Title V, Social Security Act:

Honoring Our Past, Celebrating Our Future

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Children & Youth With Special Health Care Needs

BONNIE STRICKLAND: Well, hello, good afternoon. I'm Bonnie Strickland, the director of the Division of Services for children with special healthcare needs at the Maternal and Child Health Bureau. I have the distinct pleasure today of introducing this session on improving children's health, a vision for the future. And I can think of no better messengers for this message than Dr. Don Berwick and Katie Beckett. As most of you know, Katie's mom, Julie, worked long and hard back in 1981 and before to achieve the Medicaid home and community-based waiver. That's 30 years ago next year. This had so many implications and benefits for Katie and many other children like her. That waiver was and still is better known as the Katie Beckett waiver.

Now, note that waiver in many ways is kind of interesting because it has many of the markings of what we're looking for in good healthcare now 30 years later. It improved the quality of life not only for Katie but for her family. It improved health outcomes. It improved the patient family-centered care and it achieved cost savings. Isn't that everything that we are looking for today? So we know it's possible, we know it was possible even in 1981. But we didn't have continuous quality improvement in place like we do today and maybe if someone had done a PDSA cycle in 1981, it would have maybe happened a lot faster or if Dr. Berwick had been there, there would be been a plan to study that cycle. I say that simply because Dr. Berwick is the standard bearer for quality of care in this country through his work with the institute for healthcare improvement and many other activities. He very early on not only taught us that we can improve quality but that we must improve quality of care in this country.

So I'm going to introduce Dr. Berwick first and then appropriately Dr. Berwick, when he's finished with his remarks will introduce Katie. Dr. Berwick is the new administrator for Medicare and Medicaid

services and he oversees the Medicare, Medicaid and children's health insurance program. Together these programs provide care to nearly one in three Americans. Amazing.

Before assuming leadership there he was president and chief executive officer of the institute for healthcare improvement. Clinical professor of pediatrics and healthcare policy at the Harvard medical school. Professor of health policy and management at the Harvard School of Public Health. A pediatrician. Works at Boston Children's Hospital and consultant in pediatrics at Massachusetts General Hospital. Not only that he's served as chair of the national advisory council, the agency for healthcare research and quality and as an elected member of the Institute of Medicine. He also served on the Institute of Medicine's governing counsel from 2002 to 2007 and appointed by President Clinton in 1997 and 1998 to serve on the advisory commission on consumer protection and quality in the healthcare industry. He received his medical degree from Harvard medical school where he also graduated cum laude. I have a list of awards he's won. I won't go through them but I can assure you they are many and so join me in welcoming Dr. Don Berwick. [Applause]

Donald Berwick: Thanks much, Bonnie. Thank you for your leadership. It is a delight to get to join you on this wonderful day of celebration. I have to say a word of admiration and friendship to my long time friend, Jim Roosevelt, who is helping you celebrate the 75th anniversary of the Social Security Act. Jim's grandfather left us a remarkable legacy and as we continue to evolve our work in public policy in the medical community that legacy is hopefully getting enriched. I want to just tip my hat to all of you leaders on behalf of children and others and families throughout our country dedicated advocates to realizing the Division of systems that can support the full realization of human potential.

The Social Security Act, I guess, has special meaning to me now given my new position. It certainly marks the beginning of a majestic arc of change in our country. That arc was extended by important legislation since that remarkable law title 19 of Medicaid in 1965, the state children's health insurance program in 1997 and most recently the Affordable Care Act, a national landmark in my view. A turning point for our country, I fully believe, in terms of access and coverage and quality and cost for us. It joins that arc of history that I now feel privileged to be somewhat connected to. I was not expecting to be invited to lead CMS. I'm a pediatrician and as Bonnie said, my career has been devoted to trying to help improve healthcare. I accepted the challenge, though, very gratefully as I came to realize what possibilities there might be and are in CMS's joining communities like yours in trying to achieve for healthcare in our country what we could achieve.

This was given to me, a particular point on the day I was sworn in. I was a recess appointee, as you know. It all happened rather suddenly and I was sworn in not in D.C. but Boston, Massachusetts because

they didn't have time to get down to D.C. on the day of appointment. I went to the Federal building in Boston to be sworn in by the regional director there. As I arrived at the building, I went through security procedures of scanner and a metal detector. When I was walking through the metal detector, a guy on the other side with this big unformed guard, big man and as I walked through the metal detector he said can I talk to you? I said sure you can talk to me. You have a gun. So I went up to him and he said you're Don Berwick, aren't you? I was startled. I said how do you know? He said I study your website. The institute for healthcare improvement. I follow your work. Let me explain my name was John McCormick and gave me permission to use his name. Like the tenor. My daughter was Taylor McCormick and she died at the age of 17 months and she died because of a medical error. He said, I want to spend the rest of my life trying to prevent that from happening to another child and I'll do anything I can to help you in your new job.

It was an important moment for me. It reminded me of something I already knew which I why I took the job in the first place. Like you, I want to make care better. I don't think there need to be more Taylor McCormick stories and I think there are many other forms in American healthcare can he involve into the system that everyone wants it to be and I want to do what I can to help that and I see in the particular platform a chance to contribute to that further along with you as partners and many, many others. The Affordable Care Act is a tremendous tool. It is a lever for that. It is the most important healthcare legislation I think since Medicare and Medicaid itself were created and it is a trampoline into the future if we use it properly. It has many, many answers in it. It prohibits children with disabilities and pre-existing conditions from being denied insurance coverage. It coverages my own children under their parents policies. It makes pregnancy and newborn care and dental coverage part of every plan. Covers 30 million Americans who would otherwise wake up in the worried they could be bankrupted by health insurance they couldn't get. It's full of answers.

But in some ways what is most exciting to me about the Affordable Care Act is that it asks a big question as well. The question is, will we improve healthcare in America? Will we make it become what it can be? Will we reshape it together into forms of care and delivery that every single -- such that every single American can count on getting exactly the care they want and need exactly when and how they want to need it at a cost that we can afford. It is my intent in the time I have at CMS to try to help navigate that organization in concert with our as many stakeholders as are willing to join toward that. I've challenged our many wonderful staff and leaders in CMS to envision it as a major force and a trustworthy partner for the continual improvement of health and healthcare for all Americans. Among those, of course, are the priorities you care most about. We have to ensure that all the kids who are eligible for health coverage

through Medicaid or CHIP are enrolled in that coverage. We have to be certain they stay enrolled for as long as they are eligible.

Data from the urban institute show us we have a ways to go. The participation rate among kids eligible for Medicaid and CHIP is 82%. That leaves 5 million children in the U.S. who are eligible but aren't enrolled. The secretary has challenged states and local governments and Federal agencies and schools and civil society here to find and enroll all children through the connecting kids to coverage campaign and I ask you to join the secretary as I am in trying to accomplish that. The system in which they will enroll, the system which will take care of us, though, faces some serious challenges in what it is now capable of delivering to the people who do get into care. The Institute of Medicine in the year 1999 in the report to err is human laid out a prescription for our country in respect to making it to what it can become. Between the healthcare we have and the healthcare we could have, lies not just a gap but a chasm. Everyone was clear the distance between what healthcare is and what it could be, the chasm. It wasn't the failure of goodwill or benign intention or skill on the part of those who give care, doctors, nurses, healthcare managers, staff of all sorts with rare exceptions this care force is doing its level best.

The problem is why problems lie in the design of the delivery systems, the care giving systems in which those people work. Systems never built for the levels of reliability and safety and patient efficiency that we owe to ourselves and later. It laid out six aims for -- safe, timely, efficient and equitable aware. Care that harms no one and that is effective by deliver wry sounded care. Patient centered care as Katie has led us to see, care in which honors the dignity and individuality and values of every single individual. Meets them on their own terms. Timely and efficient and equitable care that closes socio-economic and racial gaps in healthcare coverage. What the report said and what remains true is the system as currently designed is incapable of achieving those aims. It isn't designed for that. It is not a defective workforce at all. It is the systems in which we travel, those of us who wish to do better for patients but it is possible to chain. My entire career has taught me that change and improvement of care to achieve the kind of care we want for ourselves and our children and posterity is total within our hands. In fact, it exists in places all over our country that are achieving bold levels of improvement on every single one of those Institute of Medicine dimensions.

What we have an opportunity to do in our country is to commit to the vision, the best become the norm. That the best we know how to do can be available to all of us. And to all of those we care for and about. I would like CMS to be a partner with all components of our society to deliver that to our citizens. I configured the idea of better in the paper I wrote before I took this job several years ago on health affairs called the triple aim. It refers to three goals at once. Better care, safe, effective, patient-centered, timely,

efficient equitable care. Care that we want for ourselves and loved ones when we're in care. We have our need for the care system. Better care.

The second aim of the triple aim is better health. You know better than I in the Maternal and Child Health community knows it best of all the generators of health in society do not generally lie within the healthcare system at all. Indeed, formally only about 10% of the variation in health in our communities is attributable is a variation in healthcare. The rest is because of genetic endowments but to the conditions of our life and the choices we make, the risks we take, the environment we're handed with. Economic and social disparities. Stresses in our environment. If we care about health, and we do, that's the point of healthcare after all we must engage the pursuit of health full bore. Not just as a politically correct statement but a real social investment. Better care, better health and the third part of the triple aim is lower cost through improvement. Lower cost without harming a hair on anyone's head. The kind that Katie led us to in her pursuit of innovation in public policy. We can have care that makes sense. Better care, better health, lower costs through improvement. That's the definition of the mission of my work over the past few decades and it remains so at CMS and I'll try to focus the attention of my wonderful colleagues at CMS in pure pursuit of those aims. We'll have to make commitments toward the improvement of safety for patients. I see no reason why we should subject ourselves to avoidable -- the doctors and nurses don't wish to do that nor do we as patients. There need be no more Taylor McCormick stories. We owe our patients reliable care. Care that counts and works and is aligned with the best-known science. I see no reason why people in our country should roll dice depending on where they show up. Reliability is what we want for ourselves, children and posterity and we owe ourselves patient centered care. Patients be treated with dignity, respect and individualization of care to meet their needs as they wish those needs to be met. Katie Beckett can tell you about that. The young woman you'll hear from pioneered some of the initial home and community-based Medicaid waivers as you heard. In an article that Katie wrote, she wrote about doctors and nurses and therapists in home healthcare providers how they have to take time to listen to kids with disabilities and her words how they feel about disabilities, she wrote, she said kids need to teach these adults that as kids they can have input into the decision making about their lives expressing what they need to be independent. That's patient centeredness and the kind of care that honors the individually thoroughly in terms of preferences. We need to commit to better integrated care. Those many among us who have ongoing chronic illness, burdens from physical and emotional and behavioral challenges, we need journeys, not fragments. We need care that makes sense over time and place and build care systems together with the good clinicians who wish this also to make journeys of care instead of fragments of care. You know what fragmented care is like. You have to tell your story to every doctor you see. It feels like the system has amnesia. It

can't remember you and as if the parts don't talk to each other. You wait on hold and don't get answers to questions and you feel the fragments and you end up holding the bag. We don't need that. Patients need journeys to help them through this remarkably capable and complex architecture of modern healthcare. To smooth those journeys we need organizations, cognizant of that as an aim. Integrated care, coordinated, seamless care has to be among us. So it is prevention. We can't just say the word. We have to invest upstream in the generators of ill health. We can achieve the AAA, better care, better health and lower cost through improvement if we commit to do that together. It must be together. CMS has levers, we can adjust payment, we can have new measurements and create forms of accountability and transparency and provide technical assistance and be diligent about enforcement when we need to be so the fraud and abuse can be put to an end. But we cannot by any means hope to achieve better care, better health and lower cost for our society without doing it in a vast and trusting partnership with many stakeholders throughout the nation who care about healthcare and the future. We will make stunning more progress together than we can possibly make separately. The solutions will be local and customized and do for communities what Katie wants us to do for individuals. Answers for Albuquerque will be different from Augusta. The answers for Manhattan won't look the same as rural Montana. We can help each community find the platforms for change to arrive at the care that can deliver what we want, better health, better care, and lower cost through improvement. The test will be authenticity. All improvement involves change and as we navigate together for change there will be those among us who will simply be trying to preserve the status quo under new labels. That won't help. They will not help navigate us all toward the healthcare system that we want and need but there are many among us that feel as I do, I know, that this is an historic time that we have a chance in our country to navigate toward the healthcare system we want and need all together, all together especially with those who give care and can be trusted to try hard to do so. So it's a historic time, fully -- with the vision we're celebrating today. 75 years ago a healthcare system that can meet all the needs we have as patients and individuals and families and communities. I'm very excited to be part of that and I thank you for all that you have done and will be doing to navigate us in that direction. I have the honor now to introduce a real navigator, Katie Beckett. Katie is a brave young woman who with her mother, Julie, put in motion a new system of care that allows children who need significant support to receive care at their home instead of facing a childhood spent in an institution. Before I introduce her I want to take a personal moment to reflect on a personal friend, a remarkable woman who knew Katie and Julie Beckett, Polly. I want to take a moment to remember Polly. She was a hero of mine. She is a hero for our country. She worked with Julie Beckett and others to create family voices and she then proceeded to lead that national grassroots network that speaks for kids with special healthcare needs. I came to know Polly very well in my work at the institute for healthcare improvement and she taught me a ton about dignity and listening and family and contacts and I

miss her a lot. We lost Polly in a tragic accident in June and I'll remember her today with her own words. She said let us remember as each of us makes decisions that will affect children whether we're parents, educators, health professionals or government officials it is our duty to consider if that decision either affirms or denies a child's most basic human rights. That is after all what the home and community based waivers are all about. The Katie Beckett waivers allowing kids to grow up at home by allowing states to waive parental income. It's helped tens of thousands of children to live with their families where they belong. When she was six months old she contracted --light is which affected her ability to breathe. -- she was on a ventilator and received a tracheotomy. She spent years in the hospital. As Katie puts it. It became clear that I needed to come home. But government rules and regulations interfered. Katie's mother, Julie and Katie, they changed that. They made the home and community based waiver program the new standard and for that I and many others are deeply indebted. She's written an article called whatever happened to Katie Beckett and day we have the privilege of hearing that answer from the person herself. From Katie. [Applause]

KATIE BECKETT: Thank you, Dr. Berwick, for those kind words. Let me congratulate MCHB for the 75th anniversary. Especially those -- I'm honored to be here on this auspicious occasion and I'm well aware of the important ties that bind Medicaid and Title V to help families struggling with healthcare issues. We have worked together to use the waiver program to keep children and youth at home with their families where they belong. [Applause] My mom often says that the waiver saved my life because I was sick every few months while living in the hospital. I can imagine that this is the case for many of -- living at home or in their communities is where we learn to be part of the larger picture of life. I am thrilled with the move towards affordable healthcare for all coming in President Obama's healthcare reform package. I know we want future healthcare delivery. We have learned many things from waivers and service delivery in our states and communities but we still have much to do and the young adult I am acutely aware of the difficulty families face in trying to work with outdated rules and regulations that inhibit the delivery of quality service in a more appropriate setting. We must remove those barriers. [Applause] One in particular that I do not understand is how Medicaid eligibility changes when a young adult turns 21. Just because you reach a certain age does not mean that you are miraculously cured of all the things you have endured. [Applause] Medicaid and Social Security need to come together and allow waiver services to continue for those who have been part of the state's waiver program. Institutionalization or inappropriate nursing home care should not be an option. There is no adequate transition for young adults and no organized service delivery for adults with disabilities. We must work towards that end. We encourage employment options for people with disabilities. That's why I am a strong supporter of Medicaid buy-in programs. They just make sense and lead me to look at how we

provide -- to take on that option. I do not know how it will work with the insurance exchanges but we need to keep it in mind. As we develop the benefits package for those changes, we also need to keep in mind the home and community-based alternatives needed by so many. Now that everyone will have access to health care coverage, the cost shifting should end and we should get a real handle on what inpatient and outpatient costs really are and support new alternatives in delivering care. What about home monitoring systems, electric tonic medical records and telephone systems? We need to expand personal care services and nursing options. Many families and consumers have learned how to take care of themselves and do not need a nurse except in critical care situations. With the shortage of nurses, we need to think outside the box and come up with professional alternatives. We have a real opportunity to build -- I look forward to joining with you in creating that change. Thank you. [Applause]

BONNIE STRICKLAND: Thank you, Katie, and I don't know where Don went but thank you him, too. I wanted to end with this session with just one quote from Dr. Berwick mainly because I think it sort of talks about what we've done here today and talks about patients. I'll change that a little. Families and patience. I've always been touched by this quote. He wrote this in conjunction with crossing the quality chasm. True north lies in the experience of patients and families, their loved ones and the communities in which they live. And I think that about says it. Katie and her mom have walked this walk for 30 years. They thought outside the box, they fought outside the box and I think listening to Katie is an inspiration, an absolute inspiration and I think we can learn a lot from Katie, young adults like her who have walked this walk and families to inform quality healthcare system of the future. We certainly have the opportunity as we've heard this afternoon. I would like you to join me again in thanking Katie and Don. [Applause] We have just one more -- not an announcement but I would like to take this opportunity at this point in the program to say I hope you're enjoying the meeting. I know I certainly am. At this point we want to stop for a moment and acknowledge and thank the planning committee. The members of that committee can be found in the back of your program. There are too many for me to stand here and name them. I wish we had time to do that. Would the members of the planning committee that are in the room stand and let us acknowledge your hard work over the last many, many months? [Applause] Needless to say it wouldn't have happened without you. So I will be turning -- I'm not sure where the next -- are we it? Let me look at the program. It was an exciting surprise, though, wasn't it? All right. We're ready for our next session.