

Date: 04/08/2015

Event United Spinal webinar

The ADA Legacy Project

This text is being provided in a rough-draft format. Communication Access Realtime Translation is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings.

(on stand-by for webinar to begin)

>> Good afternoon and thanks for joining the United Spinal Association webinar ADA Legacy 25 Celebration. My name is Bill Fertig, director of the spinal cord injury resource center and I will be your moderator for today's presentation. Today's webinar is one of the a series that United Spinal Association will be hosting and all of our webinars will be archived at [www.spinalcord.org](http://www.spinalcord.org). We will have time at the end of today's presentation for questions from the audience. Please use the questions window on your control panel to write in any questions that you have and we will do our best to get to them today.

If we do run short of time during the question and answer

session you may pose your question for later followup.

Mark Johnson is presently director of advocacy for Shepherd Center in Atlanta. He is serves as chair of the ADA legacy project that is working to preserve disability history, celebrate its milestones and educate the public and future generations of advocates. Mark has a masters of education degree in guidance counseling from the University of North Carolina at Charlotte. Is he a graduate of several leadership programs and past president of the final for southern communities a progress I have farm that commits to social change in South Carolina, North Carolina, and Georgia. Mark is one of the founders of adapt and has received a number of awards for his advocacy in organizing across disability in health and human service organizations. Now I'd like to hand it off to Mark Johnson to present on ADA legacy 25 celebration. Mark.

>> Mark: Thanks Bill. I appreciate the opportunity and I appreciate the folks that have tuned in this afternoon and I know everybody's out there doing good stuff and hopefully you'll keep doing good stuff and hopefully the information we provide you will be helpful.

I have a PowerPoint and I know that will be part of your

archive and I just want to give you a little history to the project. I think sometimes it's important to understand, you know, how this evolved. I know when I was involved in the tenth anniversary of ADA, you know, almost 15 years ago, you know, we had actually started the planning of it in 1997 and literally the tenth anniversary obviously didn't occur until 2010 and we did a 24-city 2-month torch relay called the spirit of ADA. So some of the same people got together in August of 2012 and -- here in Atlanta and the Amerigroup Foundation and the Shepherd Center hosted that. And about 30 people came together. Some of them were activists, some of them were folks that make documentaries. Some of them were historians, scholars. We had representatives of different government agencies and we basically talked about, you know, how little the general public knew about the disability rights movement. And part of the issue of whether or not many people know about the disability rights movement is we haven't done a great job of preserving the content nor telling the story.

And so it's hard to tell the story if you don't preserve the content so really the initial conversation for the ADA25 summit was really who are those people around the country that are doing a good job of preserving history?

You know, and to our surprise, you know, we found a couple websites that were really good and we found some folks out in Minnesota that were doing an excellent job. We found actually literally there's a small brick and mortar disability rights museum in buffalo, New York. You know, there are a handful of books out there. There are a handful of articles. Some of you might have seen on PBS or you might even own a copy of life for living. It's nice documentary that documents our movement from 1968 to 1990 when ADA passed.

So once again the summit started with that conversation about, you know, if we want more people to know about the movement then we've got to do a better job preserving the content because if you don't preserve the content, you can't tell the story. And so what happened was we came up with the concept, you know, and we called it the ADA legacy project and as bill alluded to a little bit, you know, our mission is just to honour the contributions of people with disabilities and their allies by preserving the history of the movement, by celebrating its milestones and by educating the public and future generations of advocates.

And so, you know, preservation efforts started initially.

We began to realize our significant milestone is coming up this July 26<sup>th</sup>, meaning the 25<sup>th</sup> anniversary of the Americans with Disabilities Act. And we began to educate the public through a tour that we're doing. When you think of preserve, celebrate, educate, you really kind of think of past, present, future. Past being preserving, the future be celebrating and leading.

Our fiscal sponsor is the National Council on Independent Living. Some of you might know NCIL. It's the trade group for the independent living centres around the country.

Our oversight is not a traditional board. It's a council of people who have a lot of expertise in this area. Our direction that we take is we have some work groups. We have preservation work group, a celebration work group, an education work group. We have some people raising money for the project and we have some people, you know, doing communications. And when I say we have people, you know, we basically have five part-time staff. Most of what's being done with the project and the ADA legacy tour and with the ADA25 is really being done by volunteers, you know, folks who either are pure volunteers or people who, you know, have taken parts of their job like I hear work at the

Shepherd Center, as Bill said the director of advocacy and part of my time is allocated towards this project and tour and towards the anniversary.

The role of the project is we kind of see ourselves as a clearinghouse. When we started the conversation in 2012 some of us were aware of some things but we rapidly became aware of a lot of other things. And like I say, we started finding like the museum in Buffalo, we started find think the website by the council on developmental disabilities in minute, you know, we found some folks out there in California with the Ed Roberts cam us and the Paul K long more institute. So we began to find folks and we thought might it be good to connect those folks. Might we play the role of coordinator and might we begin to communicate all the things we see happening out there in regards to preserving, celebrating and educating.

You know, the goals of the preservation group, pretty basic, you know, encourage the collection of historic materials. I know I've been involved since really the 70s and so over the years I've collected a lot of news clips, VHS. Yes, there used to be VHS tapes. I collected a lot of, you know, like buttons from the Paralympics in '96.

I've collected T-shirts I've worn at adapt functions. I've collected buttons related to the signing of ADA and myself and some folks in Georgia began to talk to the Richard Russell library in Athens Georgia at the University of Georgia about setting up an archive, a Georgia disability rights archive at that library, at that university and through a series of conversations we now have that so I donated gosh probably 95% of my content, historical materials to the library up there. And I'm sure some of you on the webinar today and some of your colleagues probably have similar boxes full of stuff. Stuff under the bed, stuff in the attic, stuff in the door, whatever, and may not totally understand its significance or its value to future generations and so, you know, clearly one of the goals of the preservation group is just to encourage collection of the materials.

The other is to connect efforts meaning, you know, what we have found is there are a number of places around the country that have pretty good photo galleries but they didn't know each other. And so when we created a publication last fall at ADA25 commemorative magazine we were able to go to several of those folks that had those galleries and pick pictures from that so that we could, you

know, have maybe the best pictures, you know, for the commemorative magazine.

As mentioned, you know, really what drives not only the project is the volunteers but also what drives the project is its partners and Ed Roberts campus, the national center for civil rights that opened up here in June of last year in Atlanta, the Smithsonian, they'll be doing some things this year at the American history museum as I mentioned the University of Georgia Richard Russell library for political research and studies. These are the types of partners that we've reached out to or they've reached out to us. For example, the national center for civil human rights you're talking about an almost eight or nine year process meaning when from he were mayor Shirley Franklin left office here in Atlanta one of the things she had on her list of things to do was to create a national center for civil and human rights downtown and not just to tell the traditional stories of rights but to tell -- you know, to make it truly a National Center for Civil and Human Rights. So one of the things we engage with them even before the project started was just a conversation about making sure that disability rights as part of the broader narrative, meaning, you know, we can talk about -- we can



talk about women's rights and we can talk about, you know, civil rights in the 50s and 60s that we've all become so familiar with some of these anniversaries are coming up, we can talk about LGBT, we can talk about any number of causes and struggles that we've been part of or that are current around the world and we just want to make sure that disability rights was included in the broader narrative. So when the center opened up last June 89 part of the exhibit included, you know, disability rights content. In fact, the top floor of the human rights gallery when you go up there, there's a life size picture of Bob Casca from Texas who is a disability rights -- there's an interview with him, you know, looping interview and there's a president of the deaf now campaign and there's touch screens that you can get some more information about the disability rights movement. Once again the volunteers drive the project and partners drive the project and fortunately we have some very good partners.

As far as celebration goes obviously we're trying to build awareness and excitement about the ADA what we refer to as ADA25. And if you go to [adalegacy.com](http://adalegacy.com) you can find out more about ADA25. You can even go to the meet I can't kit and if you want to use the logo you can use the logo. If you

want to adapt the logo like folks in Milwaukee or folks in Arkansas or folks in Texas or other folks around the country have done is they've grabbed the brand or the logo off the media kit and either assistance or their own community assistance have modified the ADA25 logo for their local events.

So one of the things we did once again started with the conversation in 2012, quickly began to identify partners and we created the adalegacy.com website in 2013, and then last year I don't know if some of you might remember but the road to freedom bus that went around the country about eight or nine years ago, a 37-foot RV wrapped in images of pre-ADA and the signing of ADA and that bus traveled the country oh, like I say about eight or nine years ago promoting the passage of the Americans with Disabilities Act amendment act. Excuse me.

And so, you know, we drug that vehicle out of storage in Sacramento, put some new wheels on it and hits the road last July. It's in hot springs, Arkansas right now. It's the 32nd stop, so 32 stops down and 42 to go and it's been once again awareness and excitement about ADA. We anticipate probably 250 plus events. Some have already occurred.

Some are occurring today as we speak and there will be occurring between now and October of this year and once again we anticipate probably about 250 plus events, many, many of them outside DC and some in DC. The tour on the bus, kind of building awareness and excitement as we get closer to the anniversary.

We worked with the national ADA network was one of the first sponsors to come on and one of the -- a very strong partner and Robin Jones up in Chicago and that network of people that work at their AD centres have been working very hard to make, you know, ADA25 a success and make the tour a success. They actually have a website [ADA anniversary.org](http://ADAanniversary.org) that actually has a tool kit in it so if you haven't started planning or even if you have started planning and maybe didn't know about that resource, that resource has a tool kit in it like I said with downloadable handouts, you know, there's a pledge on there, you know, one of the goals obviously is to try to get 25,000 individuals and organizations to sign that pledge. The interfaith community has taken that pledge and modified it for their purposes and they're out there getting signatures on the pledge. We all know that places of worship aren't covered by ADA but nonetheless they're leaders in the interfaith

community who felt they needed to embrace the principles of ADA and be a part of it. So once again, goals are build awareness about ADA25 and coordinate events as possible.

Last year in addition to kicking off the tour we created national branding. It's kind of a no-brainer slogan, disability rights are civil rights. But some of you might have remembered last year when the LBJ library in Austin, Texas hosted a summit around the 50<sup>th</sup> anniversary of the Civil Rights Act. They had three presidents involved, they had civil and human rights leaders around the country and at the last moment they added disability rights, meaning it was an after thought. It was an add-on. So clearly some of our own allies don't even see our rights as disability lights so we adopted the slogan disabilities rights are civil rights. You cannot only use that logo there, use that slogan, but you can actually buy a T-shirt on the website [adalegacy.com](http://adalegacy.com) and if you want to go in the search box and type T-shirt or shirt, you know, then you can find the website that's handling all the fulfillment for that. So once again, the conversation turned to concept, turned into website. A lot of partnerships, turned into the tart of a tour, turned into a brand, national brand with even a T-shirt and a tool kit and things

keep building so we keep trying to coordinate our partnerships through the website. We can't always do -- we try but it's hard to even keep up with the volume of information. The goal obviously is that if you're already planning something related to ADA25 that when you go into the [adalegacy.com](http://adalegacy.com) website and hit get involved and click on your state on the map, you would see yourself there or you would see some kind of contact that indicates what's going on in your city and what's going on in your state so there will be a whole lot of populating of that map in the next couple months because that's one of the big goals now is now that we're getting these calls and e-mails and people are sending us links to events that we want to post a lot of that information up on the website.

You can see there's a T-shirt. And like I said, the tour. You know, significant part started last July, doesn't end until this July, like I said, it's in hot springs right now. It's headed to Memphis then it's headed to Nashville then it's headed to DC and it keeps going. And the route is on the website. The host group contact is on the website so that if you weren't aware of the tour or if you weren't aware it was coming to your city or near your city that you would be able to go in there and talk to the contact person.

Maybe you can help make that stop even more successful, maybe you can load up a group of people and go see the bus or any number of things.

And when I say "see the bus" once again the bus is a 37-foot RV wrapped in images of pre-ADA and the signing of ADA. The bus also pulls a trailer and inside the trailer are a small number of displays and primarily pop-up displays like the history of self advocacy, some information about preservation, celebration, cation education. Some information about the bus itself and its history and how ADA became law. And all that stuff you can follow on Facebook, you know, ADA legacy tour or ADA legacy. You can follow -- we have a hashtag and you can be a Twitter follower. There are any number of ways to follow the progress of the project. There's any number of ways to follow the progress of the tour. And like I say, we're at stop 32 now, finishing up in hot springs and headed to Memphis

Celebration partners, you know, Abilities Expo. Some of you may have been to an expo. There are about six or seven expos a year. Last year the tour made a stop in three, both Houston, Boston and San José. This year there actually was

a tour stop at the LA expo without the RV and there will be actually another stop in Chicago and ultimately New York, New Jersey without the RV and that was just primarily a scheduling issue. But the expo supported the three stops last year, continues to provide the space for disability rights content at the expos coming up.

As I mentioned, the national ADA network and its ten other partners or actually 11 have been very supportive. Beacon Press, some people aren't aware but they hired Leonard Davis out of Chicago to write an anniversary book that will be available in July. Faircount Media Group down there in Tampa, Florida, I haven't even met the people but over the phone and through the computer we were able to work with them to create a very nice anniversary magazine. They printed 14,000 copies. They're gone. But it's online, available to you at [adalegacy.com](http://adalegacy.com). You can type in the commemorative magazine or you can go over and just click on commemorative magazine and you can experience the magazine. It's like a 178-page magazine that has some really good editorial in it.

We talked a little bit about the Smithsonian, you know, that they'll be involved and the cultural festival, in DC the

Kennedy Center is doing a series of events the entire month of July and if my understanding's right they're going to try to stream all of those so literally if you're not in DC on the 26<sup>th</sup> you'll be able to maybe host a house party or rent out a hall and you'll be able to online-streaming experience what's going on in DC at the Kennedy Center for the 25<sup>th</sup> anniversary of ADA.

I mentioned the National Council of independent living being our sponsor. Very appreciative of that. Other organizations like the Viscardi Center in New York. We have about another ten or so organizations in Austin helped kick off the tour this year. We recently came through Columbia, Missouri where they had 15 or more organizations posting the tour stop so, you know, in that celebration mode, you know, we all are doing important work but it's really important to come together around this anniversary and work together.

We have some education goals. I mean obviously the ideal scenario is that the project doesn't go away after July. We'd like to see the project continue, you know, beyond the anniversary because we will continue to need to preserve content and we will continue to celebrate or as we think



about celebrations, this is also the 50<sup>th</sup> anniversary of Medicaid and Medicare, and there are people I know that Medicaid and Medicare's important to their life. And in fact, I'm 63 and Medicare will become important to my life in a couple years and so it's important to look at a number of anniversaries not just this year but anniversaries coming up in the future. So the hope is that the project will continue that once again preserve, celebrate and educate.

The last goal, like I said educate, share our history and contributions, you know, raise awareness of current issues. Some people say Mark it's great to have a party and celebrate the difference ADA made but we all know a lot more needs to be done and so if you go to the website, the [adalegacy.com](http://adalegacy.com), you know, on the front page 1 of the featured partners right now is Sixby15. It's a coalition of groups that came together and identified specific things they felt still needed to be done. And you're welcome to kind of sign onto that pledge and you're welcome to work on those issues in your own state. They're not -- they're federal issues but they're state issues or they're local issues and so, you know, those are the kinds of things where we're trying to raise awareness of current issues because

what we have found since last July is the media's done a good job of asking what difference has the law made. And many of them now are asking what still needs to be done. And so if you haven't already I would encourage you, you know, to visit that website regularly, that media kit, you know, those publications, the Sixby15 website. There's just a lot of stuff there that you can use. You don't have to reinvent the wheel. You might build your own wheel but all the parts are available right there at [adalegacy.com](http://adalegacy.com). And obviously we want to promote involvement and advocacy we all know that ADA got passed because of a massive grassroots effort to tell the story, you know, and are to get, you know, civil rights for people with disabilities like other groups. So it's very important, you know, to share our history and raise awareness about current issues but, you know, none of this stuff gets done unless you get involved.

You know, some of our education partners right now are the ADA image project, Mary Lou Mobry out in Colorado is a lawyer, was a lawyer for the Department of Justice when ADA was passed. She's now with the Department of Education. You he know, out of Denver, Colorado, but she's also a talented photographer. And one of the things she did with

us is a kick starter campaign last year, raised enough money to what she's created is a coffee table book of ADA images. I don't mean the historical images like Tom Olin is famous for. Some of the images in the website, some of the images in the ADA commemorative magazine. Most of the images traveling on the tour are Tom's. They're famous, they're iconic. They're beautiful. They tell a powerful story. What Mary focused on was images that show progress and -- if you go to the website you can click on her icon. She created a calendar for 2015. I've got right here on my desk, look at it every day just some really beautiful images that really do illustrate in a visual way the difference ADA has made.

Now, I'm not naive. I'm 63 and been using a wheelchair for 43 years and I know there's a lot still needs to be done but it's really kind of neat when you sit back and look at some of the stuff and realize some of the progress that we've made together.

The disability studies we'll be putting out there quarterly about the past, present and future, the Minnesota govern's council on developmental disabilities like I said has a tremendous amount of content at their website. They're

doing a count down, a 12-month count down to the actual anniversary and each month you can go in there and see pictures and read narrative and listen to interviews and whatnot that help you understand what was happening each month leading up to the passage of ADA. National disabilities leadership alliance, you know, the National Federation of the Blind just had a major law symposium focusing on the next 50 years. I mentioned the Sixby15 campaign, you know, the national ADA symposium is here in Atlanta, you know, may 10<sup>th</sup> through the 13<sup>th</sup> they're having a reception at the National Center for Civil and Human Rights and just a -- they've been around for a number of years. It is the premier ADA symposium to attend it's going to be right here in Atlanta this year. The Society for Disability Studies, I mentioned they're putting you on out their quarterly. They'll also be in Atlanta June 12<sup>th</sup> through 13<sup>th</sup> and else that all be doing a -- some of you don't know there is a society for disability studies, you're familiar with women's studies and African-American studies buzz more and more colleges around the country there are now disabilities studies, you know, where people can learn more about the movement, learn more about the cause so that we are able to go back and do the things that were being done to people with disabilities.

Story line motion pictures is the outfit out of Boston that made the lives worth living, you know, documentary due to the generosity of Charlie Carr and some folks up there with the commission up there in Boston they were able to come up with some money and they took the documentary and they broke it down into two 15-minute pieces with a curriculum for school age kids and so, you know, when I think about, you know, my daughter's now 30 and there was the opportunities for her and, you know, folks her age were limited as far as learning about disability rights in schools. I mean, they talked about FDR but they never talked about his disability. You know, they talked about, you know, other civil rights and human rights issues but didn't really talk about disability and so, you know, the nice thing about it is some of this content that now is being preserved and some of this content now that is finding its way into journals and books and DVDs and now being available to school age kids. Now some of that's been available for awhile. The antidefamation league has some content on there. Some are a number of websites out there that have, you know, literally curriculums and individual, you know, study components that you can use with school age kids. I know one of our partners a couple years ago early on in the

project were a handful of seventh graders from Austin, Texas, and they were entering the national history day. It's a mainstream history content every year, and they chose disability rights and they interviewed a lot of people in our community involved in our movement and they ultimately won their local contest, the region or statewide contest and they finished second in the country and that website is at [adalegacy.com](http://adalegacy.com). You can see the website that these seventh graders who are now ninth graders created. They continue to be involved. That's what's exciting about it. They didn't just do the history project. They got engaged with the movement with really no personal connection until this project. So once again you go back and the preservation goals, there are celebration goals, there are education goals, there are partners doing great work and I've only hit some of those, you know, those partners. There's a significant number of others. We don't even have them all listed yet, and I really appreciate once again, you know, volunteers and part-time staff and groups I've never met except on the phone or through the internet are doing. You can become a partner, you can become a sponsor. You know, we're fortunate you can go on and see the different sponsors, people who have stepped up with not just, you know, time but actual cash to make the

project and the tour and ADA25 a reality so we're very appreciative. Like I said the national ADA network was one of the first of them mirror group and Shepherd Center early on as founding sponsors and there are other sponsors in there including some private sector companies, some foundations but there's an entire list there at the website.

You can see different sponsorship levels. You can kind of review the sponsor summaries on your PowerPoint presentation outlining the different sponsors, you know, some of the sponsors are folks that have, you know, supported a tour stop, you know, whether it's a local independent living center, whether it's a college or university, whether like out in Albuquerque last year the Southwest Conference on Disability, you know, supported a tour stop. Or like the ability center for greater Toledo on July 20<sup>th</sup> the tour will be in Toledo. Every year that center does an event with the local zoo, 10,000 people show up so when the tour stops in Toledo we park that event.

In fact, a number of events where the tour's stopping are really parties we're crashing with an invitation and so it's pretty exciting how some of these sponsors have chosen

to get involved, you know, Mitsubishi electrical foundation, you know, very youth oriented. And one of the things I mentioned, you know, in the -- is the goals to educate those future generations. There say group of people called the ADA25 generation that you may never have heard that term before but if you Google ADA25 generation you're going to find some stuff.

And what it is, it's people who acquired their disability since the passage, you know, just like we study millennials, just like we study baby boomers, just like we study other groups of people, this group of people called the ADA25 generation is a whole another group that is coming into the movement with a healthy form of expectation. You know, there are people like me who had to get involved to get a building code passed so that a parking place would be striped wide enough for me to put my ramp down. The next thing you know now we're getting on beach matting and going on the beach, you know, and it's what's next and it's what's next and it's what's next and so it's really neat to see these young folks and people like Mitsubishi electrical foundation, you know, supporting the development of this next generation of leaders. In fact I say next generation they're already leading people like Christina mills out in



California there are folks already leading the charge. In fact out there in California they have a group called YO and it's young folks that are doing great work in California and connecting with their peers around the country through social media but that's obviously something that myself and I know some people on this call didn't have access to in the past, you know, is the ability to get an issue in front of a lot of people in a short period of time. And then be present. So we're clearly once again thankful for our volunteers, clearly thankful for our sponsors, you know, clearly thankful for a lot of things that make this go.

I have a couple more things and then we'll wrap it up and if there's any questions then I'd encourage them. But obviously you can go to the website and you can hit about us and you can hit leadership and all the names of all the contact people are there, you know, people that are in charge of graphics, people that are in charge of photo galleries. One of the really neat things that happens in a community is many of the communities where the tours have been have sent us pictures and those pictures then are being turned into a photo gallery by Tim Wheat in Memphis, Tennessee and there's some really neat images from Boston, really neat images from Denver and so you'll see more and

more of those photo galleries up.

So that's a lot. That's 40 minutes of talking and talking very fast and I know I probably haven't thanked everybody or said everything but I'll probably stop at this time and go with questions.

>> Bill: Well Mark, thank you very much for that like you say fast presentation but covering an awful lot of content over the years. And we do have some questions. Mark, let's go right into them now, starting with some of the maybe the quicker ones. In the original picture at the beginning of your PowerPoint of the signing of the aid, who are all the people in the picture the attendee would like to know.

>> Mark: That's a great question. One of them seated to the left is a gentleman named Evan Kemp. Evan Kemp has passed away since but Evan had muscular dystrophy. He eventually became the commissioner of EOC at the federal level. He actually took on Jerry Lewis telethon for his pity approach to raising money. Justin darts over to the right with the hat on, Justin's infamous. He and his wife Yosko, you know, Justin's passed since. Yosko is still alive and doing great work in particularly supporting young folks and also bringing folks over from Japan to learn about

the movement. So Justin and Yosko actually were involved in Texas and they were involved in DC and Justin wore a couple hats in DC, leadership hats in DC, you know, Evan and Yosko actually traveled the country with their own money a couple times to collect stories. In fact, some of you might have remembered they were -- there were journals collected around the country can be discrimination journals, you know, collected around the country as evidence of discrimination and as testimony to why we needed an ADA.

Harold Wilke, Harold Wilke, a person of faith actually -- I think born with no arms, you know, actually handed the president the pen to sign ADA with his foot. Sandra Perino at that time -- I hope I'm saying her name right, was the chair of what's now known as the National Council on Disability. Back then it was called the national council on the handicap. Some of you -- there's a great article at the National Council on Disability's website that gives you the kind of time frame and evolution of the passage of ADA, all the people, all the groups, all the behind the scenes things that were done to ultimately get the law passed. A guy name Jonathan young wrote that. It's at the National Council on Disability website. And back when the

law was passed, Sandra was the chair of that council.

And obviously the president.

>> Bill: Thank you very much, Mark. Was great you could recites to from memory without even scrolling. That's great. I have another question. Will the display in the American history museum still be there in October?

>> Mark: No. And I -- no. Unfortunately not. The thing at the American history museum if I understand right is only three days, maybe four days long. Our plans with them is it opens up on that Friday, the 24<sup>th</sup>. It's around the 25<sup>th</sup>. And then it's actually around the 26<sup>th</sup> because the bus is supposed to arrive there around lunch time so my understanding is no. However I don't know what their web based plans are. I know right now that when they did an actual physical exhibit for the tenth anniversary of the ADA in 2000, there's actually a virtual website out there of that exhibit so I don't know the plans now but I would say stay tuned. Keep checking our website and we'll let you know if at least they're going to archive it somehow where you can experience it online but I'm not aware that there will be any physical components up at the museum past the anniversary.

>> Bill: Okay. Thanks Mark. I have a couple more tour

questions. One is -- it's a good question. I think I know the answer to it but I'm going let you field this one, Mark. Will the tour be in Washington, D.C. for United Spinal' Roll On Capitol Hill in June. And I think that might be the second link and I'll check my calendar.

>> Mark: Right. It will not. In fact, about that time it's going to be heading out to Indiana. One of our sponsors out there in Indianapolis is Wellpoint. Then it's headed up to Milwaukee, you know, where Tom used to work for the independent living center up there and there will be a stop in Madison, Milwaukee then it's actually headed up to Montana and then around the first of July it starts making it's trek back to DC so unfortunately it will not be in DC in June.

It will make a brief appearance on April 19<sup>th</sup> in DC and then its next appearance will be the 26<sup>th</sup>, 27<sup>th</sup>, 28<sup>th</sup>, 29<sup>th</sup> of July.

>> Bill: Thank you, Mark. And for the audience, United Spinal' Roll On Capitol Hill will be June 7<sup>th</sup> through 10<sup>th</sup> so a little programming blurb there.

>> Mark: And there's plenty of content at the media kit. I would encourage folks to use the website and use that content for some of their visits there, you know, kind of tie -- I know that, you know, some of your staff have been

talking about how do you tie in some of y'all's traditional asks into the overall anniversary so I think there's a tie-in but the RV itself or the tour itself won't be there.

>> Bill: Okay, great. And then again this can be located I'm sure on the tour website but can you provide offhand to the audience any tour information, any events taking place in the New York City area off the top of your head?

>> Mark: That's a great lead-in. Yeah, originally we reached out to John Kemp with Viscardi about some stops up there in New York in particular the 11<sup>th</sup> and 12<sup>th</sup> of July. That ultimately threw a qualifying the mayor's office up there and if I understand right now there's an entire month of activities being planned in New York City.

There's a famous jazz musician up there who has a daughter with a disability that has been wanting to do a disability proud parade. A lot of you might know that the oldest disability parade is over ten years old. It was done in Chicago and there's someone on the West Coast out in California, some in New Jersey now but this would be the first -- I think it's July 10<sup>th</sup>. I think you can just type in, you know, either into the legacy website or just Google, you know, New York disability pride parade so my understanding is the entire month of activities with the parade on the tenth and with the tour itself, RV being

escorted through all the burrows the 11<sup>th</sup> and 12<sup>th</sup>.

>> Bill: Well Mark, that was a great segue indeed because the very next question is who are your partners in New York City and what coordination of events were planned so I think you answered a lot of that.

>> Mark: Yeah, the mayor's office primarily and John Kemp and some of his staff at Viscardi.

>> Bill: Okay. Another question Mark, I'm interesting in advocating for improved accessibility when traveling. Some hotels don't represent rooms accurately. We know that. Some don't guarantee ADA rooms, tourism bureaus don't have information, city happens are find, et cetera. Your thoughts and are there groups working on this? Whom would you direct them to, Mark?

>> Mark: You know I guess there's a number of approaches. You know, obviously, you know, I've had issues with bed heights, you know, I've had issues of people saying the room's accessible and it is but it's not the roll-in shower that I asked for. You know, I get, you know, a little frustrated sometimes when there's one bed in a room and I have me and my family and I'm paying the same price as other people who have two beds. You know, so I just tend to be one of those who kind of takes on management while I'm there. You know, obviously there's the law that makes

certain requirements. Obviously I file complaints. I was part of a class action suit against the Hilton franchise up there in D.C. you know, I was invited to come up there for an event and speak at the event, receive an award and turned out I couldn't even stay in the same hotel. Part of what I did to that group is say I hope you're not going to hold out the words until they change and I called out the management when I did my acceptance speech so there's different approaches with different people. I think the ride thing to do is I know we get tired of hearing about this but you really are the educator. I mean, you really are the person that sometimes have to take management up and physically show him that that sink's not working right or that that roll-in shower was built wrong or that -- you know, et cetera, et cetera. See it -- you know I would be quick to say there's progress, you know, since the days of where I used to use a luggage rack in the tub. The days where now I can take my shower, commode chair into that roll-in shower. So one is I'm real thorough in my lines of questions. I will sometimes on the phone ask them to send somebody to the room to physically check it. I will ask them sometimes to take a picture of the room with their phone and send me an image. So I really do a very thorough questioning on the front end. If I get there, there are



any issues then I'm physically going to grab somebody and so them. Sometimes, you know -- every time I've been able to work out something. I'm not saying it's not frustrating, I'm not saying I shouldn't have to be doing is those things. When it's all said and done, part of our responsibility for being part of the solution is to let people know what to do.

>> Bill: Totally agree, Mark. I think we've all been there, especially anyone who is a wheelchair using has been in that situation at times and I agree, it's powerful when you are there face to face because it's pretty difficult to be ignored when you --

>> Mark: And I've had them actually call another hotel while I'm there and find me an accessible room and then pay for it. So, you know, because the fact is, you know, if common sense worked we wouldn't need to have laws. Most laws are compromised. And most people who it doesn't personally impact don't understand the law so we really are, you know, the agent of change and some of that's kind of -- you know, you've just got to be righteous every once in awhile. I didn't say pissed off, angry and screaming and hollering although I've done my fair share of that. I'm just saying he we now have tools available to us that we didn't have in the past and one of them is ADA.

>> Bill: Absolutely. Mark, could you share any final words to sum up your presentation before we depart?

>> Mark: Well, I mean, you know, there's a lot of us out there, you know, we keep hearing that figure of 50 plus 000,000 Americans and I know, you know, all of us had a mom and dad and that's even more Americans and so I just think this anniversary provides us an opportunity to really engage a lot of people. And I don't just mean the choir. So I think it's really important for -- you know, you go to the public library and you go hey by the way, I'm looking for books on disability rights and see what the public library has. You know, I know when my daughter's going on 31 and married now, but when she was in, you know, kindergarten, you know, they sing that nursery rhyme called The Wheels on the Bus Go Round and Round and all that stuff. Well I had them add a line to it. The lift on the bus goes up and down. So to me advocacy is a lifestyle. I can turn it up and turn it down but I can't turn it off. So I think real changes occurs when you just embrace it as a lifestyle and you have fun with it and that fun, you know, we have this incredible opportunity in front of us, you know, this 25<sup>th</sup> anniversary of ADA. I've got -- there are communities out there saying well, you know, give me some ideas. I say well why don't you go to your city council, you know, during

a public comment and just say hey, you know, any plans for the anniversary? You know, if not I'll be happy to help up plan some stuff. There are people going to -- there are people identifying the 25 things -- they're identifying 25 things -- the top 25 things that have been done in their community progress wise as far as curb cutting the city, maybe it was the first accessible bus, you know, maybe it was the first person with a disability hired in a particular area. Whatever it was, you identify 25 and then you identify 25 additional things that need to be done. So you can be very creative with this ADA25. You have a website loaded with resources. You have a logo that you can modify for your own community, you know, you have, you know, a lot of attention I think's going to be around the 25<sup>th</sup> through some of these -- through the tour stuff, through the pride parades that will be planned, through some of the events that are being planned, through some of the-streaming. If you're not already on board, jump on board. If you are on board, get more people on board but every day I'm asking people how will you celebrate? There's a section at the [adalegacy.com](http://adalegacy.com) website that you can click on and it shows you, gives you ideas of how you can celebrate and how you can involve other people to celebrate. And when I say celebrate, once again it's not just a party. It's an

educational opportunity.

>> Bill: Well thank you very much, Mark. And on behalf of United Spinal Association I'd like to thank Mark Johnson so much for sharing his personal experience and his professional voyage through the years of the ADA and beyond and presenting that to us today in the webinar ADA legacy 25 celebration. To sign up and register for our webinar newsletter, visit us at [www.spinalcord.org](http://www.spinalcord.org). Check out our monthly editions of the new mobility magazine which covers everything active wheelchair users need to know and visit [New Mobility.com](http://NewMobility.com) to see what we're all about and this will conclude today's presentation on the ADA legacy 25 celebration.

(End of webinar)

This text is being provided in a rough-draft format. Communication Access Realtime Translation is provided in order to facilitate communication accessibility and may not be a totally verbatim record of the proceedings.