

ERIC LARSON: Welcome. I know we still have people joining us, but we're going to go ahead and be respectful of everybody else's time and get started. Hopefully you are here for finding the right wheelchair, "Push for More: Finding the Right Wheelchair." My name is Eric Larson. I'm senior VP of membership and chapter services for National Spinal Cord Injury Association or NSCIA. We're pleased today to be hosting this presentation as part of our relatively new webinar series we've launched this year. For those of you who don't know, NSCIA is the membership division of United Spinal Association, and as part of United Spinal we are the largest nonprofit membership organization dedicated to improving the lives of people with disabilities, like spinal cord injury and disorders.

We're supported by a range of program services through United Spinal, including Users First, which is part of what you'll be hearing about today. I did want to let you know that individual membership in our organization is free, and we also have organizational membership opportunities as well. You can learn more about that or join just by visiting spinalcord.org. That's www.spinalcord.org. And you can also learn about other programs, like Users First, while you're there. We will remind you again later in the presentation, but there will be time reserved at the end for questions and answers. And in the meantime, though, you can go ahead and submit questions as they occur to you via the webinar program. And we will ask the presenter to address those toward the end of the program. If we aren't able to get to all the questions during today's presentation, which does happen, we will do our best to answer those all offline as well.

We have more than 400 people registered for today's program, and successful programs like this are usually a result of two things, steak and sizzle. Our steak today is our topic. Finding the right wheelchair obviously is critical to our audience. And our sizzle is our presenter. Ann Eubank is the director of Users First, a program of United Spinal Association. Many of you know Ann.

Users First seeks to increase access to wheeled mobility for all people, whatever their need, why ever they need a wheelchair, and they do that by empowering consumers and health care professionals. Ann holds an adjunct faculty position at Belmont University School of Occupational Therapy. She writes for various mobility publications and offers a grassroots blog online and has been immersed in the community of people who use wheelchairs for more than 20 years. During that time she's developed and presented educational programs nationally and internationally since 1995. At this point I'd like to turn the program over to Ann. It's all yours.

ANN EUBANK:

Wow, thank you so much. My name is Ann, like Eric said. I've never been called sizzle before, so I will take that as a compliment. Thank you all so much for coming. We do have some great materials today. I'm going to go through the process of finding a wheelchair, and also at the same time everything I say is online on an online education tool that I will get to **[unintelligible - 00:03:24]**. So everything I say, you will be able to get even more information in the order that I'm discussing it online. The first slide, let's see if it moves over. It's not moving over, let's see if this works. There we go.

So Users First's mission, advocate for greater access to appropriate seating and mobility. That's wheelchairs, seating systems,

cushions, backs and scooters. And we focus on the following goals. These are our main focus. We offer education and guides through the service delivery process. Kind of a big phrase, what it means is the process of getting a wheelchair. And that is a service of ours. Online we have – you can call us. We actually have social workers and people that will help you through that process. We do not recommend products; we help you through the process.

The second thing we do is we enroll all people, regardless of disability or not, who believe Americans should have access to appropriate wheeled mobility. So that gives us political power. One reason it's hard to get a wheelchair, the right wheelchair for you. I know you could probably get a wheelchair, the kind that look like what you see in the airport. That's not what I'm talking about. The one that works for you, that's unique to your abilities and your body. One reason is that our political power is less because we don't speak out. When the insurance company says, "You're not eligible and we won't pay for it," most people are like "Oh, okay, I'll take what we can afford." So Users First is a place for you to speak out and say "I wanted this one, but I had to get this one." And you can tell us that. We count you with the database and then we go to that insurance company and say, "Could you explain your policy to us?" And I'll talk more about that.

That's the third thing. We challenge policies that limit access to wheeled mobility. Up on the top left, that's a consumer, someone signing up for Users First at a show. In the middle there that good-looking guy is Paul [Tobin]; he is our president and CEO of United Spinal. And my head is behind the tabletop. In below there's myself on the right next to my colleague Rick [unintelligible -

00:05:36]. And we are at an Abilities Expo. And those are wonderful. You can find those at abilitiesexpo.com. So the first thing: we offer education and guidance, and what exactly does that mean? The service delivery process of wheeled mobility, the sound of it – sounds complicated. We're offering a map to the process of getting a wheelchair that works best for you. We do not believe in a one-size-fits-all mentality. Sometimes insurance companies do feel one size fits all. And they feel that way about all products and all services. But when it comes to a wheelchair, as probably everyone on this call would agree, that's not going to work. And where we offer that is through the Users First mobility map. Everything I'm saying today will be located online under that button.

So the overview of the process: let me go back one time. The overview of the process we broke down into seven steps. Now there's a lot of steps. The online guide has 60 pages. So you can click where you want to go and what you want to find out about. But the seven steps that I'm going to generally go over today are self assessments. That means your assessment of you and your needs, your wheelchair team. You're not alone. You must have a good team: an OT, a PT, a really good medical equipment supplier, your physician, that kind of thing. You need a prescription and an assessment. How do you find funding? How do you get this paid for? Which can be really complicated, depending on what kind of funding you have and what your insurance company is telling you. How do you order the chair, exactly how does that happen? Who orders it? Where does it show up? How do you find it? Equipment delivery would be one of the final steps, and who helps me get my chair, what happens after the delivery. And number seven, living as a wheelchair user. Many of you use a wheelchair.

It's about being connected to sources that can help through the wheelchair process – where to go if it breaks down, who to contact, what kind of maintenance, that kind of thing. And all these questions come out of – I have been immersed in the community of people who use wheelchairs for over 20 years. In those 20 years, my focus has been actually using the wheelchair – not very clinical. I'm not the person to ask about muscle testing or anything like that.

This map was developed from the thousands of people I've talked to and their questions – where there's nothing out there about how do I get this, where do I go. Even people that have been using a chair for, I have a friend that's used a chair for 18 years. And he has five, six level quadriplegia, he has spinal cord injury, and he wears a tie to work, good-looking guy. So 18 years. He knows what he's talking about, but what he didn't know when he went to the assessment is they found a new back for him that sat him up a little bit straighter and he goes “Wow, my tie looks straighter, my belly looks smaller; this is amazing.” And he Facebooked me, he's like, “This is an amazing back.” I didn't do the back; he was just talking about his process. He worked with a really good medical equipment supplier and an OT and he's post 18 years and he's very happy with his new back.

So the first step. First things first, before you go and call a medical equipment supplier – even before you go to get a prescription from a doctor. What is it that you want to do with your wheelchair?

And the more detailed you can be, the more information you can offer, the better your team can match what you do in your life and your physical abilities to the equipment that's out there. This has got a lot in it. I'm not going to go through each one because it's

really, it's really important for you to think about where, how, and what you want to do. And it can be... everything is okay to say. You know, I want to go to the ballpark, it's really important to me. Let your team know that's it. You know my family's had tickets for years. I love the Yankees. I want to go – this is where the seats are and this is what it looks like. That's important to you. So they're going to match up what is out on the market that fits your needs that will do what you want. The insurance company probably isn't that interested that you go to the ballpark. But your team will be. And they will help match you with the right equipment.

So anything that you might – you might drive a car versus ride in a car; some people take public transportation. It really depends on what area of the country. I get calls from people who live in New York City that have to deal with the subway to people who live in Montana, they have to deal with the cold and driving on gravel to get to their car. So it's really important that they know that. So another part of the self assessment is, what do you like about your current wheelchair? And that's important. I love light weight, I love that it's fast, I love the color, because everything you like, during the assessment you want to make sure they keep those elements of what you like. I love the hand rims and things that you might not actually think about because it's part of your everyday life. And so you look at these and you're like, "Oh, yes, that's right, I really do, these hand rims came in later and they have better grip and I can slow down fast, this is good."

Or my back, you might have gone from a higher back to a lower back and you either like it or you might not like it. Those things are very important. Some of the things I've heard that my chair

lasts all day and I like that it had – whatever this battery is, I loved it. Because the last one I had would not work all day. So, your team needs to know that. So they can check “Okay, that’s that battery.” They’ll know all the gadgets. Like I don’t know what kind of batteries are out there, but if you say to me you want a battery that lasts a long time, they’ll tell you which one it is and go through that with you. The other part of the self assessment is what you do not like about your current wheelchair. And actually this is what I hear most, is things like it’s either too big or too small. I’ve gotten, the gentleman on the right there is a picture and I would assume that his chair is probably a little bit too wide for him and maybe he might not be so happy about how his chest is going to one side. But I don’t know until I would ask him. How does that feel for you? Does it stop you from doing these things to do? Do you have pain?

So, is it too big, too small? Does it not have enough power? If it’s a power chair, is it too heavy? A lot of people use manual wheelchairs, they’re like, “If it could just be a little lighter I could get into my car, I could...” and that’s what you need to tell your team. I want to be able to throw it in the backseat or in the front seat with me. If it was a little lighter I’d be able to do that. I could go a lot longer during the day, I wouldn’t get tired. Or, I had shoulder surgery and I’d really like to use manual. Looking at power, but if I could use manual that would be great. It’s not comfortable and not just it’s not comfortable, but how is it not comfortable? My feet fall asleep, they tingle, they swell, however you may feel pain. I just get tired in it. And be specific about the seats and the back. Does it work for you? Is the seat too short, for instance? Your legs might go apart a little bit like that guy is

looking. Maybe you want it just like that. If it's too long, the back of your knees might get rubbed and be red.

How old is the chair? Those are the kinds of things to ask. I have had this chair for five years; can I get a new one? Every single aspect of that chair is... they basically build the chair. You can get different size wheels, frame, your feet can be in different positions. That's the kind of stuff to ask the clinician, because your feet may be really far out in front of you. When once they, the assessment – you might not realize you can probably tuck your feet in and save a lot of space field to get around different areas. That's what the team's for. And this self-assessment form, I'm going to show it to you online. I'm going to click right here. And that did not take us where I wanted it to. Let me go back one. I apologize.

Technology. I'm better with a wheelchair than I am with PowerPoint. And let's go ever so slowly there and click that from here. It's going to flash for a second.

This is the online My Wheelchair checklist. So right now online – and you can see here this great tool. You put your email address in, confirm it. City, state, I put this, my ethnicity, only for your team because that's one of the first things, it's not what I ask, it's what they ask. They might be able to, given if it's a diagnosis like if it's MS versus cerebral palsy or something like that. And down here you have physical issues. You can just check them off like this – whatever you may be. If we miss something that's not up there, I didn't want to make the form like 10 pages long. You can put whatever you want in here under notes. Let's see, is it – let me make sure you can see what I can, okay.

What do I want to do with my wheelchair? And it has a few things here; on the slide that I showed you there were a lot more. So if there's something that we didn't mention you can put it in here, like I want to go to the beach. Sounds kind of funny, doesn't it? I want to go to the beach. But a lot of people live on the beach. And there are specific things to do with wheelchairs so that it will perform better on the beach. We would ask you questions like what kind of sand, what time of day, even the tides. There are certain things you can do with air pressure. But we can answer those kind of questions for you through our UNSA tech guide. United Spinal has a sort of a tech version, a tech program. It can answer questions about for you and give you suggestions.

And we're going to move down under My Priorities, what is important to me. These are important because one priority might... you need to list like what's most important. Like if standing is really important, you can stand with a manual wheelchair, you can stand with a power wheelchair. And when you stand, if that's really important to you, your team might say that's great, so I want to let you know any standing wheelchair, there's always benefits and what you will have to work with. Like a standing wheelchair always has knee braces, knee blocks in front of it, that kind of thing. So it's important that you write down what's really important to you so they can problem solve what's most important and what product will best work for you. You might have been struggling with pressure sores for the last few years and of all things, I've been in bed for the last year, I've been in bed for two months. I cannot get another pressure sore. Then they would gear their evaluation with the OT, PT, or medical equipment supplier to look at different ways to avoid pressure sores.

And there's a lot of different techniques in the mobility map. I'm not going to go through all those today. If you all write in and want a seminar, a webinar on pressure-relieving techniques, we can do that. Within the mobility map there will be some hints and techniques of how to do that, depending what you have. And then you can write notes and things like that here. And then the last few things, which [unintelligible - 00:18:15] is the make and model of your present wheelchair. Even if it's a wheelchair that's a loaner from either a medical equipment supplier or from a hospital, because that will tell your team a lot about who you are and what you like and what you don't like. And that is it.

Then, once you're done, you submit down here and it will go right to your email inbox and then you print it from there. Or you can even send it, if you have the email of your team, you can send it to them. Pretty good, huh? Well, that's great. There's also a PDF that you can print and write in with a pen or pencil if you'd like. Not everyone's super techie, but if you're on the webinar today you are probably relatively techie. Your wheelchair team is the second step. Online on the mobility map, this is what it's going to look like. It's going to have – this is chapter two and these are different pages, 2.1, 2.-, so when you get on there, that's what it will look like.

And there's a lot more information on there that I'll go through today. I'm going to mention these people, but under each one of these there's advice. One of the main pieces of advice is that your clinician, your therapist, and your medical equipment supplier be certified. And it goes through what that certification means. So overall here's your [unintelligible - 00:19:46], you might have

others, but you and your support system, so you're number one, your family and friends, your doctor. Your doctor will write a prescription, it needs to be written in a certain way. The mobility map goes through that. And your clinician may, if you already have a connection with them, we'll help with what that prescription needs to say. Your OT or PT, generally that's who the therapist is. And the certification is called ATP or SMS. And those, in the mobility map it [unintelligible - 00:20:18] to the organization that gives that certification. That certification, those initials mean that that person has done extra schooling about wheelchairs – which is helpful. So because a wheelchair that's complex at all is not something like a new grad would be ready to do. It's someone that's had experience in the field and has worked with people with wheelchairs.

The next very important member of the team is your medical equipment supplier. That is the person that will be with the OT or PT during the evaluation, will help with finding the right equipment. They'll know a lot about different types of equipment and what might work for you. They also have the certification of ATP, which is as a technology professional. And they offer a variety of products. Sometimes I get questions on where, you know, when you go by a car you go to the Ford dealership or the Toyota dealership. Well, when you buy a wheelchair, it doesn't work that way. One supplier will have a lot of different ones. So it doesn't work by manufacturer more than by each supplier. Now the insurance company is the last one, and I put it in italics because yes, they are on our team. And I am pro insurance, I'm glad I have insurance. But insurance companies make money when they critique what we need. So they're going to always critique, what do you need, why do you need it. And we have to prove that we

need a certain kind of chair, like lightweight or a standing chair or a chair that tilts or a chair with smaller casters or something like that.

The insurance company's part of your team and I'm going to go through that a little bit. They control this process, and the more you speak up, the more you know about this process, you will have more control. I know that sounds a little lofty, but I'm going to break it down. So this slide, it looks like a lot, but stay with it. Understanding this process will give you a lot of knowledge and actually peace of mind when you get ready to get into this. So the way our system in the United States is set up for all people, anybody, no matter what insurance you have. So the funding source is on the top, Medicare, Medicaid, private insurance. That could be Aetna, Humana, United Healthcare. They, up here **[unintelligible - 00:22:58]** insurance. Found that picture, I hope you like it. They control the system. So they decide how much they're going to pay for a wheelchair.

So they say "We're going to spend, we're going to give you \$1,000 for the wheelchair." And the manufacturer says "Oh, okay. If they're only going to pay \$1,000, then we better make a wheelchair that fits into that category." So and if you have questions about this, feel free to comment or email and we can talk more about it. The manufacturers are people that make wheelchairs like **[unintelligible - 0:23:39]** Pride Mobilities, Sunrise Medical, **[unintelligible - 0:23:41]**, etc. And there's others out there. I didn't have room to put any more people. They sell the wheelchairs to the wheelchair supplier. And they can get a variety of chairs. And then the clinician can only use chairs that the wheelchair supplier has.

So when the funding agency or the insurance controls this process, as a consumer we only get what they pay for. If it's consumer-driven, which is this side on the green, it means the consumer says, "I really need whatever," and when I say need I don't mean like a chair that has a special horn on it with spinners. I mean things that you really need—they're medically necessary—that insurance companies currently don't pay for. For example, like a seat elevator on a power wheelchair. They will say it's not medically necessary. Really? So someone that can't reach up or might have upper extremity weakness or sits, how can that not be necessary to live your life? So one reason seat elevators are still not paid for is as consumers, as a group, we haven't had a strong voice going up and saying to the clinicians, I really want that and need it. And the clinician says, "Yes, you do need that, that would be great, but the funding agency says no." And I'm going to talk about what happens when they say that. But the message here is say what you need and then let's work from there. Do not take no as the first answer. When they say "Well, Medicare doesn't pay for seat elevators," the question I would encourage is why don't they? Why? And then you get involved through a consumer organization, through Users First to ask Medicare why. Because the clinician, the supplier, and the manufacturer can't get you something that the funding source doesn't pay for. Their hands are tied, so we want to really look at this funding source when it comes to that. I'll get more into that.

The more you know about your team members and their responsibilities, the easier the process will be. So if it's clear, like oh, okay, I understand. I really would like this cushion and the supplier says that Medicare or Medicaid or Blue Cross doesn't pay

enough to cover his cost. Well, that makes sense, but that's not right. And you're right, it's not right. So through Users First, what we need from you is just to be counted. You just log in, tell your story, which I'll show you how to do. "I wanted this and I was unable to because of this insurance." And I will tell you that that strategy does work and it has worked.

We are on step three. Don't worry; I'll get back to that. Step three is prescription and assessment. This is what it will look like online. You click on one of those and there'll be some nice pictures and things coming up. So there's a lot of information on there on your role, what the clinician is expected to do, what supplier's role is. And these roles all come from standards of practice. I didn't make them up [laughter]. They come from the standards of practice for OT, for PT and for ATP on what's expected. The main thing you need to remember is to find a certified supplier. So if you need a wheelchair that works for you, probably Walgreens down the street will not have it, or WalMart. Unless you just want a transport chair, I would be careful of that.

So, your prescription – you get your prescription from the doctor before your wheelchair evaluation. This prescription from your doctor may read OT or PT wheelchair evaluation. And it's highly recommended that you go to a certified OT or PT. And that's the first thing you need. Most people are connected with an OT or PT. If not, that's something that you can ask us about where's a clinic close to me, how do I find one, that kind of thing. And we can help you get connected to a resource.

Number four, finding funding. Okay, this has sort of been the theme already for the last 20 minutes. This is **[unintelligible -**

00:28:15] on the mobility map, goes through private insurance, Medicare, Medicaid, VA. What's secondary, what do I do when I get denied. When they say you don't qualify, what would I do then? Alternate funding sources, we will go through each of those steps online. I won't go through all of them right now, we don't have time. And you might not need all of them. I put a really fun picture there because sometimes funding can be overwhelming, so I thought that this **[unintelligible - 00:28:44]** Iowa, **[unintelligible - 00:28:45]** and I don't know the little girl's name. It was that one at an Abilities Expo.

So it's essential you know what type of insurance you have. That is important that you know that. If you don't know, that's another thing you can ask Users First. We will help you locate it. You probably have one of these types, Medicare, Medicaid, private or VA, or you may have cash from a settlement or your own cash. If you do and if you're really wealthy and you have a trust fund, please let me know because we work for a nonprofit and I'd love to hear from you. [Laughter] That was a joke. I know there's lots of you laughing right now even though I can't see you. You need to locate your insurance policy. Oh, it sounds like a lot of work. I know, I know, just the thought of it. But in that we will help you through this. In that handbook, it will detail what type of coverage you have for DME. That stands for Durable Medical Equipment, which is where wheelchairs fall here. Durable medical equipment is something that can be used over and over again.

So what do you do if the policy says you're not eligible? It's the policy that says that. The person that tells you, maybe your equipment supplier, they might say you have Blue Cross of Tennessee – that's just an example – and they don't pay for what

you need. And so go to your handbook, see what – I want to see what it is in writing, because sometimes their policies are very conservative, but no one’s challenged them. And sometimes all it takes is a phone call from a few consumers, really you’re not – “I have cerebral palsy, I’m 25 years old, I’m going to school and I just need this part on my wheelchair.” Why is that? Many times the insurance company will say “Oh, oh, we didn’t realize the policy says that.” What do you do if the policy says you’re not eligible? This is where the advocacy part really kicks in. It’s when you don’t hear what you want to hear.

And that’s the third part of what Users First does is challenge policies that limit access to wheeled mobility. We will work together to challenge the policy that limits your access to the wheels that you need to live your life. Pretty good picture; I took that when we were in Washington – about complex rehab. If you have a chair that’s adjustable to you, it’s called complex rehab technology. And that’s... we were in Washington talking to legislators about access to that. But how do you tell your story? How do you tell your story? Most people – all people, I don’t really want to be an advocate but I’m willing to write in and say I wanted this and I was unable to get it. But we try to make it easy, you can go to Users First, you can tell us your story. You can email us, you can call us. On the bottom of every PDF, there’s a PDF attached to each page of the mobility map and there’s a phone number, an 800 number at the bottom of that page. We encourage you to use online for education. But if you have a question that you need answered, you can call us and then **[unintelligible - 00:32:08]** we help you. Your call goes into a queue. It goes into a software program where it will never get lost. So the person taking your call, probably a social worker will say what’s up, okay, Jim

Smith. This is what you needed, this is what you have and then that will get tracked until it's resolved. So it doesn't just get put on in some email box. It literally gets tracked by a software, so that's great.

The other way is within the mobility map. We call them policy hotspots. So it makes it easy for a consumer to take action by one click. So this is an example of one where, when we talk about Medicare – if that's the page you're on, if you have Medicare. If you don't have Medicare you probably wouldn't be on this page. And it says, "Have you ever been told that Medicare will not pay for your wheelchair if you go outside with it?" And I've talked to a lot of people and they're like "Yes, actually I've been told that." Well, that speaks to a policy that's a very discriminatory policy called "in the home" rule. And I won't get too much into that. If you want a whole hour on policy, it's another webinar we can do. But that speaks to that policy. By clicking there and saying yes, then you're counted. And how that's very powerful is that United Spinal and Users First, United Spinal has a policies department that lives in Washington, DC.

If there's 300 people throughout the United States, which I'm sure is way more than that, that have had this story. Because when we go to the policy makers, what they say to us is "Gosh, we haven't heard from many constituents." We're like "Really, you're kidding me." So this is a way for you to be heard by just clicking or by telling your story. All the information we get will be **[unintelligible - 00:34:02]** in a form of which policy you are affected by. And you don't even need to know it, also if you want to absolutely get educated, but they can feel overwhelming. If you say, "I was unable to get this and this is what I was told," and we'll

put it into that and then we go to Washington. In June, we will have a roll on Capitol Hill. You can find out more about that on spinalcord.org. Roll on Capitol Hill, we'll go there and we'll talk to the congress about these issues – all these kinds of issues that relate to using a wheelchair. And there's one picture. That's my buddy Darren, and we were in Washington and a lot of us were there. Many people using wheelchairs with **[unintelligible - 00:34:51]**. That was the name of the conference and it was a good day. It felt powerful to go talk to people about policies that limit access.

So now to ordering your chair – your wheelchair supplier will order your wheelchair from the manufacturer. Manufacturer is like Nike and your supplier is like Foot Locker. So the supplier orders from the manufacturer when the insurance company approves it. So remember this. The funding source or insurance company has to say yes. The manufacturer says “Okay, I have approval.” I mean, the wheelchair supplier says I have approval, orders it from the manufacturer, and then you set up a delivery with the clinician and yourself. That's generally how the chair is ordered. There may be different variations of that, but that's a general overview. And there's more information on that in the mobility map.

Equipment delivery – this is what it will look like on the mobility map. An overview, what to expect, what to make sure you bring, you come – so these are things you want to look at; can't get into a lot of them because of time. But you want to make sure it works for you. Does it feel good, does the width, the depth, the cushion, do your legs feel like they're in the right spot? Are they much different than they used to be if you're now on the second or third chair? If it's a brand new chair to you, you won't know as much.

You won't know what you're going to know two, three years from now about what you want. The one piece of advice [unintelligible - 0:36:30] is if you take delivery of that chair and you're like really not sure about it, it's just like a lot of things that you take delivery of once you have it, it's yours. It's very difficult to return it. And that makes sense because it's specific to you. There's different things on it someone else might not need. The supplier has ordered it so they've already paid for the chair. So work with your team closely to make sure it's what you want and it works for you. And take your time in your evaluation in the beginning to make sure it works for you. Considerations for manual wheelchairs, how does it move, wheel positions, casters, camber? I'm not going to get into that, but on the mobility map all of these things are on a PowerPoint presentation that you can see that has pictures and definitions of what things are in a general sense. And same in power wheelchairs, how you operate it, what are different ways that you can manage those different things. So I see that we are at almost quarter till. So we're doing well, we're going to end up with questions and answers here pretty soon.

Living as a wheelchair user – that's what it looks like in the mobility map, and you would click on those different pages. And so it includes your vehicle and your home. In the home section there's a home assessment which you can do before you even go to your wheelchair assessment. It talks about – we tried to put in there like look at your doorways, threshold, dining room table, kitchen table, your bed. Things that you might, once you're in the clinic you might forget. You have to rush to get there, it's a hospital situation sometimes, and this will help remind you that oh, that's right, the bathroom on this hall is better than bathroom down here. Things like that. We also work with using your equipment

in your vehicle. Are you driving, are you riding, do you have a van, are you in the market for something? Do I have to use a minivan? Is there another type of vehicle I can use? That kind of thing.

And community integration is just getting connected, like you are today. If you're here today, you're connected in some way to United Spinal. This is some art for Users First, and it took me like half an hour to make this [unintelligible - 00:38:55]. And these are just different pictures of people doing different things – mostly at Abilities Expos, people who have signed up for Users First. And when they sign up, people say what am I signing up for? And I say, “You are being counted. Do you want to be counted as a wheelchair user in the United States?” Kind of like the AARP for people that are, I don't know what it is, 50 or 60 now. The reason older people have policy power is because most people like my dad, he doesn't necessarily like being a senior, but he wants to be counted as a senior for sure. And that's sort of the same thing. And you don't necessarily have to be an advocate and be like oh, real excited about wheelchair stuff, but yes I'd like to be counted as someone that uses a wheelchair. And that's what we work on. At this point, it is quarter till according to my watch here. And I wanted to address some of the questions that we have.

At this point I'm going to switch screens with our technical support person, Edwin, so that I can see your questions. You're going to see my... and we're going to go back to that for a second and then the slide should come back. There we go. And I have access to the questions right now. Give me one second. One is, “Is a copy of this presentation and handout available?” Yes. You would go like it says on that slide. You can go to usersfirst.org. And the

Users First mobility map is a button that's on the right top corner of the website. And all of this is up there. And you don't have to go in order. You can click to wherever you need to go. "Can the presentation be emailed afterward?" I'm not sure. I will check on it because I think there's over 300 people on the call. I can make – I hope that the mobility map works for you. If it doesn't, please email us and let me know if it doesn't offer you the information that you need. So a lot of people have said that.

"Will a transcript be available and archived?" Yes, this is being taped and it will be available. It will probably take about a week for it to be available. And it will be on the Users First site, along with other United Spinal websites. [Pause for seven seconds] Users First is for anyone that uses a wheelchair. Someone asked does it have to be someone with a spinal cord injury or anyone who uses a wheelchair – anyone who uses a wheelchair. That's why it's called Users First. Users First is a program of United Spinal. And if you get real technical about it, like National Spinal Cord Injury Association is also a program and is our membership. It's anything to do with the spinal cord and almost everything has to do with the spinal cord.

But yes, Users First is everyone and not just people that use a wheelchair. It's all people, because when we go to Washington, it's fantastic to say there's 20,000 members, Americans that think, "You know what, I think it's an American right to have access to your community." Every single president talks about access to the community. Everyone, it doesn't matter Republican or Democrat, they all talk about it. But if you use a wheelchair because of insurance policies, including Medicare, all of a sudden, "Oh actually, you don't." And that's pure discrimination and it is a

civil right. And our policy department works on that kind of language. Let's see. I wanted to [unintelligible - 00:43:01] some of the other, "Could you provide a resource for consumer rights, not just insurance?" Yes, we can. That kind of question, for example, yes. You're asking about lemon laws required [unintelligible - 00:43:20] that kind of thing. There are lemon laws, just like a car in different states. And the best place to ask real techie questions, you can ask Users First. If it came into the queue, I would probably send it over to usatechguide.org. They are techs, they're techie. And so they can help with warranties, what to expect, what does it cover, given your brand and your serial number, that kind of thing. And if the wheelchair is not working at all, it can happen. It's a mechanical device that will always need maintenance, just like my car. Just like a bicycle, but if it's not working at all that would be a good place to start there so you know what to expect.

Someone asked that my insurance company... I think what you're asking is my insurance company only uses one provider. That can happen. One large provider may win a contract for an insurance company. We still want to know about this because, and this is where it becomes advocacy. As an occupational therapist or physical therapist, they have a standard of practice or ethics. They need to provide the best treatment and the best products they possibly can. And if the hospital has decided to save money by using only one supplier, where then you can't... we just need to look at the details of what's missing. What are you not getting? I can't answer it completely until we work, but we do want, we will work with you on that. And we definitely want to hear about that. Because if hospitals only use one type of supplier that offers not what you used to use, then it's a detriment. And that happens with

other devices, too. It happens with people that use diabetes supplies and oxygen and things like that. And that is called competitive bidding. And it can be from a national Medicare level or it can be in a local level where a specific state Medicaid has decided to competitively bid all of these products. And it's business and that's okay and that's the United States, it's capitalism. But yet, if people are getting hurt in that process, they won't change unless people speak out. So this is an opportunity for you to do that. And we will, our policy department will speak out. Just a plug for United Spinal, I don't know if you all know that New York city cabs, taxis, all of them, will be accessible for wheelchairs within the next three years. How did that happen? How could that possibly happen? I don't know if you've been to New York City lately, but if you use a wheelchair you can't hail a cab. You'd have to call one and there's, I don't know the percentages, like one percent are accessible. And what are the chances that one percent's going to be coming around the corner when you need a cab? United Spinal worked with New York City, actually through a lawsuit, and changed that. Now other cities are following. That's what's possible and this is absolutely possible, depending on each – there's going to be a lot of you in each of these different categories, depending on your policy. And what that question spoke to was competitive bidding, and it is very detrimental in a lot of ways.

“Can you make the self assessment form available as a downloadable file?” So yes, that is made. And I think you saw that. If you have questions about that, we can walk you through it, but the self assessment is located on 1.1 once you go to the mobility map. And then it's linked in many pages because we say “Don't forget your self-assessment form.” We repeat quite a bit

because some people will come to the map on page one, some might come in at chapter five, etc. And people that don't have access to computers, you can print the PDF. I can see, there's someone here I think who's a clinician asking that. Yes, you can print the PDF form and then have your people that you're working with fill it out. You can mail it to them, you can have them fill it out while they're waiting, that kind of thing.

The certification that I talked about, ATP – that's one of the questions is Assistive Technology Practitioner and SMS is Seating and Mobility Specialist. I hope I got that right. And those are very important certifications, for example, if you used a prosthetic limb, that's under orthotics and prosthetics. They have certification and their license. The wheelchair community doesn't yet have a license like that. So this is the one certification that will show you that that professional has taken extra courses and has to continue taking extra courses to have that certification. That they should know more about wheelchairs than someone that doesn't. "Are OTs and PTs certified [unintelligible - 00:48:45] only in seating clinics?" No, there's OTs and PTs that are not in seating clinics that may have their own business, in case you don't live near a seating clinic. And that can happen. In a rural area, definitely get in touch with Users First. I have colleagues all over the country that cover very rural areas. So I would be able to reach out to the community and say "Where's the nearest seating clinic to Bozeman, Montana?" Or a clinician does it privately that can meet you somewhere, meet at their suppliers' establishment or at your home or something like that. It can get tricky, but we can certainly – there is a network out there and the network is connected to Users First for sure. Looking at your questions.

“As a therapist, can I submit stories on behalf of my patients?”
Yes, you can but we would – it would be best for them to be right with you when you're doing that. So that they have given you permission to do that. We as a social work organization certainly want to make sure that everyone has agreed to be **[unintelligible - 00:49:58]**, so you could submit stories that are general without name or any identifying information, but otherwise we definitely want people to say yes to it on their own.

One person asked a very detailed question. “I'm looking at a power wheelchair that costs \$30,000. How much will Medicare reimburse me? By the way it's my first power wheelchair; I've used a manual for 10 years.” I would not know. And the reason I wouldn't know is it would, all the details have to come together. That's a question definitely for your wheelchair team, so I would direct you back to your wheelchair team. Do you have a certified supplier, what have they talked to you about? You can log on to Medicare and find out certain things. What are they looking for, that kind of thing. I know people get lots of great wheelchairs through Medicare and I'm not a medical equipment supplier. I know the process pretty well; they know the coding and the billing very, very well. And they'll know what's been successful and what hasn't, and what you might run into. And if you want something and your supplier says Medicare never pays for that, we want to hear from you so that we can address that policy and why they won't pay for it. Yes, I can talk to you about that and get you connected and make sure you have the right resources. We are three minutes in. I'm looking at your questions or... [Pause for five seconds]

How do I find a supplier that will accept Medicare **[unintelligible - 00:51:38]**? Good question, it depends on where you live and that's another thing that we – your questions are very valuable. Bring them to us. Because we will bring them out to professionals in your area that when we would find one that's certified in your area that would accept what you're wanting. So we would certainly – Users First, when I say social work, I don't know if people understand because I am a social worker, but I'm a – this is all I've ever done is work with people that use wheelchairs. We don't do the process; we connect you with resources so that you can follow the process – and support, that kind of thing. [Pause for four seconds] **[Unintelligible - 00:52:27]** the PowerPoint. I have compliments here, thank you [pause for six seconds].

Okay, “Please talk more about Users First advice help line. Who staffs it? How do I find it?” The number is on the PDFs and you can also submit your story and there are five people that staff the helpline. And the helpline, actually, we are connected to Spinal Cord Central. Spinal Cord Central has lots of information on it, that's the staff that will follow your question and working to answer the question in an objective manner. Like I said, we won't give physical advice or even seating advice or recommendations. I think that's it for now. It is one minute before the hour. Eric, is there anything you'd like to talk about? Thank you so much for your attention. It's been wonderful. We welcome your suggestions or concerns in any way. You can log on to the map; at the bottom of each page, there's a suggestion button. You can write anything in there. Okay, thank you Eric and thank you everyone for your attention.

Eric Larson:

Thanks Ann, the only other thing I did want to mention is for those of you who might want to learn more about competitive bidding

and what we're doing as an organization to be part of fixing that process, you might want to consider registering for an upcoming webinar we have that's being put on by our public policy folks on March 29th. You can find more information on our website about that at www.spinalcord.org. Thanks Ann, and thanks everyone for attending. Have a great afternoon.

ANN EUBANK: Thank you./AT/jf/mjv/sg