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>>CART PROVIDER: On standby.

>> Good afternoon, thank you for joining us today for United Spinal presentation, pathways to employment. My name is Bill and I will be your moderator for today's presentation, a continuing group of Webinars United Spinal Association hosts. Our Webinar presentations are archived at [www.spinalcord.org](http://www.spinalcord.org). We'll have time at the end of today's presentation for questions. Please use the questions window on your control panel to write in any questions that you might have and we'll do our best to get to them today. For any questions that remain unanswered, please pose those questions directly to contact e-mail is displayed on the last slide.

>> Thanks Jimmy.

>> Today's presenters is Miss Barbara Kornblau and Dennis Heaphy. Barbara --

>> Please do not make any noise and stay low, I am on camera doing a presentation online.

>> Dennis, we can hear you, you have to mute.

>> Barbara Kornblau, is a consultant to United Spinal Association's pathways to employment program and an attorney and professor of therapy at Florida A and M University and she has written books chapters and journal articles on American With Disabilities Act, the Rehab Act and return to work issues. Dennis Heaphy, master's in divinity, master's in education and master's in public health, is a health care advocate for Disability Policy Consortium of Massachusetts. Dennis is Co-Chair of Disability Advocates Advancing our health care rights. That's coalition of disability and other health care advocates working on the dual eligible initiative and broader health care reform. He serves as Chair of the Massachusetts One Care implementation counsel. Please note the instructions for use of closed captioning for this

Webinar, appear in the chat window in case you need to use that service. Now I'd like to hand it off to Barbara and Dennis for our presentation. Barbara?

>>Barbara: Thank you Bill. Welcome everybody. Today we're doing a first in our series of Webinars for the pathway to employment program. Pathways to employment is a program of the United Spinal Association that's funded by the Neilson Foundation and we're asked to work with Neilson on a program to see how we could increase the number of people with spinal cord injuries who were working. So this program works with mentors, we have several aspects of the program. One is we match people up with mentors who are working or recently retired and we also are working with employers who want to hire people with disabilities. So we are forming partnerships. So the idea is if you live in the state of New York, New Jersey or Pennsylvania, because that's where we started the program, that we can match you up with a mentor who can help guide you through the pathways through employment. Mentors go through training where they learn about all kinds of things, some of which we are going to be talking about during the series. So if you are interested in this program, at the end of this Webinar you'll see my e-mail address. Please feel free to contact me. This is a pilot program, I apologize right now, it is only in New York, New Jersey and Pennsylvania, but hopefully maybe in the future we will be in other places, but we are sharing the information with everyone because we want everyone to benefit from this program. So this, these series of Webinars we will be looking at return to work or entering the workforce for the first time for people with spinal cord injuries. So we're going to be looking at various laws, benefits and programs that promote return to work and there are a lot of programs, many of you have heard of things like ticket to work, all heard of the American With Disabilities Act, pieces to the Rehabilitation Act that provide a lot of benefits for return to work. So we're going to be going over those in the Webinar series. We're also going to be looking ahead, how to overcome barriers that people with spinal cord injuries may face on their pathway to employment. How to find job leads, how to do job severance, what do you do in the job interview. Someone asks you a stupid question like oh did you break your leg, why are you using a wheelchair? How do you deal with some of those kinds of issues and what are job options in returning to work or entering the workforce for the first time with a spinal cord injury. So this is sort of an overview of the Webinar series and today we're going to be looking at, today we're going to be looking at some issues with why people work and to get an idea of who is in the group we wanted to have you answer this polling question and you'll see it on the screen. What is the highest level of education you have received and your answer choices are High School, training in a trade or apprenticeship, some college or college degree or above. So if you could click on your answers and we'll wait a minute while you do that. And then when you're done, I can't see this part, there we go. Oh I do have answers. So 98% of you have a college degree or above and 2% have some college. So we got a fairly educated group here today. Okay. Dennis?

>>Dennis: I'm here.

>>Barbara: Okay, do you want it 0 comment on that at all or --

>>Dennis: It looks like a large part of the folks that are here really have great opportunities to add to the workforce, which is very exciting. And so I think I'll gear my comments towards folks with some college or college degrees given that's the audience.

>>Barbara: Great.

>>Dennis: Already ahead of the game with college degree or some college compared to other folks out seeking jobs who don't have a college degree or who don't have a High School diploma.

>>Barbara: Great, thank you. So the pathways to employment program, which we call PTE, works on, with some basic assumptions and the first is that we assume that work plays an important role in people's lives. That people with spinal cord injuries want to work, they can work and, oops sorry, pardon my screen it is cut of 0, and they do work. So we all know people with spinal cord injuries who work. And we know that when a spinal cord injury happens it disrupts a person's worker role. And that causes problems, we have a lot of roles in our lives which we will talk about. There are a lot of things to help support, one that is successfully employed can also assist others in sharing their experience in offering support on their pathway to employment and how they got to where they got. Now we also know, mentioned the idea of a worker role and we have a lot of roles in our lives. If you think back to, you know, everybody here had some college. So when you were a freshman, if you went out to a bar or somewhere, first thing someone asked you what is your major? Role was a student, role was a certain major, that's how people identify to you. These are some other roles people have in their life, caregiver, taking care of children or family members, doing household chores, cooking, cleaning, things you have to do to maintain your home, being a friend to others, being a family member, participating in relationship. Here is that very valuable one which is worker. You know, in college people ask you what is your major when you are out of college they ask you what do you do? Asking really what kind of work do you do. Mentioned student, is a role, being a volunteer in your child's school or community, being a hobbyist, participating in recreation, I'm sure some of you were involved in various sport activities. being a participant in an organization, whether that's a religious community organization, whatever and a religious participant, being involved in religious and some spirituality. So the worker role is a very important role in people's lives and it is dependent on several things. It is dependent on your capabilities, your habits and he have day routines, your interests and your motivations. And following a spinal cord injury people need to explore what are my capabilities and habits, my routines, my every day interest and my motivation to work. How has my life changed and how can I adapt what I did as a worker to my current life or adapt my life to my work, how can I make that match. And if it is not going to work with what I was doing, how can I change that to something that I can do that matches my capabilities, abilities, routines, interests and motivation. So the capacity to work and interest and motivation may increase by learning more about programs that support return to work. In learning more about the successful experiences of others. When you see that others have been able to do things, it makes it easier for you to be able to do things. We have all had mentors in our lives, whether it has been a big brother, a teacher or someone who we have worked with in the past to kind of let us through the workplace and taught us the ropes. So mentors can play a very valuable role in returning to the worker role in your life. Okay. I want to ask a polling question, another polling question and this is looking at where you are now. What are you, what kinds of things are you participating in outside your home. So what activities are you currently engaged in outside of the house and that could range from volunteer work, either community, religious organizations, et cetera, disability groups. Part-time employment, if you will-time employment or not engaged in activities outside of my home. So we'll wait a minute and see about your answers to those questions. And we will take another minute or two, we should be getting our answers soon. There we go. I guess we got some double answers because it adds up to more than a hundred, I'm not good at math but I know that 69 and 42 is more than a hundred. Okay so we have 69% are in full-time employment, which is great and a large percentage, when 42% are doing volunteer work, we got 15% during part-time and 6% not engaged in activities

outside of the home. I think what I would like to do at this point is I want to talk a little bit to Dennis and see, let's see, is my screen coming back, last time it came back on its own. There it is, okay. See with Dennis, actually I think I would like to get back, I don't know if I can do that, see the pictures, okay. All right. So Dennis is working, working person, he's gone through a lot of different things with different types of employment and volunteer work and so I just wanted to start with that and maybe Dennis you could tell us a little bit about work, what does work mean to you, why is it important, why can are you working?

>>Dennis: I think, I'm working because right after, I got out of rehab I was sitting in my, sitting in my apartment and I was watching this show Kathy Lee 10 o'clock in the morning I thought oh my God this cannot be the rest of my life. I don't want spend the rest of my life with a PCA or by myself watching mindless TV from 10 in the morning to 11 o'clock at night. I got to do something. So like a lot of folks, I actually went back to school. For me it really is a matter of two things, one is I think there is an obligation to use whatever skills we have and bring them to the community or to the employment force, if we have that ability, and state regulations actually permit us to enter the workforce and/or whatever the situation we are in allows us to do that. And b, it is just, you know, loving work. You need both in your life. So employment, volunteering and being, being providing value to society is something critically important. So for me that's what work does for me it enables me to actually feel as if I'm contributing a member of the community. So that's why I did that. And I don't know if you want me to go into this, but I have done all three of these. I've worked part-time, full-time and done volunteer work. I don't know how much detail you want me to go into right now, Barbara, it is up to you.

>>Barbara: Could you tell us about your pathway to employment. How did you get back too it?

>>Dennis: Sure, sure, what I actually started doing was volunteer work. I just finished graduate school and I was looking for full-time employment because I didn't feel I would be a valued person in society if I was not working full-time, this college education. So like many of us I felt as if my value was based on my ability to be employed full-time so I could make it on my own. But someone mentored me and just said no just try volunteer work first, so I volunteered for a while, did a variety of volunteer things, which gave me a better sense of what my skills were and strengthening my body, my PCA schedule, all those sorts of things and then one of the volunteer opportunities actually turned into a part-time job and for the part-time job I started working full-time. I was working full-time for a while and I felt like as if I had made it, here I am working full-time, this is great. But the balance, working full-time became really too stressful for me, not because I couldn't work full time, but because the stress of having a 9 to 5 schedule and being responsible to at, I'm sorry my dog is just growling at someone. [laughter] Sorry about that, but just it was too much. So I needed to find a balance in my life so that I could actually live a full life and for me living a full life I was not able to do that working full-time. Now, having said that I have a part-time job, which enables me to maintain my Medicaid and Medicare which is extremely important to me. I have a lot of complex needs. But in addition to that I really almost volunteer more than full-time. But I don't have the stress of having to worry about, about everything. And so sorry about that, would you put him in the bathroom? Oh, that's why. Okay. Thanks. Someone put another dog into my apartment, I apologize for that interruption. So that was my pathway and so, and so at some point, at some point in the future I decide to go back to full-time work I will, but now it is on my terms. I don't feel as if I need to prove anything to anyone, it is actually something I'm doing for myself and it enables me to actually have a place. I'm lucky, I don't have a family, so I don't have to worry about supporting a wife, children and things like that. So in that way I don't know, if you have more questions than that?

>>Barbara: Uh-huh, has there been barriers that you face to employment?

>>Dennis: Um I think at first personal barriers. A sense of being the guy in the wheelchair in the work space and what people think of me and just like my leg bag emptied, being able to just access, getting reasonable accommodations, I think there is often times people are embarrassed, they don't know how to ask for reasonable accommodations sometimes we don't know what we need until we are in the work environment. So for me that was a real learning process, reasonable accommodation piece. So beyond that I think just is just, is learning what, learning what worked best for me. I don't know if this answered your question fully or you want me to go further?

>>Barbara: Sure, yeah, that does. I'm wondering if you could talk a little bit more about reasonable accommodations and tell us about some of your experiences in asking for them and going through the process with employers. Maybe what accommodations you have --

>>Dennis: At first I didn't want to ask for any reasonable accommodations I went into my job very anxious, trying to figure out how I was going to do this without embarrassing myself by saying I needed something. It was really challenging. But then I went to work for my old time job, I ended up having somebody from the outside, a friend of mine, set up a desk for me because I didn't want to ask the employer to do that. But now I'm very free, I ask for reasonable accommodations. For instance, if I have meetings and I have meetings a lot of times with state officials, I will say I am only available between 11 am and 4 pm for a face-to-face meeting. If you want to have a telephone meeting before 11 or after 4 I'm happy to do that, but if you want to meet, you know face-to-face it has to be during this time. Also in terms of transportation, reasonable accommodations around access to paying for transportation to certain things. Reasonable accommodations include bringing my PSA, so for my job, my PSA comes with me, drives me somewhere, they get paid the PSA rate from my employer in addition to mileage and if I need my PSA to assist me with some of my activities on the job, my employer does pay the PSA to do some of those things. I have become much more confident in the fact that my value as an employee worth, is worth the accommodations they are making for me. I think there are a lot of folks who are newly disabled, don't have that sense of I deserve this, I need this and I have a right to this. And so for me that was a process. And so I think, I don't think anyone out there, if you are concerned about reasonable accommodations, should be embarrassed or feel as if, you know, it makes you less than other employees, there are folks out there who have families, who may leave work because they got a child home sick, so they are asking for days off because child is sick or spouse or partner or parent is sick. So we need accommodations as well. And so I think the value that we bring to whatever organization we work for is, you know, is worth those accommodations. It is also, this is really pathetic, but it is reality, it also teaches folks. We often happen to be the lessons, living lessons to folks and so by asking for those accommodations we can actually empower other people, particularly folks with non-visual disabilities, folks come over to me and say, you know, I noticed you got this, how can I ask, I'm not really sure what I need.

In that way you are not just helping yourself but you are actually empowering other people who may not have, have the ability or know how to ask -- ask for what they need. How to ask, knowing how to ask is really difficult, it is really difficult. And afraid of retaliation, go ahead.

>>Barbara: No go ahead, finish your thought.

>>Dennis: If you are afraid of retaliation by an employer, you think you will get fired or, I would step back and reach out to your, to your rehab or the mentors or other folks and find out what your alternatives are to working directly with that person who you are afraid of retaliation from. Because I did have one employer where, supervisor where I was afraid to ask for accommodations because I thought that would be deemed Dennis isn't able to carry out his responsibilities. I actually was and I don't think anybody else in the organization would have any problem providing those accommodations, but this person, you know, would have. And so I just think I was much younger and so at that point I didn't ask, I just struggled through. Now I would never do that, I would never do that again, I would go to the person, go higher up and just get what I needed.

>>Barbara: You've mentioned mentors a few times. Can you tell us a little bit about the mentors that you had?

>>Dennis: Sure. The mentors I had for folks who in the beginning were folks, you know help me to accept the fact that it was okay to have a disability and be in the workplace and maybe that sounds as if I was really immature, but it was a struggle for me to, to actually just, just to be, to feel as if I could be accomplished in the workforce. So I had a couple mentors who were really good in saying Dennis, it is fine, like the expectations we have of you are x, y and z, they are realistic. For instance, know a lot of snow here in Massachusetts, while other people are going to work, I was embarrassed because I couldn't get into work. Mentors saying Dennis this is not something you have control over, so helping you get a sense of Dennis you can't control the universe. It was really critically important to me. Other folks just, you know, even saying that making the choice not to maintain that full time employment it is okay, it was important. Because that's the American dream is you are supposed to work full time. That was very helpful to me having someone do that and having peers, other folks with disabilities. I, I'm not someone who expected to spend the rest of my life doing work with folks with disabilities, it was not my dream. But it turned out I was good at it doing health care policy and health care policy with folks with disabilities population. So being around other folks with disabilities, hearing their experiences and understanding from them I think, you know, we mentored each other. And even now I have young people coming up with disabilities who are teaching me about, about what it means to have a disability and work in a very different way, they may have autism or some other disability that didn't exist before. I think sometimes, this is my own, I'll speak to myself, folks with spinal cord injuries sometimes have difficulty self-identifying Asparagine of the larger disability community. I think can be isolating, I think being able to self-identify as part of a larger, part of a larger community has enabled me to be mentored by folks I otherwise would never have met, basically engage with the community. Is that helpful?

>>Barbara: Yeah, it is very interesting to me too because I don't have a spinal cord injury but I do have a disability and I found the same thing, identifying with the larger disability community is very helpful, because there are people who have come before us who know more than we do and there's people coming after us and a lot of people coming ever a us know more than we do about things like social media. There is a lot we can learn from the next generation and when it comes to things like doing a job search, social media has, is now playing a very important role in people's job searches and there are things that, you know, we can always learn about. There's a group, for example, called federal Employees with Disabilities and they are on FaceBook, they have a FaceBook page and will post jobs on their FaceBook page. Who would of thought that being part of the larger disability community and social media that you would find job leads. So it's very interesting to see how things have changed, you

know, from our generation, helping the generation behind us and the generation behind us helping the generation in front of them. So I just thought that was kind of interesting.

>>Dennis: I think, I just, there's someone I work with who is a researcher and we talk about this, that being, going to work and having, wetting my pants is part of the experience and that there are certain things that come with the territory that other folks don't experience. And having someone else to share that with and say, you know, I had to do this, I had to do this whatever, x, y and z and my pants are soaking wet and being able to share that with someone else, not just mentoring, but understanding that all of us have experiences of not being able to get through a door or not being able to reach a switch on a computer like things like that. I think, for instance, that's why this is so critically important is that it is not just happening to you as an individual. There are hundreds of thousands of us out there that are experiencing similar things. And so, and so, you know, so having, having outreach and relationships with other folks with disabilities has been, for me, very enriching and de-isolating. Because I got, my friends are great, who don't have disabilities, but there, they don't know what it is like to actually sit at work and worry about having a bowel accident or worry about again urine bag being full or running late and having a personal care attendant waiting for you at the door at your house and wondering whether or not you will be there in time to meet that person or whether they are going to leave without you. So it is important I think to have other folks to be able to relate to about these things.

>>Barbara: Sharing with a mentor or sharing with a friend is just so critical, someone who can understand what you are going through. I wanted to move on to the next polling question, because we talked a little bit about barriers to employment. And this one looks at, if you are, everyone here is or almost everyone seems to be involved in employment. So I guess maybe we could kind of change this question a little bit to what kinds of barriers, if you could be involved more, how about that, so if you are not employed or not volunteering, you can answer the question the way it is, what's the primary reason you are not. And if you are, what kinds of barriers have you faced or do you see as barriers, seeing more involved outside the home. Transportation, personal care attendant issues, government regulations or can't find a job. And let's see where people are with this. Okay so transportation looks like a big problem. Government regulations, can't find a job, I'm surprised that personal care attendant issues is not higher. What do you think Dennis?

>>Dennis: You know I am surprised about the PCA issues. It may be the, the population of folks who are out there, maybe don't use um PCAs at the level of someone like myself, C4 spinal cord injury do. I can't really read into that. However, transportation does not surprise me. Transportation is such a huge issue.

I'm lucky, I live in Boston, I live in a city, I actually lived in Minnesota and I left Minnesota because they didn't have mass transit. For anyone who does not have access to transportation, it is a major obstacle to work.

>>Barbara: Yeah I was going to say even having access to transportation, I know when I was in Florida I used to leave at night, I was one of the last people to leave my building and the guy in the wheelchair, who is waiting for the paratransit was always still sitting there because just couldn't guarantee they were going to show up when they were supposed to show up.

>>Dennis: Right, there are a lot of cutbacks right now to paratransit systems, where those paratransit systems are, they really are in many ways our only, until I got a vehicle recently, our only access to going

where we need to go. And interesting, this is that this is also one of the major barriers to health care. It is also one of the major barriers to folks just participating in the community. So transportation is something that affects every aspect of a person with a disability is life. So I'm really not surprised about the transportation. What I am surprised about is the government regulations piece, one of the reasons I'm not in full time employment is because of my concern about making, about making money that will cause me to lose PCAs or other benefits or have to, to pay into the Medicaid system in the state to the point where the cost benefit analysis just isn't there. And so I find that really interesting. But maybe people are on here because they are struggling. There are a lot of folks who are employed full-time or struggling because primary insurance is not paying for the durable medical equipment they need or not paying for out-of-pocket expenses they have. I'm wondering if approximate we shouldn't have asked that question as well, what role does private insurance play as a barrier to actually work. For me it is, not cover what I need.

>>Barbara: Yeah it is interesting because there are, we will be talking about this in subsequent Webinars, but, you know, you can keep Medicaid, sorry, keep Medicare for a long time after you go back to work, you can buy-in to it, before Obama care when you weren't guaranteed insurance. You can keep Medicare, still there on the books but Medicare doesn't cover a lot of things that Medicaid does, it is not helpful --

>> In Massachusetts you are required by law, if employer provides insurance to take that insurance, you might have this insurance, even if you buy Medicaid as a wrap around you are not going to get the things you need because the level of coverage you are getting is not adequate, not adequate to your needs. And so, but back to the transportation piece, I do think that, that is a larger topic that um needs to be dealt with and I would be interested, I don't know if there is going to be Q and A on this, to hear what major issues are with, are around transportation. And government regulations. I think it will form a larger conversation that we are trying to have nationally about trying to improve transportation for folks.

>>Barbara: Yeah and well as part of United Spinal pathway to employment program, as I mentioned to you we are trying to, we have this program now in New York, New Jersey and Pennsylvania. We're being funded by the Neilson Foundation to get people back to work and we need to know what those barriers are and how they are affecting people, we can do as much as we can do but then if there are barriers after that then we need to go after those barriers and see what we can do to work with them and work around them and it looks like transportation is the big one. You know, that's an issue where people live and how people get to work is a real problem. Now they can't find a job there, I think there was 222% of can't find a job and we're going to be talking about in some subsequent Webinars on how to do a job search and some tips because there are some programs out there and there are some laws out there that really encourage employers to hire people with disabilities and United Spinal is partnering with several national employers who are looking to hire people with disabilities. I'll give you a little preview of something we're going to be talking about later and that's that under the Rehabilitation Act, if you are a federal contractor, federal government contractor you have to hire 7% of your people as people with disabilities. So if you're looking for a job it is good to go to companies that contract with the federal government. When you think about it, it is a lot of companies. So for example we have a relationship with CVS and there are CVS's all over the place, they contract to provide medications through government insurance, so they get federal contracts they have to hire people with disabilities. So in your job search might want to consider, gee who is a government contractor. That can give you a



little bit of a help and then self-disclosing and letting the potential employer know that you have a disability um in that situation can be an advantage, because they are looking to, actually looking to hire you and to recruit people who have disabilities. Dennis, what -- go ahead.

>>Dennis: I think for a lot of folks, this is something for me that was important, finding meaningful work. When I first became disabled, you can become a computer program, you can work from home, I had no desire to become a computer programming. It is not just finding a job, because there are lots of jobs available for telemarketing, but finding jobs that actually are meaningful can be tough, particularly if whatever it was that you studied in college is not something that is marketable or if you haven't quite figured out yet how to use the skills, use your education in a way, in a field or job that there will be meaning to you.

So I think part of it, part of the process of getting employment is better understanding, you know, what kind of jobs can we do that are meaningful that may be different from what we actually thought we were going to enter into. For me I thought I'd be spending the rest of my life outside the United States working, you know NGO, in another country, I had the opportunity to volunteer and do that sort of thing. Since I have become disabled, but that's not my career, I have been able to find other meaningful things to do. I do think that's part of the challenge for folks is if I have my eye on one goal and one way of doing things that it can, that can be difficult. And finding, go ahead --

>>Barbara: I was going to say part of finding that meaningful work is looking at, mentioned earlier, what are your skills and abilities. It may be that you have a hobby, for example, you know maybe you're the family member always arranging people for people's events and maybe that turns into a business where instead of, you know, doing flowers for cousin Susie's wedding as a favor, it now becomes something that becomes a job, it becomes a business. There are a lot of things people do in their lives that have that potential to become a business and to become an income producing thing in your life that's meaningful that you enjoy.

>>Dennis: Yeah, right. I do think in terms of the types of jobs people with disabilities can do. I think we can do any type of job we really want to. There's a woman who has a disability who is a trauma professor at a college in Boston and so you know, I think there is education on both sides from employers of folks who might have different interests and also employment of folks, you know, who may have disabilities about not, not creating a ceiling for ourselves in terms of what we are able to do. And that for me is why volunteering at first was so important. Was being able to try different things and just finding my way through that.

>>Barbara: And having a mentor that sort of guided you --

>>Dennis: Yes multiple mentors, yeah, telling me ever a I finished my first graduate degree one woman saying to me, Dennis, that's not enough you need to go to Harvard, you need to get an Harvard degree, you got a disability, you need something that's going to set you apart from other people. I can't go to Harvard, yes you can, I got a full scholarship and --

>>Barbara: Wow --

>>Dennis: Not because I'm so smart, no, no, but I said you are going to want me as a graduate of your program because I'm going to do something and so I guess it is ballsy, but I do think that the more value we can, more we can value ourselves and see our potential that the less likely we're going to get stuck in

jobs or doing things that we really don't want to do. But again going back to the purpose of this, of this Webinar and thinking of how many folks are full-time employed, I'm wondering in our follow-up Webinar whether or not that's important to figure out whether or not people are in jobs that are providing them the heaping they want or if they are looking for something else.

>>Barbara: Uh-huh, that's a good idea cause um, you know, hopefully the 69% of people who said they are working are not working at call centers, if it is something they don't want to do. We are hopeful --

>>Dennis: Working full time and worried birthday having to do a spend-down or trying to figure out how to, how to just how to maneuver every aspect of working full-time. For those of you who are working full-time and just here for more information, that's great. That's phenomenal. For those of you who are working full time and maybe having, maybe finding it challenging, I think it is important again to reach out to other folks and figure out what resources might be there for you to, a, help you to maintain that full-time job without destroying your health and/or b, to transition into part-time work if you actually have the means to do that. I shouldn't say the means, if you can do that, if you would, yeah.

>> And again if you are in New York, New Jersey or Pennsylvania and you are working you might workers assistance program to consider working with us as a mentor or if you are looking to find a job to join our program as a peer mentor, because we are always looking for people and we are hoping that we can serve more people in our program. So I think, are we ready for questions Bill?

>> Bill: We are ready for some questions. And we have some, some good insightful questions. First Dennis, a couple of questions for you to reiterate, what you are doing for your work right now as well as, you know, what led you, what type of volunteer work that you were involved in. Could you reiterate that for us?

>>Dennis: Um sure, I was, I was volunteering, I visited folks with close head injuries who were living in a Nursing Home. I volunteered, I volunteered um God, it's been so many years. I was volunteer ining a homeless shelter and that actually turned into a part-time job. I was doing a variety of things, volunteered in my local church. And so there were a number of different things. But the volunteer job at the homeless shelter actually turned into a part-time job. And so from there I actually was, I was someone who worked for the state for the department of public health, but because I was a teacher that maybe I could work on educational product from the state around American With Disabilities Act, I knew nothing about the ADA, nothing about it and they said well we don't really, we can teach what you need to know about the ADA. So I took the job and ended up becoming the ADA project coordinator for department of public health. It ended up the job was less about ADA than it really was about um working with people with public health and health care policy, which I really enjoyed. I also worked um, worked at Georgetown University for a while. And I was saying before maintaining that full-time work schedule took a lot of wear on my body and I ended up with a really serious skin ulcer and had to be in bed for over a year. And so even, so for me that, that made it clear to me that I was pushing it too far.

>> Bill: It is always a balance --

>>Dennis: You have to know your body, when Georgetown I was working my family was concerned because they could say Dennis, we can see your health is running down, you are getting sick more often. Is it worth it? And so, so that's when I transitioned to part-time, so part-time instead of full-time. But my full-time aspect of my job is really volunteer. And so what I do in health care policy is I got a degree

in public health and um I do, I work with disability advocates, general health care rights to work on, to work on health care policies that advance the, advance health care access for folks with disabilities in a way that will improve our health outcomes. Particularly around access long-term services, personal care attendant services, services for folks who may have psychiatric diagnosis, making sure those folks are getting the recovery services they need and I find, I find the, the policy work very, very interesting, fascinating, it is (The last untranslate was supposed to be thing I thought I would be doing with my life of the never had any interest when I was younger in doing policy work, I would of thought it was extremely boring. For me it is very fulfilling because it is impacting, you know, not just myself but folks who are, you know, with much more vulnerable than me with developmental disabilities or behavioral health disabilities or other needs out there who need help. So does that answer the question Bi will, will?

>> Bill: It does and you know this next question is actually for you as well as Dennis, but I think you just answered the majority of it. But let me share the question with you if you have a bit more for this person. Also a person identifying as high level quadriplegic, Dennis as well, I would like to know if you went to school while disabled and how he balanced his studies and then his transfer to the workplace. Now I think you just addressed that to a degree.

>>Dennis: Yeah it was a little tough because I went from being, I was actually, I was disabled before I went to graduate school. And graduate school is a great transition into living, living with a disability. But the transition to work was a difficult one. That's why I went to volunteer route first. Someone, a mentor saw that I was just trying to go full-force and she just said Dennis take your time. Just take your time and do the volunteer work first. And not to push yourself.

>> Great.

>> Barbara, I didn't mean to cut you off there Dennis.

>>Dennis: Go ahead.

>> Bill: A question I believe is maybe best for Barbara, Barbara if you want to come back and visit us. The question is from this person, my prior position before injury was as a video producer. Which is considered a heavy duty position because of physical, employers do not seem to have lighter duty versions of this type of position and I'm not sure what type of jobs to go after now. I'm not even sure how to ask for reasonable accommodations to be able to continue that particular career path.

>>Barbara: I'm not familiar with exactly what video, you know what is done with video production, but I would have a couple of suggestions. One is, is it possible that someone could, someone else could be your pair of hands and do some of the physical part of the job. Because I like to tell employers that it's not a vocabulary requirement that I have to carry 50 pounds, it is a job requirement that I have to move a 50 pound camera from Point A to point B and sometimes that can be accomplished putting it on a cart or on wheels or some other way and I can still get it transported or someone can transport it for me. If that's not a technical aspect of the job. So I can't really tell you the details, but the other suggestion I would have, one would be can someone else do the physical part of the job, the other suggestion would be are there related jobs, what part of the job uses your brain, your creativity and your thinking. Is there a piece of the job that could be done that way? So again I'm not sure if that industry, but can you do the film, help with the putting the film together, deciding what goes where, I assume some of that is done by computer now with cutting and pasting things. There are other aspects of the job that you

could do within that industry. So that would be my first suggestion. Sometimes we're very locked into, and I can give you an example of, you know, I'm an Occupational Therapist and I know a lot of Occupational Therapists who can't imagine having an OT who in a wheelchair. Yet I have a lot of friends who are wheelchair users who are OTs, they do hand therapy or they work in certain, they do psyche, there are certain parts of the profession that they do. So it is looking at the profession broadly and looking at what parts can I do? Can I create a job that way, can I be a consultant to others since I have the expertise on 0 how to do it. So you need to start looking that way and then maybe talking to others in the field and raising some of these issues with them. Can the job be split up this way? Can I do this? What do you think about my doing consulting. So that's how I would approach that.

>> Bill: Understood --

>>Dennis: I do think that's something, sorry, I do think that many of us do focus on what we think are physical requirements of the job that may not be. And if we look at the real job description and what's required of us the physical things really aren't there. There may be, again as you said, may be things other people can do. And so we look at that job description and consider what are the primary tasks, what are your primary responsibilities and do they actually require, you know, me to do something physical or can that be done by someone else?

>> What's the outcome that's expected, not the how you do it. But what's the outcome.

>>Dennis: Yep. Absolutely.

>> Bill: Understood. We have a number of good questions and this from California, if one is qualifying for Medicare, care giving support as well as actual help on Medicare, any income above the poverty level will impact support services. There are programs for when they don't take into account the extra help for the extra help programs that can help with medication costs up to 7 hundred thousand dollars a year.

>>Barbara: We're going to be talking a lot more about specifics of benefits in subsequent Webinars, but I will say this. This is a big problem, this is a major problem, that's why we have the choice of government regulations. But there are programs where you can buy into Medicaid or in California Medical, if you are employed in making up to a certain amount you can still have personal care attendant services through state Medicaid Medical program. Unfortunately the cutoff for that income is not something that a lot of people want to live with, they want to make more money, it is a problem, there is no question, that is an issue.

>> I have an opportunity to do freelance work, SSDI, I know the monthly cap is \$1100, I make three to five thousand one month and little or nothing for a month or three. How does SSDA handle variable income, if I can comment before you answer Barbara, I know there was for me there was an easy to manage compensation program where they worked on, under ticket to work they took into account the average over a number of months straight. Is that still the case?

>>Barbara: There are a lot of factors that enter into this um one would be what are yours, disability services, transportation or certain things that can be deducted from that. Say you mentioned \$3000 that can be deducted from that. There are ways of averaging income, looking at multiple months. There are ways to go back on to Medicaid if you go over the income amount to be able to go back because you still have a qualifying disability. So I'm giving you a lot of possibilities because there's no

right answer. But there are programs that are funded that can answer benefit questions for you that again we will be talking about more in subsequent Webinars. But there are a lot of programs that will take into account you earning more money a month or two to be able to keep earning money to eventually get off benefits.

>> Bill: What I'm hearing from that Barbara; correct me if I'm too generous with this overall assessment. What I'm hearing is don't let a little complexity or irregularity of salary from month to month deter you from seeking out employment because there are a lot of variables that could work for your favor, including deducting health care costs or medical costs out of your monthly income before, before it --

>>Barbara: Yeah certain disability related expenses, the answer is yes and before you do it you just need to check with your state, their services that are paid to advise you on benefits. So you need to -- how to do that before you do it. Dennis?

>>Dennis: Yeah I would be very cautionary and say to folks, make sure you got all the information you need in writing. And that you are able to actually have a conversation if possible. Even with somebody from a Social Security officer, from Social Security about this because it could mean losing Medicaid for a month and not having care and not getting access to medication or something else. So don't let it dissuade you from seeking the employment that you want but make sure you know in advance, because I know somebody was going through this right now. Where they actually, they lost their Medicaid for two months. And their medical provider was actually very generous and continued to see them. So just be, just be very, be sure that you get the information, I knew a guy who was life-long Marine and said, so make sure you inspect exactly what the situation is before you enter into it. Don't let it dissuade you but make sure you get the information.

>>Barbara: And Dennis mentioned getting informs from Social Security, sometimes you can get information from Social Security, get someone who really knows what they are talking about, however, there are also in every state there are non-profits that are funded to provide this kind of information specifically on benefits. And we will be talking about that in subsequent Webinars and give you the resources on who you can go to. Or if you want to e-mail me I can kind of at the end --

>> Bill: That's a great segue on your last slide you have your direct e-mail address for folks to copy down while we are finishing up. Such great questions, we are nearing the end of the hour but let's try for a couple more.

>>Barbara: I want to say on the screen if you go to spinal cord pathway to employment or resource center and download federal guides there is information in there on a lot of the things we have been talking about and how to find out more information, who to go to.

>> Bill: Great Barbara, thank you. Let me squeeze this question in, I'm 29, paraplegic, currently working full-time for a large organization. Recently received a voluntary self-identification of disability form. They are already working there and haven't completed it yet. Would it benefit me or just benefit the company? Any advice on filling that form out now that they are already an employee --

>>Barbara: I'm assuming and you know what happens when you assume, but assuming since it is a large organization that they are probably a federal government contractor. And the reason they are asking to self-identify is because they have to, they have to show the government that they have 7% of their

workforce is people with disabilities or have a plan to get 7% of their workforce of people with disabilities. So it probably um does not harm you and does help the company, but it probably helps you too. It is just so they sort of can comply with equal employment opportunities asking you race and some of the other things, they have to be able to show the government they are hiring 7% of workforce of people with disabilities, so it is not going to hurt you. Thank you.

>>Dennis: There are corporations seeking diversity and asking that information to better understand the makeup the workforce. So they might actually if you self-identify it will help them to know baseline and seek to employee employ more folks with disabilities.

>> Bill: Got it I want to let everyone know we are just about at the end of our time and we have many more great questions than we have time to address. Do not hesitate to address those questions directly to Barbara by e-mail and she will share e-mail for us. Let me try to --

>>Barbara: I hit something by accident, I hit my link. Trying to get back, oh no.

>> Last question, I'm electronics engineer, come across the lift 20 pounds, stand, finger use requirement, I'm a Quad so I can't do those particular things. How would you get through that?

>>Barbara: Okay that's been a big issue, that's been in the news lately as a matter of fact, the essential functions of your job is the outcomes you need to do, not how you to do them. So, for example if I they say I have to be able to stand so I can get files off the top file drawer I don't have to stand to get files I can just, if my files need to be moved they can get two drawer file cabinets instead of a four drawer and I can reach them from my wheelchair. When you see things like that it kind of inherently discriminatory. What I recommend is if you think you can do the job. If you see what the job is, if you are doing a job where you have to answer phones, make change, just thinking of things off the top of my head, collect files from people and you can do those things but the job also says you have to be able to lift 50 pounds um I would apply for it anyway and when they ask you about it say I've been thinking about this and I can get files, I can make change, I can answer phones, I'm not sure where lifting 50 pounds comes in but I'm sure we can make reasonable accommodations to eliminate my ability to lift 50 pounds as long as I get the task done. That's how I would handle those and, you know, they are blatantly discriminatory. So if you can get, apply for them anyway and talk your way into it. We're going to be talking more about job interviews and answering those kinds of questions and addressing those things at subsequent Webinars in the series. And if we didn't get your question my e-mail is on the screen, my name @gmail.com, I'm happy to respond.

>>Dennis: If you have questions for me you can forward those on.

>>Barbara: I'm happy to forward those to Dennis, if you live in New York, New Jersey or Pennsylvania and are interested in our pathway to employment program, getting a mentor please contact me as well and we will be happy to hook you up with someone.

>> Bill: Excellent, we reached the end of our period on behalf of United Spinal Association I'd like to thank Barbara corn and Dennis Heaphy and I apologize if I didn't pronouns your last name with the Irish accent --

>>Barbara: If you can get Kornblau I think Heaphy would be easier --

>> Thank you for sharing professional knowledge with us today on this pathways to employment. To also to the audience look forward to additional subsequent presentations on this general topic of return to employment throughout the year and thank you Barbara and Dennis for your great work today and as evidenced by the questions I think you, you reached out to a lot of people with important information today.

>>Barbara: Thank you.

>>Dennis: Thanks you guys, thank you.

>> Next Webinar is solutions for bladder and bowel management Wednesday March 16th from 3 to 4 pm eastern time. Sign-up for our Webinar newsletter by visiting us at [www.spinalcord.org](http://www.spinalcord.org), if you are not already a member join so you can check out new mobility magazine or go to [newmobility.com](http://newmobility.com) to figure out what we are all about. Thank you, that concludes today's presentation.

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