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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, D.C.

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.

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 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, 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 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 four 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 Herrera Beutler -- Congresswoman Beutler, who just had a brand new baby boy who is totally healthy. But her first daughter had -- 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, five minutes for opening statements.

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 the 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 co-sponsors -- 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, five minutes for an opening statement.

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 kids -- 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.

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

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, Representative 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' opening statements -- written opening statements will be made a part of the record. That concludes our openings 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 or for pediatrics, Harvard Medical School, and Mr. Matt Salo, executive director, National Association of Medicaid Directors.

Then Ms. Maria Isabel Frangenberg, project coordinator, Family Voice. 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's 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 five 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 five 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 -- five 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 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, M.D., M.P.H. follows:]

**********INSERT 1**********

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 five 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 the -- 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 differently 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 -- you know, 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 sharing -- creating, compiling and sharing best practices is critically important.

There is no currency in Medicaid like -- 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:]

**********INSERT 2**********

Mr. Pitts. Chair thanks the gentleman and now recognized Ms. Frangenberg five 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 of medical debt and are even saving for college for their own two children. They 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 success story -- 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 propose that -- 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:]

**********INSERT 3**********

Mr. Pitts. The chair thanks the gentlelady and now recognizes Ms. West for five 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 Hopkin 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:]

**********INSERT 4**********

Mr. Pitts. The chair thanks the gentlelady and now recognizes Dr. Koop five 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 five 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:]

**********INSERT 5**********

Mr. Pitts. Chair thanks the gentleman and now recognizes Mr. Merrill five 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 better -- 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, a 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:]

**********INSERT 6**********

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 follows:]

*********COMMITTEE INSERT 7**********

We are going to take a five-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 five minutes.

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

Mr. Pitts. Okay, ladies and gentlemen. If you'll take your seats, the premier committee on technology, 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 five 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, you know, 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, you know, 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, you know, 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 sort of 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, you know, 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. Okay. 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, you know, as I alluded to earlier there are a lot -- you know, 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 a more -- 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 five 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. Okay. Is St. Joseph's Hospital on the -- 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. Okay. Well, I'm just wondering because I've had issues for a long time that, you know, 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 -- 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 -- you know, you get them from everywhere.

Dr. Berry. Yes, we do. We do. You know, it's interesting. The whole reason why -- 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. Okay.

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

Now, understanding that and sort of 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. This is very --

Mr. Green. Thank you for the time.

Mr. Barton. Mr. Pitts has -- yes, 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 five 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 from the -- 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 follows:]

**********COMMITTEE INSERT 8**********

Mr. Barton. Before I ask my questions I want 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 three weeks ago in which it was very intense -- 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 to 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, you know, measures of the child's health specifically, patient-family experience -- you know, 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. Okay. 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, you know, making sure that we're focussing 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. Okay.

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. Okay.

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. Okay.

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. Okay.

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 home health -- health home was family -- it was the family's decision.

Is that something that we need to -- I mean, 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 mean, 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, the -- to get states to opt into the system, which is voluntary, we have an eight-quarter or two year 90 percent federal funding match, which Chairman Upton has indicated that we will fund to pay for. Is that -- 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, you know, 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 kind of cut through the clutter and say all right, that's going to -- 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, you know, at least, you know, an eight quarter enhanced match is going to allow for some of that infrastructure investment. And so it think it's really critical, if at the very least for that.

Mr. Barton. For some reason, my time expired two 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 -- I would 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, I mean, not to them but sometimes to the child as well.

And then you go in and there are all these, you know, cute little kids running around and families who are staring at you and don't really know what to make of you and it's -- 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 know, you don't really want to go to the doctor. So, you know, 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 complex clinic -- the Chronic Complex Clinic, everyone welcomes you.

There's lots of kids who have multiple disabilities. You know, 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 five or ten 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, talk 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, you know, 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, you know, 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.

You know, 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 just -- 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 seven 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. You know, 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 -- 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 five 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 four or five or -- about six months when he was eight 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 eight 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 of the bill and -- 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 I -- 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 mean, it is -- 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, you know, 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. Okay. 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 we're -- what we're seeing -- 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. You know, one of the things that some of the states say is that fee for service -- and again, to Ms. Castor's point, you know, fee for service, you know, 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, you know, 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.

[The information follows:]

**********COMMITTEE INSERT 9**********

With that, we recognize the gentlelady from Chicago, the co-chairman of the Czech Caucus with myself, Ms. Jan Schakowsky, for five 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 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 medical complex -- 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 insurance and Medicaid and how Medicaid coverage has helped Caroline to receive the health services she needs?

Ms. West. Uh-huh. 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, you know, 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 highly complex -- 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 -- it 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 five minutes.

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

So you had just said that it was really -- 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 issue 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 a 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 their -- 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, you know, 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 they will -- 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, you know, 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, you know, health homes and that's why I think it's important for our approaches when we're looking, you know, at a more targeted area like kids with medically complex conditions to make sure that we're being -- that we've got the ability, again, not to just pigeonhole 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 want -- we know this is critically important. I thank you for your time today.

Mr. Barton. Okay. 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, I appreciate -- 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.

(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, like, who's helping me here -- 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. But -- 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 -- 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 genetic mutation -- spontaneous genetic mutation.

Mr. Bilirakis. Okay. 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. Okay. Question for the panel -- is there a standardized definition of a medically complex patient? Who would like to go first?

Dr. Berry. You know, 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?

Okay. Next question -- 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. Okay. Thank you.

Mr. Barton. Dr. Berry looked like he was just bound 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 reimbursing 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, you know, 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 for their -- 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 hospice -- 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 some examples and the committee some examples of patients that come from states like New Mexico and it is an absolute struggle to get these children approved on the Medicaid -- 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.

Monitoring -- 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. Okay. Thank you. And Mr. Chairman, being an auctioneer I can do five minutes in three and a half 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, you know, I'll be looking forward to working with both of you all to see we move the bill out of the subcommittee.

Mr. Barton. Okay.

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 five minutes starting right now.

Mr. Green. And Mr. Chairman, the Missouri fellow said he could do five minutes in three. 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 important 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 know, 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, I mean, 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 for -- 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. You know, it's great that right now we do have Medicaid claims data from all of these states, right, that include their -- 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. Okay. 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. Okay.

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.]