

Date: 05/23/17
Event: United Spinal webinar

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>> Bill: Thank you for joining us today for United Spinal Association's updated webinar, Live your Life, The Disability Integration Act and why it matters to you. Today's presenter is Ms. Stephanie Woodward, advocacy Director of the Center for Disability Rights. This is Bill Fertig, Director of the spinal cord injury resource center and I will be your moderator for today's presentation, one of a continuing series of United Spinal Association webinars archived at spinalcord.org. Please use the question chat window at the bottom of your control panel to pose your questions today and we'll do our best to get to them at the end of today's presentation. For any questions remaining, please e-mail us directly. Stephanie, whose e-mail address is displayed on the last slide. Close the captioning instructions also appear in the chat window of your control panel, as well as a pdf version of the slides from today's presentation. That's in the handout section.

Stephanie Woodward, JD, is the Director of Sadrow Cassie at the Center for Disability Rights in Rochester, New York. She is a lawyer, an activist, a cat lady, and a proud disabled person. And now I'd like to hand it off to Ms. Stephanie Woodward for her detailed presentation. Stephanie?

>> Stephanie: Thanks, Bill. Just reminding everyone of the rule on Capitol Hill that's taking place, and I'm getting straight into the disability integration act. We're really excited to say that The Disability

Integration Act has been reintroduced this year in both the Senate and the house and the entire purpose of the disability integration act is to create an absolute right for people with disabilities to live in the community, because Olmstead was supposed to do that, and it's time for us to take it a step further.

The basics of the DIA are that this year, it was reintroduced in April in the Senate by minority leader Schumer. It is S. 910. In the house I'm excited to say it was just introduced last week by congressman Sensenbrenner, a long time supporter of disability rights and a Republican from Wisconsin. So we have already great bipartisan support and great leadership on this Bill, so we're excited to see how that house has moved forward.

Lots of disability rights organizations support The Disability Integration Act and you can see there's quite a lot of different disability organizations nationally from ADAPT, which is a national grassroots civil disobedience organization to AAPD. We've got Little People of America. The national council on independent living. Lots of organizations. And then this is our last slide of organizations, because we want to recognize them all, including United Spinal for being a supporter of the disability integration act.

So The Disability Integration Act actually came from the Senate report. It was the health committee. That's when senator What are Ken was in charge. Health Committee and he commissioned a report called states fail to fulfill the community living promise of the Americans with Disabilities Act. This report came 25 years of the ADA and one years of the Olmstead decision, Brooklyn Supreme Court decision that found that people with disabilities have the right to live in the most integrated setting.

And what this report found was that states aren't focusing on transitioning people from facilities back into the community. They're actually continuing to put people in institutional settings, and when people are transitioned, it's unclear if they're being transitioned into the community or into just a different segregated setting. So many -- what report has said is many states have focused on enrolling people that are currently living in community settings into home and community based settings. They're not really focusing on transitioning people living in institutional settings back into the community. And states have also continued to back fill

institution beds rather than closing them. And reallocating institutional dollars to support individuals in their own home. States aren't doing what Olmstead had promised they should be doing, and it found when individuals are transferred, it remains unclear if they're transitioned into the most institutional setting possible or less institutional. So perhaps from a nursing facility into a group home. However, the whole purpose of the Disability Integration Act is to ensure that people are being diverted and community and if they are at risk of institutionalization or being transitioned out of institutions to really fulfill that promise. So I think this is where we're going to bring in question one.

>> So question one, poll question one is are you getting the community supports and services that you need? Yes or no. Are you getting the community supports and services you need? We will wait a few moments until all the attendees have an opportunity to vote. Usually takes a few seconds. Have an opportunity to vote and then we'll see the results. It's split. The results are yes, 48% are getting the community supports and services needed. 52% not.

>> And being split is exactly what the problem is. When we have anyone saying, no you're not getting supports and services that you need, we know that there's a problem. And that's exactly why the Senate health committee made the primary recommendation that Congress should amend the ADA to clarify and strengthen the law's integration mandate in a manner that accelerates Olmstead implementation and clarifies that every individual who is eligible for long term services and supports you should Medicaid has a federally protected right to a real choice in how they receive supports and services. So that means if we're split, there's more than 50% of people answering they're not getting the support and served that they need, which means we are not doing right by the disability community in our country and we're not following the Senate recommendation from this report.

So that's why we brought in The Disability Integration Act. The Disability Integration Act amending laws that can bring risks, as well as greatness when amending it. So we'll remember that the actual DA was amended back in 2008. But in outing things, you also risk having some things taken away, and when we're living in a current state where our long is already considering having notification before

filing an ADA constitute, we don't want to create further risk by opening up the ADA. So the decision with me to create a new Bill called The Disability Integration Act, it's about constitutional rights. So the recommendation that the Senate health committee gave was that people who receive Medicaid would have a federally protected right to long-term services and supports, but we don't feel that the right to community services, community-based services is limited to only people who receive Medicaid. We believe anyone who has a long-term insurance plan that would pay for institutionalization should have the right to live in the community. So we created this as a rights Bill, not a Medicaid Bill, because as we have seen in our current political climate, programs such as Medicaid can be cut. It could be evaded. Whereas rights follow the individuals. You can't cut rights from people. You can draw a line and red line a program. And it's a constitutional right for us as well. So we always said it's a civil right, but if you look at what our constitutional rights are, our court is going back throughout history and has said that we have a right to raise a family. We have a right to choose our religion. We have a right to freedom. You don't have those rights if you're forced into an institution. There is no liberty in institutionalization, and you're certainly not going to raise a family if you're living in a facility.

So The Disability Integration Act establishes a right to choose where to receive your services and supports rather than what we currently have in our system is the easy button, and the easy button says that people with disabilities, if you need help, with generally going to go to a nursing facility.

But the proposed language is structured like the ADA and uses mechanisms created in the ADA to ensure that all individuals with disabilities have the right to live in the community and will lead an independent life, so it does not amend the ADA. I just want to be clear on that.

So we feel as though the constitutional right, because the Declaration of Independence clearly states that we hold these truths to be self-evident that all men are created equal, I would argue women, too, that they are endowed by their creator with certain inalienable rights and that among them are life, liberty, and the pursuit of happiness. All men are created equal. So when we talk about that, are we talking about all people? And if we are, then are we

ball in all rights? Because if that is the case, then people with disabilities are included in that constitutional right.

So the Disability Integration Act recognizes that the right to live in the community is right number zero for the consideration of liberty and the pursuit of happiness. And we say right number zero, because it's so common among nondisabled people to live in the community that you don't think of it as a right. It's as natural as breathing, because you don't know that you could be locked up just for doing nothing wrong, just for needing help. It's such a fundamental right that nondisabled people don't even think of it as a right, and that's why The Disability Integration Act is so upon, because it addresses this fundamental right that it's so taken for granted that nondisabled people don't even see it as a right, but if you took away from them, you certainly would see it as a right.

So when we're looking at the right for all people with disabilities to live in a community, if we don't have the right to live in the community, then we didn't exercise our right under the ADA, because quite frankly, there's no point in having a at that till at this and you can't get out and use them. And without adequate community based support and services, we simply can't live in the community. And the right to live in the community is really essential to all humans. It was restated in Olmstead. And The Disability Integration Act would then recognize that in the statute, the right to live in the community.

And the lack of adequate community-based working services has imperiled the Civil Rights of individuals with disabilities and undermines the promise of the ADA, and that's why in the very beginning of the Disability Integration Act, we have recognized that it's necessary to recognize in statute eight, row must and fully arrest tech other late right to community living, because recognizing it in court cases so far hasn't been enough.

So getting into how The Disability Integration Act works. DIA prohibits medicare and other insurance providers from denying community based services to an individual who is eligible for institutional placement. And I put the language down at the bottom of the slide. I'm going to go over to very quickly and just explain it a little bit. So no public LC or LTSS insurance provider and that's long term service and support provider, shall deny an individual with an LTSS disability who is eligible if

institutional placement or otherwise discriminate against that individual in the provision of community-based long-term services and supports that enable the individual to live in the community and lead an independent life. Essentially, what that basically means is if you have Medicaid or any other insurance that would pay for long term services, if your insurance company would pay for you to live in a nursing facility or institution and you are eligible for that institutional placement, then that insurance company would also have to pay for you to live in the community. It's just that simple. She would have to pay for the same supports and services to be provided for you in a community based setting. So getting into what is a public entity or LTSS insurance provider. So you believe ten at this at this, they fund or provide ADL, IADLs or health related tasks. So it's a state or local government. If it's activities of daily living or health-related tasks are covered by that public entity provider, so likely your state Medicaid, but we also put local government, because we do recognize that some are administered by local counties in some states. And LTSS insurance provider is a private insurance company that provides or pays for it is ADL, IADL, or health-related tasks. So assist with your activities of daily living, instrumental activities of daily living, and they interstate as interstate commerce. That means they operate within the United States or interstate as well.

So who is an individualist and an LTSS disability? This is really important, because only people with LTSS disabilities would be eligible for services and supports I remember the Disability Integration Act. Someone living with a disability who is not at risk of institutionalization or is in an institution wouldn't be eligible, because they won't need those supports and services. My CEO who is a diabetic, but fully functioning without any sort of supports or services for him right now, a diabetic who does need supports and services, it's not based on diagnosis, but rather, we start with the definition of a person with a disability under the ADA and if you need that definition, then we go to that person with a disability who also requires assistance with ADL, IADLs, or health-related tasks and is in an institution or at risk of institutionalization. So again, this is for people with significant disabilities who would otherwise be institutionalized if they didn't receive those

supports and services.

So right now, I am a person with a disability. I'm a wheelchair user. I have spina bi fi da. However, I live independently without supports and services. As I age and my disability may progress, I may become eligible under the disability integrations act, the definition of a person with a disability, if I would be eligible for institutionalization and need supports and services to stay in the community.

So what is communities based? I think this is a really important definition, because what we found is some organizations like to call themselves community based, but they're really institutional settings that like to just change their names. We often -- they call themselves gated communities, and my good friend Ari likes to say a gated community is something in BOCA where rich people put a gate up to keep the undesirables out. These settings that call themselves community based, but are really institutional settings, call themselves gated communities. The gate to keep the people in, not to keep the undesirables out. So that's how we know the difference. So we want that it was really important to identify what community based meant, and community based is a dwelling owned by the person or the family, so by the individual who would receive the services. That's A-Okay as well if you want to live with your family. A dwelling with the same terms as an ordinary lease. And that means that you wouldn't be required to receive services tie today that lease.

It would also be a group setting of less than four people with disabilities to control access to the home. So that means they can lock their doors and keep other people out if they want to. Can eat whenever they want so there's no structured meal settings. Can come and go whenever they want. That's very important. And have the same terms as an ordinary lease and also don't have their tenancy tied to services. So the landlords cannot also be the service provider. And this is really to ensure that places that are more of an institutional setting don't try to qualify themselves as a community based setting if they're truly not. And then just to have a catchall, we also included other settings in the community as a community based setting. That seemed to make pretty good sense to us.

So what are the long-term services and supports that we're talking about under The Disability Integration Act?

Our basic ADL, these are activities that people attempt to do without help. These are what nondisabled people tend to do without help such as eating, bathing, dressing, toileting, and transferring. We also included assistance in IADLs, activities that allow a person to live frequently such as housework, meals, craps, money, management, and care of others. It was very important for us to include care of others in these terms, because we had experienced many people with disabilities who have had children and were not able to get their attendant to assist them with simple things such as passing the baby from the crib to the mother in the wheelchair, because they were under state programs that said that the attendant can only help the individual, not any others, but if the individual is a parent and you need help having your baby passed to you, you should be able to have that. Or if you have a cat, you want to have a cat and you need help with feeding your cat, your attendant should be able to do that for you. So we worked hard to ensure that care of others was included in the definition of IADL to ensure that people with disabilities could be living the same lives as every other person. If you want to have a kid, if you want to have a pet, have at it. And then other health-related tasks, and other tasks related to the above. We put that in as a catchall as well. So I think it's like advanced care, catheterization, all that have good stuff. It's all included from the definitions.

And then there is a broad general prohibition that if Medicaid or another LTSS insurance provider would pay for the person to go to a nursing facility, then that insurance provider must also pay for that person to receive the same services and supports to live in the community. That is what we've been talking about in previous slides as well, but this is really the overall goal of the disability integration act is if someone will pay for you to live in a facility, they're going to be within the community. And honestly, it's going to be cheaper there as well.

So this is really all about choice and not force. We've been getting a lot of questions about, well, what if he wanted to live in a nursing home? Now I can't? No, you certainly can. If you truly want to live in a nursing facility, if that's the life for you and you've decided that's what you want be the disability integration act would not undercut your ability to choose to live in an institutional placement. States are only required to

assure that people have a choice to live in the community. The disability integration act is careful to assure that individuals are only provided community based services if it is selected by the individual.

Does the DIA restrict funding to assisted living offer group homes? No. DIA does not change the CMS definitions that allow funding to go to these facilities and, therefore, would not impact their funding. The disability enation act just ensures that feel with disabilities have a real choice in whether they want to live in assisted living, group homes, segregated settings, or in the community, because right now, we don't feel that there is a real choice when we are seeing so many people in institutions saying they want to get out, but the waiting list is 5,000 people long and so they'll never get out. That's just not a real choice to live in the community.

So I want to get in the specific prohibitions that are in The Disability Integration Act to show how these prohibitions really ensure that people would be able to live in the community. So the first one is that insurance providers can't screen people out by eligibility. They can't say that you don't have the right disability to receive these services. Number two is they cannot impose service and cost caps, so they can't say, you can only receive this if you receive 16 hours of service radar it. Or you're too expensive to live in a community. We don't believe that there is some sort of price tag where people stop having constitutional rights to freedom as it costs too much, especially when the overall aggregate most people don't need 24-hour services, so it will be cheaper on the aggregate, but even if it wasn't, I don't think we can limit people's rights with pricing tags.

Insurance companies can't fail to provide a specific service, so they can't fail to provide one service that would allow to you live in the community if you need attendant services. They can't say, oh, sorry, we don't provide that. They can't screen out by regulations and requirements. They can't ill polls waiting lists. And this one is really important to us. We have seen in many states where they're saying, we are complying with Olmstead. We allow people to get on waivers where they are waiving their right to institutional services by getting community services and then we just have a waiting list of seven years in order to get on a waiver and into the community. That isn't providing a real choice if I have

to wait seven years to hopefully get a waiver to get into the community.

The sixth one is also very important for us. Insurance providers cannot fail to provide inadequate payment to support a workforce. And what that means is we are seeing attendant wages go down and down. And when attendant wages go down, unless people want to be attendant, if we don't have an adequate workforce, then we don't have people with disabilities living in the community. It could be a good workforce to help us in the community. No attendant, no community living. So insurance providers must insure that our workforce is being paid adequately, just to have a workforce in place for us.

Insurance providers can't fail to provide intermittent supports and services. Some people with disabilities don't need constant supports and services. Sometimes they only need them intermittently. Insurance providers must provide that as well. Another one that we want was really upon was insurance providers cannot require the use of informal supports. The reason this came in is we were seeing a lot of assessments done on people with disabilities where the person giving the investment said, well, you have a mom and your mom lives with you. Therefore, you don't need 16 hours of service. You only need five hours of service, because your mom can provide the rest of those services to you. That's requiring informal support. What if your mother doesn't want to provide those services to you? What if you're a 20-year-old Mann and you don't want your mom helping you shower. That's really upon that we have autonomy and choice, so requiring informal supports, it would not be aloud under The Disability Integration Act.

Failing to offer community based services before institutionalization would also be prohibited. So that means insurance companies can't put you in a facility before they even offer to let you get supports and services in the community.

Another one, people professor in institutions, the insurance companies cannot fail to notify people in institution of their right to live in the community.

and then last, but not least, insurance providers cannot fail to make reasonable accommodations to allow a person to live in the community. One time might not be enough and we might need something he wants, another reasonable accommodation that would work for an individual

with a disability to allow them to live in the community, so insurance providers can't fail to provide those resources.

Another question that we get often is what about informal caregivers? Those DEAs support informal caregivers? Yes, as I just went over, prohibitions, the disability integration act would make it illegal to require people with long term service supports disabilities to use formal supports. That doesn't mean you can't, but it would make it illegal for insurance providers to require that you use your mom, you use your husband, you use your sister who lives with you as an informal support if that's not something you want to do.

The Disability Integration Act also requires insurance providers to support informal caregivers. And that is in section 6Bn case you want to get real deep into the disability integration act. It says that the LTSS insurance provider must insure that it supports he know formal caregivers who provide services to individuals with LTSS disabilities.

What other important aspects are there to this Bill? My favorite one is that public entities must ensure that there is sufficient affordable, accessible, end great housing, and this is important, because you cannot transition out of a nursing facility or be diverted from going into a nursing facility if there's not housing that is accessible to you and affordable to you, and we feel it's important to bent great, because we don't want to see what I lovingly calling the crip ghettos where you build a high-rise and put all the people with disabilities in there. You might as well just be living it go a nursing facility at that point, because it looks the same and feel the same. We want integrated communities. And many people with disabilities aren't satisfied with the housing actions that they currently have. So I think that would lead us into question number two. Right, Bill?

>> Bill: We can go to poll question number two very easily, which is are you happy with your current living arrangements? Yes or no. Are you happy with your current living arrangements? And we'll give folk a few minutes to make their selection. Then announce the results. The question, are you happy with your current living situation? And the answers are back, seven 3% indicate that yes, they are happy with their current living arrangements. 27%, no.

>> Stephanie: And deny, we have a problem. When 27% of people are not happy, that means that there is a large portion of people who are not satisfied with the housing options that they have. And I feel like that might be indicative of our society in general. Most times, people without disabilities are generally pretty happy with their living situation, because they got to choose it and they had plenty to choose from, whereas people, particularly people with physical disabilities, have much less choice, because the housing market doesn't offer things like houses with ramps. And if they do, it's certainly not a plethora. I can tell you that I am -- when I was shopping for a house, I was 26. I was a lawyer. I had plenty of money to spend on a house. I could not find a single house in my city that was accessible. I was forced to pay for a house that was inaccessible to me and then pay even more to get it renovated to be accessible to me, and I am thankful that I have the means to do that, but most people with disabilities aren't so fortunate to have those means and that shouldn't mean that they don't get to live in the community simply because more housing availability did you want include affordable, accessible, integrated housing. The disability integration act, by requiring public entities to ensure there is sufficient, affordable, integrated housing, it doesn't tell states how to do it. And of course, when we're talking about public entities, we are talking about places like states and cities and counties. It doesn't say how to do it. How to create that accessible housing. Just like the ADA doesn't tell businesses how to become accessible. It just says you might be accessible. So it really does lead to the public entities with a lot of flexibility on how each state chooses to ensure that there is sufficient, affordable, accessible, end great housing. So I would imagine that New York would have a different plan than Alabama would, because I'll just throw out a guess here that we are vastly different states. I haven't been to Alabama, but I could be right or wrong. However, in New York, we might choose to include a tax credit that allows individuals in the state to receive a tax credit for making our homes accessible, and that is one way to ensure that there's sufficient, affordable, integrated housing. Another state might include in their budget the building or renovating of specific housing I can't I was to ensure there's affordable, accessible, end great housing. It

doesn't matter how the state does it, because again, the methods work differently for different states. It only matters that the state gets it done, much like the ADA. It didn't matter how a business makes themselves accessible 26789 matters that they get the. It matters how they get the job done.

So let's get into the nitty-gritty of how does the disability integration acted really work, then? How will we make sure that states comply. Right? This is a real question. And we took a lot of time to think this through. And we thought it through very Thoroughly, because what we found was about 20 years of the enactment of the ADA, Amtrak came to Congress and said, we need twenties more years and hundreds ever millions more dollars to comply with the ADA. We know we were supposed to do it by now. It's been 20 years. We need at least 20 more years and a whole bunch of money. And that's because there wasn't any sort of planning required. No reporter prior to ensure that Amtrak was track to become accessible. And we didn't want that to happen with our right to live in the community. We don't want to hear from states in 20 to say, well, we tried, but can we have a few trillion dollars to make this happen Right? Because they didn't really make it happen. We thought through this process, and the first step would be that regulation for The Disability Integration Act would be released within 24 months of the DIA being signed into law. So once Congress passes it, then the president would sign it into law. Then the regulations would have to be developed and released within 24 months.

Then the self-assessments would have to be completed within 30 months. So both public entities and LTS insurance providers would complete a self-assessment within 30 months, really assessing where are we currently? How many people do we have at institution that we would have to get out? What would be our plan to get there? And then the transition must be complete within 12 years. So that includes the 24 months that the regulations are coming out. So within 12 years of the disability integration accounting signed into law, the States must be complete with their transition plan to ensure that people with disabilities are having their right to live in the community.

We understand that this can be a lightlies for some states who are already well ahead on the community based settings game, whereas for some states that are a bit behind, it might be more difficult. So that is why we have

a 5% federal enhanced FMAP included as an incentive for states, and it would include certain costs identified in the transition plan. So what that basically means ask for states that get some self-assessments on time and start following their transition plan, if they are in line with their transition plan, within those 12 years, then they would receive a 5% additional FMAP. 5% additional federal dollars in these community-based settings to ensure that they can continue with their transition plan and make it easier for states to afford community based transitions, and this is something that we got from the Obama -- the Affordable Care Act. That's what we're calling it these days. Affordable Care Act includes the community first choice option. The community first choice option currently says that states can select this community first option, and if they do, they will get a 6% enhanced federal match to help people move into the community, and that has allowed other states to law down millions upon millions of dollars to help with that cost and actually states are not only bringing in money by sponsor is SFS, but also saving money when they transition people into the communities, so it's been really great for savings in those states as well. So that's where we got the idea. We thought, well, it worked well under CFC, so we put that under The Disability Integration Act.

How will it work for states one on one? As I said before, the Disability Integration Act, by what is required, but not how to do it. States are going to decide how they get there. the transition plan in New York will be very different than a transition plan in Nebraska. I don't know how many people are institutionalized in Nebraska. I don't know how many supports and services in the community are already being provided. That's why each state would create their own transition plan, to figure out where they are and how they're going to get to the end line. It's not for The Disability Integration Act to tell states how to do this. It's only saying people with disabilities have this right to be free and you need to make it happen.

And then the federal government would review the plans and the incentives for the state plan. So that's when we would have the federal government reviewing the state's plans and how they are going to transition people from institutions and into the community, but also divert people who might be at risk of institutionalization and speech them in the community.

>> Enforcements. We really feel that enforcement is a very important part of this, just like enforcement in the ADA is he know credibly important, because as they have found, despite the fact that the ADA is now 27 years old almost, many are not complying with the Americans With Disabilities Act, and in order to get them to comply, they're forced to bring suit, which is exhausting and avenue necessary. If the law has been around for 27 years, shouldn't we be following it by now? For enforcement of the Disability Integration Act, we thought, what could be effective? The U.S. domestic of justice can rank by states and insurance companies for discrimination, so just like the Justice Department now can bring cases against states for not complying with Olmstead, they would be able to bring cases against states for not complying with disability integration act, and they would also be able to be do that for insurance companies that don't comply as well. Additionally, individuals can bring their own case, they can bring the case that they have been force intoed a facility they don't want to be in or if they are at risk of think force interested a facility. They made it clear if they are at risk, because we don't want to be forced into a nursing facility before they can enforce their right to live in the community that. Did you want make sense, and it's a lot harder to get into the community after you've been force interested a facility. A person at risk of being force interested a facility and their insurance provider isn't providing them with the support and serves they need to remain in the community, then they would be able to bring a case under the it disability integration act. And the courts can award punitive damages. This is not something that's current lay loud in the actual DA, so the ADA doesn't allow the punitive damages, and we feel that punitive damages would be very effective in ensuring that other states or insurance companies do not violate The Disability Integration Act, because too many damages can be pain. For those who are force the to pay them. If they're included, that means there's additional incentive to comply, because people don't want to pay those additional damages if they don't comply with the Disability Integration Act.

Back you do to help? Calm your Senators. We have Senators from New York and Vermont on the Bill. We had more on last session. But again, we have just been introduced last mom it's not that we don't have from last session,

about we'd like to get more. Call your Senators. Call them daily. I can't tell that you one of our greatest successes was we had people in Wisconsin call their Senators every single day. And this lasted for about seven months until their senator finally signed on to the disability integration act, and I'm not sure if she zoned out because they truly agree with the DIA or if she was just worn out for getting all the calls. Either way, we're happy, so I'll take it.

Also, call your congressional representative. We have to get a path vote in the senator and in the houses. So calling your member of Congress and getting them to sign on would be really helpful. If you want to go above and beyond, so meet with them in person. Talk about how this Bill will help and you your friends stay in the community where we have the right to be. Freedom is for everybody. Not for just nondisabled people.

And if you don't know, who to call, you can call the capitol switchboard and they can direct you to the right place, or United Spinal has a super duper link that will help you find out who your representative is so you can give them a call.

now, I am a super fast talker, which means that Bill is probably going to kill me for ending a little bit early, but I'm just going to go over these resources with you, and then I'm hoping that we, by the end here, that leaves lots of time for questions. So the first place I would strongly suggest you go if you want to learn more is the disability integration act.org. It's a super dupe internet site. You'll notice that the wrong Bill number is on our little DIA logo, because that was created last year when it was 2427. This year it is 910. However, same language. Don worry about it. There were minor tweaks, but those minor tweaks were just minor tweaks in the language to ensure that it was clear that all people with disabilities who will be forced into institutions would be eligible under the DIA. If you're a nerd like me, you can read the Bill and you can also read the united spinal one page Ore it. That's on the third link on the page and if you still have questions, e-mail me, I'm Stephanie Woodward. My e-mail is swoodward@cdrnys.org. And if you have questions, you're interested enough to reach out and hopefully we can work together to get more congressional members on this Bill and get it passed. And that's where I end and hand it over to Bill to start taking questions.

>> Bill: And in fact, we do have questions, Stephanie. Beginning with if the DIA is passed, is there an estimate of about how many people that would affect?

>> Stephanie: I can tell you that it would impact at least the people in nursing facility beds. There are over 1.2 million people with disabilities in long term nursing facility beds right now throughout the United States. So each of those individuals would be impacted by being given the choice to live in the community. Not saying that they would be required to live in the community if they don't want to, but they would all receive that choice, but when I we want over to the specific prohibitions, I also mentioned attendants getting paid well. So that affects millions more people. If you're one person with a disability and you have two attendants, you can just imagine we've now doubled the amount of people or tripled the amount of people being impacted, because those fair wages will be an impact to ensure that people with disabilities remain in the communities, and of course, the family and friends of people with disabilities who would be able to get out of institutions, or the people who will be able to remain in the community and not have to go into an institution will be impacted, because you get to stay with your family and your friends and likely in your workplace, too, if you're a person who works and you're about to lose your services. Your job will be impacted and they'll have to hire a new employee, whereas if you can receive the support and services you can stay where you are. Millions ever people will be impacted and that is probably the greatest part of this Bill.

>> Okay.

>> And we have a scenario next. Bear with us. A person living in assisted care facility, independent living to assisted living to care center is being removed from her individual, independent apartment because she needs assistants, cognitive assistants with medication. She has to have an escort to go out. She is not happen by this, and this is a buy-in type of community where you pay a fee to get in, plus a monthly rented. Is she protected under present laws? And then if you can reflect if that would be impacted by the DIA?

>> Stephanie: Well, under presented laws, if she's choosing to be there, she can choose not to be there. And she can choose other supports and services to receive. Unfortunately, if she's in an area where there's limited

supports and services, even though she's protected, that did you want mean it's a reality. Similar to we have the right not to be discriminated against in housing, but that doesn't mean it's the reality. Under the disability integration act, she certainly would be protected, because she has the right to receive supports and services where she wants to receive them, and that includes IADLs, which is those instrumental activities of daily living such as cueing or reminders to take medicine and safety cueing as well such as, hey, did you remember to shut that stove off? Those are all services that would be included under the Disability Integration Act and if this is a real scenario, I'd love to go into it further with whoever is asking this. E-mail me and I'll try to find resources in the area that you are in and hopefully find a better situation for this individual.

>> Bill: Sure. Good suggestion, Stephanie, a specific case like that might require follow-up directly with you. Excellent. The next question, what public entity is responsible to ensure the affordable housing?

>> Stephanie: So initially, this is under the administration on community living. We felt that this was an appropriate place for this to be, because I can't imagine anything better than community living to be in charge of making sure that there is community living. However, HHS would be the overall entity, and of course the Department of Justice would always be able to enforce this, because they are able to enforce any sort of discrimination under the ADA and would also have that availability under the disability integration act.

>> Bill: Okay. Next question, it's Leslie. Bear with me. So New York has the NHTB waiver and the TBI waiver and the new Olmstead housing subsidy to try to help individuals transition from institutional living into community based living. However, affordable, accessible housing is a major problem in New York. New York City. How did the DIA address this as a practical malt officer

>> Stephanie: This is an absolutely important question. For New York specifically, I can get a little bit deeper, because this is actually my area of expertise. I live in New York and I can tell you that the HUD and TDI waivers are actually -- New York State is looking to convert them into managed care. And the suggestion for keeping them alive and out of managed care has suggested they cap it at about 5,000 people for that waiver. That

means a person with a traumatic brain injury who is number 5001 wouldn't get services. So as great as the waivers are, and that's the nursing home transition diverse waiver for those who aren't familiar, they're limited, whereas The Disability Integration Act wouldn't allow those limitations. It doesn't allow caps where insurance companies or states will only choose to serve 5,000 people or only choose to serve 10,000 people. They would have to serve whoever needs the services and not put capped on time or on the amount of people and not put on waiting lists. They can't say, well, we'll serve you when we get done serving these other people or when the first 100 people die. Then we can take on another 100 people. That's not equality. That's not freedom. And it's not acceptable. So under The Disability Integration Act, people who need services, whether you're number one or five or 5001, or 50,001, you would get those services, because that's your right. If the state or your insurance company would put you in a nursing facility to receive those services, if you couldn't get them in the community, then they must provide them in the community, because you shouldn't be forced into a facility just because you need some help.

>> Bill: Okay. The next question is about wage amounts. Will fair wages mean more than that paid for fast food workers? I think the real question is what will qualify as fair wages? Because fair wages are such a subjective term.

>> Absolutely. Fair wages is incredibly subjective, and we left it in that way for a very specific purpose, because a fair wage in El Paso is different than a fair wage in New York City. So this is something that, again, the federal government, when monitoring your transition plan, would make sure that the wage you are providing is enough to attract a workforce that is sustain annual for the people in the community. So the way that we'll be able to see whether or not the fair wages are being paid are, is there enough attendants in the community to provide the services or people with disabilities being prevented from leaving nursing facilities because there's not enough attendants to help them? If there are not attendants to help them, that means that the wage is not high enough to attract and keep a workforce. So it will be further flushed on the regulations, however, it was less this way on purpose, because in Rochester, our wages are certainly different than in New York City. We're both in the same state, but

the fair wage is different in Rochester versus New York City, because the cost of living is different. So a paid attendant \$15 an hour in Rochester would be like hitting a gold mine, whereas in New York City, that may not even attract a single worker, because it wouldn't be enough to cover the bills. So we kept that saying and it may or may not be more than fast food workers, depending on the area that you live. I can tell you that we always advocate for attendants to be paid what they're worth and there's certainly nothing wrong with fast food workers, but we feel if you're flipping a human being, human beings weigh slightly more than a cheeseburger and may deserve more wages than a person flipping a cheeseburger. And that does not demean the work of the people in the fast food industry, but it can be harder to attract people to live in humans and to help shower humans than it is to lift fries out of a basket. So that is something that would have to be considered in those regional areas. Are you paying enough to attract people to do these specific services that aren't always easy or pretty?

>> Bill: Sure. Sure. And another question, Stephanie, along the same lines of retune race. With many states currently struggling to pay decent wages to current attendants or to even provide service to people in the community, a/k/a, waiting lists, do you think that the financial motives included in the DEA Bill will be sufficient?

>> Stephanie: I think that 5% is incredible. I know it sounds like a very small%, but if you think about it in terms of New York State, New York State implemented the community first choice option just about a year ago. They have already drawn down about a little over I want to say \$100 million from the 6% additional. So 5% is 1% less than 6%, but that's still significant amount of federal matching. In addition, that federal matching must go to community based services. It can not go to the general budget of the state. It must go to those community based services. And keep in mind, you're getting those bills I don't understand, but you're also bringing down the cost of the state, because for example, in New York State, it costs about \$120,000 on average to keep machine in the facility or \$40,000 to provide the same supports and services in the community. So in addition to getting money, you're also saving significant money when you transition people into the community. So I really do think

that that financial incentive can be great for states and the trek is that states need to get onboard early, because if they get onboard three years late, they've now missed out on three years without financial incentive. So it's really important for states to get onboard the moment that they can so that they can drawdown as then dollars as they can.

>> Bill: Sure, sure. Has the current DIA Bill been scored by the CBO as yet?

>> It has not get been scored by the CBO. So the numbers that we are using to estimate cost and savings are from the use of CSD and states that have collected it, but also looking at the national council on disability, did a cost savings report on home and community based services. I believe in 2012 and they created a beautiful grid state by state that shows how much money states are spending keeping people on disabilities versus in the community and when you look at the Costa analysis on that, per individual per year, it's at least three times as much to put someone in a facility than in the community. So while we don't have a CBO score yet and we are looking forward to that, we do have data that's going to show us that it will create a lot of cost savings to allow people to live in the community. We have cost savings. It will give people the freedom that they have a constitutional right. To you can't sell me more on that.

>> Bill: Understood. The reader, the attendee is complimenting the nice presentation and asks, please kindly elaborate on the financial impact of this Bill. For example, dollars saved. Well, you sort of just addressed this. For those who are capable living in a community, people who are able to direct their own care. And you did address that. I'm not sure if you'd have more to offer, Stephanie, with the way that that was worded?

>> Stephanie: First of all, thanks for the compliments. I appreciated the e-mail. Keep them coming. But the financial savings, particularly in consumer directives where people direct their own services, would be helpful, because you're saving more by having you live in the community directing your own services, and most people who are in a consumer directed plan not on a 24-hour, but even for those who are on the 24-hour service needs and they would be less costly than a facility, if you put the run together in aggregate, they are still cheaper in the community. I would strongly

suggest that you check out the cost savings report that the center for disability rate having put together on New York State, implementing PFD, and that can serve as a microcosm or what DIA can do nationwide.

>> Bill: Two quick questions to complete, because we are getting a little bit late, Stephanie. One is, is it possible to see that data, that data on pricing and savings? Because we always hear institutions are cheaper care for an individual that needs 24-hour care.

>> Stephanie: Well, with can you all still see my screen my googling? I'm just going to bring you have the cost in detail right now so you can see what I look at when I talk to my representatives. I am looking to run down among the States. So we're looking state institution. We have for Alabama, 195.275. Home and community based services. 49859. Like that's a significant savings. If you go down the list, look. State by state, it is so much cheap for community based services. If people want more information and more sources, I didn't get too deep in it, because most people think this is the most boring part of the disability integration act, but I'm happy to provide more services for people who want it. For people who just want to see basics, go into Google. Type in NCD-HCBS cost, and the first thing you'll see is cost in detail and that state by state comparison, and I really think that's very revealing as to how much states could be saving by a lot of people living if -- by how long people to live in the community.

>> Bill: Excellence. We have more questions, but no more time. So additional questions, if you wish do reach out to Stephanie directly by e-mail, she would be happy to assist you with information. One final question, Stephanie, is do we have any feedback yet as to what we think our chances are of passage of the DIA this congressional session?

>> Stephanie: No. I don't know percentage-wise, but what our odds are, but I do know that the more people who reach out, the better chances we have. So I see 86 attendees still on the line. That means 86 of you could hang up the phone and call your congressional representatives and Senators and ask them to sign and that will make a difference. So we're going to keep working on it. If you saw the long list of organizations that support created equal each of these organization will help us get more support for this Bill and hopefully get it passed this

sessi on.

>> Bill: Surely. On behalf of the United Spinal Association I'd like to thank Stephanie Woodward so much for sharing her current updates through The Disability Integration Act and why it matters to you. Thank you, Stephanie.

>> Stephanie: Thanks.

>> Bill: Sign up for and receive our webinar's newsletter and advocacy alliance information. Please visit us at finalcord.org or visit our publication site, newmobility.com, coverage for everything active wheel chair users need to know. This will conclude today's presentation. Thank you for your time, and attention to this current and important topic.

[Webinar Concludes]

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