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The Future of Medicaid Webinar Transcript

December 13, 2017

>> LEX FRIEDEN: Welcome, everyone, to the Future of Medicaid, a webinar presented by the ILRU program in conjunction with the CHRIL program. I'm Lex Frieden and I'll be your moderator for today's program. I'm here at ILRU. We have with us Connie Garner from the Washington D.C. metro area and Jean Hall from the plains of Kansas. We'll be talking about the future of Medicaid today. It's a program that's important to literally millions of people in the United States, many, many people with disabilities included. And we know that this program is not a static program. It's changing. It changes from year to year, and particularly from administration to administration, from congress to congress. There's a lot of money tied up in Medicaid, and it flows through the states according to rules set by the federal government. So we're going to discuss where these programs are likely to be, where the money is now, and have the opportunity with our experts to review some of the possibilities that lay before us.

Next slide, please, Carol. I am professor at University of Texas and Baylor College of Medicine as you know. I direct the ILRU program here at TIRR. Next program slide, please. We are on today through the courtesy of a grant from the national institute on disability independent living and rehabilitation research and the U.S. department of ‑‑ it used to be health education and welfare. It's now health and human services. Shows you my age. The CHRIL program is the collaborative on health reform and independent living. Our leader is Jay Kennedy at Washington Institute University. We're pleased to be working together with Jay and our colleagues. CHRIL provides stakeholders with accurate, current, and actionable information on how recent changes in health policy directly or indirectly impact the community living and participation of working age adults with disabilities. I would go further to say that the CHRIL program really advances opportunities for advocacy by all of us by giving us background information about health law, health policy, and health issues that we otherwise might not have.

CHRIL systematically investigates and disseminates findings about how health reforms affect people with disabilities. Next slide. Our CHRIL partners include Washington State, university of Kansas, George mason University and of course ILRU. Next slide. We have some strategic partners that work closely with us. Some of you are online today from the national council on independent living, the association of programs for rural independent living. Also the American association of health and disability, the disability research interest group, the DRIG of academy health, and finally the urban institute. We're glad to have everyone on board with us today. Welcome all of you who have joined. Next slide, please.

We have two presenters. Jean Hall from the University of Kansas will be our first presenter. Jean is an advocate scientist. She ‑‑ she represents all of us with disabilities, and the work that she does is really, really important to us. Jean has looked at a number of health policy issues from her perspective and from an objective research perspective as well. And she's begun to untie, untangle some of the important questions about how the ADA has impacted work for people with disabilities and how health law changes affect our lives by providing us with needed health care and support services in the community. Jean will talk about some of her research that she's done in that regard this afternoon. She's a professor at the University of Kansas Medical Center and really is ‑‑ I'm glad to say, one of our outstanding leaders in health policy research.

Also on the line, and I'll introduce her further later, is Connie Garner, a friend of ours and another advocate of health care for people with disabilities and also writes for people with disabilities. Without Connie, I would say we wouldn't have some of the legislation that we have today that really has given opportunity to many, many people with disabilities and families. And, you know, these two experts will give us some insights from their unique perspectives about the future of Medicaid. Without any further ado, let me simply invite Jean to add anything you'd like, Jean, to your introduction and share with us the knowledge you've brought with you today.

>> JEAN HALL: Thank you, Lex. And thank you everyone for being here today. The fun faculty would add about myself is I'm also the proud mother of triplets. Kind of an interesting piece of trivia. And Lex is speaking, he said that I examine the effects of the ADA on employment of people with disabilities, and that's very true. But also the ACA, the Affordable Care Act. Today, I'm going to be talking about Medicaid managed care. If you want to go to the next slide, please.

So part of the future of Medicaid is that Medicaid managed care is here and it's growing. Currently 39 states use some form of managed care for their Medicaid enrollees and for the majority of Medicaid enrollees across the country receive their services through the managed care program. States are increasingly moving people into managed care arrangements. Historically, people with disabilities were left out because they were seen as difficult compilation to work with. That trend has changed, in the last several years especially. States use Medicaid to increase their costs and add more predictability to their cost. If you're a managed care organization trying to provide Medicaid managed care, you're going to be interested with adults with disabilities. They make up 12% of Medicaid enrollees but they make up 36% of Medicaid cost. So their cost are about three times their enrollment and therefore they are of interest when you're trying to contain costs.

Next slide, please. And if you look at how people with disabilities are spending their Medicaid dollars, you can see that children with disabilities most of their costs go to acute care. When you look at non‑elderly adults with disabilities, about 40% of their costs are long‑term care, long‑term services and supports including home community‑based services which Connie will talk about a little bit more later on. For seniors, these long‑term care costs are also very high. Their acute care costs are also high, but most of them have Medicare to cover their acute care cost. If we go to the next slide. And if you look at where those long‑term care services and supports are provided. For non‑elderly adults with disabilities, about 80% of it is costs are occurring in community. They're not institutions and they're not really medical costs. These are things like helping people with bathing, dressing, grocery shopping, house cleaning. So if you're a managed care organization that's used to working with health care services, you might not be exactly prepared to understand what those services are and how you might contain costs. And in fact, that's been a problem area. But that's actually not what I'm going to talk about today. I'm going to focus on those acute case cost. Connie will talk about long‑term services and supports.

Next slide, please. So the information I'm going to provide you with today comes from two studies that we conducted with Kansas Medicaid enrollees with disabilities. Kansas was the first state that moved the entire Medicaid population into Medicaid managed care including people with disabilities, including people with disabilities who are on home community‑based service waivers. This happened in 2013 and it was done through an 1115 waiver process which Connie is also going to talk about. What you need to know is we conducted two studies. Our first study was with adult Medicaid beneficiaries who had physical disabilities or intellectual disabilities and used home and community‑based services. That was four to eight months after transition to Medicaid managed care occurred in our state. So it was kind of a transition period. We conducted a second study from October 2016 to February 2017 with Medicaid beneficiaries who had serious mental illnesses. We're passed the time problems being described as transition problems. It's now a robust problem that's been in operation for a few years. We saw many of the same problems that we saw at baseline.

Next slide, please. Some of the problem areas that people with disabilities are identifying in managed care include provider networks. I have that star because in 2017, the centers for Medicare and Medicaid services noted that our state does not provide sufficient data on adequacy of networks. We're also hearing similar problems with some of the marketplace coverage, the insurance that can be purchased on the insurance marketplace or the exchange that providers are not allowed to meet the needs of people with disabilities. Something that researchers and advocates need to remain on top of. Some examples of what people told us, none of the providers I've seen for years in Jackson County, Missouri, are Kansas Medicare program. Or speech therapy is a two and a half month wait because there's only one provider. It's really causing access problems for people when the provider networks are very narrow. Managed care has ‑‑ I guess they have ‑‑ they have to negotiate contracts with individual providers. To the extent they want to control their cost, they may limit the providers they work with.

We heard of people not being able to get medications they had taken for a long time. They can't get it so they're just not taking it. One individual had to pay $700 out of pocket to get a joystick on his wheelchair and the managed care organization wouldn't pay for it. That tells us the MCOs may not understand the needs of people with disabilities in the fact that this wheelchair was not much use if it didn't have a joystick on it. More problems with therapy and preauthorization and other administrative hurdles that people with disabilities have to go through to get the medications that they really need. To be a cost‑control mechanism for managed care organizations, but it becomes an access issue for people with disabilities. Almost a third of people said they were not taking at least one of their prescribed medications because of these policies. Next slide, please.

Another problem to me that was identified was transportation. Before Medicaid managed care ‑‑ let me back up one step. Non‑emergency medical transportation is a required Medicaid service so that people that have disabilities who may not have access to their own car can get transportation to go to any kind of medical appointment. Before managed care in our state, those transportation services were usually local providers who often knew the person. When we went to Medicaid managed care to keep cost down, the managed care organization may have contracted with a single provider who may or may not have been familiar with providing transportation to people with disabilities. We've heard of people getting transported incorrectly or their assistant not being able to go with them, or requiring three days' notice on the transportation. Next slide, please.

Communication was a huge issue. Again, this is an area that ‑‑ this is for Medicare and Medicaid services found Kansas to be out of compliance with. If you have managed care, you need to know if a particular provider is in network or what services are covered and they're not able to get that information in a timely manner. They say they called 800 number and it tells I don't I to go online but they don't realize not everyone has internet access. People get things in the mail and they just don't understand them. It's not user friendly. And they often get printed material that is very difficult to read, especially for people with facial impairments. A lot of problems with communication not being accessible.

Next slide, please. Finally, care for nation is part of Medicaid managed care. To me, this particular service has the most potential to actually be of great benefit to people with disabilities, to have someone navigate the health care system and coordinate different providers, different medications that you're getting, different care. So everyone who is on a home and community‑based service waiver is assigned a care coordinator or a care manager with their managed care organization. During that first survey, half of our respondents didn't even know who their care coordinator was. So it wasn't an effective system at that time. They also said they had more direct contact with their case manager, again, a local service provider. Now I have to call a number, leave a message, and then wait. There's no way to directly contact ‑‑ it's very frustrating for a lot of our respondents. If we go to the next slide.

We also heard that you have one care coordinator for medical issues, but I don't have someone for everything else, like problems with housing. Social determining health, those are becoming recognized as a big cost driver in Medicaid. If there's something wrong with your housing, heat doesn't work, it's dangerous for falls, and that's not being addressed, then your health can be affected in pretty substantial ways. If you have a fall or catching a cold or pneumonia or whatever because you don't have heat. While the care coordinators could address that, it doesn't sound like they're really equipped to address that. Then when we talk to respondents with serious mental illness, even though almost three‑quarters of them had some condition, less than one in five had a care coordinator. That promise of having care coordination through Medicaid managed care, a promise is there, but it's not being realized is what we found in Kansas. Next slide, please.

So based on the Kansas story and what we heard from other states as well, Iowa being the most recent to make a very large transition to Medicaid managed care for its population, these private for‑profit companies may not be fully prepared to meet unique needs of people with significant disabilities. Before Medicaid managed care, this was not a population they worked with, so it's new this them. They probably weren't working with people of significant disabilities including those on home and community‑based service waivers. Some of the medical issues that are problem as a result of what we found with Medicaid managed care in Kansas is that without broad provider networks or coverage limits, people are not getting the services that they need. Non‑medical issues around Medicaid managed care included transportation and communication and difficult getting information in a timely way. Long‑term services and supports including care coordination are essential to maintaining health and function of people with disabilities and that's not necessarily happened under Medicaid managed care. In conversations with our survey respondents, we got the impression that there's just a general lack of disability cultural competence and awareness of accessibility issues among the staff at Medicaid managed care organizations. Next slide, please.

So one of the implications for policy and practice and for people with disabilities. Very many people with disabilities have a really small margin of health. They have a lot of complex care needs and if they have barriers to getting care, that can quickly lead to adverse outcomes for them and also increased costs for Medicaid programs. So it's kind of a penny wise confluence, we're going to save a few bucks by not being able to change your ride within three days, but if you can't get to the doctor you may have a hospitalization that costs tens of thousands of dollars. The nationwide trend, however, and moving people with disabilities to Medicaid managed care, we need to work with MCOs to increase their capacity to meet the needs of people with disabilities. There is some research being done and some work being done to create disability‑related measures on a quality of care including access to care and the quality of the care that is actually provided. Those are not in place yet, and I guess we would have to have some assurances from CMS that they were going to have the managed care organizations report on those. I don't think that's currently happening in a systematic way. And we really do need to measure outcomes for Medicaid beneficiaries with disabilities separately from the broader Medicaid population because overall Medicaid managed care may be showing decreased cost, and potentially even better access to care for some populations, but we need to look specifically at the smaller population of people with disabilities and see if they're having the same outcomes and if not why. This is the future of Medicaid moving to managed care and we need to really be aware of the possible issues are and be at the table to address them. When we're asked or when we're even not asked probably. Next slide, please.

So I think that brings us to the first question and answer period. I'm going to turn it back over to Carol.

>> CAROL EUBANKS: Yes, we are at our first question and answer. If you would like to ask a question, please submit it in the Q&A box that's on the main webinar screen. You'll see a Q&A tab. If you can just open that and type your question. We don't have any questions yet, but we will give it a little time. See if we get any in.

We do have a question can the slide show be e‑mailed to participants. Yes, we will be posted all of our materials, the recording of the webinar and all of our materials within about 48 hours. And you can find all of our materials at CHRIL.org. Any other questions? Before we move on.

>> I see that noel is online. You must have a question for Jean.

>> CAROL EUBANKS: I guess not yet. Oh, here's one. All right. I am curious about the access to medical care with the situation of doctors not taking in clients on Medicaid.

>> JEAN HALL: Is that the entire question?

>> CAROL EUBANKS: Yes.

>> JEAN HALL: That's definitely an issue because we often need to see specialists and specialists are even less likely to accept Medicaid payments in many cases. To me, that's a state level policy issue that can be addressed to your state legislators about making the reimbursement rates for providers high enough that they're interested in providing. I know a lot of providers who actually lose money providing services to people with Medicaid because they just feel it's the right thing to do, but they can't operate at a loss all the time. It really is an advocacy issue that needs to be addressed mainly at the state level because the state gets to determine their reimbursement rates, but also at the federal level because we have to have adequate funding.

>> CAROL EUBANKS: Okay. All right. I don't see any more questions at this time. Lex, do you want to move onto ‑‑

>> LEX FRIEDEN: Let's move on now. Any of you who may be composing a question ‑‑ I know there's a lot of material here ‑‑ continue to do so. We'll have another Q&A session after Connie's finished. And some general wrap‑up commentary as well. So don't hesitate to take your time and put together a thoughtful question or two and submit them whenever you're ready. Don't wait for the Q&A period. Carol can line them up and have them ready for the next break in the action.

But now that we are moving forward, let's go to the next slide, Carol.

>> CAROL EUBANKS: Actually, Lex, if it's okay, we did get in one other question. Can I go ahead ‑‑

>> LEX FRIEDEN: Let's go for it.

>> CAROL EUBANKS: Says if I remember correctly, Connecticut chose to go back to fee‑for‑service for their disabled population. Is this a move that other states are considering?

>> JEAN HALL: You are correct. Connecticut did go back. In fact, the former director of the Kansas health and environment moved to Connecticut and he was there when they switched back. What has happened to the Medicaid program in Kansas that's a really difficult transition. Once you contract out a lot of the parts of your program, you lose a lot of the administrative employees at the state agency. So you lose a lot of the brain power that was there. I don't know if other states are contemplating that, but I know that a lot of states have heard from disability advocates that Medicaid managed care is not working out very well. Sometimes they're just moving to ask that people with disabilities be carved back out of that managed care arrangement. Which helps people with disabilities and doesn't help everyone else in Medicaid managed care. So I don't ‑‑ I have not heard specifically other states doing that. I have heard of states where there's a lot of unhappiness. Iowa just implemented Medicaid managed care and one of their care providers has already withdrawn from programs so there are issues there. While states may want to do that, they're going to find it's very difficult to do. They have to recreate a lot of infrastructure that was lost. I don't know of anyone wanting to do it. If they want to do it, it's hard to do. Connecticut has shown it can be done.

>> LEX FRIEDEN: Jean, are you aware of any studies that have been done, surveys of people with disabilities, comparing ‑‑ that are legitimate research initiatives to compare people's experiences with or without managed care? I'm aware of a lot of ‑‑ of stories that people tell. They can give anecdotes of how one approach was better than another for them, but I'm not aware of studies. Are you?

>> JEAN HALL: We also heard that anecdotally and we heard a lot of times, yes, absolutely, I was able to get things from local providers and get the services that I need to see the doctors I need. And the problem is ‑‑ I was trying to make the point in my last slide is that if you look overall at outcomes under managed care, you may find there are better outcomes. But if you drill down a little bit and look at specifically with people with disabilities, you may not find that. And that's what we need to be doing. I'm not aware of any studies at this point in time that have been ‑‑

>> LEX FRIEDEN: See, I think it's really hard to generalize. I happen to know a number of these cases and we've followed up on a number of them. And some people with Medicaid managed care have turned out ‑‑ you know, they've done very well because they've worked closely with their case navigators or case managers and they've actually been able to get benefits that they might not have been able to get through the traditional program without the ‑‑ the follow‑up that some of the managed care companies provide. On the other side of it, you find people who ‑‑ who sort of feel like they're left out. They don't have good connections with case managers or their case managers don't seem to understand their particular issues. And they feel like it doesn't work so well. So I really do think it's hard to generalize and I think it would be hard to get good data because every story somebody tells there's always of course a certain degree of reality and a certain degree of sort of perceived experience.

>> JEAN HALL: What we did hear from some people with care coordinators was that it was very helpful. Many of them didn't have care coordinators assigned and many hadn't been able to work with them. And the other thing in Kansas, for example, we have three managed care organizations. They may have different experiences under each organization. There's just a lot of variables there. Another variable is that when you work with a private managed care organization, a lot of the data that they have is proprietary. So it's hard to do some of the claims analysis that might have been done in the past.

>> LEX FRIEDEN: The other thing that I find interesting is that not all managed care is the same.

>> JEAN HALL: Exactly.

>> LEX FRIEDEN: And some states have more than one contractor, and in fact in those states, people are able to change contractors and their experience may vary depending on which managed care company they're signed up with. And that varies from state to state just because a company seems to serve people well in one state, it may not in another one. And a lot of that variability is caused by the contracting rules of the individual states.

>> JEAN HALL: Exactly. I did see a study by the common law fund that found that managed care organizations that are nonprofit actually had better services and outcomes and more satisfaction than for‑profit managed care organizations. But that's been a few years ago now. I don't know if anyone replicated that.

>> LEX FRIEDEN: One thing we can say without equivocation is that people who really are interested and they do have opinions have to share those opinions with their state legislators. In each state, there will be a committee ‑‑ the legislature that is responsible for overseeing these dollars that come in from the federal government and are processed through one or more agencies in the state. And those ‑‑ those legislative committees have a lot to say about how the state manages its business. And that kind of may be a great segue to move to Connie Garner unless you have more questions, Carol.

>> CAROL EUBANKS: No more. Let's move on.

>> LEX FRIEDEN: So we're now going to talk about Medicaid waiver options in the context of health care reform. Our presenter is Connie Garner who many of us know from her work in the U.S. Senate. Connie, for a number of years, worked with the health committee, the committee that deals with disability legislation in the Senate. She was closely associated with senator Kennedy. In fact, on several occasions, I had the opportunity to ‑‑ to talk with Senator Kennedy about health care related issues, and he always referred me to Connie. And I think, you know, he considered Connie his alter ego when it came to these issues. Certainly she helped guide a lot of the legislative initiatives that came through the health committee when the senator was responsible for many of those programs. And she worked closely as well with Senator Chris Dodd and senator Tom Harkin. I think, you know, nobody in our community, in the disability community, knows anything else more ‑‑ knows any more than Connie Garner does about how things work on the inside. And that perspective can be helpful to all of us as we try be good advocates and try to understand the implications of a lot of the legislative action that's taken.

Connie helped to draft ‑‑ you know, while ‑‑ while members of the legislature are the ones who actually write the bills, somebody has to do the writing, if you will. And Connie Garner more than anybody else is all over and all through a lot of legislation that came through the health committee, particularly including the class act. And Connie, we're so glad to have you with us here today. Thank you. And take it away.

>> CONNIE GARNER: All right. Thank you for having me this afternoon, and thank you Lex for your comments. As Lex said, I come to this conversation today kind of from three perspectives that I'd like to share. One is the 19 years that I did spent with Senator Kennedy as the policy director for disability and special populations for the health committee. That death with disability‑specific legislation, but we tried hard when disability went to that full committee level for review to actually thread the issues that were important for vulnerable populations, people with disabilities. Make sure that that lens was captured in all pieces of legislation, not just disability‑specific legislation.

So that was a great experience for me and of course working for him was an enormous learning experience. And I've been fortunate to, you know, can continue to be able to work with his family. So I come with that perspective. The second one which for me is equally as important is I still practice as a pediatric and nurse practitioner. So I have that perspective to bring for real people and the care and concerns of families particularly with children with disabilities. And then as a number of you who may be on the phone know, I do have seven children. Four boys and three girls. I do have one daughter who does have a developmental disability. She has viral encephalitis when she was 6 weeks old. Back in those days you only got 6 weeks maternity leave. I came home, she has a fever of 105. It turned out to be viral encephalitis. A lot of scatter. She can do a lot of things. And she now ‑‑ I actually ‑‑ for those of you who are disability followers out there, I ‑‑ she ‑‑ I actually did one and a half, the last three authorization of IDEA and half of the one before it. After that authorization, I actually pulled her out of IDEA at 18 so she could get a job. Because I felt like that ending period of IDEA wasn't doing anything to advance her ability to, you know, work in the community and be in the community.

So she's been for a couple years now working and making $2 more than minimum wage and doing really quite well. But it does for me speak to the reason why there does need to be some changes, I think, at some point, at a safe point in time for example to IDEA to move us forward in terms of that transition from school to the rest of your life. A little bit better than what we've done so far. So those are the perspectives that I bring to the table today. I also do ‑‑ with the work I do now at the law firm I work with now, I do actually work with two insurance companies under the hood with their Medicaid managed care and kind of what ‑‑ a lot of what their product design attempts to do in meeting the needs of a population that, frankly, from the health care as well as disability perspective, the insurers are not really used to dealing with people that have issues of chronicity really. Before, as you know, before you had health care and before we had the guarantee issue that everyone would be part of an insurance plan, a lot of those folks did not have health insurance.

So ‑‑ so I do have a little bit of experience now in looking at what the challenges are for Medicaid managed care. I do agree with a lot of what Jean said. The one thing I think is important, however, to remember in managed care is from an infrastructure point of view, trying to coordinate and make care make sense. Because as an actual provider in realtime, I can tell you a lot of what we do in the health care system does not make sense, but to try to work towards making that make sense, particularly for people with issues of chronicity which is really what most of our population have. The infrastructure of managed care does not have to be all bad. It's a matter of what happens under that infrastructure and how we argue for what we need correctly. That will strengthen that.

One of the things that I think is important to point out, too, in terms of the insurance companies ‑‑ and I'm not on this webinar to show for the insurance companies by any means. But one of the things that is true is they are beholden to the state. If we really want to make a difference in terms of what Medicaid managed care looks like, then we need to be at the table when an RFP is developed, a request for proposal is developed at the state level, because that's laying out what the state expects. The insurer is responding to that. If the state doesn't include in the RFP and doesn't demand of the proposals the things that we care about, then, you know, it's not there, they don't have to do it, number one. And number two, there may not be money for that piece to be implemented. So we want to make sure that we're at that level. That is the most important level to be really involved at the state level when an RFP regarding managed care begins to get developed in terms of the Medicaid program.

With that, Jean did a nice job of pointing out where we are with Medicaid right now. You see the first slide, 2017, where are we going and why are we in this conundrum. Next slide, please. And I think we have to look at that from a couple different perspectives. One thing I thought was quite interesting when I went back to look at things over time, the end of a year, the end of a legislative session, you begin to look backwards. There's been 100 years' span of time. There were two quotes significant. There are no facts, only interpretations and if you look at just generically over the last two years, three years, even seven years if you want to go back to the ACA, there was a lot of arguing that went on between what is the facts and what are not the facts. You know, is everything subject to interpretation only? Do we really have the facts to make decisions on? That's been an issue certainly for the last couple issues as well.

One of the things that was hard that we did and I actually was part of the development at the ACA. Interesting to be at the table for all the debates. One of the things we did not ever realize or think about was no one ever understood how really pretty sick the people that were going to the exchange would be. And that's part of what's happened in all the financing of the exchanges and health care reform. No one ever ‑‑ we never had a conversation that talked about the acuity level of the folks in the exchanges would be, but they are. They have never had health care. If you look at some of the town hall meetings and just scan the audience. You can see the amount of health issue even in the audience from cardiovascular, diabetes, orthopedic, all kinds of stuff out there. The thing that I would say to the disability community frequently, when we talk about health care, we spend most of our time talking about Medicaid. There are two things we need to remember. Not everyone who has disabilities and special needs is on Medicaid, and there's a lot of work to do if you will in the commercial side of the insurance that we have. And in addition to that, the people in the exchanges really do have disabilities. They just are not what we think about every day, but that's the reason why shoring up the financing of the exchanges has become such a challenge. The folks are pretty sick that are in there with issues of chronicity.

So those ‑‑ we didn't have the facts at the time. We interpreted what we thought would happen. The other thing that's important was a quote that said there are no solutions, only tradeoffs. I think that's a very significant quote because if you look at what's happening even right now politically, there are no solutions but there are a awful lot of tradeoffs happening in the last week, two weeks around the pieces of legislation that need to get to some completion by the end of this year. If you bring that 100 years forward and look at the ACA health care in general, there were seven years where we had nothing that was said that really mattered. People said we want to change it, we want to repeal it, we want to replace it. That's not a policy. That's not a policy. So nothing was ever done. Seven years where nothing that was said ever truly mattered. Now we're at the point where every decision that's made around health care really is going to result in significant consequences. Every single decision. So that's kind of where, I guess, and how I would argue we got to where we got to. Next slide, please. Kind of how we got today.

Think about this, we had the ACA. For better or worse, it was out there. It had a few things in it that mattered a lot and still do matter a lot to people with disabilities. First one it has the guarantee issue. Everybody is able to get health insurance. They cannot be taken out of any health insurance because of a condition or disease or debilitation or anything they have. They're able to get that coverage. That was the first thing. In order to be able to provide that and say that we would be able to manage a health insurance for everybody whether they were, you know, like my four baseball player boys who really have a lot more stuff going on than we give them credit for in terms of orthopedic issues or my daughter with a disability who's never really sick or someone born with a disability and lives with those challenges over their lifetime, it didn't matter. You had to guarantee you had a risk pool that was balanced. Enough people in the pool that balanced out people who didn't require a lot of services and supports to balance out people who really did. That was the reason they put the individual mandate in. If everybody is in the risk pool and accepts then what that looks like, then there's coverage for everyone at any time in their life.

One thing I say often that people in this country are not willing to accept and they are not ‑‑ other countries have accepted it and we are not good at it. We don't know who we're going to be 24 hours from now. We do not know that. When I see mothers come into the hospital to have a new baby, what everybody wants, do you want a boy or a girl. No, want a healthy baby. There's a number of babies who are born who run up against untoward circumstances that no one ever thought would happen. The people who ran in the Boston marathon at 6:00 in the morning when they got up, never thought they'd be in the situation they were at 6:00 at night. We've had enough issues with terrorism happening that we need to internalize it. We don't know who we're going to be 24 hours from now, and we need to as a society invest in that. And we haven't done that. And other countries are. Australia, they have a very interesting program as we talked about earlier for long‑term services and supports. For the other European countries. It's not a question for them. In our country, it's never going to be about me. It's never going to happen to me or the people I care about.

The problem is that's not true. So we have the ACA. For better or worse, we had at least a guarantee that everyone had basic health insurance coverage. A mandate that everyone needed to be able to get it. And then we thought that we had provided avenues where that could happen whether it was through Medicaid or a Medicaid expansion or an exchange or a commercial insurance product through your employer or a small business market. We thought we had avenues created where that could happen. It wasn't perfect, for sure. There are a lot of issues in it that weren't either considered or probably not necessary. I will tell you an interesting day one time with Senator Kennedy before he died in the very beginning of the conversation. Remember him banging his fist on the desk and saying, what is this about. Are we insuring the uninsured or doing through healthcare because they're not the same. Not sure he ever got the answer to that. My point is getting to at least where we got to with the ACA was not easy and there are some pieces in it that mattered for all of us. Was it too big? Maybe. What's there now is what we have until we don't have it any more.

In 2017, though, the health care fight began over again. Talked a lot of talk, but nothing really happened. You look at what happened in 2017. You had the first round of the Affordable Care Act. That was the first repeal effort. Then you had the second version of it. Then you had the third version of it. Then you had a skinny repeal that just took away the mandate and some of the issues that employers had with their piece. And then you had Graham‑Cassidy. Graham and Cassidy was an offering that was done in the Senate. And it actually ‑‑ we could have probably worked with that if we ‑‑ if folks were really willing to think about doing something different. But this is where we were. That's just in 2017. And we still haven't really gotten very far. Next slide.

So when we looked at what that health care repeal, if you will, for the health care ‑‑ the ACA would look like, CBO which is the congressional budget office which does the scoring to see how much something costs or saves, they estimated the upshot of the repeal would reduce the deficit by $150 billion over ten years. The that's a lot of money. That's, you know, someone wants that. That's big. But it would result in 24 million people losing their health insurance coverage by 2026. 14 million Medicaid beneficiaries losing Medicaid coverage. But the biggest thing and the most important for us is it reduces federal funding to the Medicaid program of $839 billion in that ten‑year period of time. That's a lot of money coming out of the basic Medicaid program that we care about. All the sudden, health care wasn't just about repealing or replacing the ACA. It was about getting into Medicaid expansion which is part of the ACA. But then it was also about going to the core Medicaid program. So we began to be reforming a lot at one time.

So those are all the things in terms of what the cost ‑‑ just a few of what the cost would be if we had repealed and replaced. We didn't have replacement. If we had repealed or changes what we know as the ACA right now. Next slide, 25. So where do we go from here? You see the last couple weeks what's happening. We have a budget that needs to get finished. Whether it will or whether the government will shut down could still be up in the air. My guess is we'll have a continuing resolution for a short period of time. Doesn't look like they could really get it together to have a giant omnibus package that's got everything we need in it. There's concerns about what will happen with the CHIP program for the kids. And then we ‑‑ the health care is ‑‑ you know, predicted to come back up next year. But the biggest concern I think also is that next year there will be a focus on the entitlement programs. What should Medicare look like if something different. Going back to what Jean said I do believe managed care as an infrastructure is the way of the future. I don't think that states will be able to stay in a fee‑for‑service molds for ‑‑ model for sure, or a carve out even for people with disabilities for a long period of time. The carve outs is a double‑edged sword. If there's a Medicaid managed care program involving in your state and saying carve those guys out, it's only going to be a temporary carve out. The question is, is it better to be on the front end of the formation event where our two cents is in there helping frame it or better to be hit by a tsunami later on when there's no chases. ‑‑ choices. Particularly our administration we have right now and Medicaid, it's not going to be something supported very well financially over time.

So it's going to be managed care. So the question is how do you look at that and how do you work with that framework and make it better. The other thing that's interesting is Medicare managed care is becoming more and more the enrolled piece of Medicare. So we have traditional Medicare. But then we have part C. There's A, B, C, D, we would like an E for long‑term services and supports. But there is a C right now that is the managed care avenue, if you will, of Medicare And the enrollment of that has almost tripped. People by the nature of their own choices and what that particular avenue was offering are actually going into managed care for their Medicare. So a lot of that's going to happen. So it's a question of on the front end of the bus or the back end of the bus at the end of the day. That's the first thing that we look at. Next slide.

If we look at disability policy, this is what becomes tougher on disability policy. The way that congress and the legislature is structured is by issue. It's Medicaid, it's Medicare, it's SSI, it's SSDI, Voc rehab, IDEA, regular ed. It all comes in silos. But the disability policy can't do that because the population threads through all of those issues. So it's not a single issue And we care a lot about equity, fairness, and opportunity for the most vulnerable citizens that we have. We want our communities to look like this picture. This is what ‑‑ in a perfect world, in a really good day, we want a day in the life of the community to look like this picture that we see. So that means we have to focus on a lot of stuff because we are not just a single issue in order to create this. 27, next slide.

And so if you look at where the definition of community, and this really is the underpinnings for home and community‑based services. If you just say home and community‑based, people will say, yeah, it's a 50 cent buzz word, what does it mean? Where does it come from? I would argue it comes mostly from these three areas. One is societal expectations. What does society expect a community to look like and be? And what ‑‑ and what are the pieces in a community that matter? Family values become one. We could argue from now until next week whether we think family values as a whole have stayed the same over the years or whether they've changed. System infrastructures are important. Where are our laws? And where are our schools? Right now, the crying needy would argue in schools ‑‑ and it's not going to matter whether it's a public school, private school, catholic school, it's not going to matter. It's going to be that we infuse some piece into those schools each day around mental health in schools. Coming from the medical system, it's not just about the guy who gets an orthopedic surgery and gets too many prescriptions. It's not just ‑‑ it's almost become the name now for substance use disorders in general. And we don't do anything to support schools in terms of what they need around mental health in schools. They get lots of support for the kids under IDEA in the mental health categories, but we need something more global that addresses this early with kids so that it doesn't get to where we're at right now which is the big crisis. But schools are a part of the societal expectations that then define that community and the school and with what it looks like.

Where are we with that? Are we taking on the information we have? I do a lot of work with the national education association which is 2 million teachers. I spend Friday and Saturday with them this last weekend. And they don't have nearly the information that we could be offering them around kids with disabilities, kids with special health care needs, families, family dynamics, mental health. Those are the teachers there in the classroom six hours a day and they care. They don't get up in the morning saying I'm going to screw everybody up. They get up in the morning to do the best they can. We don't help them with the tools in that tool kit. These are the kinds of things that begin to define what your community is about and how it looks in an effort to get back to that perfect day in the life of people with disabilities and special needs. Next slide.

Remember, we've come a long way, however. So we can't step. We need to keep evolving. I remember when I first saw this slide in like the late '90s I guess or 2000. It's on the slide there itself. Tools of the trade. This is an argument that had to go on around training, quote unquote, parents to be parents of kids with disabilities. I liked looking at all the items in here that you could get help with. That had to do with being a parent of a child with disability. Very different ‑‑ very foolish, but that's the way it was. That's the way it was. Number 29. So what's happened now in Medicaid? We talked about Medicaid and where it sits in the ACA. You either have basic Medicaid or you have the Medicaid expansion which is intended to mirror the insurance in the exchange.

The exchange is intended to mirror employer‑sponsored insurance. So where we get stuck is anyone who has Medicaid expansion doesn't have any wrap services. People who do have the basic Medicaid program, they do have long‑term services and supports. We don't have that in the expansion because it's meant to mirror what you would get in an employment if you were like an employer who could provide it. So Medicaid is growing in a lot of different places. There are a couple of different ways a state can try to control their cost. One of them was the beginning in 1983 that started with the waiver march forward. It started ‑‑ it started and still to do day and most of the waivers are called 1915C.

It's just a number. That's all it is. It was a waiver alternative to institutional care. Was the first time that we said, if you were significant enough to qualify for institutional care and if you were poor enough ‑‑ because remember, that seems to be what the definition is for people with disabilities. If you're poor enough and significant enough, you can get what you need which is a very strange way for us to be in this country continuing to look at supporting people. But that's what this was. And the waiver provided an alternative. If you met those two criteria, then we would under this waiver allow you to begin to ‑‑ allow you to get some home and community‑based services. Let's see if it worked in the community. Then it took until 2005 when the next one came along. As you see, they all have a letter attached to them. One of them said, okay, you don't have to have a waiver at all now. We're going to take that mandatory service in Medicaid which was the nursing service which was really for us was the institutional care and we're going to say, you don't have to have a waiver. You can just provide people that option in the community you want. J was the self‑directed care option. 1915K has become very popular. It's the community first choice waiver. Money follows the person is part of that. That actually is getting reintroduced yet again to see if we can get that funded.

Now, most of the states stay under the 1915. So you might argue, why didn't they just take that mandatory institutional benefit and say if you want an institution, you're in it. If you don't, then you stay home. But there was a real concern that what that would do would cause what we call a woodwork effect and there would be so much cost associated with it that the Medicaid program would get completely out of control. So they did it by waivers because remember you waive criteria. In other words, I can waive statewide. I can provide it in one part of the state and not another part of the state. I can provide it to one population and not another population. It's the way that you can control things. Eventually, though, you can only have so many of these little waivers. New York's a good example. They have a whole bunch of little waivers. One of the things that the government came out with, we're going to go with a thing called 1115. Instead of 1915, we're going to go to an 1115 waiver model. That's like a jumbo global one. One of the questions was, why don't you take all those 1915 waivers and put them all under the umbrella of this 1115 waiver. So you do see not that similar, but you do see a lot of states applying for 1115 waivers under Medicaid. They're adding that onto their basic Medicaid program as an amendment. What they're really looking for in that is to control some of their cost, some of their spending. And we're beginning to see much more flexibility offered on the part of HHS, CMS, the centers for Medicaid services, are looking ‑‑ are saying at least that they're willing to approve waivers that you and I have never seen before.

So while we're all out here arguing and, you know, yelling about Medicaid and ACA and, you know, single bills, my piece with being here today is to tell you be very careful. Because where the flexibility is coming from is in this provision of the 1115 waiver in Medicaid. And so we have to be very vigilant in looking at what the states have. Next slide, please. Now, I'll come back to this later in terms of home and community. But ‑‑ we can go through it right now. You all know this. It's defined right now from the government's point of view, this is the definition of community is defined as nature and quality of my experience. The point is it's not a place anymore. It's based on an outcome. So what I ‑‑ with the nature and the quality of my experience with my life, a day in the life of being me or my daughter is really what defines what is a good community‑based service for me. So it's about outcome, not about bricks and mortar and not about place. Next slide.

It's supposed to be person‑centered planning. So that ‑‑ you know, again, a lot of these become 50 cent buzz words unless we take them and make sense of them. So you have a planning process. We would like to see these things addressed where you look at health and long‑term services and supports. Why would you not want to look at an integrated care model? One feeds and contributes to the other. Using your preferences and your goals. Using representatives you believe can help you. And it includes paid and unpaid services related to a day in the life of what matters to you. It's essentially that number three. Next slide.

Okay. But what will happen ‑‑ and this is where I get into these 1115s, if we don't act and if we don't stay vigilant on state waivers are, we're going to be in trouble. Next slide. Now, the intended purpose of these waivers and the demos and this is very close to what the occurrence administration is saying about these, is to provide flexibilities to states to implement projects now that are likely to assist in promoting the objectives of Medicaid. You would hope that's what they would do. They're not traveling too far off of the base in terms of their flexible. They still have to make an argument, supposedly, that they're promoting the objectives of Medicaid are. When I tell you what the waivers have in them, you have to decide whether you think that's promoting the objectives that you think are important. Allow waiving of certain Medicaid requirements in order to implement the demo and test ideas. Fair. You need some flexibility to test new and different things, but you still should be tied to the goals. Increase in coverage, increase in access, great health outcomes and somehow defining efficiency and quality of care in the same sentence. Next slide.

Here is what the unintended use of these waivers seems to be looking at. It's hard for me to tell you that Massachusetts which is generally one of the most liberal states that has one of the most broadest health care program in the country has a Medicaid 1115 waiver submitted that has some pieces in it that are really troubling, I think, for people with disabilities. And they get ‑‑ they get back to a couple of the things that were reported as issues even in Kansas. The first thing they have is ‑‑ they have a capped formulary. Now, for people with disabilities, special needs, chronic illnesses, having a capped Medicaid formulary is very hard because you're going to get one drug from each class put on there. From the medical side of things, one certain drug doesn't work for everybody. Even if you get a generic drug that's an equivalent, it's not an equal. For some people, they can manage that drug when it's a generic drug and some can't. Seizure medications in particular are a little difficult with that. And so ‑‑ so when you have a capped formulary, you begin to see a lot of limits put on your choices and a very significant drive towards generics and then a lot of out of pocket that you have to pay on top of it. But Medicaid up there has a very broad formulary right now and that's a way to think about it. Other states are watching. And if Massachusetts does get approved, other states will submit the exact same thing.

Arkansas is sitting there waiting. There is mirrors ‑‑ theirs mirrors Massachusetts. I think we had one from Arizona that's now sitting. California. The other thing is there's imposed work requirements in a number of these state Medicaid programs. Now, I'm not clear yet and I haven't seen yet how they're dealing with who ‑‑ who those work requirements are imposed on. The thing that disturbs me about that was a little bit of a conversation I heard in one state I was at where they assumed that a person who had MS, let's say, that was in remission was really an able‑bodied person and therefore there should be a work requirement on them to have Medicaid. Now, they can come out of remission, stay in remission, they have absolute diagnosis that matters. The thing that's kind of scary about that to me from a medical point of view is if we're saying that when a person is on treatment and that's ‑‑ let me say brought them to equal which it never does completely, that that means they're well by the definition of well. I think that gets a little dicey when you start looking at that, you know, in different circumstances. But that's one of the questions, again, unanswered around imposed work requirements. How does that look, how does that work.

There's an increase in premiums on low income folks in a number of the waivers. There's a limit on enrollments in a number of the waivers. There are coverage lockouts. What that means ‑‑ and there's some validity. What that means if you don't pay your premium within a certain period of time, you're locked out from being able to get coverage for a longer period of time. We could say that's a bad thing. Or we could say that's asking people to be personally responsible to pay their premiums or do something about it if you can't. I suppose you could weigh that ways and you argue it. Some of these other requirements are not as easy for us.

I think the capped formulary is one. The other that we see, again, in Massachusetts and then in California, couple of the other ones that are out there, is they will no longer provide non‑emergency transportation. Now, I think that's ‑‑ the questions around that are raised are a lot. Non‑emergency transportation. So how do people who need to have transportation get to work? How do they get to the doctor's office? How do they get to their visits for therapies or for lab stuff? What equals non‑emergency transportation? People that have to have transportation to get food from a food bank, do they no longer have that? And what happens then? So I think non‑emergency transportation and whatever the definitions of that will be in different state waivers become very important. And the reason I point all of this out to you, next slide please, is because it just shows you the magnitude of how important it is to start doing state work. Because this is where it's going to matter to us. The federal government's going to move on from federal stuff in terms of health care. Medicaid is a state operated program. That is where our focus should be. We'll work on the federal level to try to not have things taken from the federal program expectation, but so much is reliant on what the states are doing and how we can be involved in that.

So we have dueling agendas at play. From a political point of view with health care, there's issues around expanded government role, should the government be involved in health care, should it not. Should it be, you know, should states have the say over feds. All that is a political conversation. And then financial is similar to the slide that you saw earlier except a little bit more updated in numbers. But there's a decrease in overall traditional Medicaid enrollment, but spending is going up. What that tells me is there's an awful lot of dual eligibles in this population now or we are seeing a lot more need for long‑term services and supports as opposed to where we were with some of the other Medicaid enrollees which are, you know, poor ‑‑ poor women, infant, and children which may not have the medical need, but they do have the poverty need to get health care.

Number 36. So these are the agendas that will be at play when we have an entitlement reform debate next year. Non‑approved requested restrictions. I'm showing you these, they have not been approved yet, but they have been requested by states in their 1115 waivers. Take Medicaid to 100% of the poverty level and that's it. If you look at Hawaii, for example, they have 400% poverty level. Lot of states have 133% of poverty level. This says, you know, a lot of the state waivers are saying 100% and that's it. Get rid of presumptive eligibility. There's the notion that for some circumstances there should be a presumptive eligibility for Medicaid so people got on and got what they needed without waiting until they go through all of the hoops. I always argued that this was unsuccessful because I always felt like we should have Medicaid presumptive eligibility in the neonatal intensive care unit. Here we have young 20‑year‑olds with a baby who's sick who they didn't expect. As they walk out of that NICU with those children who are a lifetime of challenge for them, they are in a financial hole walking out the door and never really get out. They just jump poverty buckets from that point.

My question in there, isn't there another way to do this so that these folks get a jump start early? And presumptive eligibility until discharge may have been a way to do that. The numbers of the kind of kids we're talking about are not really that high, but the impact is huge on those families. Drug screening and testing. They're asking that before you are allowed to be on Medicaid that you are drug screened and tested. And then over time, I suppose if you have a substance use issue that you'll have to continue so show drug screening and testing. Time limits on coverage. That's a little scary because I'm not sure what you do with that. I have coverage for five years and then what happens to me? So I don't know ‑‑ if I can't work and I really try and can't, is there an exemption? Time limits on coverage is one to watch. And then this non‑payment lockout which we talked about earlier which may be fair if the rules are right in terms of respecting that for some people they're not just not paying, they have trouble getting to that point and need help. If that's the case.

But these are kinds of things we see states asking for. They have not been approved, but they're there. None of the waivers have been approved yet. The thinking is they will not be until the new HHS person is actually confirmed. So that's probably going to be soon. But that's kind of where that's at. Number 37. So here was the new guidance which isn't ‑‑ you know, it's fine to look at for a minute, that was just released on waivers. Now, look at the difference in the goal up here. The CMS goal ‑‑ we talked about earlier was all in the interest of kind of the consumer. The goal now is to reduce the burden for states throughout the approval process to develop a timeline for the approval process, to expedite the process by developing ‑‑ it was all about speeding this thing up of a certain waiver. And then to approve the extension for up to ten years. That's a long time. Guess it could work, but that is a long time if it just is an approved waiver and doesn't need to show anything, doesn't need to change. So that would be something to look at as well.

Number 38. So this kind of my final slide when we talk about Medicaid going forward, change in the future. If you don't like something, change it. And if you can't change it, change the way you think about it. And I think ‑‑ and this is really what happened when we had buses in ADA in the city transit. You know, we didn't like it. We changed it. If we couldn't have changed it, what we did was have the transportation system have to change the way they thought about us in terms of accommodations. So that same principle I think holds true now in health care and particularly what we'll see next year in the effort to reform the entitlement programs. That's why I say, you know, when we talk about managed care, talk about new infrastructures of health care, they're going to be there whether it's an ACA model or a different ‑‑ they're going to be there. When we need to work within the structure to see if we can make it the best we can make it. At least we'll have the right of first refusal. We don't like it, that's another story. I don't think we've put the effort into seeing if we can get things to where they need to be before we turn in that right of first refusal.

So those are pretty much my thoughts. I'm going to turn it over to Carol for some questions or Lex.

>> CAROL EUBANKS: Yes. And thanks, Connie. We do have some questions, actually. The first one is more of a comment. So I'm going to give you that and then also ask a question. The first one says, when I assist people to apply for health insurance, it is hard for them to get it due to preexisting conditions. The second one says to your point about how we perceive the future. Is there any systematic effort aimed at addressing the deep levels of fatalism paired with cynicism that hold citizens and policymakers back from making substantive policy changes? Is there thoughtful effort to change the current dialogue? Do you have thoughts or recommendations around an advocacy agenda, not just policy specifics, but the dialogue that frames those policies? Turn on your audio, Connie.

>> CONNIE GARNER: Sorry about that.

>> CAROL EUBANKS: That's okay.

>> CONNIE GARNER: Let's go back to question number one that you had because I think that's a little bit easier to answer. The individual who said they were having trouble when they tried to get people insurance because of preexisting conditions. Now, that should not be happening now. Now, where ‑‑ you shouldn't be having trouble getting insured. Where the problem is is what the insurance costs sometimes. Now, there are parameters right now in the ACA around that so that people ‑‑ yes they can get in, but they can't be charged so much that it's out of sight for them. So whatever's happening with that, we should try to help you with that, whoever you are, because that should not be the case. That particular thing should not be the case. If you said we're having trouble getting services and supports for someone who does have insurance, then I think you're probably correct in a lot of cases. Initial coverage, I think it's tough to have that be a problem right now. But happy to help you if you need some help with that. I think that was the first question.

What was the second one, Carol?

>> CAROL EUBANKS: It's kind of long. Is there any ‑‑ sorry, systematic effort aimed at fatalism paired with cynicism that holds citizens and policymakers back from making substantive policy changes?

>> CONNIE GARNER: Stop with that. Let's answer that first. Is there a way? Well, it feels like there's a collision of a few things happening right now, and I do think there's a way. There always is a way. At the end of this year, everything will have passed that needs to get passed. People will stop grand standing. It is interesting though because the culture you have right now in congress ‑‑ those people are elected by you and I. So it's really our fault. If we don't like what's happening in congress, if we don't like what's happening in the White House, whatever it is, we're the guys responsible for that. Not the person even in there. We are. Because we're the ones that do the electing of people. We can do it because somebody looks good on TV, because they have the right issues, or because they've shown they can do something. I don't think we spend enough time looking at the right pieces of that.

So I don't I do have a difficult situation in the congress right now because you first of all have a lot of people who are new. The thing that people forget is that the staff people do an awful lot of the work. I think Lex pointed that out a little bit. And the members just sort of be elect the members. And the staff really do a lot. From the amount of time I spent up there, I can tell you there's an awful lot of young staff there that unfortunately a lot of folks left and didn't get the mentoring that maybe they should have. So they're at the mercy of the last person that walks in the door. They're not ‑‑ they haven't had the experience to be able to analyze things in their own right on their own merits. So I think as congress starts to look different if we do get a different mix of folks that are up there, doesn't matter, republican or democrat, people that want to try to get things done. I think that's the issue. Do people want to grandstand? Do they want to fall on their sword on, you know, kind of principles that they believe, or do they want to get something done.

I was just kind of fortunate because I worked for a guy, Kennedy, who was very good at getting things done. Really good. You know, he could be the best lefty out there yelling and screaming at the microphone. He could be political when he needed to. Having worked for him for that length of time, his thing to us was, you get to the table, you get to the middle, or you don't come back and tell me what you had. So we had to learn to negotiate. We had to learn to understand there were two sides to a story. We had ‑‑ it's not even finesse. I don't really think we have a lot of that right now. You know, I watched him work with George Bush. I watched George Bush say good‑bye to him for the last time in the White House. I saw people that knew how to work together long after CNN is turned off at night and could really get things done. That's a piece I think we're missing now.

You have a lot of new people in the house and Senate, members and staff. Overtime, I think that will come back together. As far as where are we as a culture is a little bit of an issue. And that's probably why we don't seem to work together well, even as people. Long‑term services and supports for people under 65, the aging population is a big deal. Somehow people in this country don't think it's about them. Yet we can't get that off the ground worth a damn. I just ‑‑ I don't know whether something bad ‑‑ they say single events are the only things that really change people. I'm not sure if that's true. But I think we just have to keep working on it. I think we should be positive about disability because the amount of change that's happened over time, if you look back is just ‑‑ is just great. I mean, it's great. And it's moving forward. But it's got to get cranked. People with disabilities shouldn't have to be poor and shouldn't have to be significant to be able to have a life. And we're still in that mode. And a lot of different frames.

But I think if we work on it and people understand it and they understand it's not a special interest it's about all of us that I think we can get there. So I don't think it's going to stay as negative as it feels like it is right now. And she had some more, I think, to that question.

>> CAROL EUBANKS: Yes. I think both of these could go together. Is there any thoughtful effort to help us change the current damaging dialogue, which I think you included in that last response. Do you have thoughts or recommendations around an advocacy agenda, the dialogue that frames those policies?

>> CONNIE GARNER: We need to do something different with the curriculums that are in high schools for sure, maybe even grade schools around this issue of social consciousness, I think, and of each other and really leadership and, you know, how ‑‑ what all that means. But it's more than just math, reading and science, and not that it has to be a separate thing. But it ought to be within those curriculum defines and it really isn't. In the colleges, we need to have more emphasis on what's happening right now. I have a lot of these kids and they're all in their 20s. Four of them ‑‑ just got the fourth one in college. They all played baseball. They all have friends. When you talk to them, if I ask them ‑‑ they're spread around three different universities. If I talk to them and say what do you think about what's going on in the world right now? What do you think about Korea? They have no interest and they don't know anything about it. Not the handful relative to the rest of the numbers, but handful in terms of the numbers that you see in the government world kind of thing. But just the general Joe Blow kids out there working in different professions that need to care about the country. They have just checked out on all this. These are not just the absolute type people. They're the other folks as well.

I really think we have kind of let down the younger folks on the issues that are important to think about in terms of their country and what matters and loyalty and, you know, caring and stuff like that. So I would tell you that I think somehow we have to figure out how to get that back into curriculum in school and how really teacher prep programs could be bumped up a little bit to address some of that, too. So the teachers come out with a little bit more on that. So there's ‑‑ that's my thoughts on that one.

>> CAROL EUBANKS: Thank you. Samuel is asking in your opinion, what is the place for the Medicaid buy‑in programs in terms of social determinates of health, particularly employment and health.

>> CONNIE GARNER: I think this is a good question. I was the staff person at least for Kennedy that worked on the ticket to work program and we had that buy‑in at that point. It was an effort to say why are we making people have to be poor to get what they need. And so that's why that buy‑in was there. There's a buy‑in in the ticket program. There was a buy‑in in family opportunity for families that had kids parking under social security numbers so that the kids could get Medicaid. So I think there is a place for the Medicaid buy‑in and social determinants of health. I'm hoping that the insurance companies will finally get this. When they pick up the Medicaid managed care contracts in the state, I am fascinated ‑‑ and they pick up disability populations ‑‑ I am fascinated how they are front loading the system with things I never thought they would do. And the reason that they're doing that, employment supports are part of them that you have here in your question, and a lot of social determinants. I think they're finally understanding that if you front load the system with those kind of services and supports, people can go to work, they have a day in the life in their neighborhood, then you see less true expenses from their perspective, illness.

We did a little bit of the study at one of the centers I was working with at united cerebral palsy for a while. It was interesting. We were looking at people in wheelchairs and when you do home visits. This is pretty rural area. When I would go out as a nurse to do a home visit, it was interesting. People were lining carbohydrates along the counter in the kitchen because they could reach them and it was easy to get to and all that. Then they would go into the center for some day at this time. But a lot of folks had ‑‑ you could tell would probably have ‑‑ be on the verge of diabetes or have high values for the tests we did that can show you're getting closer to diabetes. What we did was, I guess, nine months of making sure these folks were given breakfast and lunch, couldn't control dinner. Just to see if by changing, giving that support if they're A1C levels which is the test you do to predict and to look at what your sugar levels are over a three‑month period of time would go down and they did. I would argue to the insurance company on that front, you should be paying for what we're doing in activities and stuff because it's saving you ‑‑ it's saving you money on the big stuff. Once somebody gets the big stuff it's a long cost investment over the years.

I think for the first time I'm seeing where insurers are pushing that and seeing cost effectiveness in investing up front. So I think that's good. Now, the big question is ‑‑ this is my next question to them is, now that you've learned the importance of that, when are you going to pull it through to the commercial side of insurance so that people who work, who have employer‑sponsored insurance that trigger a certain need, get that need met so that they don't have to go on Medicaid. That's almost like our next front. We're starting to work on that. We're going to go back with this long‑term services and supports issue, this class act issue. We've let three years go by to see what would happen. Nothing happened. We're going back on that one more time. If they do entitlement reform next year and start working on it, we need it then more than we ever needed it. So that was the buy‑in question. Looks like Noel had a question, too, Carol.

>> CAROL EUBANKS: Let's see. Waivers possibly being granted ten‑year extension.

>> CONNIE GARNER: So yeah. I think they're the same concern that I would have on this. If they give me a ten‑year extension for this waiver, what's the parameters around it. What's the outcome measures I have to show. When do I have to show that? Population ‑‑ remember, they can waive down to a certain population. They can waive serving everybody and just serve one population. They roll in all the DD populations from the 1915 ‑‑ three of the 1915 waivers, that would be the population and that would be it. But I do think that your question's a good one and there should be research or at least data collection on what's happening with that. Just can't be a ten‑year kind of pass‑through.

>> CAROL EUBANKS: Okay. Well, we are just about out of time. Thank you, Connie. Lex, I'm going to turn it over to you to wrap it up.

>> LEX FRIEDEN: All right. Well, I really do appreciate Connie, your responses to the questions and your delightful informative presentation. We covered a lot of material. Jean, your presentation was really great to have all the background on where the Medicaid money is going. It's important for all of us to understand that. I think we've gained a lot of knowledge about where we as advocates can be effective in what to look for ‑‑ forward to in the next year or two as congress debates some of these important issues and as the states act to implement more and tweak more the managed Medicare ‑‑ Medicaid managed care programs.

The ILRU program is pleased to have had the opportunity to put on this webinar in association with CHRIL. We'd like for you all to fill out the survey, give us some feedback so that we can tweak the program in future months and we will have a series of these webinars dealing with important health care ‑‑ health policy issues. So please stay tuned for the schedule on that. Fill out the survey. You can reach Connie or Jean or me by our e‑mail addresses and they're all online here for you And your good feedback is really, really helpful to us in improving these programs. I want to thank everybody for joining us. I want to thank our presenters in particular. I want to thank the CHRIL program and all our partners there. And finally, I want to thank the national institute of disability independent living rehabilitation research for sponsoring CHRIL and enabling us to carry on this program of education and technical assistance.

Our research is ongoing. If you have suggestions about additional research that we should be doing pertinent to this topic, please send it in and share it with us. We look forward to getting together future webinars, future conferences, future trainings and so forth. Thank you all once again. Have a great afternoon And happy holidays, happy Hanukkah, merry Christmas, and enjoy the holiday season. Thank you all very much. Bye‑bye.

[ Webinar concluded at 4:30 p.m. ET ]