

**Welcome Plenary: Celebrating 50 Years of
Medicaid, Medicare, and the Older Americans Act**

September 1, 2015

MARTHA ROHERTY: Good morning and welcome to the 2015 HCBS Conference! If you can all take a seat, that would be great. As you can tell, I have lost my voice already. This is our largest ever conference. We have 1,400 people here this year, so this is amazing!

[Applause]

MARTHA ROHERTY: I also can tell you that we have somebody from every state, Guam and the Virgin Islands here as well, so we are really thrilled that we were able to generate that much of an interest in this topic. The conference has grown exponentially over the last couple of years and I think it's because of a real recognition of the fine work that the states are doing for long-term services and support.

We have leaders on aging, physical disability, behavioral health, we have ombudsman, lots of managed care here, and then our friends obviously with I/DD, we have Veterans groups, software designers, companies that specialize, and many of our partners and folks from the White House as well as some congressional staffers. I really want to thank the national planning committee for their leadership and strong support and direction for us for the conference. And now we're going to do a little show about what's new at NASUAD and how you can get along at the conference. So the ten things you need to know and how to make the most of the conference, and some fun facts, too.

The first is how do you pronounce our name? Because everybody wants to know. We decided to tell you. Hollywood. NASUAD, okay? I want to thank other friends at the SCAN foundation for pointing out that's the most appropriate way are saying NASUAD (pronouncing,

so Hollywood, NASUAD. This is Jay, you will meet him in a second, the first vice president, Gary Jessee, second vice president, Lowell Arye, the treasurer is Lora Connolly, the secretary is Jim Rothrock and the past president is Lance Robertson. Meet you're NASUAD team members, now when you see how small this staff is and that this staff does this entire conference without any outside help, you're going to be amazed. So here we go! Ali and Brian and Camille and Damon and Katlin and Kelsey, I put all the Ks up on top, I guess, Ajah, Kim and Deb, and Nanette and Rachel and Linda, that's the whole group that does the work for you. We have several projects we're really excited about this year. The first is a product that our good friend Anne Montgomery helped us to come up with. I never thought we would be able to get this done but we have the book to celebrate the 50th anniversary of the Older Americans Act and we left one on every table. We collected a story from every state, one individual from every state that was nominated by their state, somebody that's outstanding and fabulous, they're really, really fun stories. I should share with you that this year, I had an opportunity to do a lot of 50th anniversary celebrations and my favorite probably was I was out in the state of Montana, and they were celebrating Centurions. He said his greatest accomplishment was that he had driven himself to the event, learned how to use an iPhone 6 that year, at 106 years old, and he was in really amazing shape so it's been a fun year.

The National Core Indicator- Aging and Disabilities project continues to take off. We encourage you to go to the session and learn more about it. Another core project that we're working on, and that we're really taking charge of, is our work around senior hunger, it's a tragedy that 1 in 6 seniors is hungry in America and we're working really hard with our partners to solve that problem.

On your table you will see the State of the States document, an annual survey we do that

assesses where the states are in their aging and physical disability programs. We also have two new infographics on your table today, and we're excited about them, we have in the past done one on Aging in America and then this year we added Disability in America. I want you to know that on the back page of each of them there's a profile of somebody with a disability. In addition to having the national profile, we have them broken down state by state, we also have created a slide deck for each of you, so if you want to use these in your own presentations, just email our office, we can send you copies of the infographic and we can send copies of your state profile. I hope you are all receiving the Friday updates from NASUAD, they're a wealth of information, you don't get spammed from Martha as much anymore, I only send the one on Fridays.

And then we have two important tools to talk about, we have an online learning center, NASUAD IQ, which provides terrific curriculums that are all available for free, we have two or three new ones, we have one on disabilities that's very new, that converts the CIRS-A to the AB, and then we have one on elder abuse and one on elder justice.

Stay tuned because we're shortly going to have a new report on oral health for seniors, and for individuals with disabilities. It's a survey that's out in the field right now. So we want you to keep in touch throughout the conference. Many of you have been here and have downloaded the app already, but it's the HCBS conference app it's available in your app store. We're having a great time getting some very good content descriptions written about the conference, and it's just a really terrific way to keep in touch, the PowerPoints for the conference are on the app. For the speakers that handed the PowerPoints in ahead of time, for those that didn't, they will be loaded after the conference.

We also want you to start tweeting or hashtag is HCBS 2015, that's also the password minus the hashtag to use the Wi-Fi here for free. So let me go over a little bit of the highlights for

the week because we've got an exciting week ahead. First, you're going to hear from Kathy Greenlee and then we have Vicki, who is going to be the breaking news at the conference when she talks about the CMS issues. We're going to be inspired by Josh Linkner, who is an entrepreneur in a health IT company, we're going to be informed by Dr. Petersen on Alzheimer's disease and dementia and we're going to have a rigorous debate on the future of finance and our long-term services and support systems with a variety of experts on our last day, the closing session and it's likely to be very fun. Throughout the conference we encourage you to share with your peers, learn from partners, mingle with your experts, ask questions, ask questions through the app, share your state's experiences, and of course just really have a good time. These are some of the scenes from last year's conference and things we saw and learned. Okay, Merrill wasn't really having a press conference but it was too good to pass up. Don't forget to visit the exhibit hall and mingle with all of our sponsors, they're so amazing. We have 75 sponsors this year and we absolutely could not do the conference without the sponsors and exhibitors. We were really fortunate to have the ADA Legacy Bus agree to partner with us and they will be outside for the next three days. The photographer is here and he'll be able to take your pictures at the ADA legacy bus. How many of you already have toured the legacy bus? Oh, good. Just a few of you. It's a fantastic experience. So please, please, please, it will be right outside and you will be able to go out there for the next three days and see some amazing things. We got our band back, for those of you who were here last year, the band is back. So yeah, we're going to have another party from 7:00 until 11:00 tonight so I'm going to rest my voice. We are not dressing up and having all that fancy dinner stuff, no, we're just going to party from 7:00 until 11:00 to celebrate the 50 years of Medicare/Medicaid and the Older Americans Act with our official band "Millennium" and it will be a really fun time. We're also have having a film screening of

Glenn Campbell's "I'll Be Me," that will be tomorrow at 8:00 in this room and there will be popcorn and pretzels and other things. Don't forget to join us midyear for our spring event, which is going to be held in conjunction with the Iowa Governor's Conference on Aging and Disabilities and dates are the 23rd through the 24th of May. And with that, I'm going to take this opportunity to introduce NASUAD's board president and my good friend, Jay Bulot, who is going to introduce our next speakers. Thank you.

[Applause]

JAY BULOT: Thank you, Martha. What a great looking crowd. I was headed up to miss lunch yesterday standing in the back trying to find a seat and I expressed to a few people that I think this is our first year in this hotel and we may have outgrown it already which is fantastic to see so many leaders on aging and disability meeting to talk about long-term services and supports and how we move our states and our country forward in providing better and higher quality services to those individuals we serve through our offices and organizations and through our states.

So I want to welcome everybody to the HCBS conference. It's been, so far, the last three days for the state directors and the board members a packed agenda for us, planning what's going to happen through NASUAD and our organizations through the next year as well getting exposed to some of the individuals who you will be hearing throughout the rest of this conference on innovations that are happening. I want to mention something new that we have this year, we have an assistive technology lab set up for those individuals who are unfamiliar with technology, and how technology can help serve individuals in the home and in the community. Stop by-- it's in the Fairchild room, I believe, high tech, low-tech basic stuff that all individuals can benefit from but especially those we serve. Our partners with Georgia Tech have assisted us and I believe the Washington AT folks are also here providing some technology for us to view and demo. We had

some speakers yesterday talk about the pill robots and other unique innovations that are happening in the world of technology, so we have some of that for you to look at but let me get up and gear and I'll introduce our next speaker who I don't think really needs an introduction but I'll do so anyway. Assistant Secretary Kathy Greenlee, she came to us from Kansas as an ombudsman and she's been our assistant secretary for the last several years. We've seen a lot of innovations coming from what the Administration on Aging and now the Administration on Community Living, bringing together all the different partners that we have historically worked with in the states or that we should be working with in our states to figure out how we bring our resources and energy and our knowledge together to better serve those in our states. I think Kathy has provided a great level of leadership at the national level and how that can be done with our federal partners so with that, Kathy.

[Applause]

KATHY GREENLEE: Good morning, everyone! How are you? It's early! I wore red so you can find me up here. It's nice to be with you again, I passed my 6-year anniversary in June making this is the 7th year in my job, probably the 7th time I've spoken at that conference, so Jay, thank you, it's mighty nice to be here with you, it's nice to be here with Vicki and our partners from CMS, I know we have other federal partners with us, and I want to give everybody a collective shout out that we could provide so much rich information. And I also want to recognize my staff, so I want them to wave at me, I have a number of ACL staff here, they're all over the place including Evan Walker up front, our Deputy Assistant Secretary for Aging. They found us regional staff, people who saw us with those clown noses on last night, so it's probably already going around Washington and your Twitter page. We have wonderful staff, we have people who have been around for a long time, really committed to the work and so glad that we

could have four of five of the regional administrators come for the conference. There were two major milestones celebrated last year, we celebrated the 50th anniversary of NASUAD, I don't know what the name was at that point, and Martha's 50th birthday, so we did those 50ths last year and this year, of course, the focus of the conference is to celebrate the other 50-year milestones, the 50-year anniversary of Medicare, Medicaid and the Older American's act which is what this opening session is designed to do, really recognize the contributions, so I'm going to start with a quiz. And my staff can't answer. Do you know which of these programs, which of these three programs is the oldest? They're all having their 50th anniversary but which is the oldest? This is the one time that the Older American's Act is first, the Older American's Act was signed into law on July the 14th and then we got around two weeks later to having President Johnson sign Medicare and Medicaid which were signed into law on July 30th. I sometimes think as advocates that we specialize in being frustrated with these programs, that we see the problems up close and personal, and that we push these programs because we know they can do more. We know we need more funding for the Older American's Act, we know there are gaps in Medicare and particularly when you talk about oral health. I was interested in Martha's slide on oral health and we know we need to do more rebalancing in Medicaid. And we stop and criticize and are frustrated with these programs on a regular basis. But I think the purpose of a 50-year celebration is to stop and change that conversation at least momentarily and say wow, if you haven't said wow about these programs lately, you should. You should stop looking at the holes and the cracks and seeing the problems and look at the foundation of support that these programs have created for people in our country, for older adults and people with disabilities. These three problems coupled with Social Security demonstrate that we as a nation have made tremendous investments in the health and life of citizens as they age and are disabled. There was on a point in

time, it happened to me about five years ago, when I realized the wow about these programs. It was the time that I, as your Assistant Secretary for Aging first put on my flag pin, which I do have and started to represent -- internationally. When you face the world, it creates a tremendous sense of accomplishment and pride. We are a leader among nations and we're not alone but it is a proud moment to have the opportunity to speak at a venue and say this is what my country believes in and this is what my country has done. I've spoken to you many times but I think it's important to be on a 50th anniversary celebration to acknowledge the investments we've made and the commitment it's taken to get here. Yet I'm still an advocate at heart so like most of us here I look at the past 50 years with a sense of accomplishment and regret, with the clarity of 50 years of hindsight, I take and see a lack of strategic planning for connecting these programs together, I've spoken about this before publicly, I call that the lack of relativity, meaning for each one person, how much should we invest in each of these programs for health care, for long-term care and for prevention.

Because Medicaid and Medicare are entitlements, the funding investments across these programs are not balanced. {prevention, whether it's the Older Americans Act, the Developmental Disability Act or the Rehab Act, in independent living programs, prevention has drawn a short straw. The Older American's Act is a tremendously important program, I saw it highlighted by the President during his remarks on July 6th at the White House Conference on Aging, and we saw the Senate pass the reauthorization of the Older Americans Act three days later. We continue to be engaged with members of the House and we are very hopeful that the staff will also move soon to reauthorize this law. Because I want to cover some of the major milestone, Vicki will talk about Medicare and Medicaid but I want to talk about the highlights of the Older American's Act over the last 50 years because what we have now is not what we

started with in 1965. It was established in 1965 by the Administration on Aging, at that point it was at the Department of Health, Education and Welfare, after that, the department was broken into smaller pieces and in 1965 it was created.

In 1969, we got foster grandparents and retired senior volunteers and they existed over the corporation for community services but they were birthed by us at AoA through our demonstration projects. In 1972, Congress arrested funds for the National Intrusion Program. In 1973 we established the industries on aging and it was also an important year in 1973 because Arthur Flemming was named Commissioner on Aging. This was a historic event in the field of aging and really more broadly. Commissioner Flemming had the unique position of having been the secretary of HCW. He was the secretary of HCW under President Eisenhower. In 1974, we got grants for social services like the title 3, B&D, the internal supports we have that are not nutrition. In '75 we were authorized by grants to tribal organizations. In '78 there were a number of changes, the one we talk about most significantly is the establishment of the Long-term Care Ombudsman Program. In '84, reauthorization reaffirmed the roles of states and AAAs in coordinating communicate-based services so this coordination role that we still struggle with and look to for opportunity has been here since 1984. In 1992, we elevated the position of Commissioner of Aging to the Assistant Secretary for Aging-- the position that I hold and this was a joint project by Fernando and Joyce. It was one of his major legacies as we elevated the position. In the year 2000, we created a national caregiver family support program. Edwin moderated and talked about her pride and work in creating the national family care give program, its one issue she does consider as one of her major legacies and contributions. In 2006, is Josafina here?, the Aging and Disability Resource Centers with a part of reauthorization and we again took a step forward to figure out how to better coordinate information and referral across

aging and disability, and now we wait for the next reauthorization. And I have said this always, since we've been working on this reauthorization that we also have to pay attention to the fact that it is the funding that is as important as the way the law is written, and we must keep talking about both.

So last year, or actually, it was this year, the day after the White House Conference, Jeanette, Fernando, and I went to Philadelphia and spoke on a panel at the National Association of Area Agencies on Aging conference, very similar to the panel we did here last year and there's a picture of that panel in overbook this morning, on the page right before my picture. The description of this opening session, and we -- the four of us, this is the first time the four of us this year were ever together at the same time, and it's clear when you get the four of us together that you can see the passage of time and the medley really that exists as we hold the baton and pass it forward from one person to the next. Each of us, in our own way, has created opportunity, while also responding to the circumstances in the larger environment. But when you talk to us in sequence, you will hear the drum beat of change, it is the only constant. In all of this history, there's a small detail that fascinates me, celebrate July 30th, 1965 as the anniversary of Medicare, I always wonder what it was like on July 31st, the next day. Now immediate Medicare was not a new concept, we started talking about a health program, at least talking specifically about older adults back when we were wrestling with Social Security but in 1964 it became a more concerted effort a bigger push and certainly a lot of support by '65 from President Johnson, so with that type of legacy, it doesn't just fall from the sky, there would have been a tremendous amount of preplanning. On July 31st, 1965, the day after President Johnson signed the bill, July 31 is day one, can you imagine being the manager in charge? Can you imagine here, here's this massive new healthcare law that will provide healthcare to all the older people in this country, please go

build it. Can you imagine doing that? Who did they hire first? What did the first organizational chart look like? Because what's fascinating to me about that day is that the people who were doing that work were making history and they knew it at the time. They were about to change the country, and one of the first changes that came immediately when the program went live, because it went live a year later, was that Medicare desegregated the hospitals in this country, and this is another wonderful part of the rich legacy of the Medicare program. We do have some inkling about who got handed this job, associates security at that point was still part of HCW, it was there that you saw staff given the project, I brought a show and tell, which is unusual, I wanted to tell you about the summer edition, the summer of the generation's journal published by the American Society on Aging. This is talking about specifically the history of Medicare and I want to give due credit to John Rather, the editor of this book, it's a very nice article about what it was like to work at HCW and have the support of President Johnson and John Gardner as they worked to integrate 7,000 hospitals in this country who were subject to protections for the Civil Rights Act of 1964. There's also a wonderful article about Dorothy Rice working at SSA and she does talk about the first day in 1966 when they staffed the phones and prepared for them to ring and were believed to hear and see that they didn't because they were well prepared, so if you really want to get geeky on Medicare history, I would suggest this. I'm curious, if that's ever happened to you, not Medicare, but if you've ever been the person in charge or the person up close on what I call a day one event. Can you point to a day it changed? Have you ever been standing in the ark of history as it's being made? That's what happened with Medicare. Has happened to you? Some change is as dramatic and distinct as a before and after, in July of this year we also celebrated the 25th anniversary of the Americans with Disabilities Act. If you talk to the advocates who created the law, who built the movement, who are still doing the work

today, they can tell you about before and after, they created a day that had a day one, there was that of change when the ADA passed. And to think about the answer for myself, I realize that during the past 6 years, I have seen you close or experienced day one on three occasions, on March 24th, 2010, the day after the Affordable Care Act passed on March 23rd. The leaders at HHS have always had a true appreciation for the significance of the work, the potential to create lasting change, a sense of air really before and after and it's been amazing to be on the senior leadership team at HHS at a time where this federal agency is implementing comprehensive healthcare reform. The second day for me, I don't remember the exact date, I remember the event, was April 2010 when secretary Sibelius called me and asked me to take on the challenge of building the Class Act program, community living assistant supports and services that was a part of the ACA, that's when I first started thinking of day one of Medicare because when you're asked to build a federal program, you immediately start looking for for an actuary. On April 19th, 2012, the day after the creation the HCL and Henry Claypool, Melissa, and I on the date after we created, it felt like we had staged a coup. We created a home for non-Medicaid services that support people with disabilities and older adults, so that they can live in the community and we created a strong bridge to the Medicaid program to Vicky Wachino and the staff at CMS. The hard part was not the view looking forward it's the view looking back, I look and appreciate the significance of this change, the many positive outcomes we learned by working across the populations who share values and goals. I do also understand the cost, the cost was the departure from what it had been. What I wanted most when we were doing this work in 2012 was to talk to Dr. Flemming, who I mentioned earlier, I wanted his guidance. I kept asking what Dr. Flemming would do. And I wondered if this change was okay with him because he is the visionary we all look to as the cornerstone in the field. The fact that he died in

1996 makes this part harder. The fact I was looking at a video of him one technically of time and went to a meeting and said I've been listening to dramatic phlegm, people thought I was having a séance, I was like no, but I thought his guidance issues, I was looking to the video, I have a book about him, I haven't read the whole thing, I kind of flipped through it, I wanted to talk to him to embrace the future I see, wanted to get his permission to let go of the past. I was talking about this yesterday with Alex, Alex is my assistant, a very bright person who helps me and she did politely point out that Dr. Flemming would have taken my call but then would have told me I can hang up now, he's not living at we are. We really are equipped to make these critical decisions about this massive change including understanding when to let go. Plus as I confessed to Alex, I did the best next thing, I called an engineer, the first Assistant Secretary for Aging and I said, Fernando I'm about to make a significant change and having his support has always meant a tremendous amount to me because he bridged the world between aging and disability. By acknowledging the 50th anniversaries of Medicare, Medicaid, and the Older Americans Act we are applauding three important day one events, but I think at a conference like this, we would be remiss, derelict in our duty, to forget when Katie Beckett was granted the Medicare effort. I wanted to meet Julie and tell her about the pride that this came from Iowa. It made me undoubtedly proud for me but that was the day in 1981 when we do the right thing for a child and her family and that decision, Iowa made the decision, and it was supported here in D.C. That decision changed the course of Medicaid forever. From that day one, we created home and community-based services. But as important as these day one events are, I think most change is not that dramatic, most change is incremental, like the revisions and the alterations to the Older Americans Act that I just recited. Also like the progress towards rebalancing sometimes we call it balancing because it wasn't ever balanced in the first place, with regard to Medicaid long-term

supports and services even the move to managed care for long-term services and supports has been steady. It has had bursts of energy but it just didn't start in last few years. I think most of us in our career will have a few of these day one events and a lifetime of daily progress forward. If you look at the conference program which I have, you will see a listings of both, this is a conference about education, evolution, and change in home and community-based services. Some change has a starting pistol, most does not. Some of you have been at this for a very long time, my friends and colleagues I've worked with both here and in the Kansas, others of you are new, whether you are a first timer or long timer you're all in the change mix together right now. So I want you to look at the workshop topics this week. Aging and disability resource centers, the HCBS settlings rule, HCBS quality measure, health information technology, supportive decision making, employment outcomes and support, and managed care, we can't call Dr. Flemming, we can't call the people from 1965, they wouldn't even understand. This is ours. This is ours to learn and ours to do.

1965, July in particular was important; we wouldn't be here without it. But as we celebrate, the vision of 1965, it's important to realize and recognize the tedium of daily work, the grind of advocacy, the frustration of program design, and the opportunity of new ideas, the single steps every day since 1965 that brought us to today. And it's fun to come to these 50 year celebrations to kind of forecast the next 50. I think that's both possible and impossible to do. There will be more day one events, more big change that's kind of visible to the naked eye, I think those are the event tabs are the hardest to predict. What we can predict is steady, on January 1st, 2011, the first baby boomers turned 65. Here they come every day. By the year 2044, the U.S. will be majority/minority for the first time, are we ready? Are we prepared to embrace our rich diversity as a country now and tomorrow? And technology will continue to

astound us and provide opportunity for improved health and independence. We will build the next 50 years one day at a time, one decision at a time by trying to help one person at a time.

But I encourage you ever so often to look around, to look up, to lift your eyes off the paper, get out of the your cube, stop looking at the problem and say wow, just wow! We really can make a difference in people's lives. That's the most we can do. Don't forget to be proud! Our future awaits, thank you all very much.

[Applause]

JAY BULOT: Thank you, Kathy. Our next speaker is Vicki Wachino, and she is the Director for the Center on Medicaid and CHIP services within CMS. At the Department of Human Service, Vicki leads activities related to the national CHIP policy and works closely with states with this Medicaid and CHIP programs. In her other past career at CMS or in her last job, she was responsible for implementing major provisions with the Affordable Care Act, she is a nationally recognized expert on health policy particularly as it pertains to health coverage for low-income populations, she's also served as Health Policy Director of the Center for Budget and Policy Priorities, as the Associate Director of the Kaiser Family Foundation Family Commission on Medicare and the underinsured and she also worked as a White House Office of Management and Budget. Vicki.

[Applause]

VICTORIA WACHINO: Good morning! Thank you for having me this morning. Thanks so much to Jay and also Kathy, who I have to tell you Kathy and her team at ACL are amazing partners of ours at CMS helping us move towards greater integration and also keeping our focus on what matters most which is the consumer.

We have so much to celebrate this year, as you heard from Kathy. We have the

50th anniversary of the Older Americans Act, the 25th anniversary of the ADA and the 50th anniversary of two pivotal programs in the healthcare system and the social fabric of more than society, Medicare and Medicaid so to me it's no wonder you cancelled the dinner and decided to go straight to the party tonight, because there is really a lot of achievement to celebrate. This morning, I wasn't to reflect on that achievement, on where we are now, on where we've come from in the Medicaid program, and to lay the seeds where we're going and the work we do with you and all of our partners at CMS in setting a direction for the next 50 years in Medicaid. Let's start with Medicare. In 1965, when immediate care was first enacted, one out of three seniors in the United States lived in poverty, think about that, 1 in 3 seniors and compare that with the landscape of seniors you know now and think about how much Medicare has contributed to the financial security of our seniors. In 1965, more than half of all seniors lacked health since IRS, now, that number is 2%, that's another remarkable measure of change and growth in our ability to support the health needs of seniors and our ability to support their well-being and our ability to support their financial security.

But it probably won't surprise you having heard a little bit about my background and my focus that what I'm really here to talk to you about today is Medicaid. Right now, the Medicaid programs provides health insurance and obviously key coverage for long-term services and supports to more than 70 million Americans and think about the breadth of the people that the program covers. It covers children, it covers pregnant women, it covers adults, parents, it covers seniors, it covers people with disabilities. And it is designed to meet the needs of that broad and diverse low-income population in the best way possible. And to do it, at all stages of their lives, Medicare is really the program that intersects with people at all stages of their lives, first pregnancy, birth, adulthood, senior hood, and obviously, playing a very key role for

supporting people with disabilities.

If you look back over the course of time, as Kathy said most change is incremental but if you've able to take a look back on it, you see clear evolution in the program, and I won't get to gobbled into every nook and cranny but the 50th anniversary has given us a chance to do a bit of reflection on the past 50 years, and if you look back, here's a little bit of what you see in terms of progress the program has made. Since its initial enactment in 1965, so in looking fully at the early years of the program and into the '70s we established a broad comprehensive benefit program for children, that weren't there at the inception?

That was add the over time, you go to the early '80s and see the creation of home and community-based waivers we now have 300, it didn't start out that way, that was added to over time and as Kathy noted thanks to the in part to the leadership of people like Julie Beckett how much we needed to make progress in serving the needs of children who wanted and needed and best served by receiving care at home.

Moving forward, there were a remarkable progress in coverage for pregnant women annual children throughout the 1980s, throughout the 1990s and culminating with for children with the enactment of the children's health in program in 1997. And that led to remarkable reductions in the rate of insurance for low-income children, thanks to both Medicaid and CHIP. And of course, most recently, the coverage expansions of the Affordable Care Act which by offering the opportunity for states to cover low-income adults really solidified Medicaid's role as the base of coverage and the base of the health system in the United States by covering all -- nearly all low income Americans. And that's remarkable progress and that's what we've created together over the past 50 years.

But as important as it is for to us reflect on those accomplishments, it's much more important for us to tell the story of Medicaid's role now and warning I'm going to come back to you all with an ask related to that at the end and to look forward to the next 50 years. And that's what I want to spend the rest of my time with you on this morning. We working with states and providers and partners like you are really building on Medicaid's past successes to strengthen many of the key areas that we need to solidify that base of coverage and to make sure that Medicaid is providing the best possible care to our populations.

Let's start with coverage and eligibility, CMS stated yesterday that since the start of the first marketplace open enrollment period in 2013, 13 million people have gained coverage through Medicaid and CHIP, that's really remarkable progress in expanding coverage and enrolling eligible people.

[Applause]

VICTORIA WACHINO: And progress like that is underpinned not just by the availability of coverage not just by making permeable Jill but making it easier for eligible people to enroll in coverage and since 2015 and the enactment of the ACA we've really dedicated ourselves all the CMS working with states, working with partners to make the eligibility process smooth and easy and we can see the positive effects that is having in enrolling people who are eligible and reaching our populations and again just yesterday, we were able to take the next step in those efforts by offering new easy options for states without a waiver to come to us and take up opportunities to enroll many people who are already enrolled into Medicaid seamlessly and easily and without requiring newly information from individuals and we're going to keep at that and keep simplifying our base of coverage. At the same time we're going to keep working with

states on Medicaid expansion and if you've been following our progress, you know that CMS is committed to working with states to develop an approach to expansion for low-income adults that meets every state's needs that is tailored to the needs of the state to make sure that it really maximizes the impact of that coverage and doing it in a way that maintains key beneficiary protections so that people are able to afford and also see the care they need, we have worked with 28 states and D.C. successfully so far, I would ask that you watch the influence later today for perhaps a little bit more focus on this front, and obviously, it's a major focus for CMS to make that strong and to make sure that Medicaid through expansion is supporting the health system and states bringing fiscal benefits to state economy, maintaining people's ability to get healthcare, be healthy, participate in the workforce and lead healthy and productive lives.

So that's what we're doing on the coverage front. The other critical piece of the equation for us is strengthening care delivery, and you hear a lot from people like me at CMS right now about delivery system reform, it is a major priority on the part of everyone in the administration and in CMS. And really, what it's about is providing the strongest possible care to the patient at the highest quality care while also managing cost it's really in theory that simple. And you see the models that CMS is taking or maybe you've heard about some of them, the state innovation model which supports states in launching multi-payer or payment reform efforts and taking up new payment models, you may have seen some of our other programs, our dual-eligible financial alignment program, you may have heard about some of our delivery system reform waivers that support states in moving to broader delivery system care and you hopefully have heard a little bit about our Medicaid accelerator program which we launched just over a year ago to provide program support to states as they identified the ways to move forward with strengthening their care delivery systems and in key areas.

And that's what people -- those are all critically important and what people typically think of when they think of delivery system reform. I would argue though that the work we are doing with you all on home and community-based care and that we've been doing for decades moving people and working with people to make sure that they have the choices to remain in their communities that they're receiving community I've based independent care whenever they can is also delivery system reform and it's delivery system reform that has been going on for like I said more than a decade. This year, we reviewed our most recent data that shows the distribution of how Medicaid is paying for long-term services and supports and for the first time in 2013, we are spending more in home and community-based care than we are in institutional based care.

[Applause]

VICTORIA WACHINO: That is clearly a major milestone, and directly attributable to the work people like you have been doing through a variety of mechanisms. Through our home and community-based waivers through our balancing incentive programs through community first choice, through money follows the person, you all know these programs you've worked with all of them, you know that the contribution they have made to that kind of progress and more important, you know the contribution they have made to the people with whom you directly work in your states and in your communities. And I ask that you continue to keep those people in mind and again I'm coming back to them later.

However, we also know that we're not satisfied with that progress, that there is more to be done. And we know in particular that beneath that national average, there's particular progress to be made in advancing home and community-based care for seniors and people with physical disabilities. And I should say that the CMS team and many of them are here, I see Melissa, Jodie, you can't hide from me, and their teams are here to help you and will remain here

over the next several days and I encourage you and it sounds like their sessions have been very popular so far so I probably don't need to make this pitch but go hang out with them and tell them what you're hearing and what your concerns are because they bring those concerns directly to our meeting table, and we work through them together in getting your input on how things are going and they're absolutely key.

Now, obviously the next and critical step in our efforts is the success of the implementation of the regulation to be released in 2014 concerning home and community-based settings, those rules I think establish a terrific vision for the program and for home and community-based care, and also to make sure that that beneficiaries have choice amongst settings and we're supporting their ability to live in the community and be independent to the maximum extent possible. We are, as you may have heard if you attended some of the CMS session interest's middle of looking at state's transition plans and working with states to identify a path forward. It is intensive work, and it is hard work, and we really need people, our state partners to share our focus on this problem, to help us work through challenges and we need community input on how it's going and the public process that is associated with the transition plan is absolutely vital to us, and a key part of what we use to inform our determination of progress in meeting settings requirements in every state and I think you'll hear a little bit more about the settings rules from some of the more specific sessions with my team over the next day.

We're also taking new steps to advance delivery system reform and innovation in home and community-based care, I spoke a moment ago about our new administration accelerator program to support states with delivery system reform and we identified four key areas one and I want go into it all of them but slips after we launched IAP last year was to get stakeholder input to we could jointly determine what's really important for us to focus on together, in advancing

our delivery system reform in states and one of the clear answers was promote community integration, so we establish as an IAP focus area community integration with a special focus on promoting value-based purchasing in home and community-based settings and we explicitly did that to help support and foster innovation specifically in those environments. We also through IAP recently established an opportunity for 6 states to work actively with their Medicare and Medicaid data to look to avail themselves and help us support the analysis of data across programs so we can get a better and much more holistic view into how beneficiaries are treated.

The last area, which I also considered delivery system reform and that I wanted to spend some time with you on this morning is modernizing Medicaid's managed care role. As you all well know, our managed care rules until this year had not been updated in more than a decade, and you might have noticed that a lot has changed in the managed care environments in Medicaid, managed care's role in Medicaid has grown substantially as of a couple of years A, 58% of our beneficiaries were served through managed care. And that wasn't the case when our rules were last updated in 2002. Many other things have changed, there are now much more -- much broader availability of insurance products including new marketplaces and as you all know, the role of managed care in giving long-term services and supports to seniors and people with disabilities has also grown substantially -- has also grown substantially and we wanted to make sure that our regulations kept up with that growth and also did whatever we could to ensure that we were promoting access through network adequacy on long-term services and supports that we were supporting care coordination, a that we were making sure that we were appropriately placing responsibilities on states and plans to identify critical incidents posed risk and we maintained stakeholder input as the delivery systems around long-term services and supports continue to evolve.

We proposed those rules on June 1st, the comment period closed on July 27th, we received just under 900 comments, when I say why aren't we done yet, and we are going through those now and developing the final rules, so to all of those of you who commented on those, thank you.

So you see that Medicaid has evolved significantly and that we are laying the ground work for the next chapters in the program's future. Clearly, the work you all are doing in advancing home and community-based care is a very high priority for CMS and as you heard from Kathy a very high priority for the administration. And I wanted to say thinking about Kathy's remarks and thinking about the shared commitment that the administration has for the delivery system reform if we think bottom delivery systems and care from the beneficiary perspective and look at exactly what it is, what services that the beneficiary needs and the quality of those and how we pay for them, I think that is the path to continued progress on banking down some of the silos that Kathy acknowledged we still have progress to make, because then it's no longer about whose paying for what, or who's rules matter it's about the patient and in think little illuminate the path. I told you I would conclude with an ask, that it presents on looking back for the success of on program and the and this is an ask on top of all of what you may consider to be your primary responsibilities of developing programs and policies and operations that serve people well and the ask is that you think about the people you know who Medicaid touches and the way its improving their lives now and that you are tell that story. We know the role that Medicaid plays for seniors, we know the role is plays in making Medicare coverage more affordable, we know the role that Medicaid plays in people with disabilities and supporting their choice of care provider and promoting their independence in promoting for some people with disabilities their ability to maintain their health coverage while they seek and gain employment,

we know the role it plays for people, we need to tell that story consistently to each other, to people like me, to policy makers elsewhere, to tell the story of the people -- of the role that Medicaid plays in people's lives, the importance of the program, and the importance of continuing to work for more progress in the future. So that is the my ask, I ask that you give that a little bit of reflection before you hit the dance floor this evening and then, you know, part like it's 2015! Thank you also much for having me this morning.

[Applause]

MARTHA ROHERTY: Thank you, Vicki. It is a real honor and privilege that both Kathy Greenlee and Vicki mentioned Julie Beckett. Four years ago, NASUAD started a new award. Katie spent the first years of her life at the pediatric intensive care unit at the hospital in Iowa and the family and doctors wanted Katie to live at home but at that time there was no Medicaid coverage medical services provided in the community. Julie challenged this policy and was ultimately successful in carving out an exception in the Medicaid program that allows children with disabilities to receive services in their homes and in their communities. Thanks to her mother's tireless advocacy on December 19th, 1981, Katie moved home, known as the Katie Beckett waiver since its inception in 1928, this monumental policy shift has allowed more than half a million children to live at home as access the treatments they need. Katie was a national hero who championed the right of individuals to live in whatever place they called home. It's an honor and privilege of mine to know Katie and it's because of Katie and Julie's refusal to let limitations define her daughter that children have been able to live with their families and in their homes, through Katie's spirit, tenacity and courage. Even though Katie's spirit, tenacity and courage is missed every day, the legacy the Beckett's created for all you was in love and loss will remain. The past award winners include Senator Tom Harkin, Senator Bob Dole and the

former First Lady Rosalyn Smith Carter. It's with great privilege and pride to award this 2015 Katie Beckett Award to Nancy Thayler, whose tireless efforts on behalf of individuals with disabilities, the board of NASUAD decided to present this award to Nancy when she announced her retirement, where she served as executive director of NASDDS, our sister organization. She was a fearless leader on behalf of the states before Congress or even at CMS and as many of you know she can be unwavering in her determination to make the entirety of the home and community-based system one that provides a higher quality of life for the consumers and their systems. During her tenure, she left the DD directors and their -- led the DD directors to the misuse of cytotropic meds and partnered with us to expand age and disability, she fought for employment first policies to be the norm for people with disability, she sought innovative solutions to the issues that long plagued our system in housing and transportation, as a federal advocate, Nancy worked to help clarify the Department of Labor's regulation and its impact on consumers and their families. Nancy was a very powerful, influential partner at our quarterly meetings and our CMS partners barely lived to tell balance it from the home and community-based services to the quality improvement metrics to the definition of adult services. Nancy has been steadfast in her support of the home and community-based program and has been a visionary leader in promotes services and supports for the consumers and their family. It was our understanding that Nancy was planning on retiring, returning to her beloved Pennsylvania and potentially running for school board but also teach piano on the side, imagine my shock and surprise when out of the blue, she called and said she was returning to state government in Pennsylvania to lead the Office of Developmental Programs within the Department of Human Services. I can truly to think of no one more deserving of Katie Beckett Award than Nancy.

[Applause]

NANCY THALER: This really was a surprise. It's beautiful!

[Applause]

NANCY THALER: It's beautiful and I am truly surprised! I thank you very much. I'm interested in the line about CMS staff barely living through my advocacy but they're all here and in good friends. I just say you that, the work we do is intensely and deeply important, and in home and community-based service systems, we are -- we have such power to determine the power to facilitate people just having a regular life in the community with their families and friends, and it's interesting being back in state government again, and trying to do it again, it is really hard work that we do in state agencies, the money requires a lot of accountability and it's very easy to contrive rules and impede people as they weren't getting Medicaid, my favorite standard in the new HCBS regs is people will live a life like people who are not in a Medicaid waiver and in think that is the standard we all aspire to you that very much for this.

[Applause]

JULIE BECKETT: Hello, I'm Julie Beckett, and I just want to say just --

[Applause]

Thank you. Thank you. I just want to say a few things just a couple of things as far as CMS and Medicaid and all of that, you know, it's been an amazing journey, and really, you know, who knew that Katie was going to make such a difference in so many lives? And she really has. And, you know, even though I miss her every day, it's about who lost her daughter said, you know, I miss her but I feel her love around me all the time. And that's how I always feel, especially in a room like this, with people who have helped people like Katie and how many things have changed. I remember the day that Congressman Tom received a letter that said

Medicaid didn't pay for home care and you know you sit back and think to yourself that was just 30 years ago, I mean, look at what we're doing all this stuff is so new and so important P. So to me, thank you for all the work that you do, keep in mind there are families in each one of your states that I work with under family to family health information centers that can help guide you in some of the many things that have to have for children, not just the elderly, although, it's a major part of what am happens, but disability and all those major things life events that people don't expect to happen, it just happens and thank you for being there when they need you!

[Applause]

VICKI WACHINO: Nancy, you couldn't have beaten the CMS staff down too badly because we also have an award for you! And I don't think I will expand significantly on what Martha's already said about your very impressive career. But I will tell you that in the different places you've served in Pennsylvania in your first tenure at NASDDS, at CMS, what people say about you is that you are a go-to thought leader on HCBS services, you set the standard, and that your commitment to quality of care and making sure that people are consistently served in the most appropriate setting is unparalleled. For that reason, Acting Administrator Andy Slavitt would like to award you the Administrator Citation from CMS in recognition and appreciation of your leadership, performance and dedication to public service and the programs of the Department of Health and Human service, thank you.

[Applause]

MARTHA ROHERTY: Now we are going to call the other advocates up on the stage, because -- I think I actually may have surprised Nancy. So I thought when we were planning the conference, we thought that one of the things that would make the most sense is if we were able to have advocates come and talk and share their experiences as we've heard from the 50 years of

the Older Americans Act and the 50 years of Medicare and Medicaid, I think it's just as important to hear from advocates about what they believe the future of the program will look like and what some of the concerns that they have are, so joining us on the panel, obviously, Julie Beckett is here, and we have Liz Weintraub. She's an advocacy specialist at the Association of the University Centers on Disabilities. Nancy Thayler is here obviously representing not only in her current role as a director in Pennsylvania but Nancy's also the mother of an adult child with special needs, and then we have John Winske, the Executive Director of the Disability Policy Consortium. I heard John speak in Florida maybe 6 months ago or so and I found him so captivating and eloquent that I really wanted him to be a part of this conversation here this morning.

I am going to do a strip tease kind of thing and take my mic off so Julie can get miked up. Hang on a second but while I do that, John, can you share with the audience what you think the biggest problem with long-term services and supports is right now and what -- if you could fix anything in the system, what's something that you would want to go and fix?

JOHN WINSKE: I think one of the key things we need to do is to continue to empower the services, and to walk and I think we approach people with the mentality that this is the services they have and this is what we have to offer and that we don't often engage people and say what do you need? What can we build around you? To empower you to stay in the community but also to take ownership of the services you receive and take ownership of your life in the community and particularly in -- when it relates to medical care, the idea that we really have to empower people to control their own destiny, and we do things for people, to people rather than helping them to do it themselves or at least have a strong role in determining their future.

MARTHA ROHERTY: Do you think there is a unique challenge with various populations

receiving services? I mean, that's some of the internal debate and interest that we have, particularly around the HCBS regulations and some of the challenges that they lay out by grouping everybody together; do you see differences in the needs of the different populations?

LIZ WEINTRAUB : Yes, I do. And can I also comment on and give a life experience. About what John was talking about? When this was two years ago, I broke my ankle, and my provider said because I'm married and I have very capable -- a very capable husband to take care of me, that he should be able to -- he should need to take care of me. And because of my issue, I can't use -- I need to use a wheelchair and so therefore, that caused a lot of issues with getting things and helping me get dressed and whatever. Well, he can't always help stop his day and what he needs to do, he has a job, too, and providers need to do what I want. And then another example was my mother always helps me with shopping and supporting me in going shopping, clothes shopping, and my -- and when she got sick, I said I really need someone to help me do that, because I miss my mother's role in that, and no one could do that because they said because of the Medicaid, they can't provide that. All they could provide is basic cleaning and basic housework and all of that, so I think that providers need to listen to what I want and what other people want and yes, I'm very capable of doing different things but that doesn't mean that I don't need the help and support.

MARTHA ROHERTY: That leads to another question, I think it's really -- that was very astute -- a very astute answer but then Julie, what do you think -- what's the impact kind of on that relies on the family care given -- reliance on the family caregiver in terms of the overall system, we do rely on the family caregiver for a lot of things and how do you think that's going to affect the program as we go forward?

JULIE BECKETT: I think as we move forward, I really do agree with Liz and believe that

they should be talking to the family and communicating with the family not this is what we have to offer and this is what you can take or leave, you know, with Katie, she couldn't drive, she had poor depth perception and seizures early on in her life but it made it very difficult for her coordination-wise et cetera et cetera so the primary transportation came from me, which is fine, except then you have to figure out how all that's supposed to happen, public transportation was not really something that was available for Katie, and those things are really important to think about how the person who is receiving the services feels about the services and what in fact could you do to major that service a little bit better for their doctor for them and a lot easier for their family members who are legal working hard to keep them at home. It was great to have Katie at home, you know, the first -- you know, she spent the first year in the pediatric intensive care unit we lived in fish bowl, everybody know about Katie but we didn't know about anybody else, we had to live with hospital rules but when we got home people would invite us to places and ask us if we'd like that do something and we'd say that's fine as long as Katie can come because after three years where is did we want to go without Katie? That's all there was to it but it's really an important aspect of really living a home and community-based life and that's really important to them.

MARTHA ROHERTY: Nancy, since you're queen for the day, what if you had pixie dust to fix whatever problem you like, what would you fix?

NANCY THALER: Now that I have some composure, I'd like to thank the national board and Martha, Martha's been a good sister friend all those years so thank you.

I'm stumped I was trying to think of that when Liz was talking. I think about in non-Medicaid world how easy our life has become through technology, everything's an app, I can download an app on my cell phone and find most anything out and execute an any business I

want to the execute, I go to my card and I swipe my card, you just walk in, pass your card, get your car and jump in and there's so little bureaucracy in the transactions of our daily life but in the Medicaid system there is still a tremendous amount of but rocks are a from the moment people come in to be get eligibility determined, planning has become a checks accountability for every unit of service and regarding that has become very cumbersome and in our efforts to get people everything they need we seem to have wrapped around all kinds much requirements and obstacles, and I am struggling with how to maintain accountability, meet the assurances on the comfortable for a tremendous amount of money and have that invisible and seamless for people, and a so if I had fairy dust, I would make that happen, I don't know how to make that happen, I'm intrigued to try to make that happen in the next couple of years but it was a challenge for us to make people's lives -- you know, I think the about the Disney experience all the people behind the scenes working all of their magic so that the guests can have a magical experience, and I just don't think our folk are magic jam experience and I guess that the next generations of our work is to figure out how to keep the back room nice and tight and accountability but not have it interfere with people having a real life.

MARTHA ROHERTY: I was similarly emotional about giving you the award so I didn't do what I had hoped I would do, which is to ask you to spend five minutes telling you what your organization is and your role in the organization so the audience has a better sense, and in addition, I left my cell phone there and if people want to -- yeah, if people want to send questions via the app, they can do that and then we can be reading those, too, or people can come up to the mic and ask questions, but if you don't mind -- John, I'm sorry.

JOHN WINSKE: We're a research and advocacy organization by and for people with disabilities, we have 12 employees, all of them are either people with disabilities themselves or

family members of people with disabilities. We really cover the gamut from people with disabilities to people who have a history of access and behavioral services living with mental illness and we really came about because of a desire to affect public policy in our state for people with disabilities. Right now, we are serving as the ombudsman program in the fiscal alignment project, as far as I know, we're the ombudsman program in the country, that is run by people with disabilities and I think that that allows us to bring a real different look to the program, not only am I in the ombudsman program. I'm also a consumer, somebody who is in the duals program, and we're also partnering with Mass General Hospital to study some of the issues being raised in the project, such as how do we measure the health outcomes for people with disabilities because the normal metrics really don't fit, I mean, what's my blood pressure today sort of doesn't fit, you know, or somebody who has severe mental illness, they got out of bed today and they went to a community program or even went to the local store to buy a quarter of milk, that can be really progress, that can show really improvement in their health outcomes but we wouldn't pick that up without using any of the normal models that are out there.

MARTHA ROHERTY: Julie?

JULIE BECKETT: Well, currently, after 4 years at the University of Iowa, which gave Katie back health insurance in 1984, so Medicaid didn't have to pay the whole bill for a very long period of time, I worked first as a parent coordinator under the title V program there at the university, I helped found family voices, which is a national organization of families of kids with special healthcare needs and we do a lot of mentoring and support, we help to establish the family health information centers that are available in each one of the states and I hope that aging and disability resource centers reach out to them and are working with them. We mainly work with children and young adults and I'm on their board of directors right now, I was their policy

person for many years. I am currently the co-chair of the family partnership network under the American Academy of Pediatrics, pediatricians realize that they learn a lot from families when they engage them in conversation about what their kids are doing and how their kids are doing, and so we're helping to establish this network so that pediatricians can learn how to talk to families and we're establishing a mentorship piece and they think that's a lot of what we're talking about here is we need to learn from our peers about many of the things that we do, so those are my two big things, I said I retired and I'm actually busier now than I was before and that's okay, that's what happens, I get phone calls all the times from families. I just got a kid out of a hospital in Minnesota back home to North Dakota who was having trouble realizing that they could get this kid home from Minneapolis. But it put the family back together and everybody seems to be doing well. I met a gentleman on the plane who has a son with autism, lives in Idaho, I said I would get back to him, there are things that the HCBS has been getting has gone from 40 hours a week to 4 hours a week and somehow that just doesn't measure up so it's those kinds of things that I still do for a living. Not actually for a living but just might have life, period, that's Katie!

LIZ WEINTRAUB: Thank you for allowing me to be on this panel. I work at University Centers and I'm on their policy team, and mostly what I do for them is I have a video every Tuesday comes out, that will come out this afternoon where I break down policies or I interview policymakers about policies in a language that we, people with disabilities or family members will be able to understand, because for such a long time, I believe, he believed that people if we want -- I believe that people if we want to be a part of the advocacy community, and advocate here in D.C. on or on the state level, then we need to understand what is going on and we -- we haven't been able because they talk -- they talk in language that I can't understand, maybe you

can.

[Laughter]

LIZ WEINTRAUB: But -- and today, I which this edition might be of interest to you, I interviewed the principal of advisor first for ACL, and the -- I forget her name, her -- Sharon Lewis and her daughter about -- I interviewed Sharon about the new community-based services and then Sharon's daughter who is a rising freshman in college about her dreams and what she would like in her future, and so I -- that comes out every Tuesday as I said and I hope -- I don't do it just for me, I do it for everyone else because I really believe that even though I'm a -- what they call a self-advocate, a person with -- because I am advocating for myself, I can't just advocate for myself anymore because if I am advocating for myself, and if I'm just here for myself then why am I here? So that's what I do.

MARTHA ROHERTY: Thanks.

[Applause]

MARTHA ROHERTY: Nancy, do you want to share?

NANCY THALER: Currently, I'm the director of Pennsylvania's -- In the Offices of Developmental Programs, it's the program people with developmental disabilities including autism, and I guess that after all this time, one of the things that I think I've come trails and it has a lot to do with the demographics of the United States and maybe my own demographics but as we look at the next couple of decades we can see as a consequence of the baby beam there are going to be a lot of people having a need for supports in the community whether they -- whether it's Medicaid or whether they have a lot of money and they hire somebody to work for them or when they take their daughter out of the workforce but there are a lot of people needing supports and as we look at the data both in aging and disability, it's pretty obvious that the system, the

federal and state systems are not the long-term care system in the United States. Families are, 85% of families caregiving, 85% of the caregiving for seniors is provided by spouses and children and or people with developmental, we're talking in most places 90% and the people in service and not in service because their waiting lists are living with families so my mission is to try to get Pennsylvania to learn how to make it as easy as possible for families and their sons and daughters and brother as sisters to keep doing what they're doing and not too think we are the solutions, but that we are a partner with them to help them living a great life!

[Applause]

MARTHA ROHERTY: Does anybody in the audience have questions? If not I'm going to go to the app. How can we create the best relationship so that self-advocates and service providers are working together towards common goals?

JOHN WINSKE: I mean, I think for allies and one of the things that I want to say I'm happy with celebrating today, I am a success story. I'm 53 years old, and living with muscular dystrophy, in the early 1960s to be raised in home and luckily in my lifetime, along came the ADA and along came Medicaid and allowed me to get the services I need to live in the community. But as we celebrate, I think we have to be honest and realize that another narrative is being written and the alternate narrative does not include Medicaid in some people's minds and it doesn't even include immediate care in some people's minds. And I found that it that breath taking myself after 50 years that we're still having that discussion and we really have to redirect the narrative, we know the story, we know the successes, we know that our work has allowed millions and millions of people to not die in poverty, to live in their homes comfortably, to die at home comfortably, and if we don't tell that story then this alternative reality that is being woven, I'm sorry, that's what it is, it's being woven and told and if you tell a lie enough, lies become

reality. So, you know, that's one of the things I really wanted to stress today is that you asked me to answer a question and that is as service providers and as consumers, if we don't tell that story, then shame on us! Because we really have to tell that, and we have to have to have money to back us up and we've got to spend that money basis ever-wisely but we really have to make sure the truth is out there.

MARTHA ROHERTY: Anybody else want to weigh in on that question?

JULIE BECKETT: I would just like to add one of the nice things that the happened early on Katie came home from the hospital is CMS really talked up the issue of Katie and I used to visit states and talk at different conferences hosted by Medicaid in that particular state it really got people to understand that this is not something they needed to fear, they thought there would be people coming out of the woodwork, well, the deal was they should have realized how important it was to work on that. That was a real partnership between what we were doing as the Beckett family and what CMS was trying to do in these different states. So partnership is a key, it's making sure that you're feeling that the way and one of the key things that happens -- that's happening in Iowa right now we have one of those state Medicaid -- we have one of those Medicaid innovation grants on health home, and out of that health home dialogue the nice part about it is they have hired and trained 55 families to actually meet the families who are applying to be a part of Medicaid trying get into services under Medicaid so they're actually meeting with a family person at the same time they're asking for the types of services that they need, so the interpretation comments off a lot different than when a social worker or social services person meets with them it's really a family person because when a family talks to another family they realize they've been there, and that's what you really need in this conversation, and it's that partnership between the family advocates and the social services people, the Title V people in

our particular state that has made this such a success, so I would say partnership is a key in anything that you do.

LIZ WEINTRAUB: And I would also say going along with what Julie was saying, I think that you really need to listen to me and to Julie, and to Nancy and to John because we're -- we know what we've want, and we know our family members, and yes, providers listen to CMS and the government and all that, but at the end of the day, whose services are we getting? They're my services and I need to have a say in what I want. It's not really up to CMS, it's not really up to whatever waiver, it's up to what we want.

[Applause]

MARTHA ROHERTY: Nancy, did you want all night? Well, I'm just going to ask you one more time, pixie dust throws up in the air, how do you fix the program, what would you like to see in the next 10 years?

JOHN WINSKE: I think in the next 10 years I'd like to see the ability of government to get good data. We do a decent job of telling the individual stories, but we don't always do the best job of getting the data together to back up the results that we're delivering and as the money gets tighter, we had better be able to tell that story fiscally as well. And government does a very poor job of insetting in the technology and documenting the types of things that businesses document every day. So I think that, along with a pleasingly -- building services around a person and really empowering people to control their own destiny, you know, amazed as I said before here I am, and you know, when I was born, they probably thought I'd live to be 15 or 20 and here I am. And we have this two booms on, an aging boom we're getting older as a society and more people are going to need services, but people like myself are expensive, you know, it's not cheap for the services that I need to live a healthy and active life. And I'm living way beyond expectations and

so are literally millions of other people. When we build our cost projections, we have to think about these things, in that our success literally means that it costs more, and we have to be able to document it what we're doing and the success we're having, and why it makes sense so that we can we know the argument on our levels.

[Applause]

NANCY THALER: I would agree with what John said. Thank you. I guess if I had the pixie dust, you know, we would like to be able to say we could do, I'd like to see us be able to, as John said, I do think collecting the data and not just the individual stories while the individual stories really bring up how important things are for individuals, it's really talking about the combined effort. CMS followed Katie for the first 10 years outside of the hospital to see what the cost savings really were and actually, she saved just the federal portion of Medicaid \$350,000 each year she was home for those 10 years. That's a lot of money. That's a lot of money! And we need to think about how we utilize the system. I mentioned the family navigator, they actually are trained they go through training and get a credential that tells people they have been trained they're not just a family person who show up and how important that is that people warrant the kind of experiences that these families have had as a credentialed person, as opposed to just being anybody, I mean, there are so many ways we could do things, so much more simply if we just allowed it to happen, in many ways. My Aunt Winnie, who is now in Oregon, but who is suffering from dementia, she has a daughter who is 45 years old who has severe downs and has many issues in her life. They live together out in Oregon and it's just her son Joe and his wife Joyce that kind of take care of the two of them, and just out of the clear blue, four women came up to them at church and said, you know, we'd like to be able to help out, is there something we can do? So now they come every day, somebody different comes but it's like Winnie is having

a visitor, not somebody coming to take care of her and it really is in the way you do things that, you know, thinking outside the box, that's my pixie dust, thinking outside the box.

[Applause]

MARTHA ROHERTY: I think we could listen to you all day and learn so much but unfortunately, we've come to the point be where we have to break and move to the next set of programs, I have lots of important announcements though, so don't leave. The exhibit hall is going to open at 11:30 today, please stop by the booths and this year we're doing exhibit hall bingo, so if you have invoiced everybody', you have the chance to win a 150 gift card. We're also excited as I said to have the ADA bus, but we had a little glitch in the ADA bus and it's not going to be able to be here today, it will be here tomorrow. The lunch today is in the exhibit hall from 12:00 to 1:00 and please spend some time visiting with the executors. Many of you have asked, the PowerPoints will be available on the app and will be on the website, give us two weeks to get them up on the website but they're on the app now. We are having our reception and band come from 6:00 to 7:30 tonight at the reception in the exhibit hall and the dance starts from 7:20:11. Again, you don't have to answer it up fancy like you did last year but if you brought your dress, bring it on, we'd love to see it.

We want you to wear your badge every day and one thing that we are asking you to look at this year is the many, many new people and they have a first time notice on their badge, so if there's a new person, please welcome them. In addition, we partnered with ACIA who is the autism self-advocacy network and if there are individual there who have a red card on their badge that indicates that they would prefer not to have a conversation, so please just be respectful of their needs and their desires to not engage in a conversation with you.

I'm going to turn over for my BFF Gary, who wants to talk to you a lit bit about our

sponsors.

GARY JESSEE: Good morning. So just a couple of things, is everyone enjoying the conference so far?

[Applause]

GARY JESSEE: So how many of you were in the intensives yesterday? A lot of you. The intensives were packed and I'll just say that this conference over the years certainly we're getting bigger and bigger, I think everyone agrees this venue is much better than where we were before. But I'll tell you that the board and the staff at NASUAD, you keep asking for more and we keep trying to deliver more, it is a testament that if you walk around the conversations, the content in the sessions, even all the networking in the hotel and everywhere else, we end up, is just a testament of what this conference means to all of you. I wanted to acknowledge Martha and the team who put this together, a major, makes, feat and so wanted to publicly thank them for their support.

[Applause]

GARY JESSEE: And then just a couple of other things, you know a conference like this it looks really easy to put on where you it's really not. A lot of fights, drama, tension, all those things, just kidding but you know what I'll say about this is that the sponsor who stand by this conference, the heads in the states they're presenting quality, cost effective ways for us to do better, innovation, certainly many of the people in this room we contract with to help us deliver services so they are our partners on the ground and really making a difference in people's lives. And so at least twice during this conference we're going to publicly acknowledge some of them, and what I'm going to do, and I'll just say what would a conference be without these sponsors? Your hands wouldn't be clearance there would be no hand sanitizer, no notepad, no water bottle,

no stress balls, the stress would just be off the roof, but really, all kidding aside, they make a tremendous difference in the work we do, and so I'm going to acknowledge a few of them right now. And then rhyme going to just ask that they stand and then we'll -- and then I'm going to ask that they stand, and then we'll all clap because we're going to get up and leave anyway so with that I'm going to announce a few, so if you would stand if you're here, in our platinum category, Centene Corporation. They're way back there, just keep standing, you're okay. But we'll clap at the end, how about that? Dentaquest. In our diamond category, AARP, Blue Cross and Blue Shield, CIGNA health, they're just all out working, Harmony, UnitedHealthcare, and our emerald category, AmeriHealth, Humana, we want to acknowledge all of you for your contributions to our conference.

[Applause]

We also -- we also want to knowledge FEI who is sponsoring the app, how do y'all like the app? Great.

[Applause]

GARY JESSEE: I mean, you go to twiddling around like this and everybody's on their phone so if you're not paying attention during this session at least you could say I was putting something on the app about how great everything is. There is so much going on in the app, some of you I know have attention deficit disorder because you are posting like a hundred things in a session. And so keep posting, because it prompting conversations. Wo with that we're going to conclude this initial plenary session, please take every opportunity to get to know your colleagues from across the nation and we'll see you very soon whether out in the hall or somewhere else!

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