definition for a medically complex child in ACE, do you have any advice on how we should define these kids?

As the parent of a medically complex child, I have a different view when asked how we should define complex kids. I see my daughter and I know that she is very medically complex and fragile. I see so many other children and their families who we have met in the more than nineteen years we have spent navigating a health care system not designed for our children. The ACE Kids Act offers a definition of children with complex medical conditions. Leading clinicians who have spent decades caring for these children worked to develop this definition, and I believe this is an appropriate and well-informed way to define this population as we move forward on a national level to improve care and the quality of life for these children and their families.

August 15, 2016

Dr. Steven Koop
Medical Director
Gillette Children's Specialty Healthcare
200 University Avenue East
St. Paul, MN 55101

Dear Dr. Koop:

Thank you for appearing before the Subcommittee on Health on July 7, 2016, to testify at the hearing entitled "Examining the Advancing Care for Exceptional Kids Act."

Pursuant to the Rules of the Committee on Energy and Commerce, the hearing record remains open for ten business days to permit Members to submit additional questions for the record, which are attached. The format of your responses to these questions should be as follows: (1) the name of the Member whose question you are addressing, (2) the complete text of the question you are addressing in bold, and (3) your answer to that question in plain text.

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Thank you again for your time and effort preparing and delivering testimony before the Subcommittee.

Sincerely,

Joseph R. Pitts
Chairman
Subcommittee on Health

cc: The Honorable Gene Green, Ranking Member, Subcommittee on Health

Attachment



August 30, 2016

The Honorable Joseph R. Pitts, Chairman
Subcommittee on Health
Committee on Energy and Commerce
2125 Rayburn House Office Building
Washington, DC 20515-6115

Dear Chairman Pitts:

On behalf of our leadership, thank you again for affording Gillette Children's Specialty Healthcare the opportunity to provide testimony at the July 7 hearing titled "Examining the Advancing Care for Exceptional Kids Act." We are grateful for the attention Congress is giving to improving care for children on Medicaid as a result of their medically complex condition and especially for your staff's work to improve pending legislation.

Attached please find responses from Gillette Children's Specialty Healthcare to the follow-up questions you provided. Again, thank you for your work. Gillette's leadership stands ready to assist you in continuing Congressional efforts to improve Medicaid for our patients.

Sincerely,

Dr. Steven Koop, M.D.
Medical Director

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Duluth
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Additional Questions for the Record

The Honorable Joseph R. Pitts

- 1. In your testimony you note that Gillette provided inpatient care to Medicaid children from 18 states. Would you please discuss how your hospital has worked with Medicaid programs and families to provide access to care to children from other states?**

Gillette Children's Specialty Healthcare is a specialty hospital that focuses on conditions of the musculoskeletal and neurological systems. Our unique focus means that we care for children that require lifelong care coordination and benefit from medical interventions. 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.

Because of this, Gillette sees patients from a number of states each year. Children with disorders like Rett Syndrome, which occurs 1 in every 10,000 female births, or Guillain-Barré syndrome, which occurs 1 out of every 100,000 people, need to be able to see a rare disease specialist familiar with their unique healthcare needs. For some conditions that are statistically uncommon, it is possible that there are only a handful of physicians and clinics in the entire country that specialize in treating the condition. This is particularly true for pediatric specialists. Families may continue to see their primary care provider near their home but be willing to travel long distances for diagnosis and specialty care needs.

This is why patients come to Gillette. They come because often they cannot access the specialized care they need in their state.

In these cases when patients seek out Gillette or are referred by a provider, we work with their state Medicaid programs to facilitate their care. Gillette is currently enrolled with the Medicaid programs of eight states including Minnesota. In addition, we work with many other state Medicaid departments to arrange for treatment for individual cases when requested by the state. Although the process can be cumbersome, specialty hospitals are accustomed to working with states other than our home state to get care approved and ensure that families receive the services they need. Further, our social workers and physicians work with out-of-state patients to help coordinate care, provide services to ease the burden on these families (including assistance with lodging and transportation), and explain the pathways to receive coverage under Medicaid, which are not always streamlined, even within states. For example, to enroll a child in Medical Assistance

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(Minnesota's Medicaid program) as a result of medical complexity or disability our social workers help families through a process that varies based on which of the the 87 counties in Minnesota in which the patient resides.

As described in our testimony, in recent years, Gillette's inpatient unit (not including outpatient clinic visits) served patients who are Medicaid and Medicaid eligible from 18 states.

The Honorable Joe Barton

- 1. A majority of the witnesses recommended adding quality standards for health homes and providers that are specific to the needs of this pediatric complex population. What specific quality measures do you believe are key for states to use to ensure this population is served well?**

Quality measures are a critically important part of the effort to improve care for children with medically complex conditions. Our recommendation would be to focus on quality measures that demonstrate functional outcomes that are meaningful to the child and family. We would look to metrics that measure effective care coordination, easing the burden on enrollment and approval of services, and measures of patient function across domains such as movement and communication. All measures should be based at least in part on the patients and families' evaluation and satisfaction.

We would also recommend considering unplanned readmissions as this data can demonstrate the success of care coordination efforts in helping to keep children with medically complex conditions from returning to an inpatient setting in the hospital. In addition, research on health-related quality of life shows that this and related measures, such as functional status and patient perception of satisfaction, are important for meeting a child and family where they are at based on their unique abilities and condition.

The Honorable Cathy Castor

- 1. How would national level data help establish best practices for this population of children?**

As we stated in our testimony, we are grateful that the Subcommittee has put forth language that prioritizes a data-based solution and sharing of the learnings. We had previously recommended that the ACE Kids Act as introduced be amended to create a

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study to help us better understand this vulnerable population of patients on Medicaid and highlight best practices for achieving the goals of the ACE Kids Act.

We believe it is paramount that we understand the children enrolled in Medicaid who would be affected by any proposed changes and the number and types of providers currently serving these children. The reality is that we have little longitudinal data about young people with childhood-onset complex musculoskeletal and neurological conditions. We simply do not know, in a comprehensive manner, the nature of the healthcare resources they require between birth and any age you choose to specify. That's a problem because it is hard to talk about best practices without knowing what is needed, expected, or commonly utilized during the years of growth and development.

We need national level data that is equal to or more robust than Medicare claims data. We need to learn what currently impacts a provider's ability to refer patients across state lines, what are the obstacles to payers paying out-of-state providers, what influences a family's ability to get a child in the care of the most appropriate specialist, and what are the trends or themes in where and how gaps in access affect families. From these learnings we could begin to highlight best practices and develop an effective solution for where and how families and providers are experiencing challenges. National data should look at existing gaps in care, including supply, distribution and shortages in pediatric subspecialties and the number of medically complex Medicaid children crossing state lines and for what types of services. This is foundational to any federal effort to revamp Medicaid.

2. Are there ideas we can learn from the current CMMI initiatives that are focused on children with medical complexities or is it too soon?

There is a dearth of data available on the number of children who have medically complex conditions (including how that population is defined), access to Medicaid including enrollment and cross-state lines coverage, and care examination and highlighting of best practices in covering children in Medicaid and protecting access to specialty care.

The CMMI Coordinating All Resources Effectively (CARE) initiative for children with medical complexity is one example of a data effort underway aimed at improving care to children who have medically complex conditions. The study funded by the CARE Award is beginning to provide data that will be useful for national discussions but it is not complete yet. A number of the outcomes are not yet reported and/or available for analysis

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widely. In addition, this initiative is hospital-centered, focused on large, acute hospitals, rather than being centered on patients and families. Further, specialty hospitals, family practice providers, clinical centers and other providers are not included in the effort.

Before we create a far-reaching superstructure that could disrupt the care children currently receive, we must first work together to collect comprehensive, patient-centered data on access, care coordination, and outcomes for children with complex medical conditions. This is why we are so supportive of the MACPAC study in the House Discussion Draft, and why in our comments submitted to the Committee we recommended Congress focus first on data before implementing new systems.

3. We are still working on the definition for medically complex children in ACE, do you have any advice on how we should define these kids?

The definition of children who have medically complex conditions must not be excessively rigid or descriptive, yet limiting enough to truly identify “medically complex” children. For example, a definition that was too broad would group children with conditions that are not truly medically complex. Language that is too restrictive in naming specific diagnoses, disorders, or diseases may leave out children who are medically complex. We recommended in our comments to the House Energy and Commerce Committee that the definition list 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.

Further, it is important to ensure that the definition not lead to rankings in medical complexity, which could lead to prioritizing one child over another. To ensure focused, adequate access to needed care the definition must protect the care for all children with medically complex conditions.

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August 15, 2016

Mr. Rick Merrill
President and CEO
Cook's Children's Health System
801 Seventh Avenue
Fort Worth, TX 76104

Dear Mr. Merrill:

Dear Mr. Merrill:

Thank you for appearing before the Subcommittee on Health on July 7, 2016, to testify at the hearing entitled "Examining the Advancing Care for Exceptional Kids Act."

Pursuant to the Rules of the Committee on Energy and Commerce, the hearing record remains open for ten business days to permit Members to submit additional questions for the record, which are attached. The format of your responses to these questions should be as follows: (1) the name of the Member whose question you are addressing, (2) the complete text of the question you are addressing in bold, and (3) your answer to that question in plain text.

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Sincerely,

Joseph R. Pitts
Chairman
Subcommittee on Health

cc: The Honorable Gene Green, Ranking Member, Subcommittee on Health

Attachment

The Honorable Joseph R. Pitts

1. **In your testimony you stated that “we lack, at the most basic level, standard definitions for children with medical complexity.” If we do not have a definition of what constitutes medical complexity and therefore do not have an appropriate way to identify children with medical complexity, then how can we create a system of care targeted to this population? Should we first do studies or research on how to define and identify the population?**

Many studies have already been completed by the clinical experts in the field on definitions of this population. The ACE Kids Act proposes a definition that can be applied nationally, and this definition was advanced by the leading clinicians caring for these children. With the ACE Kids Act, we will have a definition that the leading researchers in the country agree is appropriate to define the population.

2. **You noted in your testimony that we lack comprehensive national data about some of the particulars about how children with medical complexity are served in Medicaid. It seems like you both favor a federal solution. Yet, managed care plans, State programs, children’s hospitals and others already have a tremendous amount of data and analytical capability to marshal data. If this is as urgent and important as you suggest, I assume committed parties are already participating in some form of public-private partnerships. Could you share with the committee what you and others are doing to leverage existing resources to collaborate on data and analytics?**

While data exists, it is neither uniformly captured nor shared. The available data is locked inside of 50 separate states in non-standard format, and in many cases fully controlled by many separate state-based health plans who compete with each other and don’t share data with each other or providers. The data we have at Cook Children’s is from our own health plan in Texas, and while it is only a small sample of the state and the nation, it is key to better coordinating care and reducing costs.

3. **As I understand it, Cook Children’s has a Medicaid managed care plan, which already is or will soon be covering children with medical complexity as well as other Medicaid beneficiaries. Please describe how your health plan coordinates care for children. Why is a health home option needed if states have the option to serve these children through managed care plans which already provide care coordination services?**

We provide an integrated pediatric subspecialty health home at Cook Children’s that is very similar to what is proposed by ACE Kids Act. The standards for our health home go far beyond the minimums defined by our state or any other state sending children to us for care. This level of pediatric subspecialty coordination is not occurring on any broad

basis outside the small number of plans similar to our own. Even in a state such as Texas with a mature Medicaid managed care model we do not see evidence of plans providing this level of integrated and coordinated care for this population.

- 4. Mr. Merrill, as a Medicaid health plan, how do you provide needed services to enrollees if those services are not available from an in-network or in-state provider? Do you have procedures in place to allow enrollees to access out-of-state or out-of-network care if medically necessary?**

Yes, the pediatric specialists in our medical home understand our local, state and national pediatric program options and coordinate referrals and communications when we cannot provide the services at Cook Children's.

Managed care organizations can negotiate case rate agreements, individually, with any provider that is out of network. We can and do negotiate such case rate agreements. As the CEO of a hospital, I often am confronted with either case rate agreements we have negotiated to accept an out of state patient, that is not paid, or that is later denied for lack of authorization or some other bureaucratic rationale. Moreover, several states have created barriers that either prohibit or make it very difficult for a patient to receive care out of state.

The Honorable Joe Barton

- 1. Given the population of children this legislation is trying to help, can you please elaborate and list the additional services medically complex children require, besides medical care?**

These children require a coordinated set of social, educational, home, behavioral and vocational services, and importantly a very close connection with their parents and guardians to ensure these services can be managed. Specific examples of additional services include: learning assistance; technology/living support; motor skill development; behavioral health; transportation; reminder/recall notices; medication management; home health services, durable medical equipment, physical, occupational and speech therapy and other therapies.

- 2. Since Cook Children's is not only a hospital but also has a managed care plan for children on Medicaid, can you please discuss the health home services your managed care plan currently provides? What additional benefits would be provided by the proposed health home model described in the ACE Kids discussion draft?**

Each family has a care plan and all our providers work from this plan; each family is attached to a primary care team to ensure not just all medical and behavioral care are provided, but that all the needed social, educational, home and vocational services are coordinated. All data from all our children is collected on a standardized basis and used to improve care and costs, and shared across all our providers.

- 3. A majority of the witnesses recommended adding quality standards for health homes and providers that are specific to the needs of this pediatric complex population. What specific quality measure do you believe are key for states to use to ensure this population is served well?**

Cook Children's currently employs a number of quality standards for this population such as reduced inpatient days, reduced ER visits and reduced stress on the families of these patients. That said, we would not recommend identifying specific quality measures in the legislation since the field will continue to evolve, particularly with the new national data outlined in the legislation. We would instead suggest a process for identifying measures that are appropriate for this population and areas to focus on for measures that are important for children with medical complexity, including: health and wellbeing, care management, coordination/integration of care, child and family experience, access to medical care across settings, and cost.

The Honorable Kathy Castor

- 1. How would national level data help establish best practices for this population of children?**

National level data is needed for the analysis of utilization data and the development of best practices for both optimal payment models and optimal care delivery models for this population particularly given the relatively small, heterogeneous population of these highly complex patients. Similar to what is very successfully done today with Medicare, where national data exists, we'd have the opportunity to study best practices, choose protocols with the most favorable costs to reduce unnecessary expenses, and support national collaboration across all our states, plans and providers to accelerate learning and outcomes.

- 2. Are there ideas we can learn from the current CMMI initiatives that are focused on children with medical complexities or is it too soon?**

It is too soon, but simply having a shared definition of the children and their problems, and sharing this across our participating CMMI award sites, has allowed us to work together on best practice, best cost, and best outcome for these children. This works!

3. We are still working on the definition for a medically complex child in ACE, do you have any advice on how we should define these kids?

Many studies have already been completed by the clinical experts in the field on definitions of this population. The ACE Kids Act proposes a definition that can be applied nationally, and this definition was advanced by the leading clinicians caring for these children. With the ACE Kids Act, we will have a definition that the leading researchers in the country agree is appropriate to define the population.