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>>CART PROVIDER: On standby. >>Bill: Thank you for joining us today for United Spinal Association Webinar, Understanding Health Care Needs of People with Disabilities, my name is Bill and I'll be your moderator for today's presentation. Today is one of a continuing series that we will be hosting and all of our Webinars will be archived at www.spinalcord.org. We will have time at the end of today's presentation for questions, please use the questions window at the bottom of your control panel, to write in any questions that you may have and we'll do our best to get to them today. For any questions remaining unanswered, please pose those questions directly to the presenter whose contact information will be displayed on that last slide. Today's presenter is Karl Cooper of the American Association on Health and Disability, AAHD, I'm going to skip over a few of the acronyms along the way here if you don't be mind. Karl has spent most of his professional career addressing the needs of individuals with disabilities. Since October 2013 he has been the Project Manager at the American Association on Health and Disability for the National Disability Navigator Resource Collaborative. Before that he worked in the policy departments of the National Disability Rights Network and the National Association of States United for Aging and Disabilities in Washington DC. Prior to moving to DC in 2012 he practiced law for 14 years in the greater Philadelphia area, opening his own firm in 2006, where he was able to devote time to pro-bono advocacy for those affected by physical and developmental disabilities. As part of that work, he drew on his own personal experience of person with physical disabilities and helped consumers navigate the complex area, areas of employment, education, health insurance and Medicaid. In addition to his work at the NDNRC, Karl also serves on the Maryland Health Benefit Exchanges advisory committee and the executive committee for the disability section of the American Public Health Association. He received his law degree from Philadelphia University School of Law in 1997 and a BA in communications, political science, from Cedarville University in 1994. Please note the instructions for closed captioning for this Webinar appear

in the chat window. Now I'd like to hand it off to Mr. Karl Cooper, Esquire, to begin his presentation. Karl?

>>Karl: Thanks Phil, I appreciate the opportunity to speak with your group again, as I have the last couple years on the project that we have the National Disability Navigator Resource Collaborative, I will refer to it throughout the presentation as the NDNRC. For those of you, first of all, who aren't familiar with my organization, I am with the American Association on Health and Disability, we are a national cross-disability organization located in Rockville Maryland outside of Washington DC, for children and adults with disabilities. In terms of what is the NDNRC specifically, the NDNRC came out of concern of national disability organizations that navigators and those doing enrollment assistance would not have a sufficient knowledge base to assist individuals with disabilities as they make their health care enrollment decisions. Several of these organizations began discussing ways to reach out to the navigators, to provide technical assistance and better prepare them for assisting this population, cross-disability organizations in order to provide the information and support to the navigators who are helping with the ACA insurance marketplaces. In terms of exactly who makes up the NDNRC, there are ten partner organizations that make up the NDNRC, specifically my organization, National Disability Navigator Resource Collaborative along with United Spinal Association, who is hosting this Webinar for us today, we also have Association of University Centers on Disabilities, Autism Speaks, Christopher Wood Reefe Foundation, Family Voices, the National Alliance on Mental Illness, National Multiple Sclerosis Society and Arc, we are in the cross-disability makeup of our partners. It is estimated when the Affordable Care Act was passed in 2010 in a between ages of 16 and 25 either uninsured or preexisting condition or disability, these individuals faced multiple options when they have been enrolling for health care coverage under health care act, including Medicaid, possible Medicaid buy-in or expansion in their state and exchange marketplace insurance coverage. So as you can see on the slide, it is the mission of NDNRC to provide cross-disability information and support to navigators and other enrollment specialists, thereby ensuring people with disabilities receive accurate information when selecting and enrolling in insurance through the Affordable Care Act marketplaces.

And the main way we do that, in terms of getting those resources out is through our website. You can see the url there is www.nationaldisabilitynavigator.org, this is a screen shot of the home page you would see when you go there. There is several drop down menus that go across there, about us have information about partner organizations I mentioned as well as some of the friend organizations that help us get the word out about the project and community outreach collaboratives, I'll be talking about them later, that's where you can access their information as well as the COC information is on the slider, the big picture you see in the middle is a picture that changes and one of the pictures is the COC and the map of where they are located and if you click on that you can get specific information. I'll be talking about those later in my presentation. You can also see under the conversations tab you can ask a question and submit a question and there's also a place where you can get answers to frequently asked questions. Materials, which is the most important part in interpreters of what we have in terms of resources we put out, is where you can find our guide and fact sheets as well as prior presentations we have done. Go a little further down on the home page you'll come to this map, first of all note over in the top left there is our Twitter feed on our home page, if you are on Twitter, if you want you can follow us, our handle on Twitter is@ NDNRC home page at the bottom is state resource guide map where you can click and get information that is specific to your state. So if you click on that, you're going to get information, as you can see in this particular instance, the state of Colorado, if it is a state with a state

exchange you can find out exactly the contact information for that state exchange. You can also see at the top there we have whether or not it is a state exchange or a federal exchange and then also indicates whether the state has expanded Medicaid or not, which is something that is changing with some of the states as we progress through the ACA implementation. We also have information for the community outreach collaborative or COCs I mentioned for each state that has them. Which is in 17 different states, we also have information on each state for the Assistive Technology program that you, some people may benefit from. We also have state specific resources for all 50 states plus the District and we also, anything in our news or blog feed that is specific to a state will show up on state page as well. In terms of our resources and links, we do have a separate page for resources and links that are for resources done by other organizations. These, the categories under there are disability specific resources, which are from our partner and friend organizations, this includes things like tool kit from Arc and draft questions on rehab from therapy association, we also have enrollment resources for mental and behavioral health, which includes resources from national council of behavioral health and mental health America. Enrollment resources for populations with special health care needs, this has areas that go beyond just disability, but resources for organizations such as American Heart Association and the national health council and then the next two categories, ACA marketplace and Medicare, ACA marketplace and Medicaid, resources from CNC as well as organizations specific to those programs like national council on aging and senior citizen law center for Medicare, state health policy has it relates to Medicaid. The overview categories is our largest category, one resource we always like to point out the very top of that category is resource guide that was put out by Georgetown University center on health insurance reforms, it is another project that was funded by the Robert Johnson foundation, which is where we received our funding, it deals with a lot of technical issues anyone doing enrollment will find helpful in terms of some of the technical things that go into enrollment and working through the health care.gov system. Enrollment statistics is a category that includes statistics put out by government and other organizations relates to how enrollment is going, finally the last two categories, ACA resources for government and other enrollment resources includes basic resources from governmental entities as well as other organizations that have been assisting and encouraging enrollment. As I mentioned earlier, one of the resources we are most excited about is the disability guide, it was released in January of 2014 and was rereleased again last year with some edited, it provides information to navigators and other enrollment specialists about special consideration with people with disabilities, they face as they shop health care coverage. Once again, since it is on there the cover of the guide, I would like to point out and thank the Robert Johnson foundation, who was the organization that was critical and important in providing the funding for the project and is the reason we are able to bring all these great resources to you. Also, one of our partner organizations, disability rights education defense fund is the one that authored this guide and we're very thankful to them for their help and assistance in drafting this particular guide as well. In terms of what you'll find in the guide, in is the table of contents and I'm not going to take the time to go ahead and read all the categories and what's included there, but there are as you can see a lot of different things that deal with areas that sort of provide a 101 for people that are doing enrollment work around disability and some of the things that come up in terms of who makes up the population and what barriers they face and also some basic issues when it comes to Medicaid eligibility. In terms of the specific sections, it is a special interest lots of times is what do navigators need to know about disability and this includes these questions that you can see on this slide such as some of the things that deals with how is disability defined, why is understanding disability important, what is disability literacy and et cetera quit, how can navigators ensure effective communication. So you can

see it deals with a lot of various areas that navigators need to know when they are assisting individuals with disabilities. In our first two years of putting out resources we also put out 17 topical fact sheets, you can see on the screen the first fine of those, first three really deal with getting answers to what is included in various plans. If you are trying to figure out exactly what's covered and want to know where to go to get them answered those are the three fact sheets you want to look through. If you want to deal with specific issues, whether like rehab or rehabilitation or prescription meds or mental health and substance abuse, any of those issues are dealt with some of these other fact sheets, as well as the Medicaid issues that come up, medically frail status and also the marketplace application process, going on to some of the other fact sheets you can see that we also have process for Medicaid eligibility and how that's determined. Also with Medicaid we have information for people on HDAA waiting list and Medicaid buy-in, those are the various fact sheets we have that we have put out on the project and is something I would encourage you to go ahead and check out they deal with specific information. We also starting last year decided to come up, came up with an idea to specifically just disseminate population specific fact sheets. So in other words, what to know when you are assisting a consumer with and then a specific disability area. So for instance you can see we already dealt with autism spectrum disorder, children with special health care needs, intellectual disability, mental illness, multiple sclerosis and veterans, once again thanks to United Spinal and vet first program, they are the ones that helped us right that particular fact sheet. Then two news ones we put out this year, one on blood disorders, blood clots, another one on traumatic brain injury, we are still hoping to put out more this year on cerebral palsy and spine by that we are working with organizations to help us write those fact sheets as well. I mentioned earlier our community outreach collaboratives, we realized in year one of this project there has been a general shift towards outreach and not as much focus on technical enrollment piece. We recognize people with disabilities many times don't, distrust so-called experts they don't perceive as having expertise with disability or even their specific disability. So in year two we came up with an idea to fund 11 community outreach collaboratives, which we have expanded to 18 locations in year three.

And these are located in 17 states, you can see on this map. The COCs have two primary tasks first to build collaborative with other disability organizations in their area and also we want them to have cross-disability collaboration and work as a dissemination outreach resource with local or state navigators and their sisters. We are proud COCs represent organizations with geographic, different disability community and we also, as I said, we got 18 COCs in 17 different states and included in this is also at least one COC at each of the ten HHSS Regions. In terms of where these COCs are located these are the ones we funded in year two and I would encourage, you if you live in any of these states to make sure you check out these organizations, if you are looking for assistance with enrollment and are looking for someone to help point you in the right direction as to who can help you do the enrollment. I would encourage you to go ahead and check these out, the contact information can be found on the website and specifically you can go to the state pages as well to get the information, if you want to access it that way. As I said, we funded seven more organizations in year three, and these are the ones that we covered for this year and they, like I said, so it is more, some new states that we decided to try and do additional outreach for, specifically looking to try to hit some of the states that didn't have enrollment as high as others such as Florida, Texas and Louisiana, also we decided to add Montana this past year, because they are a newly, a new state to Medicaid expansion, so we wanted to make sure we had a presence there as well.

And you can see the link at the bottom there, if you want to get the information specifically about where those locations are and contact information, that's the link to get to that specific page. I always say that when people are enrolling in insurance it is like playing a game of jeopardy.

And specifically health insurance jeopardy. So those of you who aren't familiar with the game show, in the game show Jeopardy, if you are familiar, you know it is not about the correct answer, instead it is about making sure that you are asking the right question. Specifically, when they are making their enrollment decisions, making sure they are going to cover the areas they need. This is a round called double jeopardy, if you watched last year's presentation I went through the first round of that when we dealt with a lot of topical fact sheets we addressed in year one. But this time we're going to go based on some of the population specific fact sheets that we dealt with for year two, to come up with some basic things about what you need to be thinking about, helping with various areas and special needs that they have as they are going through their decisions in terms of making the right choice. I will point out that if you missed last year's presentation I will be talking at the very end of the jeopardy part of this presentation, about where you can get those specific information, we have those videos up on YouTube and I can provide the access, the link to that, so you can access those and get that information. So let's go ahead and play our game and take intellectual disabilities for $4000, autism spectrum disorder, cerebral palsy, attention deficit, hyperactivity disorder and seizures and mental illness. What are the question, what are some common co-occurring conditions for people with intellectual disabilities. Moving on depression, anxiety, obesity and diabetes and these are some common secondary conditions people with intellectual disabilities encounter. So you can already see many times with these disabilities, you'll see on all these disabilities, that many times it is not just that disability, but there is something else going on as well that you need to be thinking about. The next one, more than 80% of US medical school students report receiving no clinical training regarding people with disabilities and instance, who are the physicians they see and are they in the network of providers. So really when you think about it, these are providers that really don't have the background with this particular population. The reason that is important is because many times these patients, when they get into to see a doctor and they develop a comfort level with the doctor about their situation and their condition, especially people that have, you know, intellectual disabilities, they are going to be wanting to stay with those doctors as a result because many of the other doctors they would end up going to see might not have any sort of experience with their particular population. As a result of that, it is something that we need to make sure if you are enrolling someone you want to make sure their doctor they see that they like is in the network of providers.

Moving on, physical, occupational, behavioral and speech.

And these are some common therapies used for people with intellectual disabilities.

And finally on this category, therapies that help with basic social skills, fine motor skills to help dress themselves, how to administer his or her own medication safely and how to use the phone.

And these are examples of what are examples of habilitation therapies for people with intellectual disabilities. It is important to remember people with intellectual disabilities do have many times additional health needs more so than other people.

And in fact people with a disability in general, not just intellectual disabilities, but people with disabilities in general are over twice as likely not to see a doctor due to cost, more than 30% more likely

to be obese, 60% more likely to smoke and over two and a half times more likely to develop diabetes. So you can see they are going to usually have additional health care needs that are going to go beyond just those particular issues that come up with their disability. Moving on to mental illness, psychiatrist, psychologist, psychiatric or mental health nurse practitioner, mental health nurse, social worker, licensed professional counsellor and peer specialist. What is this list? These are who are the type of providers that individuals with mental illness see. So you can see there is a wide array of practitioners they are going to want to see, making sure they are all, the ones they do see are in the network is going to be critical. Antidepressants, antianxiety medications, mood stabilizers, antipsychotic medications and stimulant medications, what are common drugs prescribed for people with mental illness is the question you really need to be thinking about, what is the ones this particular person that you are helping is going to want or need. So they are going to be making, you want to make sure those drugs are in the form they are looking for and also the cost is going to affect, because many times when it comes to prescription drugs the cost becomes very much an issue in making sure in terms of how the drugs are tiered that if they are paying a higher cost for something that might be on a specialty tier that that's going to come into play and when you are looking at the overall cost of a plan, you can't just look at the premium, you got to look at the deductibles and co-pays to really figure out what the bottom line for this person is going to be, in making sure maybe paying for a little more of a premium might be a good idea in their case because in the long-run it is going to save them money. Cognitive behavioral therapy, dialectic a, l behavior therapy, cognitive enhancement therapy, psyche dynamic therapy, individual psychotherapy, group therapy an family therapy, this of course some common therapies utilized by peal with mental illness. Finding out what is covered in terms of mental health coverage and what levels, under law mental health is supposed to be done on par with other conditions so if certain therapies have limitations on visits they can put the same limitations on mental health therapies, but if they don't have limitations on other types of therapies they are not allowed to put limits on membrane potential health therapies. So it is one things you got to make sure, if that's not the case, just because it is the law does not, excuse me, all plans comply with that. If that's the case you need to make sure that that's brought, that awareness is brought to the person that's looking at it and also making sure it gets reported because technically that plan is in violation. Substance use disorders, heart disease, hypertension and diabetes. Once again, looking at common co-occurring conditions for people with mental illness. So this is just another area, another disability that has many times other things that are going on with the individual that they need treatment for.

And lack of network adequacy, limited provider networks, lack of patient in coverage, high out-of-pocket costs, wait times to see providers, what are common issues with mental health treatment and qualified health plans. I always like to say, in terms of the ACA, we have come a long ways, things are much improved than they had been before the ACA, but there are still issues, especially with mental heat treatment some of these issues are exacerbated even more. Making sure the network the person is looking at, they are considering is going to be able to have a network of providers that will be able to meet their needs is important and then also making sure that they are looking at the overall cost of the plan. Let's move on now to multiple sclerosis, this is the type of specialist or doctor that diagnosis and treats individuals with MS.

And that is what is a neurologist. Now many people with MS wills just treat with regular family physician, but neurologist is generally the one they will see initially in terms of making a diagnosis and reading the tests that need to be done. That brings us to our next issue, these are the tests used to help

diagnose MS and are an important component of monitoring disease progression. This is what are periodic Magnetic Resonance imaging or commonly known of course as MRIs.

And they are many times not done always on-going. But it is something that is usually used to sort of track how the condition is progressing and if it is something that is, that the symptoms are getting worst, it is going to be something that's what is going to be done, so you are going to want to make sure when someone like this is enrolling in health insurance with MS, that they are looking at plans that are going to cover these tests and are also going to make sure that the specific, the co-pays and everything associated with it aren't going to be too burdensome. Moving on, current, as of, excuse me, currently this is the number of drugs approved by the US Food & Drug Administration, which are available to reduce current disease activity and disease progression for many people with relapsing forms of MS. In this instance question is what is 13. That brings us to the next issue, of those 13 drugs, the number of MS disease modifying therapies which are considered specialty pharmaceuticals, I talked earlier about drug tiering, most people are familiar with drug tiers though know with most insurance plans there is a co-pay you pay for generic drugs and one for name brands. There is also one beyond that for specialty farm substitute pharmaceuticals, even higher. How many of these drugs are considered specialty pharmaceuticals, answer is what is all of them. It is something you need to make sure what is the overall cost for this individual is going to be, on specialty tiers usually going to be paying a much higher co-pay for them and as a result you got to take that in and factor that in to the overall cost of the plan, paying a little more than a premium may save a lot more money in out-of-pocket costs. Bladder problems, infections, bowel dysfunction, depression, dizziness and vertigo, emotional changes, fatigue, itching, pain sexual dysfunction, spasticity, tremors and walking difficulties, what are common symptoms that patients with MS seek treatment for, certainly not all inclusive, but just goes to show MS is going to look different for just about everyone that has it and just because you know one person with MS, the symptoms they deal with, it could be very different for someone else with the same condition and how it manifests itself might be very different. So some people might have some of these problems but not all of them, some of them might have very few of these issues and some of them might have a lot more of these issues. So it is one of those things you have to look on an individual basis and figure out what this individual is going to need the treatment for. Let's move on to next category of paralysis. Stroke, multiple sclerosis, spinal cord injury, traumatic brain injury, cerebral palsy and spina bifida, what are some common causes of paralysis, obviously paralysis can be caused by multitude of different situations, this is just a list of some of the things that can potentially cause paralysis and what is the type, this is the type of doctor who specializes in physical medicine and rehabilitation, which is a doctor that someone with paralysis is going to see quite often to maintain physical capability they do have, the answer is what is a Physiatrist. Different in therapies someone born with paralysis versus someone who is paralyzed later in life, we talked a moment ago about the various things that can cause paralysis, obviously some of those are going to be situations that a person is born with and some of those, like spinal cord injury is going to be something that happens later in life, so what's the difference? In terms of medical treatment it is the difference between something being habilitation and rehabilitation, it is in the prefix of re, where re is getting something back or doing something over so in rehabilitation it is gaining a, a function that you had before and trying to regain that function, whereas habilitation is trying to learn some sort of function or activity that you were never able to do before. So it is dealt with many times differently in health plans where they pay for a rehabilitation much easier and on a much um scale that's going to be much more beneficial to rehab than to habilitation and understanding exactly the importance of habilitation therapy and making sure that's covered in a plan for someone who is going to

need it is very important just because it is the same type of therapy, if rehab versus habilitation, it is going to be usually many times dealt with differently by the plans. Moving on to our next one, in addition to rehab and habilitation therapies, these are other critical health care services, a person with paralysis needs to have access to.

And this is what are durable medical equipment and disposable medical supplies. There is a category, Essential Health Benefits required to be covered in every qualified health plan. The phrase of medical devices, medical devices has not been defined by the federal government. So it has been left up to the states and individual plans to figure out exactly what medical devices means. So durable medical equipment and disposable medical supplies, we might think they are all part of medical devices, some define them differently, may include some not the others, you need to understand exactly what is covered in terms of medical devices and making sure you understand what gets covered in terms of the specific needs of the individual that you are helping.

And then finally infections, bladder and bowel management, chronic pain, respiratory health and depression. This is what are some common secondary conditions for people with paralysis. Once again someone with a disability also going to have co-occurring conditions, something else they are going to need a treatment for, it is going to go beyond just the paralysis itself, so they need to make sure they are getting other treatment for all the various health conditions that they have. Let's move on to the veterans category and these are veterans whose health care meets the minimum essential coverage requirements under the ACA. This is what is any veteran enrolled in the VA's health care system under ACA, they have to pay the tax penalty, any veteran enrolled in the VA health system has a plan that meets essential minimum health care coverage required under the Act. They wouldn't have to worry about paying the penalty. The minimum activity duty requirement for veterans who enlisted after September 7, 1980, this is what is 24 continuous months or the full period for which a veteran was called to active duty. So that's what would be required for them to then be minimum required for them to be able to enroll in the coverage for, through the VA. The number of priority groups used to determine who gets access to VA health care services, and this is what is 8. So for example veterans who have a VA as rated at least 50% service connected disability, so a veteran with a disability or disabilities related to military service are placed in priority group one. Veterans who receive VA pension services, war time veterans 65 and older or low income, or under 65 permanently disabled are enrolled in group number 5. All these different groups have different, the different priority groups then determines exactly what benefits they can access through the VA health care services.

And understanding those is important then to make sure the veteran has the coverage that he or she is going to need. This is the service rating for service connected disabilities where the veteran pays no co-pays for any care regardless of whether related to a service-connected disability or not.

And this is what is a veteran who is rated by the VA at 50% or greater for their service-connected disability. If service-connected disability is 50% or greater then all of their, they don't have to pay any co-pays for any of the care regardless of whether it is related to the disabilities causing the 50% or not. It doesn't the matter, ultimately they will not have to pay any of the co-pays.

And these are family members of a veteran who are eligible for VA health care, who are depends of a veteran who has been rated permanently and totally disabled for a service-connected disability by VA or not included on this but also someone who is killed and their dependents would be covered as well. Let's talk generally a little more about accessibility and what needs to happen in terms of when you are

meeting with someone and what is needed. We will look at through the prism of the disabilities that we just talked about. This is one thing you need to think about when assisting a consumer with paralysis, this is usually easiest one, one people think automatically when assessing people with disability, what is building accessibility, it goes beyond making sure you have curb cuts outside, the door is something a wheelchair can get into, there is an elevator if needed, goes to the issue of how the office is set up, wheelchair can get around without much difficulty and looking at all those, it goes beyond just the external getting into the building, it is once you get into the building you move around successfully in it as well. This is the one thing you need to think about when assisting a consumer with multiple sclerosis with low vision. We said earlier multiple sclerosis can have many different issues and man tests itself in many different ways, one is low vision. If you have someone meeting with that has low vision, what is having materials available in alternative formats like large print or someone that is blind you would want something that potentially is in braille as well that maybe that person could access. Moving on, this is the one thing you need to think about when assisting a consumer with intellectual disabilities, what is asking questions that verify the person understands the information. Unfortunately many times people with intellectual disabilities are going to look at an issue and might not understand things, but they feel like they should because you told them and they are afraid to ask questions.

And if you ask them a simple question like do you understand what I said, they are going to feel pressured to say yes. So many times the better way to handle that is asking the question in a more active way and making sure that they are able to explain it and saying, you know, can you explain what exactly, can you tell me what you understand that I just said? So asking the person a question basically says, you know, can you explain to me, you know, what your understanding is of what I've told you about this health plan or whatever it is you are talking. Asking the question to make them engage and explain it back so if you have to take some extra time with the individual that will be necessary. So making sure then that ultimately if the person is struggling with getting it, taking the extra time to really explain it to the individual is something that you are probably going to want to do when you are scheduling your meetings with someone like that. This is the one thing you need to think about when assisting a consumer with mental illness and this is what is educating yourself about mental health conditions. There is so much misinformation, stigma around mental health that many times people will not necessarily understand everything that's involved and many of the things that are required in terms of their health care treatment, so educating yourself about some of those issues is going to go a long way to helping those individuals and being able to make sure they are making the correct decisions about their health care plans.

And finally while we didn't deal with this specifically as an issue on terms of a population group, this is one thing you need to think about when assisting a consumer who is deaf or hard of hearing, you need to ask what is the individual's preferred method of communication.

So making sure that if the person wants to read lips that you are going ahead and doing that, if they want to write notes back and forth that's fine, if they ask for American Sign Language interpreter, make sure that you have something, someone available that you know of, if you can find that out ahead of time and maybe have someone ready that you know that you can call in an instance where you are going to need someone like that, that can be very helpful. Of course after final jeopardy always comes final jeopardy, we want to talk briefly about disability etiquette. This is the one word that sums up best quality you can have when dealing with anyone with a disability, this is what is respect. Just have respect for the individual you are dealing with and making sure you are treating them as you would treat

anyone else that you are talking to that individual and not to someone that came with them unless the person asks you to and trying to meet their needs in a way that is best for them and allowing them to explain to you the best way to communicate with them and best way to explain things to them so they can get the information they need to be able to make the best decisions. As I mentioned earlier, the, put the health insurance jeopardy round 1 up on YouTube. You can see the link to the channel for our YouTube channel is on this particular slide and you can access that and watch all six videos. The six videos that we have done are on prescription drugs, medical devices, rehabilitation, habilitation, Medicaid eligibility, summary of benefits and coverage and mental health issues. So they are in six different videos all they range in time for from about three minutes up to I think six minutes in time so you can watch them in short increments if you want and/or there is a play list that you can watch them all straight through if you want to do that as well. So I encourage you to check that out, if you missed last year's presentation and I want to be able to find out more about getting some of the answers to the questions that these population groups may have. In terms of advocacy, one of the things we like to talk about is some of the ongoing challenges that we see within the population. So limited provider networks are one of the things we see, limited formularies is another problem, then of course discriminatory pharmacy design, talked about muscle sclerosis, if that is a discriminatory pharmacy design and that really, that respect is becomes very problematic for those people. You know plan transparency is something we are always trying to advocate for, getting answers from questions, what prescriptions are covered, if they are in a higher tier, some issues have gotten a lot better with some of the things required for plans on the federal exchange, but still getting some of those answers can be much more difficult than it really needs to be.

And there is also, in terms of the plan transparency, sometimes this leads to another problem which is high out-of-pocket costs and if it is not clear how much the out-of-pocket costs is going to be, then the person finds out after they utilize health care coverage that can become really problematic. Also an issue of confusion on the definition of rehabilitation, habilitation services and supports, like I mentioned. Also seen a confusion on the coverage of prosthetic devices and durable medical equipment. As I told you about the problem that we have seen with the medical devices essential health benefit requirement and that not being in fine term. There is also confusion about coordinating exchange coverage between Medicare and Medicaid, for instance those people that are deemed to be eligible for SSDI, they have a two year waiting period before Medicare and what do you do with those individuals while in two year waiting period, what some of them, income is low, but others if they have family members that work and are disqualified they may then need some sort of other coverage and that was something that we, that you should look into in terms of making sure they have, maybe they might be a I believe to get exchange coverage to cover them until the Medicare is available. We also seen delays in getting plan information once people are enrolled and obviously for continuity of care issue that can be really problematic, person enrolls and doesn't get insurance information until much later and finding out exactly how they are covered and whether they are covered and how to utilize that coverage becomes very problematic, especially if they need it in the first month or two of enrollment. Then finally communication issues for deaf and hard of hearing, one of the most common questions we get from navigators and one of those things we are always constantly explaining to them, that they really need to make sure they are looking at, that navigators are making sure that they are having every way available to them that they can communicate with an individual so that they can meet that person's communication needs as they would prefer. If you want to stay involved with our project here are some links you can check out, obviously main link for the website, we also have a newsletter that comes out

every Friday, those are archived so you can see those, my organization also has a newsletter so if you want to receive that there is a link there for you to sign up for that newsletter and finally the resource center with a lot of different things on disability and public health you can check that out as well. With that I'll entertain any questions that you may have.

>> Thank you Karl. Reminding the audience to submit any remaining questions you have and we will try to get through them live here today. So who should people contact for states without a COC, is there a national help line for that? Person is actually indicating their location as Florida, for instance.

>>Karl: Okay in Florida we actually do have a COC now, in north Florida, in Jacksonville, multiple sclerosis branch office there in Jacksonville. You can check that out but for someone who is not in a state with a COC, really you can contact our office if there are specific issues that come occupy. My contact informing is there and you can feel free and go ahead and reach out to me. If there is local help and people we can direct you to we will be happy to do that and hopefully find a resource closer to you in case you want to actually find some local help.

>> Thank you. Karl, so what actually is the service connected status, you had mentioned if someone is service connected then they necessarily, if I read you right, then they necessarily have full appropriate coverage, but what is service connected versus non-service connected?

>>Karl: Yeah it has to do with what was the cause of their disability. If their disability was connected in some way to their service in the military. So if they were injured, you know, while they were, you know, abroad, that would be a service connected disability and that would then qualify them for certain levels of care under the priority groups.

>> Okay, thank you.

And reminding the audience that you can contact us at our vets first department for any questions about individual cases of whether or not the VA is considering certain individual to be service connected, we address that routinely, thank you Karl. Another question

>>Karl: I was going to say I should point out vets first was very helpful in helping us write vet fact sheet, they are the ones that helped us put the particular scenarios, they double-checked me I don't claim to be an expert on veteran areas, they were helpful to me in putting that part of the presentation together.

>> It is a MRI

>>Karl: Complicated area, thanks for mentioning that.

>> Another question, is it straight forward to determine whether or not a plan covers ones monthly medical supplies or whatever as in like a wheelchair or appropriate wheelchair. Is it straight forward to determine prior to signing up for a particular plan, whether or not what you need in your case is going to be covered?

>> Um easiest way for me to answer that is no. Let me explain a little bit about my own situation. I use a wheelchair myself and so when I was looking at plans on the Maryland exchange I went to try to see if I could find out what was covered in terms of durable medical equipment, I still had a hard time getting the answers to those questions. So it is one of those things that many times, I think a lot of individuals really struggle with, they don't even know what questions to ask, that's why I always sort of underline

that issue, it is so important you are making sure you ask the right questions, once you know what to ask the second problem is in getting the answers. I will say this CNC did put something in a requirement that has made it a lot easier to get some of those answers. Into this year's open enrollment, just changed for this year and that is that if you look at the plans summary of benefits and coverage, if you are looking at a plan on health care.gov, you can click to see a copy of the benefits and coverage. At the top of summary of benefits and coverage there is supposed to be, you know, by law now under regulation, there is supposed to be a link to the plan website that gives us any specific information about the plan, essentially will give you the plan documents. So the summary of benefit and is usually a couple of pages, doesn't have all the information you are going to need. It is one of those, if you need to get some of those answers that are more complex, such as durable medical equipment, you are going to really need to look at those plan documents. Now once again I will say this, so I just of tested it out again this year when I found out they made that change and I went on a couple different states website and checked and a couple different plans and trying to see if I can get the information. I will say the good you ins is I was able to find the information every single time that I wanted to. As it related to, I was looking specifically for two things, durable medical equipment and rehabilitation and habilitation therapies just to see if I could find information on those two things. I was able to get the answer every single time. The bad news is, I am someone that's obviously, I'm an attorney by education, so I have a higher degree agreement of education and it still took me many times, you know, 45 minutes to an hour reading through plan documentation to find the answer. So that's something that becomes a little more, get a little more sophisticated that some consumers might have difficulty with and they are going to need to maybe seek out assistance because that will be something they are going to want to have, someone maybe help them go through those plan documents to figure out exactly what is covered.

>> Thank you, I appreciate the detail on that. I too have that same situation, but I don't digress into my story just right now because we have a couple other questions. Could you please elaborate on what medically frail status and discriminatory pharmacy designs are.

>>Karl: Okay yeah those are two separate things. Medically frail status is a new thing that came up with the Affordable Care Act. What that basically what that does is it gave states the flexibility to determine their Medicaid eligibility in every state and there is what is called an alternative benefit plan that a state can develop. So if a state has traditional Medicaid plan they have, they had before the ACA, then they also were allowed to develop this alternative benefit plan that's available as well and some of us in medically frail status become eligible for that plan or can go traditional Medicaid group. So really have an option to go with either one and medically frail can be, is defined by the state, so there is not a federal definition for that. So really it was a way for the government to give some states a little more flexibility in how they were designing their Medicaid expansion and how they were going to be able to do that in a way that was going to be meet population specific needs. So that's sort of what that medically frail designation is. In terms of discriminatory pharmacy design, something completely different, discriminatory pharmacy design is really where a health insurance company sets up their health plan in a way that is discriminatory in how it pays for drugs. So for instance the one example I used during my presentation was multiple sclerosis, which is a perfect example because there is 13 drugs that have been approved to treat multiple sclerosis and all of those drugs are on specialty tiers, so that really is discriminatory in the way it is set up. Because the law says under the Affordable Care Act the law says they are not allowed to charge people based on their health conditions. So but if it they set up the plan in a way that essentially discriminates against one group of people by saying all of your

drugs have to be on this higher tier, then really that's discriminatory in the way it is set up. Another population we have seen this with pharmacy design as well is in HIV w a lot of specialty drugs HIV AIDS people use, so it is one of those, it is another area where the pharmacy designs many times are discriminatory because doesn't have anything on the lower tiers because the prescription drugs are set up in tiers, most people like I said understand the generic versus name brand drugs, but then there is usually a third or maybe even a fourth tier in terms of what the co-pays are. So those people if they have specialty drugs are usually paying co-pays much, much higher than what the average person is paying, for that reason it is discriminatory. Because they have no other options is really what it boils down to, if they put everything on specialty tier they have no other options.

>> I understand, thank you, thank you for the detailed explanation. The next question is, what has been your experience and I'll insert my additional blur about here, with your command of the data, command of the information along with being a consumer, this is pretty good question for you. Hope it doesn't feel like it is loaded. What has been your experience with states that have moved to Medicaid managed care?

>>Karl: Um, Medicaid managed care is, you know, it is one of those things that it is obviously going to vary so much from state to state.

And in terms of the most of the Medicaid managed care that exists is being done now for people that were already sort of qualified for Medicaid. So it was, it is not really necessary doing Medicaid exceptions population, that's going to be the next thing that's really probably, coming next is they are going to want to use Medicaid managed care for some of these folks, some of the states already, I don't know that there's, I have not heard specifically if there is a difference in terms of how these people have met the health care market and whether or not it has impacted them and their ability to access the care that they need. That is something that we will and we have done it before when Medicaid managed care was coming to long-term services and sports when we monitored that before as an organizational, the only thing I can say is haven't seen any specific reports that have dealt with it, if anything does come out we would probably report on our website so you can check back regularly on news feed, we would probably put it on there to let people know what we found on that. Right now I can't say I have heard anything one way or another, good or bad, in terms of how that is working.

>> Okay, thank you for that. Reverting back to the prior question, do you see those tiers, I think we are talking about the pharmacy tiers, with patients with systemic Lupus, for example. Something you can address specifically?

>> Um, I don't know specifically in terms of how it is dealt with on every single, you know, condition and every single disease, but I do know, I have heard specifically we're involved with national health council which is a national organization made up of beyond just disability but it goes to disease organizations and stuff like that and my understanding from my meetings at the national health council, I think Lupus is dealt with in many of the same ways, I don't know if same degree that all of them on specialty tiers but I do think disport gnat amount on specialty tiers for Lupus.

>> Okay, thank you. Then another revert back to an earlier issue. What is the COC again?

>>Karl: COC first of all stands for community outreach collaborative and it is we set up that exists in, there is 18 locations and 17 different states and like I said you can go, if you go to the home page you

will see where you can get the information on the COCs and if you are in a state with a COC, if you go to the state page on our website it will appear there as well for the contact information. Really what we expect the COCs to do is act as a bridge between disability organizations and navigators. It is a two-way thing, we want them to first of all make referrals if they have a constituent looking for assistance with enrollment we want the COC to be able to point them to a navigator that's local to them. But we also want it to go the other way so if a COC has a specific question about a disability the COC can direct them to a local disability organization or maybe sometimes there is referrals back for other issues, for instance, you know, one thing that navigators obviously aren't going to deal with when talking about health care access is transportation to get there. Maybe the COC, maybe they make a referral back to the COC, the COC can find that person a help with a disability organization so they can get the transportation they need so they can go to the doctor.

>> Thank you. We have covered a lot of material today. I want to remind the audience that all of this material, the entire presentation will be archived within about a week at www.spinalcord.org, on behalf of the United Spinal Association, I'd like to thank Mr. Karl Cooper, of AAHD so much for sharing personal experience and professional knowledge with us today on the topic of understanding the health care coverage needs of people with disabilities. Our next Webinar will be nutrition and exercise tips for wheelchair users on Wednesday, January 22nd from 3 to 4 pm eastern. To sign up and receive our Webinar newsletter visit us at with.spinalcord.org, thank you Karl Cooper for your presentation today, we really appreciate the detailed approach.

>>Karl: Thank you very much for having me.

>> Check out our new mobility magazine which covers everything visit newmobile.com to see what we are all about. This will conclude our presentation today and many thanks for your attention. Thank you.