

The Affordable Care Act and Persons with Disabilities: An Introduction and Overview

Presented by Karl Cooper

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Good afternoon, and welcome to our webinar. The Affordable Care Act and persons with disabilities, an introduction and overview. The webinar is presented by the collaborative on health reform and independent living, a partnership of leading National Disability Research and information organizations. The collaborative is funded with a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research. The grant is a five-year disability research projects grant.

Today's presenter is Karl Cooper. Karl is with the American Association of Health and Disability. Karl is also the director of the National Disability Navigator Resource Collaborative. And during our webinar today Karl will also provide some information about the Navigator Resource Project. There'll be more about Karl just before he begins his presentation. Now we have a few housekeeping details to cover with you.

This webinar is being recorded and will be available on demand within just a couple of days. You can go to the CHRIL -- that's the collaborative website, it's CHRIL.ORG. That's for collaborative on health reform and independent living. You can -- at that time that you want to go to the Website you can find all of the materials for the presentation including the PowerPoint, the audio, and any other supplemental materials that may be posted subsequent to this presentation.

Today you'll have an opportunity to ask questions during the webinar. We'll pause a few times for you to ask questions. You can do that in several ways. You can enter your question into the text field on the mainstream of the webinar. The presenter will see your question. May be able to answer it during the presentation or if not, during the times that we pause for questions and answers. You could also ask your question by phone. You can wait to ask that question until you're prompted to do so and you'll be given instructions on how to ask the question at that time. How you can be put into the question queue.

In addition, if you're participating in the full-screen captioning feature of this webinar, which some -- some participants prefer, you can enter your question into the text field or chat box on that screen and it will be transferred into the mainstream of the webinar so that the presenter will see your question and be able to respond to it.

There is a PowerPoint presentation for today's webinar. It's on the screen now so if you're participating by web, you'll see the first slide of the presentation on your screen. If you're participating by telephone only, you'll still want to have a copy of that PowerPoint with you so that you can refer to the slides as we proceed. You received a copy of that presentation with the e-mail message that you received with registration information. And there will also be a link to it on the webinar screen.

So be sure to have that presentation either on the screen of your computer or printed out and in front of you as we go through the webinar.

And one final bit of housekeeping. At the end of the webinar, there will be a link to an evaluation. And, Carol Eubanks will ask you to pause after the webinar is over and complete the evaluation. We take evaluations very seriously. We use them to improve the work that we do in the future. We'll be very grateful if you will take those few minutes to complete the evaluation.

Now, let's move to slide two. This is an overview of the Collaborative on Health Reform and Independent Living. It shows the partner organizations. Includes Washington State University, the lead organization. The University of Kansas. George Mason University. ILRU, independent living research utilization. There are also strategic partners. Those partners are the National Council on Independent Living, the Association for Rural Independent Living, the American Association of Health and Disability. The Urban Institute and Academy Health. Let's move to slide three, please.

Let's cover the key personnel of the collaborative. Jae Kennedy is the principal investigator and he's the director of the collaborative. Jae is at Washington State University and on faculty there.

Co-investigators include Jean Hall at the University of Kansas, Gilbert Gimm at George Mason University. Lex Frieden at the University of Texas Health Science Center in Houston and also of ILRU. I am Richard Petty. I am the Director of Training and I am with the National Center for Aging and Disability and I'm also with ILRU.

Slide four, please. This lists some of the other key personnel of the Collaborative. And you'll be getting to know them over the next five years. And the products of their research. Next slide. Which is slide five. The objective of the collaborative is to provide to the stakeholders of the project -- that's a large group, and we'll talk about that as we proceed -- provide to the stakeholder's current, actionable, accurate information on the effects of disability policy on the working-age population of people with disabilities.

And certainly included in that is disability legislation and disability policy. Notably the Affordable Care Act. The collaborative will engage in a systemic program of research and information dissemination over the five years of the project.

Now, let's go to slide six where ILRU's Carol Eubanks will cover the activities of the project. And then I'll return for a few moments to introduce our presenter. Carol.

>> Thanks, Richard. Hi, everyone. I'm going to go over the research and knowledge translation activities of the CHRIL project. We're going to start with the research activities on slide six. First, documenting the experiences of working-age adults with disabilities in obtaining and maintaining health insurance and identifying the impact of insurance on their access, health, and function through phone interviews, Internet surveys, and analysis of the Urban Institute's Health Reform monitoring survey, HRMS. Second, assessing the health insurance information, training and technical assistance needs of Centers for Independent Living, CILs, and other stakeholders through Internet surveys, phone interviews of directors, and at independent living conferences.

Third, analyzing post-reform insurance coverage trends among working-age adults with disabilities using the National Health Interview Survey, NHIS.

Moving to slide seven. Number four is identifying gaps in coverage and potential areas of undue cost burden for people with disabilities by analyzing health care expenditures, including premium costs, deductibles, and co-pays using the medical expenditure panel survey, MEPS.

And the fifth and final CHRIL research activity is assisting the impact of the Affordable Care Act on disability program enrollment and work force participation by testing how the Medicaid expansion influences SSI activity using the American Community Survey, ACS.

Moving to slide eight, there are five CHRIL project knowledge translation affidavits. The first is, presenting research findings at ten to 15 professional and scientific meetings, including the annual meetings of the Academy of Health, National Council on Independent Living, Association on Programs for Rural Independent Living, and the National Association of Rehabilitation Research and Training Centers. And the second is submitting at least ten manuscripts for scientific and professional journals and preparing and updating at least five fact sheets and two chart books for program administrators and disability advocates.

Continuing on slide nine, the third is offering two health reform webinars per year and creating at least three self-paced tutorials on various aspects of health care policy, organization, and financing.

Fourth is training two to three graduate research Assistants per year and establishing a summer internship program for two to three undergraduates with disabilities per year at ILRU in Houston, Texas. And the fifth and final CHRIL project knowledge translation activity is developing and maintaining the CHRIL Website, WWW.chril.org, with access to all publications and presentations in accessible formats.

Okay, Richard, I'll give you the floor back now.

>> Thank you, Carol. Well, as you can see, Jae Kennedy and the Collaborative team have carved out an ambitious agenda of research and training and we look forward to sharing the results of that training and much other information over the five years of the project. It's now my pleasure to introduce our presenter.

Karl Cooper is a -- an attorney and an advocate. He spent much of his career addressing the needs of persons with disabilities. As I noted earlier, he is on staff of the American Association of Health and Disability where he leads a National collaborative there that involves supporting organizations that assist people with disabilities to sign up for health care under the Affordable Care Act programs.

You'll be hearing a great deal from Karl over the next five years in his role as dissemination consultant for the Collaborative. And you have much to anticipate in Karl's work with us. Karl is a professional and we are fortunate to have him on the project. Karl, welcome to the webinar.

>> Thank you, Richard. And it's a pleasure to be with you this afternoon and to present on the Americans with Disabilities -- excuse me, the Affordable Care Act and what it means for people with disabilities. And really with -- in terms of what this has meant in terms of what it does for those individuals and how it's impacted them in terms of as it's been implemented. The end result. And then I'll also be sharing a little bit about some of the resources we have as part of the project they work on as well.

So we're on slide ten if you are following along on the slide deck. And if you're on that, you'll see the disability law timeline there in terms of what disability laws existed prior to the passage of the Affordable Care Act. And specifically you'll see 1973 was the Rehab Act, section 504, eliminated discrimination for any organization that had -- that received money from the federal government.

And then it was additional rights for people with disabilities were expanded, 1975. Dealt with education and what is now referred to the Individuals with Disabilities Education Act. In 1984, voting rights with the voting accessibility for the elderly and handicapped Act. In 1986, the Air Carrier Act. The fair housing Act amended in 1988 to include people with disabilities as a protected class. And then finally the law that most people know, the Americans with Disabilities Act, passed in 1990, dealt with public services, employment, public transportation, et cetera.

So as you are looking at the timeline, you will see everything is covered except for health care. And there was discussions when the ADA was being considered about putting something in there about health care and insurance. But it was determined at that point that it was too difficult to pass the law with that provision in there. So that was left for another day.

So essentially what you have is everything but health care is taken care of for folks with disabilities by the time we come to 2010 when the ACA was being considered.

Going in terms what the ACA was really meant to deal with. It was meant to deal with the uninsured problem. We are on slide 11 which shows a chart that shows the per capita medical spending among the non-elderly and insurance status and source of payment for 2013. It has to the left the bar graph -- it's a bar graph to the left, you'll see it deals with the amount of people that were uninsured for the entire year. And in the middle column is where there was some sort of part-year insurance that they lost coverage to the year, or gained coverage throughout the year. And then the final shows payments that were made for people that were fully insured throughout the year.

Obviously the people that are being cared for the most, and most dollars being spent are the ones that do have insurance throughout the year. But that doesn't mean that they're healthier. So what ends up happening is you'll see that the ones all the way to the left, the ones that are uninsured for the full year ends up becoming an issue of -- those are the folks that end up not getting the care that they need and also you'll see that the indirect payment source, or uncompensated care, ends up being significant.

Total uncompensated care when the Affordable Care Act was being considered was \$84.9 billion. 60% was hospital-based care. And anyone that does anything with health care will tell you that taking care of people in the hospital setting is one of the least efficient ways to do so. So that was the problem that the Affordable Care Act was trying to deal with. Was this issue of the uninsured problem and trying to get people so that everyone was able to get coverage so that there was going to be a much more efficient use of resources and people could get care earlier in the process?

Moving on now to slide 12. We're going to look at a couple of the key provisions that are found in the Affordable Care Act. What you have are the three main things that the Affordable Care Act did. It set up the health insurance marketplaces where people could go and buy insurance and provided for premium tax credits for anyone at 400% of the federal poverty level or lower. So it covers a lot of middle and lower income earners.

And also in terms of the -- the next thing it does is provide for guaranteed issue. So in other words everyone is able to get coverage. And then finally the individual mandate requires everyone to have coverage or they face a tax penalty. If you really want to understand how these three really act together and have a real -- really sort of set up the -- how the Affordable Care Act works and has the three legs of the stool, the Supreme Court decision that was decided last year on the premium tax credits, chief Justice John Roberts wrote the majority opinion in that case. And in the beginning of that opinion he really breaks down the three legs of this stool and how any one of them, if you take it out, sort of makes the whole thing collapse.

So it really sets up that idea that if you are going to have guaranteed issue, which I'm going to get into in a moment, exactly what's covered in that, because that's very important for people with disabilities, but if you're going to have this guaranteed issue, you need the other legs of the stool to make it work. Moving on now to slide 13.

This is talking about the guaranteed issue clauses. This means no denial of coverage for pre-existing conditions. And they also, then, cannot cancel coverage due to serious medical conditions. Because if they were allowed to do that, it would be pointless if they could kick you off once you started using your coverage too much or became much more costly to them. If they could cancel service due to that that would sort of defeat the first purpose. And then the last one really ties it all together. Which is the insurance companies are not allowed to set premiums based on disability or chronic conditions. In fact the only things that insurance companies are allowed to take into consideration are your age and whether or not you're a smoker.

So those are really what it boils down to. Because people with disabilities -- if they were allowed to charge you based on a disability or a chronic condition or something like that, they could obviously price those people out of the market so it would be unaffordable. What it does, it provides for that guaranteed issue. Everyone who wants insurance is going to be able to get it, get it at a rate that will be comparable to everyone else that is their same age.

Moving on in terms of what else it means for people with disabilities. There are other provisions within the Affordable Care Act that really in some cases they affect everyone. But in this instance it also means that it has an impact on specifically people with disabilities.

So, for instance, the one provision that most people know about, no lifetime monetary caps. And that's what it means. Just that. Monetary caps. There are limits on services. Therapies, devices. And that's one of the issues that we have seen. And I can talk about that a little bit later when we get into the some of the ongoing challenges that we have. But essentially they are not allowed to put dollar limitations on individuals that would -- before had resulted in people that once they had had used up so much coverage they were no longer allowed to have any insurance that was going to cover them for the rest of their lives. It also provides for ten essential health benefits required in every qualified health plan.

Some of the ones important specifically for people with disabilities include prescription drugs are required to be in everything. Laboratory tests. Preventive services. Mental health and substance use disorder services. And services and medical devices. Medical devices is undefined as of yet by HHS. So you'll see a lot of those things that are going to help individuals with disabilities are covered in those ten essential health benefits.

And then finally there was also the Medicaid reforms which are very important for folks with disabilities. The first two Medicaid reforms I have, the expanded money follows the person, and also created the balancing incentive program. These are both programs which allow states some flexibility in designing plans that sort of get away from the institutional bias and allow people to be cared for in home and community-based services. Which is obviously a much more inclusive way to take care of individuals and gets them out of the institutions so that they can live with their friend and family as they would prefer.

And it also creates the alternative benefit plan which just once again gives more flexibility to the states in designing exactly what is going to be covered by Medicaid plans so that they can have the traditional Medicaid plan, but they can also structure an alternative benefit plan that might help some individuals differently.

Moving on to slide 15. And since I am an attorney, I've got to put the language up there for section -- that should be actually 1557. Which basically is the provision which says that individuals are not allowed to be discriminated based on disability. You can see there on the ground -- under the grounds, prohibited, under section 794 of title 29. That is the rehab Act that I talked about earlier that was the first provision that sort of got rid of discrimination against people with disabilities. So this is the specific language that deals with that, and this is important because it is really the final piece of the puzzle when we were talking about that disability law timeline earlier that really is the final piece of the puzzle and allows for folks with disabilities to have coverage in every area so that they're not just protected in certain areas. But they're not allowed to be discriminated in every area. And that includes health care and health insurance.

Which really, what it boils down to, it means it becomes an issue of -- it's a civil rights law, really. The Affordable Care Act is viewed by many in the disability community as such. And it's important in terms of many of the protections found in there, that those are continued. Moving on now to slide 16.

And this shows where we stand currently as it relates to Medicaid expansion. The law originally provided for all states to expand Medicaid. And that includes all individuals under 100% of the federal poverty level. This was the case until the Supreme Court decided in 2012 that the federal government could not require the states to expand Medicaid. So essentially the Medicaid expansion became optional. So this map shows exactly which states have expanded Medicaid or are in the process of expanding Medicaid. In the case of Montana and Louisiana, relatively new to the process. But those are the states that are expanding Medicaid, those that aren't states have not adopted the Medicaid expansion as of yet.

At this point I will open up and see if we have any specific questions from the audience.

>> Okay. And this is Carol. If you have a question and you are on the phone, you can press star pound to indicate you have a question. You can also submit your questions in the chat box on the bottom of the webinar platform and I will voice those questions. And don't forget, if you are on the full screen CART captioning, we are logged into the chat there, and you can welcome to use that chat box as well. Let's see. I'm waiting to see if we have any questions. Looks like someone is typing. We'll wait a minute for questions to populate into the screen.

There are no audio questions at this time. Looks like we have some folks typing. So we'll wait. Okay. Sharon Brown. In the alternative benefit plans, is that in addition to Medicaid or is that in place of Medicaid?

>> Yeah, the alternative benefit plan is a provision that allows the states to develop a second set of benefits, really. But the individual does have to choose, then, between traditional Medicaid or the alternative benefit plan. And that's one of the things that when I get into my navigator project, one of the things we talked about is really trying to help people decide what's the best plan for them in terms of a health insurance plan on the marketplace. But if there is an alternative benefit plan in their state, it's an issue as to which is the better fit there. Just because they have the alternative benefit plan, it doesn't necessarily mean it's going to be best for that individual.

>> Okay. Any other questions? If you have any questions, please submit them in the chat box or press star pound if you are on the phone. Okay. Here's another question. What are the chances of assuring unlimited inpatient rehab as part of the ACA?

>> That's going to vary from state to state because of the way the marketplace is set up. The states have all their own individual benchmark plans. So what is covered in any specific health insurance plan is dictated state to state. And therefore some of those things are going to be -- they might be more beneficial to certain particular therapies or something like that in one state where it'll be very different in another.

So that's something that if you want to advocate for, that would be something you would want to do at the state level. Also, when the states are determining what their benchmark plan is, that would be one of the times to get into that discussion as well.

>> Okay. Well, looks like -- I think we can move on. Yes. Go ahead, Karl.

>> All right. So we'll move on. And just a little bit of background. First of all. About my project. As Richard said, I am with the American Association on Health and Disability, we are a national non-profit organization located in Rockville, Maryland, outside of Washington, D.C. It's our mission to promote health and wellness initiatives for children and adults with disabilities. We reduce health disparities, advocate for community inclusion, work to promote full accessibility and integrate disability into the public health agenda. So people are thinking about the disability component that goes in with public health.

That's a little bit about my organization. And one of the things that we do, we have the project, which is the National disability navigator resource collaborative. The NDNRC. When the Affordable Care Act was passed in 2010, 3.5 million people between the ages of 16 and 65 were uninsured and had pre-existing medical conditions and/or disabilities. These individuals faced multiple options when enrolling for health care under the Affordable Care Act. Medicaid in their state, possible Medicaid buy in, possible Medicaid expansion and of course the exchange or marketplace coverage. It came out of the concern that the navigators, the people from CMS designated to assist individuals in enrolling, that they would not have the sufficient knowledge base to assist individuals with disabilities as they made health care enrollment decisions.

Several of the organizations wanted to better prepare them for assisting this population of consumers. As you can see on the slide, it's the mission to provide cross-disability information and support to navigators and other enrollment specials, there are ensuring people with

disabilities receive accurate information when selecting and enrolling in numbers through the Affordable Care Act marketplaces. The NDNRC is made up of ten organizations. My organization, the American Association on health and disability. The Association of Centers on disability, autism speak, Christopher and Dana Reeve foundation, the national alliance on mental illness, the National -- the arc, and united spinal association. You can see one of the main strengths is in the makeup of the partners. We want as issues come up and we are looking for help for any particular population of individuals within the disability community that we have some expertise in our collaborative that will be able to help those individuals.

I should also point out at this time as well that this particular project was made possible for the first three years through funding bit the record Wood Johnson foundation. We're thankful to them for providing the funding so that we could do this work reaching out to the navigators.

We do this -- the -- we do the navigators is done mainly through our Website, www.nationaldisabilitynavigator.org. You can see a screen shot of the home page. When you go to the home page, see the scrolling picture there that changes that's on the disability guide there now. I'll be talking about that in a moment.

But it also has other menus across the top. The about us includes information about our partners I just mentioned, friend organizations, and the community outreach collaboratives that I'll be talking about later. We also have a place for conversations. People can submit a question. And frequently asked questions. A materials section which I'll be talking about in a moment with our disability guide and fact sheets. Resources and links which I'll be talking about in moment. And we also have -- if you see below there, it talks about our blog. We feature stories, highlight resources and trends. And news to use, new material comes out, we try to highlight in those particular news to use segments.

We have a resources and links page. Where we have multiple different category you can see the different categories we want. Many from our partner and friend organizations touch as toolkit from the arc, and the American occupational therapy association. And we have enrollment resources on mental and behavioral health, resources from the National Council for Behavioral Health. Enrollment resources for special health care needs. You can find resources from the American heart Association and the National health council. Under enrollment resources with the ACA marketplace and Medicaid and Medicare, and they have the resources from CNS as well as organizations specific to the programs, such as the National Council on aging, and the senior citizens law for Medicare, and the policy for Medicaid. We have the generic category, or overview, the largest category.

For any of you who do enrollment work and assist individuals in enrolling for health insurance, the resource we leave at the top of the that particular list is the one from the Georgetown University Center on health insurance reforms. A navigator guide that deals with all sorts of issues beyond just disability. But any technical issues you may have questions about. It's a great resource, I encourage you to check it out. We have enrollment statistics. Which basically contains outreach information. And it was recently -- any information recently put out as it relates to Medicaid funding or Medicaid enrollment or other numbers that come out as it relates to the ACA enrollment.

And then finally the last two categories, ACA resources from government and ACA enrollment resources are catch-all areas where you'll find information from the government or other organizations that are working on assisting and encouraging enrollment.

Moving on to slide number 23. It deals with the graphic that we have which is the cover page for our disability guide. And as I mentioned earlier, one of the resources that we are most excited about is our disability guide. It was released right shortly after we started the program in January of 2014. We did revise it once last year. And it provides information to navigators and other enrollment specialists about what people with disabilities face as they shop for health care coverage.

Moving on, this is sort of the table of contents for the guide. The introduction is -- talks about how the disability guide is meant to supplement the training that Afghan navigators receive, and put out by CMS in terms of the training initially done by CMS. This is to supplement it. It's a disability 101 for people helping with enrollment.

What are the purposes of the supplemental disability guide? Provides the objectives of the guide, strengthening disability literacy, identify and provide accommodations and assisting and identifying issues central to people with disabilities. Key question for navigators is a basic overview of the important questions answered by the guide. Who are people with disabilities and what problems and barriers have people with disabilities historically encountered when obtaining health insurance? These sections provide a basic background with those unfamiliar with who make up the population of people with disabilities and the historic disparities that these people have faced in health care.

How do disability rights laws affect the marketplace provides a basic explanation of how the ADA as well as the ACA affects those who are providing enrollment services. What do navigators need to know about disability? This is a sort of a -- one of the larger sections of the guide and deals with a lot of different questions such as how is disability defined? What does it mean when you get to the disability question on the streamlined application? Why is understanding disability important? What is disability literacy? What is disability ask? Gets into some of the issues that relate to the physical accessibility and also making sure that things are available from a communication standpoint that people -- that navigators can make sure they are able to communicate with every individual that they could potentially meet with and making them as it relates to their communication needs.

And then how is Medicaid eligibility being determined for people with disabilities? This begins a basic discussion for Medicaid for people with disabilities. And the fact sheets get into more detail. This is the beginning of the discussion. And the list of five scenarios that people could meet with talks through a Q and A in terms of what to think about. What kind of accommodations. And it provides an understanding of how they can be prepared to identify and assist individuals with visual or hearing issues.

And then finally the last three sections, the fact sheets, resources and glossary is a summary of things you can find in the guide.

Moving on now to slide number 25 where we find the fact sheets that we have -- that we've released. So far we have 17 topical fact sheets. The first three deal with getting answers to the information about various insurance programs. So dealing with the summary of benefits and coverage, getting the evidence of coverage document, contacting customer service and getting the answers to the questions. Then into more specific areas, such as rehab and services and devices, prescription meds. Also working with navigators and other disability organizations. Moving to slide 26, deal with some more fact sheets we have, including mental health and substance abuse parity. Dealing with some of the Medicaid issues I talked about early, such as

the medically frail status, and the Medicaid eligibility determines. Also deal with medical supplies. And we also deal with sort of some of the discrimination laws and how they interact with and affect people with disabilities as it relates to the marketplace.

Moving on to slide 27, we have more topical fact sheets dealing with, once again, more on Medicaid eligibility. Some other referral and resources lists and where you can find more information. We have information for people that are on HCBS waiting lists. We deal with Medicaid buy-in. We also have a fact sheet that works. The moving from coverage to care for people with disabilities. That is more aimed at the consumer. So if someone can hand it to the consumer after they have enrolled, so they have an idea how to use the insurance. And finally, disability etiquette in a compact way so if a navigator has a specific question about the best way to interact with people with disabilities, that provides that information.

In year two of our project we expanded also to population-specific fact sheets. We found when we were doing some of the topical fact sheets that the ones that dealt with more specific information seemed to be getting more use. So that's when we came up with the idea to sort of branch out and get into disability-specific issues that come up. And they can refer them to maybe some of the other fact sheets as the case may warrant. So you'll see here the list of fact sheets that we have released so far. What to know when assisting a consumer. And you can see the list of disabilities that we have there. Looking to expand this. That's something you can be looking at to see if we are adding additional fact sheets on there. But that's something we try to routinely do, and continue to add to that and make sure we're providing information for as many different disabilities as we can.

Many of our partner organizations that deal with these specific disabilities are the ones that helped us write these. We have some trend organizations that deal with some of these specific disabilities and they helped write them as well. Written by folks that deal with the disabilities and understand the medical needs of those populations.

At this point I'll open it up for any specific questions you have on the resources that we have available through the NDNRC.

1. >> Okay. And if you have a question and you're on the phone, you can press star pound to indicate you have a question. And those of you that may have a question or, you know, want to ask -- or have any comments about something, go ahead and type it in the chat box now. If you are in the full-screen CART captioning, we are logged into chat there and you are welcome to use that chat box as well. So we'll wait a moment and see if we have any questions.

>> This is Richard Petty, while we're waiting for questions, would you expand a little bit on what the barriers that individuals with disabilities experience in -- in trying to secure health insurance whether Medicaid or otherwise? And maybe even especially if they're not Medicaid-eligible and still seeking insurance.

>> Sure. Some of the challenges I'll be getting into in a moment. So I don't want to steal too much of my thunder there. But what I will talk about is historically a lot of the issues that have happened before. Obviously the ACA dealt with in terms of, you know, making it so that people with disabilities can no longer be discriminated against and denied coverage for pre-existing conditions. That was one of the main things that the ACA dealt with. But the thing that does, then, historically, then, you have a group of folks that in the past was unable to get insurance.

And now they are new to the marketplace. And many times they do not understand what ends up coming up regarding specific, you know, specifically what's provided for insurance, how insurance works, what a deductible means, what a copay is. And a lot of these types of issues that many people who have had insurance their whole lives take for granted and have an understanding of. But for people who never had insurance, it's really an education and making sure they understand these issues. And making sure as they look at their insurance plans they're really taking all those factors into consideration.

The reason being, the one thing we found, especially after year one of the ACA, is when people enrolled, many times they just picked the -- the plan with the lowest premium at the level that they wanted if so if they wanted a silver plan, looked for the cheapest silver plan and that's the one they bought. The problem with that is, many times folks with disabilities are higher utilizers of health care. So their out of pocket costs are going to be a lot more. They're more likely to hit their deductible limits. And as a result, if you fact in all those different things, many times it's more advantageous for someone who's going to be utilizing the health care more to pay a little more for the premium and pay a lot less than out of pocket costs. So it's one of those things that's really a matter of trying to figure out what are my costs going to be as I go through the year and trying to figure out what is the best economically to pay if it means paying an extra 50 bucks a month, for instance, to get a lower deductible. You know, it might be worth it in the long run to pay that extra 50 bucks a month in your premium rather than having a lot more out of pocket costs -- out of pocket costs down the road.

>> All right. It looks like we have two similar questions. One of them is how can we get a copy of the resource guide? And the other one is about your population-specific fact sheets. Are they in order or just listed?

>> In terms of -- the answer to both questions is similar. And that is where it is -- there's a place on our Website that has our resources. So if you go to the home page of the Website at the top you'll see materials. That will have a dropdown menu that has links to the disability guide and also the fact sheets. Also that big picture that you saw, I had on the home screen up there earlier that changes. One of those slides is for the guide. It will take you directly to the guide. You can download a PDF of it for later if you want and keep that for later. My contact information, I think, is available at the end of this presentation as well. If you want, you can contact me and we do have a limited number of those in hard copies.

And we can mail some of those out to the degree we still have them. We also have -- feel free to contact me if you're looking for that. In terms of the fact sheets, also listed under the NDNRC materials slide. And if you go to that particular page of the Website, you'll see all the topical fact sheets listed and then all the specific fact sheets. In order, alphabetically by disability. But they're individual fact sheets. So they can be downloaded individually. You don't have to download all of them if you don't want them. One or two that deal with a specific disability that you deal with more, you can download just one disability fact sheet if you want to do that.

>> Okay. Look like we don't have any more questions at this time.

>> Okay. Then let's continue to move on to slide 30. Where I talk a little bit about health insurance jeopardy. This is one of the things that I sort of was getting into a little bit when I was talking to -- answering Richard's question. And that is the idea of making sure that individuals, when they're looking at their health insurance, are really making sure that they are asking the right questions. I refer to it as health insurance jeopardy. And I have a whole technical

assistance piece I do for people that do assist individuals who enroll for insurance where I sort of take them through various scenarios and tell them, listen. It's not about -- the answer to the question isn't as important as the question itself. Make sure you understand what the needs of that individual is so that you're looking at the plans and making sure it's going to cover what that individual needs.

So, for instance, they might have very specific prescription drug needs. If that's the case, you need to make sure that those prescription drugs are going to be covered in the formulary, and they're also going to be -- the way they're structured is in a cost-effective way as well. Because there is a tier within the drug formulary, and you may pay more for one than another plan which has a more favorable way to tier the drugs. Ask the right questions. What doctors do they see? Prescription drugs? Do they need use of durable medical equipment or other medical supplies? Anything like that. Those are the types of questions that individuals need to make sure they're asking to they get enrolled in the right plan.

We have a series of these that I did that, like I said, I do them for the navigators. There was six categories I did the first year, six more in the second year. The first year ones are already on YouTube and on the link that you'll see there. You can go to our YouTube channel. And look at and watch the videos in terms of their short, three to six-minute increments. Deal with issues such as prescription drugs, medical devices, and mental health issues. A lot of different things that people with disabilities are going to be affected by and making sure that individuals are asking the right questions about the plans that they're looking at.

Moving on to slide 31, this shows a map of our community outreach collaborative. And one of the things that we realized in the first year of our project was there was a general shift towards outreach and away from the technical assistance piece of the enrollment process. That the individuals were much more focused on trying to reach individuals and not necessarily once the process was sort of ironed out, it really began a matter of trying to see what we can do to reach individuals.

We recognized in seeing that shift that many people with disabilities have a distrust of experts, quote, and unquote. That they don't perceive as having expertise with their disability. So they may be reluctant to see a navigator or enrollment specialist to get assistance in enrolling for health care. So in year two, funded an initiative. Started with 11COCs, as we call them, in year two. Then expanded that in year three to include more states. Specifically we now have 18CRCs located in 17 different states. They have two primary tasks. The first is to build cross-disability collaborations with other disability organizations so we can make sure that there's adequate information getting out there about the enrollment process and what people need to know and allows them then to make referrals to the navigators.

And secondly, we want them to have a cross-disability collaboration, then, that works as dissemination outreach with their local assisters. We want the COCs to be a bridge between the disability organizations and the enrollment assisters. And if they have questions, the COC can make sure they get referred to a navigator that's going to be able to assist them. And if the navigator has a question about someone they're helping, the COC can be a referral source to get the information they need so that they can get proper assistance to those individuals and make sure that they're enrolling in health care that's going to be the best fit for that particular individual.

So you can see the states that are listed there. If you are in one of the states that is -- or one of the dots are on the map, you can reach out to them and work with them. If you're looking for a local partner that will be able to help. So you can find that at our Website the link to where the addresses for the community outreach collaborative is provided on the slide. You can reach out to them. You can also go to the Website and the -- once again -- under the about us you'll find the link to the community outreach collaborative or in that slide that I talked about the changes at the top of the home page. One of the slides in there is for the community outreach collaborative. You'll see it once again, that map. And you can get the information on those particular COCs and find out where they're located.

Let's talk a little bit about some of the ongoing challenges. We have noted people with disabilities have had as it relates to the ACA, as it has been implemented. The implementation of the -- excuse me, the ACA has been a great leap forward for people with disabilities as it relates to health insurance and getting access to health care. But it is not perfect. So there are still issues that come up. And these are some of the ongoing challenges that we've noted. So first of all, is limited provider networks? Many times health insurance companies, in order to make things more affordable are making the networks of doctors and providers more narrow, which can create problems for people with disabilities, especially if the doctor they were seeing beforehand is not in the new network, or if it means they have a difficulty finding a specialist that deals with the issues that they need. And specifically maybe if there is one maybe that person isn't accepting new patients.

And it can sometimes really cause a problem if there is limited provider networks. The same goes with the limited formulary. I talked about the drug formularies. And it can have an effect on what ends up happening with those folks with their coverage and how the drug tiering can be done in a way that can be discriminatory.

And that really goes to point three, the discriminatory pharmacy design. Many specialized drugs for people with disabilities, such as multiple sclerosis are on higher tiers. That's a problem for those individuals. When they are looking at their annual deductibles, if their drugs are on the highest tier, and they have the highest copays, many times the deductibles are met automatically. You need to factor in that cost what looking at the coverage for the individual and what they need. They're going spend the entire deductible throughout the course of the year because of the way the pharmacy design is set up.

Another issue that we have is plan transparency. And deals with a lot of perhaps specifically it deals with the prescription drug issue I was just talking about in terms of getting answers to the questions about what prescriptions are covered in the formulary and on a higher tier and what the costs are associated with it and what plans are covered? Excuse me, plan transparency is also needed as it relates to the cost of consumers. So they can determine what is covered and the issue becoming -- knowing the exact cost that will be passed on over the course of the year is really an issue. So lack of transparency as it relates to those out of pocket obligations really becomes an issue. It also then becomes an issue as it relates to durable medical equipment.

The example I like to use is my own example. I use a wheelchair. And when I was looking at coverage -- living in Maryland -- I looked at the Maryland exchange and was looking for coverage on the Maryland exchange to see if I could find information about durable medical equipment. I was someone who knew what to ask, look for, and I still had a hard time getting answers to questions in terms of trying to figure out what was covered and what wasn't covered

as it related to durable medical equipment. As a result of that, imagine how much more difficult it is for someone that doesn't even know those are questions that they really need to be thinking about. They might just assume that their wheelchair is going to be covered when in fact it may not be. So that's another thing that really becomes a challenge in getting answers to questions that people need.

The other is high out of pocket costs. Talked a little bit about the fact that many automatically meet the deductibles within the first month or two of enrollment. And once they hit those deductibles, it can become cost prohibitive to utilize their insurance because they can't afford the deductibles if they are done in a way that makes them pay everything up front. It can really be cost prohibitive when they utilize their insurance, or especially trying get a prescription filled. Those high out of the pocket costs can become a problem for folks that are higher utilizers.

Confusion on the rehabilitation and habilitation support services. It becomes an issue. Many insurance companies, despite the fact that the therapy is exactly the same, deal with things very differently. The common example I like to use for this is a speech language therapy. If someone has a stroke and they lose their ability to speak, and they go to speech therapy, it's considered rehabilitation because they are gaining something back that they had before.

Whereas if you have a child that has a speech issue early on in life and never really was able to communicate effectively through maybe some sort of disability or autism or something like that where they're really trying to work on their speech. Then it's habilitation. And the fact that the therapist is the same therapist and they're doing many of the same things, the insurance companies will handle these types of things completely different. Because one is rehab, and one is habilitation. It really becomes an issue for those individuals, because it can end up being two completely different ways that the insurance company covers it even though it's the same exact therapy and the same exact provider.

Well, now move on to slide number 33. And the other ongoing challenge that we have -- other ongoing challenges we have which including confusion on the coverage of prosthetic devices and durable medical equipment. I talked about my own experience. But there's issues with prosthetic devices, what's covered and some of the limitations that you deal with. I talked about earlier how there's no longer a monetary cap on the Affordable Care Act did away with the monetary caps on services. But that does not eliminate limits on the actual therapy or services or devices or whatever.

So there are sometimes instances where this becomes a problem for someone with a prosthetic device. We have encountered situations where there was the one limb per lifetime. It's problematic for the problem is -- ends up -- the individual obviously if they have lost two limbs, it becomes a problem if only one of them is covered. Or the other part, they have only lost one limb, if that prosthetic needs to be -- breaks down over time and needs to be replaced, it becomes an issue. So all of those become real problems, then, as it relates to how some of these health insurance plans are structured.

Number eight, confusion about coordinating exchange coverage with Medicare and Medicaid. One of the things we look at a lot is a process that's referred to as churning. Which is people that are at incomes that are very close to a situation where they may or may not qualify for Medicaid. And what that ends up doing is it could end up making them go back and forth between Medicaid and exchange coverage. Especially if they have the kind much work that is seasonal or is very up and down and very sporadic. Then it could end up being that their

income prohibits them from being on Medicaid certain times of the year, but allows them other times of the year. And many times that affects the continuity of care with that individual because maybe the provider that they see in Medicaid is not covered by the health insurance plan or vice versa.

Also, issues with Medicare. People that are on disability and are in that two-year waiting period to get into the Medicare system. How do you deal with those people while they're waiting for Medicare and really trying to address some of those issues becomes an -- becomes problematic for some of those folks to be able to cover themselves while waiting for their Medicare to kick in.

Number nine is delays in getting plan information once they're enrolled. Obviously this can become a real problem because, you know, individuals enroll, but they need to see a doctor right away. If it takes a month or so for them to get their health insurance card, that can be very problematic, especially if they have an urgent health care need. And finally the issue of communication issues for people who are deaf or hard of hearing is another issue that we look at a lot. Navigators ask us a lot in terms of how to interact with those folks, whether to find American Sign Language interpreters. And getting to those issues is something we have tried to look at. And find a solution for those folks and make sure they are helping those individuals. And sometimes with those folks, if they are meeting with the individual and they have a question, they have to call into the CMS call center, the CMS call center, in order to talk to the navigator needs confirmation from the individual. If the individual is deaf or hard of hearing, it can become a problem because they cannot give their consent.

So that many times becomes another communication issue that we have looked at and tried to address through some -- through some advocacy work we have done with CMS. So those are some of the things we have sort of seen. And it's one of the -- one of the problems that we've tried to address and really look at making sure that those folks are covered and getting the answers to the questions that they need.

So at this point we will open it up for any other questions. I don't think my -- now that I think about it, I don't think my -- my communication information or my contact information, excuse me, made it on the slides. So I'll provide that. The best way to get a hold of me is by e-mail. You can reach me at kcooper@aaht.us. That's kcooper@aaht.us.

>> Thanks, Karl. We do have several questions now. So for those of you that are on the phone, you can press star pound to indicate that you have a question. And then we will start with some of them in the webinar platform.

So Sara says, united health care has pulled out of any insurance's exchange. I have heard this is a concern nationally. How is this impacting the competition and prices of plans in the exchanges?

>> That's a big question right now. I don't know that we really know the answer to that. That's something that's probably going to have to play out in the next couple of months. I know that obviously, you know, insurance companies are going to be submitting their rates and it's one of the things that, you know, is really going to be sort of monitored. We do sort of try to monitor that stuff and we report that out on our news to use section of our Website.

If you don't receive our weekly update that we send out every Friday, you can go to our Website and sign up to receive weekly e-mails. When we put out information. So we follow a lot of the

different studies that come out as a result of that. And we try to put them in the weekly updates and on our Website. So that's another way you can sort of keep tabs on that stuff. Right now I don't know the answer to that question.

>> Okay. Sharon Brown, one of the things I do with my consumers is get to know what they need in the way of insurance. As I worked with insurance prior to this position, I'm able to read the policies and ask all kinds of questions. That was a comment there.

Sara asks, are there opportunities to get involved in the community outreach collaborative? And she also asks, have organizations and states been able to identify funding outside of the CACs to help with navigation and support, IE, Medicaid funding?

>> The -- in terms of -- there's a couple different questions, obviously you're asking. The COCs, first of all, if you're in a state with a COC, you can find that on our Website. And I would encourage you to reach out and let them know you're trying to do what you can to really help foster enrollment in your particular area. And, you know, maybe they can use your help trying to get the word out about some of the things we're trying to do.

In terms of the funding question that you have, there's multiple different ways that question is answered. Because there are multiple different ways that enrollment assisting has been funded. There's CMS has funded navigators in all the federally-facilitated states. If you are in a state that used healthcare.gov and there are navigators to help provide assistance to those individuals looking to enroll. And there's a list of those that you could find. And find out exactly where that assistance can be gotten.

If you're in a state-based marketplace, they have some kind of enrollment assisters funded through the state-based marketplace. But that is going to vary in terms of how they're set up from state to state with those states in the marketplace. If you're not sure, by the way, if it's a state-based or on the federal marketplace, go to our Website at the bottom of the home page, you'll see a U.S. map. You can click on your state. And you can get the -- if you click on that state, on the state page for that -- for your state, it will tell you if your state has expanded Medicaid and if your state is a state or federal-based marketplace. So you can get that information.

The other way that they're also funded is the federally-qualified health centers. Referred to as community health centers. Do have funding from HRSA, an agency within HHS that provides funding to the community health centers to act as what are referred to as CACs. Not to be confused with our COCs. CACs are certified application counselors. And they do the same work that the navigators do in helping people enroll. Because they recognize in a lot of those community health centers, they are assisting individuals without insurance. It's a way to get people where they are and get them enrolled in coverage.

>> And are there any plans to reach out to state CACs?

>> I'm not sure I follow that question.

>> Okay. All right.

>> I will say -- I will say this -- in terms of our project, if that's what they're talking about, if they're talking about our particular project, we have done outreach to the CMS-funded navigators in the federally-facilitated marketplaces and done as much as we can to reach the assisters and

navigators in the state-based marketplaces as well. We tried to hit all. You can see when you look at the states covered in the COCs that the COCs are in both states. They're in states with state-based marketplaces and also in states with a federally-facilitated marketplace.

>> Okay. And Meg, in New York we have had consumers who Medicaid applications were lost by the marketplace. What recourse is available to them?

>> That's a tough issue. I do know that many times they can usually get a special enrollment period if there was a mix-up within the marketplace. And they can still get enrolled even if it has been lost. I would encourage you, if you're in the state of New York, one of our COCs is also -- our COC in New York is the Center for Independence of the Disabled in New York. CIDNY. And they are specifically they have the information that they do a lot of that type of advocacy work and try to help people with Medicaid applications. They're located in New York City. That might not necessarily be close to you. But they might be able to give you some information that's New York-specific. I encourage you to reach out to them. I'm sure they would be more than willing to help.

>> Okay. And Daniel Davis from ACL is asking, what are the biggest research gaps that both speakers see as needing to be addressed? And where is the knowledge based efficient, and is it up to policy makers to catch up and implement?

>> I'll take a stab at this, and ask Richard or Jae if they have thoughts on this. One of the biggest issues I have seen is the real basic enrollment numbers. There's no way to find out exactly how many people were enrolled in the -- through the ACA marketplaces. There's no way to do that from the CMS data. CMS doesn't ask that question. The only place on the marketplace application deals with disability is specifically a Medicaid question. Many people, even if they have a disability, for instance, when I went to the Maryland application process, I answered no on that because I knew from an income level I wasn't going to qualify for Medicaid. I didn't want the Medicaid application to be caught up. I answered no even though I have a disability of my own. It's one of those things -- that's one of the problems that we had is really trying to find really good data on exactly how the ACA and the numbers of people with the ACA has reached with people with disabilities.

Richard or Jae, you are the academics. Turn that over to you if you see any other specific research questions.

>> Jae, are you still on with?

>> Yeah, I'll give it a shot. Well, Daniel, right now we're just starting to get information from the national health survey. They're looking at this issue. So although full implementation of the ACA happened in 2014, the data is just getting publically released now. So we're interested in very basic questions about, you know, how many people with disabilities are still uninsured. And the people newly insured, how many of them are sticking with the insurance plans that they received on the marketplace? How many affected by the Medicaid expansion? Simple descriptive stuff. Longer term we're interested in whether these new insurance options are going to allow people with disabilities to consider, you know, returning to work or staying in the work force instead of dropping out so that they can become eligible for SSDI and SSI and the public insurance benefits.

So there's a lot of questions that we're going to be looking at over the next five years. And I certainly encourage you, if you have some specific suggestions, to contact us and we'll try and fit that into our research agenda. We are going to be doing a -- a policy forum at the annual meeting for the National Council on Independent Living this summer and soliciting feedback from heads of CILs as well. So that's another opportunity to help us shape our research agenda. But we want this to be useful for the disability community. And we're eager to get feedback.

>> Okay. Good. All right. We have another question from Aramis. Why not make it mandatory for insurance to participate with Medicaid? They must be an ACA provider as well?

>> I guess that's more of a policy question to be dealt with sort of at the national, you know, but from Medicare perspective. I think it would be hard to really -- you can't force a company to do work. And I think sort of the flipside of that is you might end up did issue it might end up having an unintended consequence of having people pull out of Medicare. And if the insurance companies decide that the ACA is not affordable, then they might decide, well, if we have to do both, we're not going to do either.

So I think that's something that maybe policy makers could take a look at. But it could become problematic and result in some unintended consequences.

>> Okay. Looks like somebody maybe typing another question. In the meantime let's go here.

>> Karl, while we're waiting for that, I -- I have a question with you wearing your advocacy hat. And that is what your sense, or maybe if there's a national advocacy perspective, of what additional state -- additional states implementing Medicaid expansion. We know of some very high-profile instances in which states and legislatures have said they have absolutely no intent to be part of Medicaid expansion. But overall of those states that are not part, do you have any sense of whether there may be some that are more likely to make the move into Medicaid expansion than others?

>> I would say this. I mean, we have already seen some states, you know, that you thought wouldn't expand start to expand. I mean, that's already happened. You know, Montana and Louisiana being the latest examples of that. And the states that still have not expanded, I'm of the belief that it may take several years. But I think eventually they all will expand. If for no other reason than they'll realize that their dollars -- the federal dollars going into the Medicaid expansion come from every state. So they are paying for the health care coverage of individuals in other states and not their own.

And that's -- I think at the end of the day it's going to become an economic decision for these states that they're going to recognize that they're being pennywise and pound foolish. So I think that over time -- I'm also hopeful over time, of course. And this may be wishful thinking, but I'm hopeful that the ACA becomes less controversial. And as the ACA becomes less controversial, and sort of that whole issue dies down, it becomes more of what people are used to. I think also states that will sort of precipitate it as well. Where states will decide that you know what? It's not worth us holding out. And it'll just take a few to start doing that, and eventually if you have the last couple holdouts, I think they'll recognize we're footing the bill for everyone else and we're to the getting the benefit out of it.

>> Okay.

>> That may be all wishful thinking, though.

>> Okay. Sara says, I want to commend this collaborative for the work that they are doing. Thank you. How long will the collaborative be around and what are your future directions and priorities?

>> That is a great question. Like I had said, our -- the collaborative was funded through the foundation for three years. Our funding is up as of October. We're looking for ways to sustain the project. And that is something that we'll hopefully be able to find a way to continue the project. Ideally we'd love to be able to continue to expand the COCs and maybe add additional states. If we aren't in a position to do that, we'd like to potentially also put out additional fact sheets that relate to different disabilities. So increase the number of disability populations, specific factions that we deal with. Those are the kind of things we want to continue to do. And like I said, we're in the process of seeing what we can do to find additional funding. If someone has ideas, I'm more than willing to listen to them.

>> All right. I don't see any other questions at this time. No audio questions. So I think we can wrap this -- start wrapping this up. Okay. On slide 34 you'll find the evaluation form for today's webinar. So we would appreciate it if you will fill it out. Richard did mention, you know, that we take it seriously and we do like to get feedback to improve our programs.

And we really do hope that you'll fill it out. So with that, I will keep this link open so that you can click it and go straight out to the survey and take the survey. And I think that's it, guys. So thank you so much for joining today. Bye, everybody.