

**ROUGHLY EDITED TRANSCRIPT**

**"No Wrong Question: A Smorgasbord of Resources for Day-to-Day Disability Issues"**

**May 29, 2014**

**3:00 p.m. EDT**

**Captioning Provided by:  
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>> Can everybody hear me okay? Great.

>> ELISSA ELLIS: It's about three minutes after. So we're going to go ahead and get started. I'm Elissa Ellis. This is my first IL Conversation since Kathy hatchery tired. So bear with me. The IL Conversation is presented by the IL-Net, a national training and technical assistance program of ILRU, Independent Living Research Utilization, and is organized and facilitated by APRIL. We're happy you all could join us and we're looking forward to a lively discussion. We have an hour and a half, so we'll start out with an introduction of our speaker and then he will discuss "No Wrong Question: A Smorgasbord of Resources for Day-to-Day Disability Issues." We want to keep this as conversation able possible, and I know questions will come up as we go through this material. So we'll open it up at the end for questions.

Mike, if you come to a natural break and you want to take some questions, that's fine. If not, we can do it at the end.

A little housekeeping before we start. Print documents and links are available at [WWW.APRIL-rural.org](http://WWW.APRIL-rural.org). We are providing CART captioning services today and that can be accessed via the APRIL website that I just gave you. You'll probably see today's IL Conversation on the front page and notice the highlighted areas and you'll find a link to the CART.

You can send questions via the chat line as we go along. I would like to ask everyone to put your phones on mute once we begin the presentation. This is a bridge line. It's pretty sensitive to background noise, paper shuffling, anything, it's going to pick it up. So \*6 will mute your phone.

I also want to remind folks that cell phones and speakerphones tend to cause distortion on the line. So if you have the ability to access a land line that would be great. I understand that you may not have access to a land line.

Once we get to the Q&A part I will try to moderate the discussion, but if we could try to be as courteous as possible and not talk over each other, that would be great.

And we'll try to go one question at a time. And I would like to introduce our presenter today, Michael Collins. I'll tell you a little about him and turn it over to him.

Mike Collins recently retired from the position of Executive Director of the National Council on Disability in Washington D.C., a position he held since June 2007. NCD is an independent federal agency charged with advising the president and Congress about the broad spectrum of issues of importance to people with disabilities. Mike's government executive experience spanned 18 years, beginning with appointment as assistant director to the Washington State Department of Licensing, continuing as regional terminals manager for the ferry system of Washington state Department of Transportation, and included over 10 years spent as the first Executive Director of the California State Independent Living Council.

Mike also had a varied disability public service career before moving to our nation's capital, including more than eight years spent as a consultant and trainer on the Americans with Disabilities Act, the ADA. Accessibility, emergency preparedness and disability awareness. While living in Washington State, he served as an appointee to the Governor's committee on disability issues & employment, the barrier-free technical advisory group of the state building code council, two separate transit advisory committees, and the state independent living advisory council.

Since his disabling injury ended his 23-year railroad career in 1988, Mr. Collins has become known as the "boundary spanner" for bringing information about disability and independent living to the attention of individuals and organizations that have never considered the concept. Over 100 articles written by Michael Collins have been published in magazines, newspapers and professional journals. These cover subjects as diverse as travel, cost-effective application of the ADA, and life from a "wheeler's" perspective. Mike is also a member of the "BLOG Squad" for the Christopher & Dana Reeve Paralysis Foundation, where his articles are published online on a regular basis. An integral part of his success in these ventures is his ability to personalize the disability "experience."

A graduate of Bellevue Community College and University of Washington, Mr. Collins is a member of the University of Washington Bothell Alumni Council and of the advisory board for the National Center for Personal Assistance Services at UCSF. He serves as a peer mentor for the Northwest Regional Spinal Cord Injury System, is a contributing editor for "New Mobility" magazine, where his Everyday Advocacy and Motorvation columns appear, and is past chair of the Disability Task Force of the National Fire Protection Association. He is currently completing work with a technical standards committee of the Rehabilitation Engineering Society of North America, which developed standards for emergency stair travel devices used by individuals with disabilities. Mr. Collins is also a founding board member of Global Mobility, an international charitable organization that distributes new and refurbished mobility devices to people in developing countries around the world. Besides these long-running commitments, he serves on several other committees and is a board member of organizations that work to improve the quality of life, safety and independence of people with disabilities.

Prior to a recreational ski racing accident, which resulted in quadriplegia at the C5 level, Mike was an accomplished weekend athlete who completed regularly in multiple life sport events. He also coached, organized races and experienced event announcer, outdoorsman and most importantly proud father of two exceptional daughters. They have since gifted him

with three grandsons who are the pride of his life and keep him young while enjoying his semi-retirement in Redmond, Washington.

Again, Mike is here today to talk about "No Wrong Question: A Smorgasbord of Resources for Day-to-Day Disability Issues." And I would like to turn it over to Mike.

>> MICHAEL COLLINS: Thank you very much, Elissa. I apologize to everybody. I didn't realize that we were going to do that long form. That was an expensive call on your part. So thanks for bearing with it if you did.

My name is Michael Collins, and I have retired recently, but that recently has now morphed into four years since I left Washington D.C. But fortunately with my writing and the contacts I've made across the country during the past several years, it's been possible to keep my oar in the water, so to speak and try to keep abreast of all the changes.

Don't presume anybody on this call has the same disability as me or that I can guess what your issues are, but I hope I hit on a few of them here today.

I just realized while Elissa was talking I last addressed APRIL at a conference in October of 2006, and a lot hasn't changed since then.

With that, I'm going to kind of wade into some topics here, and we will take breaks, and if you have a question along the way, I think there's a way that you can send a note to Elissa and she's welcome to interrupt me at any time.

So without further ado, I hope you can all understand me and hear me. I picked up some kind of allergy yesterday evening and went a night without sleep. So my voice may be a little bit different today.

I want to discuss some of the things that are going on in this country right now that impact all of us, and when I say all of us, it means people with disabilities and people without disabilities, and that's emergency preparedness.

We've all been watching the news lately, and there's been fires in multiple states, a huge mudslide in Washington State that killed 33 -- 34 people, one that killed three people in Colorado. We're facing forest fires and wildland fires on a daily basis. And I think it's important that we all revisit what is important and how we can be better prepared to protect ourselves and our families whenever the inevitable emergency arrives.

Now, I don't live in tornado country, and I can't imagine what it's like now with the increase in tornadoes, but I did live in southern Illinois and Missouri for a while, saw tornadoes, lived under the warnings. So I know that there isn't much you can do once something like that gets there. The same with the floods that hit New Orleans and many other cities since then. Earthquakes that strike California on a regular basis and even the Midwest. And we're all living under threats of terrorism, both today and for the past 10 or 12 years.

We're fortunately not getting a lot of hurricanes lately, and we can all be grateful for that. But we should be prepared for all those things to happen. Some of you live in areas like Kansas where there is a lot greater incidence of tornadoes, but you also get hit with winter cold spells, summer heat spells, and there are times when you're going to be dealing with the same type of problems that the big cities have, somebody taking over a school, a shopping mall or a community to do wrong.

So, I hate it when I see those things happening because I know nobody in that community could be anticipating that or been preparing the individual person who just decides

to take it upon themselves to make other people's lives end or make them worse.

I'm going to do something for APRIL when I get done, I'm going to send a file, and I don't know if you have PowerPoint or not, but I'm going to send a PowerPoint file that you can link to this presentation. It will have a lot of detailed information about emergency preparedness for people with disabilities.

But there are several things we need to be more involved in. Those of you may remember a couple of high profile lawsuits that took place about four years ago against Los Angeles and then subsequently New York City because they had little if any planning for people with disabilities in their emergency response plans, and the Department of Transportation and the homeland security agency did not like that, and as a result there was a settlement and they pledged to upgrade their plans.

We can do something right along with our communities when it comes to disaster preparation, and I'm not going to go through the long list of items that all of us should have available to ourselves and our families, but I think it's important that we just think for a second about what's going to happen if there is an emergency in your home or your community. And I benefited early in my career from -- if you could call it a benefit -- I was working with the National Fire Protection Association Disability Task Force I was chair of, and we had a meeting in San Diego and about that time the wildfires struck along with the Santa Ana winds like the wildfires that struck there last month and they burned down entire cities, and during that time I ended up trapped east of the city because the highways were closed and I couldn't get back into San Diego where I was staying. I saw a lot of people who were evacuated, many who evacuated without having a clue where they were going. The highways were plugged. There were no police out directing people to safety. The shelters that they identified didn't have any known accessibility. And they ended up, as a result, driving back from Eastern California into San Diego via Northern Mexico during the night. That's not something I would recommend to others, but sometimes you've got to do what you've got to do.

I think it's important that you prepare to evacuate at all times. You should all have an emergency kit that's kept in a closet by your front door where somebody can grab it on the way out. A three or four-day supply of your medications, all your emergency numbers, copies of your identification, just in case you leave your wallet by your bed when you move out in the middle of the night, and a plan to notify others in your family or your household of your plan, and working together to figure out how you can evacuate in a timely manner.

Part of the evacuation process that has been a real problem has been transportation, and we all know that if you're in a power wheelchair, like I am, it's not going to be easy to find quick wheelchair accessible transportation on short notice. This has been a problem in most disasters, and it's a problem not only for the evacuation and getting people to a shelter, but getting people home afterwards when the emergency vehicles may not have been running and the shelters are closing down and everybody is taking home all of the goods that they were given... the cases of water, emergency food, sometimes clothing that seem to show up in Red Cross shelters and other shelters after a disaster.

There have been some real problems in this area, and I'm very pleased that we have Marcie Roth working at FEMA, and she has been for several years, to really raise awareness about how critical our needs are in these disasters. So I'm sure many of you know her personally, or at least know of her, and I would really like to single FEMA out for taking the

steps necessary to make it safer for all of us. Since I left Washington D.C., FEMA has hired regional coordinators to Converse with the disability community, to work in disasters, and it's really great because their infrastructure at the federal level has also been strengthened. She's had the support of her superiors all the way through and made good use of the power that she's had. So if you haven't been to one of the FEMA meetings, if you haven't been on their website, just take a few minutes to do it. There are a lot of great hints there and a lot of great contacts that you can use in your own house and in your own community.

I would presume that some of you have taken that on personally, and I am really pleased, because when I first starting about this many years ago there wasn't a lot of interest on the part of the disability community. I applaud APRIL because they invited me to that 2006 conference to talk about this. In many communities they didn't talk about people with disabilities until they showed up in an inaccessible shelter with no services, no cots they could transfer onto and no transportation or interpreters to deal with their issues.

So we've come a long way, but we can come a lot farther. Everybody gets a little bit better prepared.

If you haven't already checked into it, I would recommend also that you get signed up on your local smart 911 system. Those are being expanded across the country. What that is it's a database so when you call 911 for whatever reason, particularly in an emergency, they have your information already on file, and if you have a disability or you have a particular concern about where you're living, such as a service dog that's vicious in the middle of the night even though the dog is really friendly during the day, you can put that information in there so that first responders are not surprised. And you can also take the Community Emergency Response Team training and form local CERT teams or join teams already in place. That is very worthwhile even if you don't feel there is anything you can do actively in an emergency. There are jobs that people can take on even if it's only to provide information to others who are concerned about what's happening in their lives.

So with that I'm going to jump off to another subject. I'm going to go ahead, Elissa -- is there anyone that's got a pressing question on emergency preparedness or disasters? I'll entertain a couple of questions here and then we'll follow up at the end. Just be sure if you're trying to talk to us that you take your phone off mute. Just temporarily.

All right. Dead silence. The.

>> PARTICIPANT: Yes, good afternoon. My name is David with the Center for Independent Living, and my question is: For the national database for persons with disabilities, now, is -- what number would they call to provide that information about their particular disability or something that they would like first responders to know?

>> MICHAEL COLLINS: If you don't have the smart 911 system in place in your community yet, you can simply call your local fire station and find out if they will take that information, and that's what we did before this super system was being developed that's covering more of the country. So it's good to have that relationship with your first responders. I know I've gotten to know mine personally a couple of times when I ended up on the floor during a transfer. So I think it's an important relationship that they know who you are, where you live, what your conditions or concerns are, if you have any, and you don't need to have a complex system.

Now, a lot of communities send out email updates with that smart 911 system is in

place, and you can simply type in in a browser "smarter 911" all one word and you should be able to get -- you can Google it and you should be able to get a locator and see if there is that service, the formal service available, but don't let that stop you from contacting the local first responders and let them know about yourself and your concerns.

>> PARTICIPANT: Thank you.

>> MICHAEL COLLINS: All right. Thank you for the question. We'll move right along.

Now, most of you probably have traveled, at least to go to a conference somewhere or get to Kansas City or wherever you were wanting to get out of your hometown. So you've dealt with the transportation network one way or another. Some of you may be relegated to buses or trains because you don't have a major airport. But air travel for people with disabilities has been very problematic in certain circumstances in the past, but it's being improved, and the air carrier access act which was passed in the late '80s, did a lot to make it easier for us to travel and gave us rights and informed not only the individuals with disabilities and their companions about what was important when you travel, how to be prepared, but also it informed the airlines what their responsibilities were and provided a means for people to file a complaint immediately upon arrival somewhere if they were mistreated or if their rights were violated during a flight. I've done that in the past, as has anybody who has traveled with a powered wheelchair or scooter or even a manual wheelchair or somebody who has require special services, like somebody to help them through the terminal if they have a vision loss or somebody to help communicate should they not be able to communicate with airline staff.

So, as those things happen you can get to a complaint resolution officer at the final leg of your trip, file a complaint, and you will get a response both from the airlines and from the Department of Transportation in a fairly short time. If you have damage to your equipment, usually the airline will arrange to make repairs should you be traveling somewhere like Washington D.C. They have contracts with local vendors who can do those repairs. And I've had to use them several times on trips, including Washington D.C. and New Orleans and St. Louis. So there are people located around the country that will come out on a weekend and replace a broken joystick or a flat tire. And we can do things to minimize the opportunity for that damage to happen, but when it does inevitably, there's a way to get resolution.

One of the things that the Air Carrier Access Act changed to in 2009 is it carried foreign airlines to the air carrier access coverage. So we theoretically have the same rights on foreign carriers as long as footprint touches the United States. It's well worth it to go online if you're planning a trip to take a look at the brochures that they have available through the Department of Transportation, and there's a brochure, and it's a New Horizons. It's a travel brochure for people with disabilities that you can print out and carry with you. You can also print out a copy of the Air Carrier Access Act in case somewhere along the way somebody gives you problems, and I have a couple individuals who have contacted me recently just for that reason. In one case a gentleman was trying to make a reservation. He needed aisle seating. He wanted to be able to access the restroom even though he couldn't walk. So he wanted to be on an aisle seat and be as close to the front of the plane as possible. Now, any plane over 100, any jet, has to have portable wheelchair on board to make it available for those of us who might want to try reaching what is probably an inaccessible restroom. But this individual was told that because airlines have put all these fees on lately that the aisle

seats were now premium seats. Well in the new carrier access act half of the armrests on airlines -- or on airplanes are supposed to be removable. Unfortunately, those are just the new planes that are coming on board. So this gentleman had very limited aisle seats to choose from that had a removable armrest. They were closer to the front of the plane. But the airline was trying to charge him premium seating. He was urged to contact them again, to bring up the Air Carrier Access Act in his conversation, read them the Section about the inability to charge more for people with disabilities, and he was eventually successful in getting the seat he needed.

Now, if you've ever seen those portable wheelchairs they carry on an airplane, you really don't want to try to use them. They didn't have an aisle chair one time, and so they were in a hurry to get a plane boarded, so they decided to pull the portable wheelchair out of the back of the plane and put me on it. Well, turns out to be like an upside down milk crate with a little sling back on it, no foot rest, sits real low to the ground and has four wheels on it. So they had to hold my feet, hold my back, and two people had to maneuver me down the aisle. It wasn't very dignified, but I certainly knew when we were done that I did not plan to use it again. When we arrived at the destination there was an aisle chair there.

Now, the other issue that was brought up just recently was somebody who wanted to put his wheelchair seat in the airline seat so that -- in the airplane seat so he could protect himself from pressure sores and it would be more comfortable. Now, the airline said that he wouldn't be able to do that because they had their own seats and it should be safe for him, but that if he wanted to put his cushion on top of an airline seat, the airplane seat, could do that, but we all know if you're seating with your hips above the armrests and the back is below your head, you're not going to be secure and it's not a safe way to travel. So he was recommended to call the airline, talk to customer service, and they all have customer service, even though they don't deliver it very often, and make sure that they understood his needs and that this was a medical necessity r that he needed that cushion to protect himself from further difficulties and that he would be able to move the airline seat out -- he wanted to be able to move the airline's seat out of the seat base and put his own there. He was successful in doing that, and the only problem that I could see happening with that is that if he had a J cushion or something that had a solid base that would be too wide for those skinny little seats that they call airline seating nowadays. So there are a couple things that those gentlemen found out and that's that it's good to let people know you're coming. You're not required to do that unless you have a power wheelchair, would be using oxygen or have greater needs the airline would need to take care of while traveling. It's a good idea to do that. I always whenever I fly let them know who I am, let them know I have been on their planes before, we've had a couple problems, I don't want them to happen again, and then to tell them if they need resources I will send them a copy of the Air Carrier Access Act with the area highlighted that refers to whatever service/problems they're talking about delivering.

One of the issues that often happens is people want to have their service animals with them. Now, with the new changes in the ADA, service animals were more clearly defined as dogs and miniature horses. No longer could people take their cats and lizards and snakes along in the airline cabin and calling those services animals. So you can expect that your dog -- and I'm not sure about the horses thing, but as far as I know that hasn't happened yet, but you could have your dog with you on the plane for your entire trip and they can sit

beneath your feet or underneath the chair directly ahead of you just as if you would put a carry-on bag in there.

There was one trip for -- I think it was on Southwest Airlines, there were six of us sitting across the front of the plane, and five of the individuals were going to a conference, and they all had service dogs, and they were all impeccably behaved for the entire trip and actually they were more of an attraction for the other passengers. They were always stopping and wanting to talk to the individuals as they -- as people passed back and forth to the restrooms.

Are there any particular questions about air travel? Other problems that people have had that I might be able to provide a little bit of information about?

All right. Moving along. The ADA in many of my BLOGs for the Christopher and Dana Reeve foundation revolve around the ADA and access, both physical and programmatic access. As I said, I've had years' experience as an ADA consultant. I helped work on the regulations after the ADA was passed back in 1990. And I worked on the state level to help modify state building codes so that they were substantially equivalent, which is the term they use, with the ADA and so that all new construction is supposedly accessible where it needs to be. Unfortunately, housing has not kept up with some of the businesses, the buildings, the infrastructure, government buildings, and I've been very disappointed because housing only -- housing regulations only cover multi-unit housing. So if you want to live by yourself in a new development that has individual homes and you want an accessible home, there is no requirement that they create it for you, and -- one of the things that happened to me not long after my injury in 1988 is I tried to get a builder of a new apartment building to modify the bathroom, and they hadn't even moved the bathtub in. It was just framed in. And to put a roll-in shower so I could move into the apartment and have attendant care there. And the owner refused to do it. He said he wasn't required to. And he was right at the time. There was no requirement. It was pre-ADA. But it was just an attitude that has been so pervasive over the years that even though I offered to pay the costs he wasn't going to do it because he didn't have to do it.

The ADA, the Americans with Disabilities Act, has brought us a long way, but there's still a long way to go. I know that for myself I run across problems with parking on a regular basis. I drive a wheelchair van that has a lift on it. So I need van accessible parking or I need the ability to take two normal parking spaces, angle across them, and hope that I won't come back to my vehicle and find key marks all the way down the door. You know, this has happened to me already, and it's happened to several of my friends, and it's unfortunate that we live in a society where people don't recognize that you're driving an accessible vehicle even though there are big signs posted on it asking people to keep clear of the doors. They would rather leave nasty notes, use little spray cans or a key scratch to let you know they were there and how brilliant they are. So, it's too bad, but one thing you can do is when you get confronted by somebody that's giving you problems that way, if you catch them in the act, or if you find somebody parked illegally in the space that you need or your friends will need, you can pick up the phone, call local law enforcement, and in most cases, if they have the personnel available, they'll come right out and ticket the person who is parked illegally. We've had a series of television exposés out here in the West Coast for the last several year due to the fact that people are using accessible parking placards and monopolizing the use of parking spaces downtown and around government buildings. This was especially pervasive in



California when I worked in Sacramento, and it's also very common on the streets of the big cities where there may still be the option to park free if you have accessible plates or a disability placard. So people borrow them. They steal them. They forge them. And they simply use those that belong to their relatives until they get caught. So in Sacramento one day I traveled around the block -- a block near some of the state office buildings, just around one block. There were 40-some vehicles parked with accessible placards. Now, I knew a lot of the people with disabilities who worked in California state government, and those with mobility disabilities did not rise to that number around that particular agency. So I would encourage you if you're having a problem with it and your local community that you work with the building owners and you work with the local building council or the city public works to make sure that all new construction and all new buildings have the required minimum of accessible parking and van accessible parking.

Now, they have changed the dimensions of those parking spaces slightly in the new ADA, but they are still sufficient for those of us with vans to use right along with other vehicles.

The other thing that you can do is you can kind of be a crusader for the rest of the disability community by going into a business, talking to the owner, talking to the manager, and letting them know that you're very concerned because they don't have sufficient accessible parking. I can tell you that there are new facilities in this area, including hospitals, which have an even greater requirement for accessible spaces, that don't have enough. Some of these facilities are new, within the last two or three years, and they need to be upgraded even now. So those type of situations benefit from conversations with the managers, owners and also the local public works or building office. So don't be shy about that. Somebody else might appreciate it down the road. I know in California for a while they had a vigilante group of individuals, some of whom I know, who would go out with the city's blessing and actually give a warning or give a ticket to people who are illegally parked in accessible parking spaces. Now, I understand that was stopped because there might have been a little abuse of that privilege, but it's still something that raised awareness, got coverage in the press and hopefully made a difference in a few cases.

Are there any ADA-related questions?

>> PARTICIPANT: This is Pam. How do you determine the number -- what that minimum number is? Is it based on space of the parking lot or what?

>> MICHAEL COLLINS: Yeah, it's based on the number of parking spaces in the lot as a whole, and just going off memory, it used to be for every 100 spaces there was a requirement for 8, but on any parking lot if there's only one or two parking spaces, a minimum of one accessible parking space must be present, and it must be van accessible.

>> PARTICIPANT: Okay.

>> MICHAEL COLLINS: I think I'm right on the 8 per 100. But I do know that 1 out of every 8 needed to be van accessible, which means that it had a wider access aisle for getting off the ramp or off of a lift. But that's in the ADA regulations, and if you go to the Department of Justice website or go to [ADA.gov](http://ADA.gov) you'll get more ADA information, including all of the requirements. And there's also a great question answered answer Section on there for frequently asked questions, and they really anticipated what you're going to be asking. Most important subjects have been covered there.

>> PARTICIPANT: Thank you.

>> MICHAEL COLLINS: So I would urge you to do that.

I'm going to move on here to talk a little bit about what's happening with health insurance and healthcare. Now, I've been a Medicare client for a number of years now because of my disability, and my age now, but it's important that you realize that we are supposedly getting benefits from the healthcare act thanks to improvements that have been made for everybody. Unfortunately, at the same time there have been improvements in healthcare overall, there have been problems related to the fact that the center for Medicare/Medicaid services or CMS, has put into place a competitive bidding program for wheelchairs and other durable medical equipment. This is an issue that if you're working in disability you know about it already, but just a couple of really important factors. In the first place, there has been a huge consolidation in the vendor industry. There are far fewer places to go. In some cases people might have to travel over 100 miles to get to their nearest wheelchair repair facility. And some of the people that got the contracts are not even capable of doing the repairs to the equipment they sold.

The other issue is unless you're dealing with a complex rehabilitation wheelchair, one that requires such things as tilting and recline functions, you may not get exactly what you need. Immediate care or CMS has started putting in a policy that rental of equipment is their preferred situation. So if you receive a wheelchair but you need some type of access re for it, they may recommend that the vendor or a different vendor rent you whatever you need. This is a real problem because if you have a wheelchair that has batteries from a different vendor and a wheelchair come from your local vendor, what are you going to do when the batteries go bad? Your local vendor isn't going to service that wheelchair because they didn't sell you those batteries. This is causing problems across the country. Congress was against this, CMS did it as a project, as a demonstration project. I'm thinking it's been about five or six years that that started. But since then it's taken off, and I know that in the case of my wheelchair vendor they've had four name changes in the past three years. They've shut down offices. They've moved to bigger locations when they merged. And there's a real problem with trying to get the service you need. And in some cases it's taking vendors a very long time to get the necessary parts because providers -- other providers, the wholesale outlets, the manufacturers, do not have the same capacity for replacement parts as they did in the past. Their hands have been tied. So they don't deal with instantaneous responses. I recently required a new switch on my wheelchair, a tilt switch, and it took almost four months for me to get it and in the past I've had it fast forwarded to the vendor in less than a week from the manufacturer. So that's a concern if somebody is stranded with a broken down wheelchair or scooter at home, they can't get out, they can't get to work, or they have to have somebody push them around in a manual chair, and a lot of us don't have somebody to do that on a daily basis.

Has anybody else had a problem with their medical insurance, their Medicare or Medicaid? Is everybody pleased to death with how it's going?

>> PARTICIPANT: My name is Brittany and I'm in Joplin. I'm in a wheelchair and I'm also totally blind, and I know I've struggled. I'm going on my fifth wheelchair, and I struggle. It took about a year to get my insurance to approve the verification to pay for a percentage of my manual chair.

>> MICHAEL COLLINS: A year?

>> PARTICIPANT: Yeah.

>> MICHAEL COLLINS: Well, unfortunately -- I mean, fortunately, you got it approved. Because I've been dealing with another gentleman the past couple of weeks who had a stroke. So he lost vision in one eye. And he was paraplegic and using a manual wheelchair. But because he had that stroke he had to -- he needs to upgrade to a power device, whether it's a scooter or a wheelchair, and Medicare and the skilled nursing facility where he was would not even train him in how to use it because they said it was dangerous for him to have vision in just one eye and he was driving a wheelchair. Well, people turn their heads when they're driving all the time. Nobody looks straight ahead. I've met individuals who were also blind and do use power wheelchairs and had a cane with a ball on it out in front of them when they were traveling down the street. Kind of set me back the first time I saw that, but after talking to them, it was just second nature. So people presupposing what our capabilities are based on the disability, that's all wrong. That shouldn't be happening.

>> PARTICIPANT: Yeah, I am totally blind, and I propel my manual wheelchair with my legs. So I use a cane to know where I'm going.

>> MICHAEL COLLINS: Right. And I imagine you're as safe as anybody else on the street when you're using that method of getting around. At least in your own environment.

>> PARTICIPANT: I've never had an accident.

>> MICHAEL COLLINS: That's great.

By the way, I send my condolences to you and the people of Joplin after all the tornadoes that were there last year. So that was really disappointing situation.

>> PARTICIPANT: Yeah, it's coming alive quick, though.

>> PARTICIPANT: Yeah.

>> MICHAEL COLLINS: Well, any of those disasters, there's usually a few more people with disabilities who join our group, and they do it because they're injured in things like floods and hurricanes and tornadoes or fires and they didn't choose to join this fraternity, but they're here with us. So we need to be aware of that for any of these disasters and make sure people in shelters and neighborhoods and through churches know that there are resources like Centers for Independent Living that they can rely on to provide them information and referrals and resources and help with housing and transportation and that type of thing. It's not easy living independently with a disability when you haven't had one in the past, and a lot of people get transferred into our corps very quickly. I want to talk about driving. I assume some of you on here drive, have driven or want to drive your own vehicles. One of the columns I worked on and I write for "New Mobility" is called motorvation, and that's about anything to do with driving with a disability. I've covered such things adds lift-equipped pickup trucks so that you can drive a pickup if you can drive any type of vehicle. They have a lift so that you can lift your wheelchair right up underneath the wheel. And I'm also going to be doing one on motorcycles. A lot of individuals who you wouldn't think could drive a motorcycle because of their paralysis actually do that by a lot -- by a variety of means. So I'm looking for subjects, if anybody has a concern about driving. I do know that one thing is how do you afford to do it? There are a few resources out there, not many, and the national mobility equipment dealers association has helped coordinate with several independent dealers to get funding through financial institutions that are supposedly available to people with disabilities. There are also state specific projects that are designed to help people with disabilities buy

assistive technology or help paid for modifications to their vehicles so they can drive them or ride as passengers. The issues with those types of programs is in many cases they're through banks or other financial institutions that still require those who are seeking the funding to have good credit. Well, a lot of times it's hard to have enough credit to purchase a car or a house when you've been living on social service -- or SSI, excuse me, supplementary -- SSI or SSDI, and if you don't have that credit history, you may not get the loan. The other option is the State Division of Vocational Rehabilitation or department of rehabilitation, whatever it's called, and those agencies are also state specific, and some of them have programs where they will make funding available for modifying a vehicle if you purchase it yourself, and so you can buy a vehicle, like a van that's not modified, and they will sometimes pay for some or all of those modifications.

Now, there isn't a requirement for payback if you get DVR funding or vocational rehab funding, but there is a requirement that you be seeking an education to get employment or that the vehicle is necessary for employment purposes, and sometimes that may be difficult to prove, but I know it's very difficult to try to find employment if you don't have reliable transportation. So if you're thinking about trying to get a vehicle or if you already have one or can get one donated to you, there are means of getting it modified so you can drive. Believe me, you don't -- you can't presume what type of modifications might be required. Some modifications can cost thousands of dollars, and I'm talking about 50 or \$60,000 just to make it possible for a person with a high level of paralysis to drive the vehicle safely. But those type of improvements are funded, at least partially in many states.

And they're trying to develop new means of controlling the vehicle. I don't know if any of you looked on the Internet and you saw that Sam Schmidt, who was an Indy-car racer/driver who was paralyzed several years ago and became quadriplegic, he now -- he now co-owns a team of 3 or four Indianapolis 500 type racers, and -- just before the last Indy 500 he actually drove a modified Corvette around the track in Indianapolis motor speedway. Now, this wouldn't have been any type of news except he is quadriplegic at the C4 level, so he actually had to be transferred in. He couldn't use his arms or hands. But they have set the vehicle up so that by wearing a hat that had reflectors on it he could actually tilt his head from side to side to steer the vehicle, he could bite down on a bite -- some type of a bite valve in his mouth to apply the brakes. And if he wanted to go faster, he could simply lift his head up, tilt it back, and it would speed up in increments like it was with cruise control. And he drove it around the track, and I believe he achieved somewhere around 90 miles an hour, which may not seem like much for an Indianapolis racer, but when you're driving a Corvette for the first time after many years, I'm sure it was as much speed as anybody expected him to have. So, down the road those types of advancements may become available to all of us, but I see every day that like Google just announced they're making a car that can be driven without hands and without the use of feet. It can drive itself. That would be pretty handy if you lived in a flat area without real heavy traffic and you needed to go to the grocery store. All you would supposedly have to do is give it the destination and suddenly you would find yourself on the way to the grocery store. So those may seem like long-off, far-off fantasies for now, but the way things are going with computers, they could be available somewhere in your neighborhood fairly soon.

I want to talk just a little bit about some of the things that I've seen happening that are

trends we all need to be aware of. For one thing, the National Council on Independent Living and APRIL have been working for years to try to get Congress to grant more funding for independent living, and they also have been looking at perhaps getting a different home for the agency instead of the Department of Education. RSA, the Rehab Services Administration, is located in the Department of Education. So it doesn't get the same type of attention that educational programs do and schools. So I don't want to weigh in on a political argument here, but it's important to keep abreast of those types of activities taking place at the national level and support NCIL and APRIL and the other organizations that are trying to move the agency, and I think at this time they were hoping -- or most recently they were hoping for it to be placed within the Department of Labor because that's where a lot of us need to be, working. So I'm hoping that there will be some news on that front sometime in the next few years, but with not already funding programs adequately and new programs not being introduced, it may be a far off fantasy on my part.

Are there any questions up till now? You guys have been doing well with your questions. You haven't stumped me too badly, but I suppose I'm due.

All right. We have about 20-some minutes to go here. So I think it's interesting when you think a bit about where we've come, and especially if you look at how we can live in the community. Now, there are programs that are out there that allow people with disabilities to get funding and to create congregate housing that has services available. There's a program in Portland that is called quad housing, and it's a group of people with disabilities who have banded together to have an accessible apartment building of their own and they also have services available so that they can share attendant care or other type services like that that they need. I haven't visited the program. I don't know if it's as good as they say it is. But if you have an interested in creating something like that in your community, you'd be wise to get a hold of them and determine what they did to set it up and how you might find funding to set it up in your community. I know in the past there was funding available for people with psychiatric disabilities, but a lot of us didn't want and don't want to live in a location that is only housing people with disabilities, even if they are similar disabilities. So those programs are for people who want them, but having accessible housing is critical, especially if it's affordable, and Section 8 housing has not been increasing every year -- or every budget cycle in Washington. They state that they're increasing it, but it's very incremental. So there's not a huge influx of housing available, and a lot of it is taken up by individuals who are not disabled but who happen to be located in those accessible units. And the name of that organization in Portland, in case you want to look it up, is Quadriplegic United Against Disability, Incorporated. You can look that up on your browser and check it out for yourself, contact them by email, and see if that's something that might interest you or your friends. And if you do create something like that or are seriously considering it, I would like to hear about it. I would like to share the news with others who are reading my columns, my BLOGs and let people know there are options they may want to consider down the road.

I recently had an inquiry from a gentleman who has been in Section 8 housing for the past nine years, and because he's paralyzed as a high level and requires a live-in attendant and also has equipment like breathing equipment and exercise equipment in order to do his range of motion, he was granted the ability to have a three-bedroom house or apartment and only pay for two bedrooms. Well after, I think it was eight or nine years, he recently found out he

has been overpaying. They had been charging him for the three bedroom unit even though he wasn't supposed to have to pay for it. So he contacted the housing authority in the county. They said, yes, we'll make that change, and we'll postdate it for two months so we won't take the normal amount out of your SSI check. Turns out he -- he wants to get all eight years of overpayment back and they're not willing to budge on that. So he's going to be contacting the housing -- the department of Housing and Urban Development and also the local statewide disability rights law firm and seeing about getting that entire refund, because it could make a real difference in his life and in all of our lives. So that's another resource you should all be aware of. There are disability rights law firms. They may have a simple name like Disability Rights California or Disability Rights Washington, but these are law firms that are set up with a National Network, and their purpose is to protect the rights of people with all types of disabilities and they deal with complaints. They deal with lawsuits in some cases. And they can advocate for you if you have an issue with a landlord or a vendor for equipment. If it comes to the point where they need to represent you in court, they can do that without cost. So it's a really good resource to have, and there's a national disability rights network, NDRN, and you can go online and look that up, and they can give you the state offices, make those contacts, and even if you don't need them for something now, let them know that you and the staff at your independent living center are available to provide them resources locally or to work with them if they have an individual that needs some type of assistance you might be able to provide.

A lot of times people don't look for that resource. They think that when they have an ADA complaint, for instance, their only option is to hire an attorney and file a lawsuit, make a formal complaint with the Department of Justice. Those things are all feasible, but you don't have to do that yourself if you can get a pro bono disability rights firm to back you up and represent you in those cases. So I will actually tell you that I plan to do that in the near future on a situation I've been working with that's proved without -- I haven't had any good results from it yet. So I'm tired of it and going to be working with my statewide disability rights agency to -- law firm to represent me and try to get the corrections made.

The same -- if you have an ADA, an Air Carrier Access complaint you can file your complaint with the federal agencies that are responsible, like the Department of Justice for ADA, or like the Department of Transportation for an FAA, Federal Aviation Administration, for Air Carrier Access Act problems, but you don't have to do that by yourself. You can go ahead and let somebody else do it and sit back, be the witness, be the complainant, and who knows, you may not get any money out of it, but that's not the purpose. The purpose is trying to get everything improved so it's more accessible for all of us. There is a trend where I live where our Congress or state legislature has been doing political infighting for the past several years based on their political parties, not working together, and not fully funding important programs, and some of those important programs are education, healthcare and transportation. As a result, our local transit agency, which is countywide, has recently come up with a proposal that if the local citizens don't pass the funding initiative to increase our taxes, they are going to impact over 150 bus routes, transit routes. Now, I recently wrote a letter to the editor about this because nobody thinks of who is really hurt in these types of situations. The routes that are going to be impacted, over 70 of them are going to be cut all together. They're going to take service away. Another 84 or 82 are going to have service

reduced. So where they were running from four or five in the morning until 10:00 at night, they will suddenly be reduce to do rush hours only between 5:00 and 7:00 a.m. and the other service would be 7:00 -- 5:00 to 7:00 p.m.

I may be losing my phone here. Is anybody having trouble hearing me? Is anybody else hearing a beep?

>> PARTICIPANT: I am hearing the beep.

>> MICHAEL COLLINS: Maybe it's not me, then, I hope. I wrote a letter to the editor about this because the people who are going to be impacted are not those who have their own cars and can drive to a park and ride or whose employers are paying for their service, their transportation costs in a bus or van pool. It's going to be the care attendants, restaurant workers and the students that need to ride late in the evening or early in the morning, and nobody talks about the paratransit network. We all know if they cut bus service, they'll cut the paratransit network. I live in more of a rural area, or suburban area, and I'm afraid the paratransit network may disappear for a lot of senior citizens and people with disabilities who rely on that as their only transportation. So we'll see what happens, but it's probably going to happen in your communities if it hasn't already, and when there are cuts to be made for budget purposes, we can all step up and try to raise awareness about who is really hurt the most when those things happen.

I'm going to go ahead and take a couple questions if there are any. In case I get cut off, I'll have to call back on another line, but I'm hoping that we get through this.

Elissa, did you have any written questions that came in or --

>> ELISSA ELLIS: We did get a comment from the chat line regarding the vehicle modification. For anybody living in Kansas there's a program called the K-loan program, WWW.K-loan.net.

>> MICHAEL COLLINS: And that's the assistive technology funding that's available in several states that I mentioned that usually goes to the financial institution and the intended purpose is to get us loans to purchase vehicles that we couldn't afford otherwise. So thanks for sharing that, whoever did.

>> ELISSA ELLIS: That was Bill Cochran at SKIL in Kansas.

>> MICHAEL COLLINS: Thanks, Bill. Are there other questions? I either put everybody to sleep, overwhelmed them with information they're still writing down, or nobody cares. But I'm hoping you all care because what you're doing is critical, and APRIL has done great work with their transportation grants working through the University of Montana and Alexander Enders and Dr. Tom Seekins. And you have other good advocates in Kansas, too. You have Dr. Glen White at the University of Kansas and Mike Oxford at an ILC and many more people who never stop raising awareness and making things happen. So I think that I could probably point out people in every state that are involved with this network that really do a good job and have truly met the letter of the law when independent living centers were created originally out of the Rehab Act. Nobody anticipated there would be this many centers and branch offices, but you guys have all survived, you're doing a good job, and I applaud you and encourage you to keep it up and keep expanding your reach and your influence because you do make a difference.

>> ELISSA ELLIS: Okay. Well, we're coming up on just about 10 minutes short. I think we're good. Does anybody have any more questions? Okay. Well, thank you all for

being here today. Thanks to our CART provider and SKIL in Kansas for recording the call. I would like to invite you to visit the APRIL website where you will find the documents discussed today. I'll get that PowerPoint up there that Mike talked about earlier in the call. An archived copy of the transcript for the presentation. Go to [WWW.APRIL-rural.org](http://WWW.APRIL-rural.org) and look for IL Conversations. If you have any questions about today's discussion you can reach me at [APRIL-Elissa@SBCglobal.net](mailto:APRIL-Elissa@SBCglobal.net). And this IL Conversation is presented by the IL-Net, which is operated by the Independent Living Research Utilization program at TIRR Memorial Hermann in partnership with APRIL and NCIL. Support for the presentation was provided by the Department of Education Rehabilitation Services Administration. No official endorsement of the Department of Education should be inferred.

Thanks so much. Good-bye.

>> MICHAEL COLLINS: Thank you all for inviting me.