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United Spinal

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>>CART Provider: Standing by.

>> Thank you for joining us today for United Spinal Association's webinar helping people with disabilities get healthcare coverage they need. Today's distinguished presenter is Karl Cooper, Esquire. This is Bill Furgic, and I will be your moderator for today's presentation. One of a continuing of United Spinal Association webinars archived at www.spinalcord.org. A reminder please use the questions chat window on your control panel to pose your question and we'll do our best to get to them at the end. Please e-mail directly to the presenter whose address is displayed on the last slide. Closed captioning instructions also appear in the chat window of your control panel as is a copy of today's PowerPoint presentation. Mr. Karl Cooper is an attorney and disability advocate and has spent most of his professional career addressing the needs of individuals with disabilities. Currently he served as a director of public health programs at the American association on health and disability. He started at AHHD in October 2013 working as project manager for the National Disability Navigator Resource Collaborative which provides technical assistance to navigators and other enrollment specialists as they help persons with disabilities enroll for health insurance through the Affordable Care Act marketplaces. In this role Karl also advocates for the needs of people with disabilities who are enrolling for health insurance coverage in the marketplace. Presently in addition to his work with NDNRC, Karl also serves on the Maryland health benefit exchanges standing advisory committee and the executive committee for the

disability section of the American public health association. Karl received his law degree from Villanova University law school in 1997 and a BA in communications and political science from Cedarville University in 1994. Again, you can ask your questions during the presentation and we will filter them for and ask of attorney Karl Cooper after his direct presentation. Karl.

>> Karl: Thanks bill. It's a pleasure again to be with your organization and be presenting again on your webinar. I am with the American association on health and disability and for those of you who aren't familiar with our organization we're a national cross disability organization located in Rockville Maryland which is just outside DC if you're not familiar with that area. And it's the mission of AHD to advance initial active for children and adults with disabilities we do that through a number of ways including advocating for inclusive health programs, working to include disability in the public health agenda and working generally towards providing wellness initiatives and programs for people with disabilities. In terms of the projects that I've led for the last three years the National Disability Navigator Resource Collaborative or as I'll refer to its NDNRC what is the NDNRC it came out of a concern of national disability organizations navigators would not have a sufficient knowledge base to assist people with disabilities. Several of these organizations began discussing ways to reach out to the navigators to provide technical assistance and prepare them for assisting this population of consumers so the NDNRC is an initiative of those national cross disability organizations in order to provide

disability information and support to navigators and enrollment specialists as they assist people through the marketplaces. Who makes up the NDNRC we do have ten partner organizations including the American association on health and disability wills my organization the lead organization. United Spinal Association has also been a great partner as well as one of those partners. Association of University centers on Disabilities, Autism Speaks, the Christopher and Dana Reeve Foundation, Family Voices, National Alliance on Mental Illness, and National Multiple Sclerosis Society. One of the main strengths is in the cross disability make-up of our partner organizations. It's estimated when the Affordable Care Act in 20103.5 million people between the ages of 16 and 65 were uninsured and had preexisting medical conditions. These individuals face multiple options when enrolling including Medicaid, possible Medicaid buy in in their state. Possible Medicaid and exchange marketplace coverage and all the options available there. As you can see on the slide it's the mission of the NDNRC to provide cross disability information and support to navigators and other enrollment specialists thereby ensuring people with disabilities receive accurate information. One of the main ways we do that is through our website which you can find at www.nationaldisabilitynavigator.org. When you go there this is a copy of the home page that you will see. There are drop down menus that are across the top there the about us has information about our partner organizations that I mentioned. We also have a lot of organizations that serve as what we refer to as the friends of the NDNRC and essentially

what those organizations do is they help us disseminate the information about the NDNRC and the resources available for our project. We also have the conversations tab which allows you to gives you a place where you can ask a question and also has some frequently asked questions and gives you access to our blog and news items and archived news letters that we have sent out. Under our materials section you'll find areas where we have our disability guide which I'll be talking about in a moment we have several fact sheets available there. As well as different presentations such as the one we're doing today you can see archived versions of those under the materials section. And then we also have resources and links which I'll be talking about in a moment as well. You can see the slider that goes across there that has lots of information and it's a direct way to get to the disability guide or statement we put out and below there you can see the blog which is where we feature stories and highlight resources and trends and sort of usually try and highlight some of the major things that are happening as it relates to the implementation of the Affordable Care Act. Further down on the page is our state resource guide map and that takes you to individual state pages. I do also want to point out on the lower down here you see the Twitter feed there to the left and if you want to follow us you can follow us our Twitter is @ NDNRC if you go to the resource guide and click on one of the states it will take you to a state specific page and there you're going to find a lot of different information including marketplace if it's state based or federal exchange. If the state has expanded Medicaid or not. A couple of states we have state

specific fact sheets so some of the fact sheets we've taken and modified them for a different state. We also if it is a state based exchange we have the information for how you can reach the state based exchange individually. I'll be talking about our community outreach collaborative. In Washington state you can see that you get the direct contact information for that state. And we also have information for different state affiliates for our partner organizations as well as state specific resources. So for all the states plus the direct of Colombia we have state specific resources you can look up and gives you information specific for that state as it relates to ACA implementation. I mentioned earlier our resources and links page and here we have a bunch of different categories of resources that are available including our disability specific resources which many of these are from our partner organizations or friend organizations such as we have a toolkit from the arc, American occupational therapy association. On our enrollment resources we have resources from SAMSA, the National Council for Behavioral Health and Health America. On the enrollment resources for populations with special healthcare needs you can find resources from organizations such as the American heart association and the national health council. The next two categories, the ACA marketplace and Medicare and ACA marketplace and Medicaid have resources from CMS which is the federal agency that runs those two programs as well as organizations specific such as the national council on aging and national law center, national state policy for Medicaid. We have our overview category which is our largest category and has a lot of great

resources. The one resource that's at the top of that that we always try to highlight is a resource guide that deals with a bunch of different issues not just disability issues but any sort of issues that navigators are having as it relates to assistance with enrollment that's put out by the Georgetown University on health insurance reforms which was a program that was also funded by the Robert wood Johnson foundation which is a foundation that originally funded our project and for the first three years of our project provided the fund to go allow us to provide all these resources. We have enrollment statistics which provide information recently put out by either CMS or other organizations as it relates to what is happening with enrollment. We also have our ACA resources from the government which include basic resources from healthcare.gov, HHS, as well as some Spanish resources from CMS and our ACA enrollment resources from our organizations that have been encouraging and insisting with enrollment such as enroll America and families U.S.A. Our disability guide is one of the things I mentioned earlier it's probably the resource that we are most proud of and it is a comprehensive guide to a helping individuals who do enrollment to give them some basic understanding of what is going on with folks with disabilities and what they need. So it was released in January of 2014 right as the ACA implementation was really taking effect it's been updated as well and it provides just basic information about special considerations people with disabilities phase as they shop for their healthcare. Once again it was made possible by the funding for the Robert wood Johnson foundation and it was written by one of our partner

organizations the disability rights education defense fund so we're thankful to them for helping us to put that together.

In the disability guide you're going to find a lot of different things such as in the introduction it gives a supplement, I should say it describes the guide as a supplement for training navigators in providing sort of supplements the information that put out by CMS. They had done a training for navigators and enrollment specialists and it acts as a disability 101 for people with helping with enrollment. The purposes of the disability guide provides the objectives of the guide as strengthening disability literacy helping identify and provide appropriate accommodation and assisting in identifying central issues to healthcare people with disabilities. The key questions for navigators is the basic overview of some of the important questions which are answered by the guide. Who are people with disabilities and what problems and barriers do people with disabilities historically encounter. Provide a basic background for those completely unfamiliar with who makes up the disability population and what has disparities they based. How disability rights affect the marketplace provides a basic explanation of how the ADA affects those who are providing enrollment services. Next section what the navigators need to know about disability I'll deal with that in the next slide. How is Medicaid eligibility being determined begins the basic discussion of Medicaid categories for people with disabilities and the fact sheets continue to build off of that. We also have some specific scenarios that they can sort of look at and see what they might want to be thinking about

for various individuals that they could be assisting. And what type of accommodations should navigators know, reviews methods to communicate effectively, the section also helps navigators and enrollment specialists learn how to be prepared both indicate and assist individuals with visual or hearing issues. Moving onto the what the navigators need to know about disability that section I have referenced earlier deals with a lot of different questions and I'm not going to go through all of these questions but basic will I it sort of gives the basic information that people need to know about how is disability defined, what is disability literacy and etiquette and some basics about physical accessibility and what they need to do in terms of being able to communicate effectively and really adequately equal wait the plans that people are looking at for adequacy of network providers and some of the essential health benefits that they need.

We also have 17 topical fact sheets that we've released to date. The first three sort of provide a basic way for understanding how to get the information that you're going to need to answer the questions that we raise in a lot of the other fact sheets so it deals with the summary of benefits and coverage, it deals with the evidence of coverage document and it also deals with trying to get information from customer service when you're trying to specifically get information for a individual that they're trying to assist.

The rest of the fact sheets I'm not going to go ahead and read all of them but they deal with a lot of specific scenarios such as rehabilitation and devices or prescription meds or mental health and

also some of the Medicaid categories such as the medically frail status and then we also have information for some of the broader issues that you have to deal with such as how section 504 of the rehabilitation act affects the marketplace and what they need -- what navigators need to understand about that. Also some information about Medicaid that as it relates to HCBS waiting lists or Medicaid buy in program and general fact sheets that deal with disability etiquette and one fact sheet that's sort of designed for the consumer. Most fact sheets are written for navigators and assisters. The only fact sheet that's geared toward the consumer and 16 moving from coverage to care which basically is a primer for individuals once they've got their care how do you use it effectively. And since that one is designed for consumers that is the only fact sheet that we have translated into Spanish. Then we came up with the idea one of the things that we sort of recognized after the first year of doing the program, a lot of fact sheets that had much more specific information were the ones that were more, were used to a higher degree so we came up with an idea for year 2 and then we built on it in year 3 to come up with what we refer to as population specific fact sheets so what to know when assisting a consumer with a specific condition. These are the population specific fact sheets that we've addressed or done to date and they were all written by organizations that specifically deal with those particular disabilities and those populations so they really understand the health needs of those individuals and it's -- they follow a similar template the only one that's different is the veteran fact sheet. But they follow a similar

template and basically provide the same information and lots of times we'll refer to the other fact sheets for more specifics on issues that might relate to say prescription drugs or durable medical equipment or something like that. One of the things we realized after year one also was there was a general shift towards outreach and not as much focused on the technical enrollment piece so we recognized people with disability may have a distrust of experts that they don't perceive as having expertise with their disability. In year 2 we started by funding 1 community outreach collaboratives or what we refer to as COC. COC decreased outreach efforts and enrollment of people in the ACA and COC do this through primary tasks. They build cross disability tasks and second they works as dissemination with their local and/or state navigators and assisters and basically the way I always say it is they sort of act as a bridge between the disability organizations and the navigators so someone in a disability that's a member of a disability organization is looking for a referral to a navigator they can provide that level referral. If the navigators have specific questions about a specific disability then the COC can act as a referral based maybe local disability organization which can assist them. We're very proud that the COC represent with diversity within the disability community. We initially started out with 11 and we expanded that to 17 and we have 11 of those COC's they are in 17 different states and are located in 9 -- excuse me are located in all ten of the HHS regions. If you want specific information about these the way I would encourage you to find the information out we have a page for the COC and also the information

for each individual state. These were the original 11 COC's that we had for year 2. So if you live in one of those states and want to encourage people to reach out to this organization so that they can get the assistance they need, and like I said they're contact information is on the COC page or individual state pages and as I said for year 3 we expanded that to 17 states 18 COC's we have two in Texas that work together. And the link there for the community outreach collaboratives is at the bottom of the page you can check out specifically. The ACA is not a perfect act and there are issues that still are ongoing with it and I will be talking at greater length about the ACA and where it stands politically towards the end of my presentation. But for now I do want to take a look at some of the ongoing challenges we've noted. They are issues such as limited provider networks where the networks do not adequately meet the needs of those folks with disabilities that need to find a provider that's going to be in their network and have the specialty that they need. Limited formularies and discriminatory pharmacy designs go land in land with some of the drug formularies not covering the drugs needed or set up in a way that is really discriminatory I will be talking about that in a moment. Planned transparency. Trying to figure out what is covered and the costs associated with that that sort of goes hand in hand with the high out-of-pocket costs and really understanding one of the things we always try to stress to folks with disability who are looking to enroll or folks assisting them they really need to look at the out-of-pocket expenses and not just the premium. You can't just pick a plan just based on the

out-of-pocket premium. If you factor in the costs it's sometimes better to pay more in premium. There's confusion over the definition of rehabilitation and habitation. Confusion on prosthetic devices and durable medical equipment and what is covered there. I always like to tell people as a wheelchair user myself I had a difficult time lots of times trying to find out what was covered in a plan as it related to my wheelchair. Confusion about coordinating exchange coverage with Medicare and Medicaid when the exchange can act as a bridge to one of these programs. Delays in getting plan information once people are enrolled and that can obviously upset continuity of care.

Communication issues for deaf and hard-of-hearing. The most common questions I get from navigators specifically what they can do to better communicate with folks who are deaf or hard-of-hearing and what their requirements are as it relates to providing sign language interpreter or using some other method for communication. Now one of the things I always talk about when I refer to people with disabilities enrolling is I like to refer to it as a game of health insurance jeopardy. When I say for those of you familiar with the game show you know it's not about the answer in jeopardy it's about asking the right question. If individuals aren't asking the right questions they are not going to get enrolled in the proper care. So I'm not going to go through a whole thing I'll be providing information for you in a moment about exactly what the -- if you want to view this whole series how you can do that, but for now we're going to go ahead and just play a sample of these questions. The first is prescription drugs and if the individual takes

a prescription muscle relaxant the question is does the qualified health plan have a tiered prescription medicine benefit. This is one example we make sure folks with disabilities are thinking about. Tiered prescription medication benefit is one where an insurance company will provide you to start out with a generic before you're able to move to the name brand drug and lots of times that is a problem if they've tried the generic and it doesn't work. We've encouraged individuals to look at the plan. Moving onto medical devices if an individual is a wheelchair user one of the things you need to ask is whether the qualified health plan covers durable medical equipment. I'll be talking about essential health benefits in a moment but essential health benefits including medical devices but medical devices has never been divide by HHS. It's been left to the states and insurance companies. Durable medical equipment is many times covered different ways in different states. Knowing exactly what that is very important. Moving on another thing with medical devices is supplies. So if an individual indicates that his condition requires to use a catheter you need to ask the question does the qualified health plan cover disposable medical supplies. The same reason the DME is an issue, it's an issue to make sure those are provided as well. Rehabilitation and habilitation benefits the consumer using rehabilitation therapy says she has to go repeatedly. Does the qualified health plan put limitations on the number of rehab visits. I'll be talking in a moment about sort of the benefits of the ACA being the fact it got rid of lifetime caps but there are monetary caps and so they are allowed to

put service limitations on individuals and understanding what those service limitations are is important if you're evaluating a plan. With medicate eligibility arrive at the question regarding disability. In this instance you want to ask the question does the individual want to apply for Medicaid. If you answer yes to this question it will put them into a Medicaid eligibility determination and for some individuals you may not want that because even if they have a disability you know they're not going to qualify for Medicaid because of various financial reasons and therefore they may want to answer no to this question even if they have a disability because they don't want their application to get held up in that eligibility determination because it could delay when they could get their coverage by. Summary of benefits and coverage. We talk about a wheelchair using and we need to ask the does the summary of benefits and coverage say what the cost is going to be for services such as durable medical equipment. Finding out what costs are that's not as easy on the summary of benefits and coverage but one of the things that is available that HHS requires is for a link to the website where they can get more specifics information such as the evidence of coverage documents which provides more specific information. With mental health I always tell people that's the unknown. That's the question they need to be thinking about. Does the individual need coverage for mental health as they may not self-report that to you. If you're trying to assist someone with mental health enroll they might not tell you they have a mental health condition due to some of the stigmas associated with it. And that's important because you might not be giving them the

advice that they need so trying to figure out exactly what coverage people need is important regardless of whether it's mental health or some other form of invisible disability. Asking questions specifically to a consumer about what kind of doctors they see what kind of medications they take will lead you understanding a fuller idea what their issues are to make sure that they get enrolled in the appropriate plan. For double jeopardy we did it based off disability specific fact sheets. For intellectual disabilities autism spectrum cerebral palsy, seizure and mental illness. What are some common co-occurring conditions for people with intellectual disabilities. Co-occurring conditions is something we emphasize a lot in this specific -- excuse me. Something we really stress a lot for individuals with all types of disabilities because lots of times you could get so focused on one specific area you neglect another area of their health needs and understanding there are co-occurring conditions for individuals is very important. With mental illness lack of network adequacy limited provider network lack of parity in coverage high out-of-pocket costs and wait times to see providers. What are common issues with mental health treatment in qualified health plans. I talked about this a little bit before and this just sort of underscores some of the issues. Network adequacies is making sure they are going to be able to see the doctors they want and many times individuals this is for mental health or any disability really if they are seeing a specialist lots of times they have a good relationship with that individual and they don't want to lose that doctor so making sure that doctor is in their network is

important to them. With multiple sclerosis the 13 drugs approved by the U.S. food and drug administration which are available to reduce disease activity and disease progression for MS this is a number which are considered specialty pharmaceutical and the question is what is all of them. This gets into that discriminatory pharmacy design I spoke about earlier and really understanding that lots of times the way these insurance companies have set these pharmaceutical designs up really is discriminatory against some people with disabilities. We see this a lot with MS, the HIV AIDS groups always talk about this with their drugs as well. Many times they are put on the specialty pharmaceutical level which makes them much more expensive. The tiering of those drugs, you can have a tier that is the generic drug then you can also have sort of the name brand drug but also go to even a third or fourth tier which deals with specialty pharmaceuticals where their copays and out-of-pocket costs are a lot higher. For paralysis this is the differences between someone born with paralysis or later in life and this is the difference between rehabilitation and habilitation. Even though it might be the exact same therapy the insurance companies view them differently. The insurance companies are more likely to pay for rehabilitation than habilitation and that becomes problematic for individuals born with a disability and as a result it might limit their ability to get some of the services that they need. With veterans this is a number of pry or groups used to determine who gets access to VA healthcare services and this is with this, the answer is 8. For example veterans who have a VA that is rated at least 50% service connected

disability the veteran has disability or disabilities related to service they are placed in priority group 1. Veterans who receive a VA pension which are benefits for wartime veterans age 56 or older or low income or permanently disabled they are in priority group 5. Those are examples of the groups and that determines who gets priority for various services. For accessibility we have a whole thing on accessibility and different issues that come up with different populations. And this is the one thing you want to think about when assisting a consumer who is deaf or hard-of-hearing. In this instance what is the individual's preferred method of communication. If they have a sign language interpreter that's what you should do. If they want to read your lips that's what you should do, if they want to write and pass nodes back and forth that's what you should do. You should follow their lead. We also have a final jeopardy question which is basically categories disability etiquette and this is the one word that sums up the best quality you can have when dealing with anyone with a disability. The question is what is respect. Having respect for the individual goes a long way if you treat them as you would want to be treated then it goes a long way to helping that individual and winning their trust. Now all of these I only touched on a handful of these jeopardy questions we have different scenarios for each of those questions. If you want to see all the rounds of jeopardy rounds 1 and 2 they are on our YouTube channel which you can find the link for there. You can view them one by one they range in length from about 3 to I think up to 7 minutes in length so you can watch them very easily individually

at one setting if you want to. And then come back and watch another one later. In terms of the Affordable Care Act generally I do want to talk about it because obviously it's been in the news a lot lately and there is a lot of question as to what is going to happen. I am not going to pretend to be able to tell the future and tell you what is exactly going to happen with the Affordable Care Act as it relates to the new congress and the new administration but what I can tell you is some of the basic principles that the Affordable Care Act has stood for with people with disabilities. That's what I want to do with the few moments at the end. For instance the disability law time line so you have a basic idea what led up to the Affordable Care Act the Rehabilitation Act Section 504 came out in 1973 and that dealt with basic issues as it related to getting rid of discrimination as it relates to those individuals who were receiving moneys from the government. The I DEA came about in 1975 which dealt with education. Voting for the accessibility for elderly handicapped act in 1984 dealing with voting rights. Err year access act dealt with air. Housing gets included as a protected class in 1988. 1990 is the big one Americans with Disabilities Act which provides for prohibitions against discrimination in the areas of public service employment public transportation et cetera. Basically by the time the ADA is passed you've addressed everything but healthcare. They were talking about putting it in the ADA and ultimately decided it was going to be too controversial to pass so healthcare was saved for another day and that's where the Affordable Care Act comes into play section 15557 closes that

final hole. As an attorney I've got to put the language up there I'm not going to bother you and read it but the ACA does represent that final area of disability discrimination being eliminated so it is in many ways a civil rights bill for disability and the main section that addresses that is 1557 if you're wondering when it refers to section 794 of title 29 that is the rehab act was the first law that outlawed discrimination against people with disabilities. As far as the Affordable Care Act what does it mean for people with disabilities. No denial of coverage for preexisting conditions, no cancellation of coverage due to serious medical conditions, and no setting premiums based on disability or chronic conditions. We refer to these as the guaranteed issue clauses. Anyone that wants coverage can get it. Anyone that has coverage cannot lose it because of their medical conditions or because they're using too much. And you can't be judged for your premiums based on your utilization and how much you're utilizing your healthcare and if you have a disability or other sort of chronic condition. Some other things though it does mean that are important no lifetime monetary caps, the tenet essential health plans. And it means monetary. There are limits on surfaces therapies and devices I spoke of. The 10 eye essential health benefits include areas that help folks with disabilities including mental health and substance use disorder services, prescription drugs, services and devices to help you recover if you're injured or have a disability such as physical and occupational therapy speech language pathology psychiatric rehabilitation and more. And basic some basic preventative services as well. So a lot of these

things are very advantageous for people with disabilities. The other thing the Affordable Care Act did is it put in place Medicaid reforms. It follows the and creating the balancing incentive program as well as the community first choice program I don't have that on here but all of those programs really sort of are aimed at trying to help people with a disability live and stay in their home and community rather than have to go into an institution to receive care so it basically helps with that rebalancing so that you do not have to receive care in an institution you can receive it in your home or community based setting and also created an alternative benefit plan that is available that states have a flexibility to create a set of alternative benefits. Finally one of the things I want to point that we did recently last month we put out a state of 8 core principles we feel need to be taken into account with any ACA replacement plan.

>> We lost audio. Just thought I'd mention that.

>> I thought I put it back on. Can you hear me now?

>> Yes, sir we can.

>> Sorry about that. I was trying to unmute and mute myself when I was coughing because I have a cold. So I thought I'd clicked it back on but I guess I hadn't. I apologize for that. The prohibition the first of these 8 core principles that we are trying to really try and push forward that need to be made as part of any replacement for the Affordable Care Act. There is a republican congress in place and they will have a republican president they are intent on repealing the ACA and replacing it with something these are 8 principles we feel need to

be part of any replacement plan. The first of those is the prohibition against denial for coverage of preexisting conditions. Obviously people with disabilities and other chronic conditions need to be able to purchase coverage if they want to. The guaranteed renewability of coverage. Basically just because you're using too much does not mean that you should be allowed to be terminated. In other words, so the first point is sort of being able to buy it they beginning and when it ends. The individual should be able to determine when the coverage end unless there's nonpayment of premiums. The individual if they want the coverage and they're responsible and they pay for it they should be able to keep the coverage as long as they want it. The prohibition against individual underwriting is really important. And this is something that many times gets lost. You hear people say we want to keep the prohibition against denial of people with preexisting conditions but they don't specifically say if they want to keep the prohibition against individual underwriting. Basically what that says is that person with a disability can't be charged more because they have a disabling condition something that's going to essentially cost the insurance company more because if they're allowed to do that then insurance companies will simply be able to price those people out of the market what good is a right to be able to buy insurance if the insurance company can turn around and charge you so much that you won't be able to buy it. Four is the essential health benefits being required in every qualified health plan that we feel needs to be continued. Once again it's sort of an extension of the last point because if every plan is

not required to cover certain core benefits what the insurance companies will be able to pick and choose what they're going to provide and if someone such as myself uses durable medical equipment and I need that covered in my insurance plan they will be able to once again charge we so much I won't be able to afford it. What good is the right to buy the coverage or prohibition against denial of the coverage if they can then deny me the services I so desperately need. Next prohibition against lifetime monetary caps which is basically says that they cannot say that once they've paid a certain amount of money that you can't be -- they can't be charged anymore. And that's obviously important because people with disabilities obviously generally have a higher utilization and end up using more in healthcare. Prohibition against discrimination in health programs that's section 1557 we still is vital and needs to be maintained as part of the protections to close that final area of discrimination that existed before the ACA. The extension of the mental health parity to the individual and small group markets. The mental health parity addiction and equity act was passed in 2008 I believe and essentially provided for mental health parity for large group plans. The ACA took that protection and extended it to individuals in the small group market we feel that is something that needs to be maintained and finally Medicaid expansion. Medicaid expansion has been used in several states now. In fact the imagine at this of states now have expanded Medicaid and people with disabilities in those states have greatly benefitted as a result. They no longer have to worry about their disability status affecting whether or not

they can receive Medicaid benefits or not if they decide that they want to go out and try and find employment they don't have to worry about that affecting their medicine indicated eligibility unless it affects their income. Their basic eligibility they can receive and if they lose the job they don't have to worry about reapplying on Medicaid they can just become part of the medicine indicated expansion. There was a study last month put out by the American journal of public health that underscored the fact people with disabilities have a higher rate of employment in states where Medicaid has been expanded versus those where it has not. Finally if you want to stay involved with our project you can sign up to receive updates at our website we also have a newsletter we put out every Friday so you can find the archived news letters at that web address. My organization also has a newsletter that comes out and you can sign up to receive that newsletter at the 3rd hyper link there and finally the last link is just our general resource center which has a lot of different resources related to public health programs and people with disabilities. So with that I will go ahead and open it up to questions if we have any.

>> Great presentation Karl. Good overview including the historical time line leading up to ACA as well. A lot of us have seen some of those dates but you know in the perspective of leading it up to the ACA and what the ACA then encompasses I think it gives a great overview perspective so thank you for that. So it's great to see the flexibility of AAHD and response to changes and needs after implementation of ACA. Do you have comments on the flexibility that you've exercised, how

that's come to be and what, more importantly what the outcomes have been of the flexibility of changing your approaches and changing outreach in response to ACA implementation over time.

>> Karl: Yeah that's been more a matter of trying to follow the trends as we've seen it on the larger scale not just folks with disabilities but generally everybody remembers those first few months when healthcare.gov got started and how it got off to a rocky start. That first year was when we were starting this project so we were also focused on a lot of the technical issues that were related to folks with disabilities. And so that was sort of our focus initially as well and then we started to notice towards the end of year one once the technical issues had worked themselves out and all the kinks were done that's when we really started to take a look and saw a shift from individuals looking for specific, going away from the specific questions as it related to the technical pieces and moving more towards the outreach trying to make sure that they were covering everyone ask getting everyone covered. That was sort of the -- we had saw that happen in year one so that's when we decided to come out in year two and move towards helping with the push to get folks enrolled and let them know and we got a lot of -- I think we ended up getting a lot of positive feedback as a result of some of the initiatives we took with the community outreach collaboratives. They found it the community outreach collaboratives found it helpful to be plugged into the national picture and have an idea what was happening and we found it very valuable to have sort of a ears to the ground network that we could call on when there was questions that came

up so we could call on them if there was a specific question that someone had about how ACA implementation was affecting folks with disabilities. We had a group that we could call on and say what are you hearing what are you seeing and that way it sort of allowed us to provide that last, close that last loop so we could really bring that information in and provide that then to those people that were asking the questions and it helped us inform us a lot more as to what was happening on the bigger picture. So having that was invaluable and then also like I said the other thing that we did that we got a lot of positive feedback for was the population specific fact sheets and the way I sort of pitched them to the navigators when we put them out was you know hey this is something that if you're meeting with someone and you want a quick primer on how to assist an individual with say for instance multiple sclerosis is one of the fact sheets and if you've got someone with that you don't understand this is a fact sheet you can pull off your shelf read through it understand some basic medical issues that this person is going to have and ask them, you can be a little more informed when you're asking them questions about what their needs are. That was the way we looked at it and I think that we ended up getting a lot of positive feedback from those as well and we're happy to provide those and we were really thankful for our disability organizations that we work with, partner organizations that we work with that they were the ones that helped us author those fact sheets so that we could have, we knew there was expertise behind it, behind individuals population and knew health needs of that population so they would be able to do it in a way that

was going to be most helpful.

>> Well, thank you Karl and that's a great segue into an MS related question. What do you see as the status of coverage for MS, and this goes to your earlier comparison of habilitation with rehabilitation and as other chronic disorders have often, folks with them have often fallen through the cracks because of it not being a sudden onset. What do you see as the current status of coverage for MS habilitation or rehabilitation.

>> Karl: Yeah one of the main problems we have with that that I didn't get into as much detail with I touched on it briefly, but sort of the broad area of, the service limitations that get put on because a lot of folks with MS rely on rehabilitation therapy as a way to continue to maintain their independence, whether it's physical therapy to help them so they can continue to walk and keep their mobility where it is that they can maintain an independent lifestyle that's a very important issue. And lots of times here is the dirty little secret is insurance companies don't like to pay for something if it's not going to get you better. And you Noah lot of these folks it's not going to get them better, the rehabilitation isn't going to get them better but it's going to keep them from having their condition progress to where they will need other medical -- have other medical needs. So it's really trying to get insurance companies to recognize that because lots of times they just, that's a problem and that's an issue that we've seen that lots of times insurance companies just don't get. So understanding that's why we always say it's so important for people that are in that situation

to understand exactly what the service limitations are. If they're going to tell you that you can only have so many rehabilitation physical therapy visits a year, then you need to know that because that's going to, that could potentially impact how much benefit you'll get out of that. So if that's the case you may want to think about another plan that's going to more adequately meet your needs.

>> Sure. Thank you for that. From an attendee who has a spinal cord injury now for 9 years, how do you see insurance being able to help the spinal cord injury disabled with more advanced modalities as the years go by? I don't have more details than that, Karl, but I take it advancements in care advancement in equipment.

>> Karl: Yeah. And lots of times those advanced treatments insurance companies always a lot of times are a little behind on what they will pay to and what they won't. We do a lot of work with the national health council that is a national organization that sort of, it's made up of a lot of different organizations, there's disability organizations part of it, there's also though some medical companies that are part of it. There's some provider groups is the other big area that is represented in the national health council and so they're talking a lot in that group when we meet with them, they are constantly talking about these treatments that are being tested and making sure that they're done so in a way that the benefit is really shown and demonstrated so that when they do go for payment they will be able to get that and that's one of those things that I think is always an ongoing thing and there's a lot that people talk about with prescription drug trials and the outcomes

of those and whether or not insurance companies want to pay for that drug benefit or not when it's new but it's the same kind of conversation you have with those kind of things. So those are things that as things are being tested it's very important that you know we as people with disabilities understand exactly what it is that the needs are and that we're, we make sure we're at the table so that they can understand the importance of it and they're making sure that when they do go and they present it to the insurance companies or in many cases with CMS for Medicare and Medicaid reimbursement that they're, the stakeholders that are important are there especially folks that are going to have specific needs of those. So that's a great area where individuals can get involved in advocacy is looking for those when they hear of things that are coming down the line is trying to figure out what exactly they can do to really promote those so insurance companies and CMS will ultimately reimburse for those therapies.

>> Well, we had seen a shortfall in coverage of the I-Bot a few years ago when it came out and now the I-Bot 2 that I see much discussion on that point is what will be the price point what will be the likelihood of coverage compared to the prior time around so yes it will be very interesting to see what happens in that. And that also segues into this question or questions. Has coverage for wheelchairs generally increased, decreased or stayed pretty much the same under the ACA I guess that implies from the prior to the ACA days has wheelchair coverage increased, decreased or stayed about the same in your view?

>> Karl: It's a little harder to answer that question than you would

think. And in theory it should have increased because the essential health benefits require medical devices to be covered so in theory you would think that would include wheelchairs. The problem is that lots of times the devil is in the details and while they may have expanded the coverage maybe to certain areas or allow for certain reimbursement for certain equipment it may have gotten, what may have gotten lost is the, some of the costs associated with it might have gotten higher. While they might be, more plans might be covering it, it's entirely, I think probably what has happened is the coverage itself has not necessarily improved. So you've got more plans that are now covering wheelchairs than covering it before but they're doing it at less of a cost to them and more of a cost to the consumer if you understand that.
>> It does and I think you're spot on with that because we see incidences in the resource center where because of the costs increase in the exact same model of wheelchair over a period of years has then seemingly been the cause of denial for instance of titanium frames versus aluminum and therefore the consumer ends up responsible for a high copay to be able to receive their new wheelchair of the exact same model in titanium this time around as opposed to reverting to aluminum when prior full 100% coverage had been given to that exact same model of wheelchair exact same company with titanium and now titanium was an out of pocket upgrade.
>> I'd also like to use my own story for this. Sometimes you have to understand how to play the game. I had mentioned I do use a wheelchair. Couple year back when I had to get it replaced because it was breaking down it's the way these things go and I use a power chair. So the getting

it replaced they sent me to the DME company to have it evaluated have the old one evaluated and the guy wrote up you know an estimate of what it would cost to replace this thing that ended up far exceeding what a new wheelchair would have cost. He turned it into the insurance company and the insurance company approved it. So sometimes, so I called the insurance company up and I said do you realize what you just did. There was a far cheaper option and that was just to buy a new chair which is what we were trying to accomplish and sometimes you've got to understand how to play that game because the insurance company just was, they just plat flat out approved it they figured that's just what happens. But you know when I explained it to them they were like oh, then just have them write up an estimate as to what a new chair will cost. We did that and it got approved. Sometimes you've got to, it takes a couple of rounds this is what I'm trying say so get things approved appropriately.

>> Sure. Sure. We have one more question for you Karl and for the audience. And that is with senior citizens receiving Social Security can they receive insurance under the ACA.

>> Karl: If you have, there is something called minimal essential coverage and if you have minimal essential coverage which Medicare is considered minimal essential coverage you cannot get the subsidies. So for instance when you hear about what a potential plan could cost it will be a lot cheaper because of the subsidies that these people are receiving. If they are, so if you do have Medicare then that meets the minimum essential coverage which means you can't get access to the

subsidies which probably means any coverage on the ACA marketplace is going to be too expensive. So the answer to the question is can they get coverage through the ACA marketplace yes but it's probably not cost-efficient.

>> Okay. I think we're going to end on that question Karl on behalf of United Spinal Association I'd like to thank Karl Cooper he is squire so much for sharing his wealth of professional knowledge about helping people with disabilities get healthcare coverage they need. Our next webinar will be about employment with a disability specifically the job interview segment of seeking employment and that will be on January 24th from 3 to 4:00 p.m. eastern time. Karl I thank you so much for your presentation today.

>> Karl: Thank you.

>> To sign up for and receive our news letters and our webinar notices advocacy you alliance visit us at www.spinalcord.org or visit us at numability.com. This will conclude today's presentation. Thank you for your time and presentation on the important topic of healthcare selection. Thank you.

[End of presentation]