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>> Thank you for joining us today for United Spinal Association's webinar, Live Your Life: The Disability Integration Act and why it matters to you. Today's presenters are Ms. Stephanie Woodward, Advocacy Director of the Center for Disability Rights, as well as Alex Bennewith, VP of Government Relations here at United Spinal. This is Bill Fertig, Director of Spinal Cord Injury Resource Center and I'll be your moderator for today's presentation, one of a continuing series of United Spinal webinars archived at spinal.ought.org. Use the questions chat window at the bottom of your control panel to track questions. We'll do our best to get to them today at the end of the direct presentation. For any questions remaining unanswered, please e-mail those directly to the presenter, whose addresses are displayed upon the last slide. Closed captioning instructions also appear in the control panel of your chat window, as well as the pdf version of the handouts in today's presentation in the handout association your control panel.

Stephanie Woodward, JD, and the Director of Advocacy at the Center for Disability Rights in Rochester, New York. She is a lawyer and activist, and a proud disabled person.

Alexandra Bennewith is MPA, Vice President of Government Relations at United Spinal Association. Bennewith directs advocacy strategy for legislation and

regulations regarding health and disability policy at the federal level with the United States Congress, state levels of government, and with the United States executive branch, including the White House. The U.S. Food and Drug Administration, the National Institutes of Health, and the centers for Medicare and medication services, CMS. Bennewith is a steering committee co-chair and member of multiple coalitions and committees focused on healthcare, rehabilitation, community supports and services, employment and disability rights issues, including the steering committee co-chair of the ITEM coalition, focusing on individual's access to medical equipment, assistive technology, and devices, and has presented to multiple stakeholders on a range of issues. She is also co-chair of the national disabilities leadership alliance employment team and has over 17 years of government affairs and public affairs experience. She graduated from Brandeis university with a bachelor of arts and received her master's of public administration from the American University.

And now I'd like to hand it off first to Alex Bennewith with a brief advocacy update, followed by Ms. Stephanie Woodward, for a more detailed presentation on today's topic. Alex?

>> Alexandra Bennewith: thank you, Bill. Thanks, everyone, for taking the time today. I think Ware going to go on to the next slide now. I'm going to spend a couple minutes only so we can get to the meat of the webinar. We're lucky to have Stephanie speak to us today, and she will be speaking at our Roll on Capitol Hill event in June, June 26th through the 29th. The Disability Integration Act is going to be one of our key policy priorities at that event, and we'll have a lot of Capitol Hill meetings, around 200 or so. And a couple of the other issues we'll be focusing on are durable medical equipment issues and medical research issues, but I don't want to spend the time focused on that right now. I just wanted to go to the next slide.

These are our sponsors. Thank you to them for our support of our issues and of united spinal. Go to the next slide, please. I just wanted to make sure they had their recognition in their support of us, and I'm going to move it along to Stephanie to start the DIA webinar. Thanks, Stephanie. Over to you.

>> Stephanie Woodward: Thank you so much, Alex. I'm

excited to be talking to you-all today about The Disability Integration Act. Disability integration act really is about creating an absolute right for all people with disabilities to live in the community. So first I just want to tell you about the basics of The Disability Integration Act. This is major disability rights legislation. I'm thinking of it on the same scale as the Americans with Disabilities Act. Our sponsor for this is senator Schumer, and he's been a great sponsor. We do have six cosponsors so far in the Senate and working to get more, and we are also working on our house introduction with the same. And we have a ton of sponsors. So I want to just go through and highlight some of our sponsors. This page and the next two pages highlight some of our national supporters, but if you go to The Disability Integration Act.org, and you'll see that link at the end of this, you'll see over 400 supporter organizations throughout the United States supporting this. But first and foremost, ADAPT is a supporter of this, because ADAPT really did work hard on this legislation, drafting and promoting it. I also would like to point out the autistic self advocacy network, because they were very helpful to us in drafting the community definition for the disability integration act. Our next page of sponsors, you'll see that the National Council on Independent Living, they were very helpful. Very thankful for it their support on this. And the national coalition for mental health recovering also helped us with definitions to ensure that The Disability Integration Act really was inclusive of all people with disabilities. And then a number of our supporters really showing that we have quite a diverse amount of supporters, including SEIU, and sometimes they're on differing sides, so it's really great we've come together and really believe that all people with disabilities should have a right to live in the community. And you'll see United Spinal is listed as well, and we are so thankful for United Spinal's support on this and for the opportunity to talk to y'all about this in this webinar.

So to really talk about why this is needed, we have to start with where we are right now. So the Senate HELP committee in 2013, and health is the health and labor pensions committee, released a report about where we are in the United States on disability. What it found was that we're falling behind on community living. So here's where I'd like to throw out our first question, our first full

question to talk about community living and how you guys feel about institutional living versus community living. There you go. Can you --

>> Alexandra Bennewith: Can you see the question? The question is do you ever to be forced into a nursing home? Yes or no. We'll give you a couple minutes to answer the question. I think we know the answer.

>> Bill Fertig: It will be just a couple of minutes until we have everyone vote and post the results.

>> Stephanie Woodward: And keeping in mind that forced doesn't mean that you're physically pushed in there. It means you don't get that support that you need.

>> Bill Fertig: And the results are in. Not surprisingly, 98% voted no to the question, do you ever want to be forced into a nursing home.

>> Stephanie Woodward: All right. For that two% of you that does want to be forced, don't you worry. The disability integration act won't take that away from you, but what's surprising is if you see that poll, 98% said no, and yet 25 years of the ADA at this time the of the report and 14 years of the Olmstead decision that said people have the right to live in the community, the Senate health committee found that states are still failing to fulfill the community living promise of the ADA.

So what does that mean? The report found that states are focused on transitioning people in facilities back into the community. That means they're not looking at getting people out of nursing facilities that have been forced there back into their own homes. In fact, rather than working on getting people out, they've been putting more people in institutional settings. And when there is a transition, it's unclear if a person is transitioned into the community. Sometimes they're transitioned from one facility to maybe a less restrictive facility, but not into the community. And this report also found that there should be a reallocation of these dollars to support community settings, because quite frankly, on the aggregate, it is cheaper for people with disabilities to live in the community, not to mention we're happier there.

So one of the biggest recommendations, really the primary recommendation from this report was 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 support under Medicaid

has a federally protected right to a real choice in how they receive services and support. And we agree with this. We have to do more to ensure that supreme a real choice to live in the community. But we took it a step further in creating this act, we've created a new law. It doesn't amend the ADA. The proposed structure ensures that all people with disabilities have the right to live in the community and lead an independent life, but it doesn't amend the ADA. You will see similarities between the structure, because the ADA is a Civil Rights law and so is the disability integration act. So the HELP recommendation from the HELP committee says individuals on Medicaid have a right to have community services. We believe that all people with disabilities have that right, not just those receiving medicate. That's why we brought into the disability integration act to really include everyone. This is a civil right issue, not a programmatic issue. And rights follow people. Programs can be defunded. Programs can be crossed out, red lined. Civil Rights is very hard to take those away.

So it really just establishes the right to choose where we receive those services that we need in order to live independently in the community.

So when we're talking about the Civil Rights, I know that we've all heard these words before, but I think it's important that we go through this and really been it. The declaration of independence says that all men are created wall and that he have inalienable rights, which are life, liberty, and the pursuit of happiness. When we reflect on this, all men or all people are equal in their rights. And where are disabled people on this? Are we treated equal when I it comes to life? To our lives? Our right to live? How people value our lives. And what about our labor any liberty is being free without restraint, but when we aren't given the services and supports we need in the community, we're forced into a nursing facility where we can't live without restraint, so where is our liberty then? And pursuit of happiness, I'm a person with a disability living happily, but I'm not sure that I have been treated equally in my pursuit of happiness. So the disability integration act really is working to address this, particularly the liberty part of this.

So if you look at the slide, you'll see two goldfish. One goldfish saying how is the water? And the other goldfish saying, what the hell is water? They don't even

know what it is, because it's so fundamental to them. So right to live in the community is right number zero for people to exercise their liberty and pursuit of happiness. And you think, right number zero? Because it's so fundamental that nondisabled people don't even think of it as a right. It's there. If you asked your nondisabled friends, what if someone locked you away, even if you didn't commit any crime? They would be confused. What do you mean? You can't lock me up. I've asked this of people and they get upset about even the question. Like how could someone lock you up if you haven't done anything wrong? And that's what happens to people with disabilities daily. We need help, so we get locked away in institutional settings. And it's easy for it to happen to us. And because we don't have that real right and that real choice to live in the community. So if we don't have the right to live in the community, we can't exercise our right under the ADA. And the easiest way I can explain this is my friends who are living in a nursing facility could care less about curb cuts, because a curb cut means nothing to a person who cannot get outside of the walls that they're trapped in. These basic things we secure in the ADA don't mean anything to a person who is locked away. So the ADA has this promise that we could all live equal and free in the community, but if we don't have the right to live in the community, because all we have right now is an Olmstead decision that states are really not taking seriously, then what happens? Without adequate community-based services, we can't live in the community. So The Disability Integration Act recognizes in statute the right to live in the community and to receive those community-based services.

So moving on to the next slide, how does The Disability Integration Act work? Essentially, what happens is it prohibits Medicaid and other insurance providers from denying those community-based long-term services and supports to an individual who is eligible for an institutional placement. And you'll see on the slide the exact words from the disability integration act. You'll see the exact prohibition. Essentially, it means if an insurance provider would pay for you to go into a nursing facility because you need support, then they must also pay for you to receive those same supports and services in the community. Help showering and transferring and dressing and eating. So you have to go to a nursing facility. The

Disability Integration Act would then require, well, if you would pay for them to go to a nursing facility because they need all of that help, then you have to pay for that same assistance to be available in the community, so that person has a real choice to live in their own home in the community.

So I'm just going to go over some of the specifics of what this bill really entails. So what's a public entity? Because it's really public entities and insurance providers that are going to be impacted. A public entity is a state or local government that either funds or it provides the activities of daily living, the instrumental activities of daily living, or the health-related tasks. The funds provide that assistance. And LTSS insurance provider is a long-term services and support insurance provider, and that's a private insurer that operates in commerce throughout the United States that provides or pays for those same things. So any insurer that pays for these assistances to have them either in the nursing facility or in the community. So that's who is being impacted right now, besides the people with disabilities. This is how we're actually creating the real choice.

So who else is impacted? Individuals with LTSS disability. And what that means is that the person who is already defined as a person with disability under the ADA who also requires assistance with activities of daily living, instrumental activities of daily living, or health-related tasks. And either in an institution or at risk of institutionalization.

So what that means is it can't just be any person with a disability. There are plenty of people with disabilities out there who don't have long-term services and support needs. My boss is a diabetic. He is under the ADA, a person with a disability, and rightfully so. But he wouldn't be a person with an LTSS disability under The Disability Integration Act, because he doesn't require assistance with his ADLs or IADLs and he is not at risk of institutionalization.

Another example is me. I'm a person with spina bifida. I use a wheelchair. However, I don't require assistance with my activities of daily living and I'm not at risk of institutionalization, at least not yet. However, in the future, as I have more needs, I may be. So it's really important to remember. It's not just a person with a disability. It's a person with a disability that requires assistance, and being in an institution, pretty

easy to identify. Being at risk of institutionalization can mean that you would be forced into an institution without the that long-term service and support in the community. So if you don't receive your attendant services and you would be forced into a nursing facility, that means you are at risk of institutionalization.

So community. So what is community-based? We talk about the right to live in the community, but then there's sometimes a little bit of different perspective on what community means. So we've spent a lot of time creating this definition, mostly because we don't want there to be a person in a segregated set and go call it a community. And one of the best examples I have is my friend Ari, who runs the [indiscernible] advocacy network says that sometimes institutions are putting little houses on the institutional property and putting a gate around it and saying, well, it's in the community, because they are in the community and not in the institution. They're on the property of the institution. And he says, well, my aunt lives in a mansion in Boca Raton and she has a gate around it. I think that's a gated community. But that's to keep people out. When you have a gate around you to keep you in, that's really just a segregated setting.

So in the community, a dwelling owned by the person or their family, so it's either you or your parents or your sister or your aunt, whoever. You get to choose, though. Or it's a dwelling rented under the terms of an ordinary lease. So you rent it, just like a nondisabled person would be able to rent. There's no extra terms just because you have a disability. It can be a group setting up to four people. However, what's really important about this is that these group settings, think about it, if it's a group setting with up to four people with disabilities, it is only counted as community if those people with disabilities have control to the access of their home. They get to lock the door, not someone else. They can eat whenever they want. They get to make that decision. There's not scheduled meal times where those are the only times they can eat. They can come and go whenever they want. There's not any rules like that. And they would have the same terms as an ordinary lease. There's nothing extra because of their disability, a housing setting where a lot of people with disabilities used to live there, but you must also get your services from there. So you have the right to disconnect those. They can be, but they can't

be required that their tenancy is tied to those services, and any setting that's in the community.

So I want to get into what is an ADL? What is an IADL? What are health-related tasks? Because those are the forms of long-term services and supports that the disability experience is really focused on. So an ADL is things that people do without help daily, generally. So it's your basic eating, bathing, dressing, toileting, transferring. It's very much things that attendants frequently help with. If you have consumer-based programs in your state already, these are tasks that generally attendants can help with without the state thing. Assistance of IADLs, which are the instrumental activities of daily living, are really where sometimes things get more restricted, and that's where we really worked on this definition and felt that it was really important for people not only with physical disabilities, but people with other disabilities that just need some help with some other activities in their life. Things like housework. Not as fundamental as eating, but it is pretty fundamental. Meal preparation, money management, so managing your finances. This is especially helpful. Imagine you've been in an institution since you were 15. What we often see is kids are put into institutions. We get them out when they're in their twenties, but they never got to go to school and take a life skills class about finances. So having some help with money management can be the difference between paying your rent and keeping your apartment or getting kicked out because you didn't have those skills yet. It's also helpful for people with intellectual disabilities. And one of the big things that we added in was care of others. In care of others, it's a really important one. And I want to talk about that for a second. We had a woman named Carmen. She was a quadriplegic and she was a great person. She was a board member of our SILC. She got pregnant and her consumer directed service told her, well, you have to abort the child. And she is like, excuse me? You don't get to make that judgment for on me. No, I'm not doing that. And so she had her child, but there are so many regulations that said, well, your attendant cannot help you with the care of others. So your attendant can't help you with raising your child and we're not asking our attendants to help -- I'm not asking you to help me raise my child. If I have a physical disability and I need my attendant to help me put my baby in their crib, that should be something

that is allowed. But currently, there is a lot of assistance that is not allowed. So to us, that one aspect can be a huge thing, particularly for people with disabilities who want to be parents and are wondering, how am I going to do this? And to talk with parents for disabilities who are like, my God, what a difference it would have made in my life if I had that assistance. Care of others can also include pets. Right now there's some regulations in programs across the state that say, nope, we can't help with your pet care. I'm a girl with a physical disability with four cats. Changing the cat litter is not something that I can ever see myself doing in any way that doesn't result in cat poop on me, and that's not something I want to do. Right now, attendant services are allowed to do some things like changing cat litter. And you know what if 23 if you want your attendant to help with you the care of your pet, you should be allowed to have that. That's why really important for us to have that listed under an instrumental activity of daily living under The Disability Integration Act. So DIA has the basic fundamentals, but it's also got these fun little specific perks that I think are really important to helping us really have that pursuit of happiness that we've often been just denied our liberty and not even considered our pursuit of happiness, and this really does adding some extra.

Moving on to health-related tasks, health-related tasks are the things that you have is that true often allowed to be performed by attendants under consumer-directed programs, but aren't allowed under a traditional Home. So things like medication. So giving pills or helping inject your insulin or vent users, assistance with the vent. So these are things that if you are a person with a disability and you trick your own services, your attendant is allowed to do. However, if you're going through a traditional home healthcare agency, they're not allowed to do. Disability integration act says if you need that assistance, you should be able to get that assistance in your home and you shouldn't be forced into a nursing facility just because an attendant can't do that health-related task for you. So that means states are going to have to find a way to allow these health-related tasks to be performed in the community.

And then as a catchall, in case we missed absolutely anything, we added other tasks related to the above. And we think that it's important to have a catchall, because

as society moves on, things will change and we don't want these definitions to be so concrete that if something comes up in the future where we need a little assistance with something else that it wouldn't fit into one of these categories. So the catchall is really important.

That was a long one, but I hope it was worth hearing. So I want to talk about just the general idea here. The general broad prohibition is that if Medicaid or another insurance provider that provides long-term services and support would pay for a person to go to a nursing facility, then the insurance provider must also pay for that person to receive the same services and supports to live in the community. That is really the basics of what The Disability Integration Act is. So right now you'll hear people say, well, you could live in the community if you wanted to. Sure we could, but we don't have that real choice, because I could say all day long that I can live in the community, but if I don't have that support and service that I need, then I don't have that right. So this is really creating the structure that allows you to really have the right to live in the community. So if your private insurer would pay for you to go to a nursing facility because you need help showering and dressing, then they must also pay for those same services and approximate supports for you to live in your own home, have an attendant come to your house and help you with those things.

So when talking about The Disability Integration Act, there are sometimes we get some questions about, well, then I won't have the choice to live in an institution. So for you two% that were really interested in being forced into a facility, don't worry. You still can go to a facility. The only difference is the force part. You still can choose that institutional placement. You wouldn't be forced there. So states are only required to assure that people have the choice to live in the community under The Disability Integration Act. The Disability Integration Act is really careful to ensure that individuals are provided community-based long-term service and supports, only if they choose them. So community-based services is not something that's going to be forced on you. If you really do want to go in that nursing facility, have at it. Go for it. But if you don't, you could have that same right not to, because right now what we have is nursing facilities are the easy way. You need help, you go to this facility. What we want is the community to be the easy button, and

if you still want to go to an institutional placement, you can do that. The disability integration act isn't going to restrict any funding to assisted living or group homes. It doesn't change the CMS definitions that allow funding for these facilities, and it's not going to impact their funding whatsoever. Again, it's only going to ensure that people with disabilities have a real choice whether they live in assisted living, a group home, a segregated setting, or out in the community. That's really what this is all about. It's not about cutting people's funding streams. It's not about funding streams whatsoever. It's about your right, your right to choose where you live.

So there's about 11 specific prohibitions, and I'm just going to go over them really quickly with you, talk about what are these things that the disability integration acted is simply not going to allow anymore. So the very first and foremost, and all of these 11 prohibition have his come out of things that we've seen all the time of why people are forced into facilities. My first one screening people out with disabilities. So insurance providers can't say, well, you're not eligible to live in the community because you got your disability after you turned 26. Therefore, we're not going to cover it. Or you have a spinal cord disability, but you weren't born with it. Therefore, we're not going to cover you. So screening out by that kind of eligibility, not allowed anymore.

Imposing service or cost caps. So that means say you have high needs. You need 24-hour-a-day service. Right now, some states and some programs are imposing cost caps or service caps saying, well, the most we'll ever provide anyone is 15 hours of service a day. So since you need more than that, you have to go to a facility. Absolutely not. We're not having that. There's no service caps. There's no cost caps. There's no saying you cost too much money to live in the community, because yes, some people do cost more to living in the community, but if you bring us all together and you look at the aggregate, it is so much cheap tore let us all live in the community, because in New York State alone, about \$90,000 a year for one person with a disability to live in a community. That's outrageous. Or to live in the facility. So \$90,000 for a facility where you get to watch judge Judy reruns and watch crappy food or significantly less money where you get to live in your own home, eat whatever you want, my choice would be pizza rolls, and do whatever you want, listen to your Biggie

Smalls music all day long if you want, because nobody is going to stop you, because you're in your own home. It's cheaper and you feel free.

Failing to provide a specific service is the third one. So a program that says, well, they do allow people to live in community, but we don't provide health-related tasks. Or we don't help people who need this specific thing. Absolutely not. If you would pay for them to receive it in the facility, you have to do it in the community, too.

Screening out by regulations or different requirements. Again, these are just little things that insurance providers are using to try to say, you're not eligible.

So moving on, we're looking at the next set of prohibitions, and these are, again, all from things that [indiscernible]. Number five, you are probably familiar with this. Providers will not be allowed to impose a waiting list anymore. This is ridiculous. What we see is places like Utah, protesting in Utah and Arkansas because of the years long waiting list that people have just to get community services. People are dying in nursing facilities on a waiting list to get in the community. That's ridiculous. Why should you wait to live in the community if an insurance provider is paying thousands for you to live in a facility? They can bring that thousands over to pay for you to live in the community.

Number six is a really important one for us as well, and ADAPT has worked tirelessly on this, and we've found that having a workforce to provide attendant services is incredibly important. However, if states and insurance providers aren't paying attendants adequate wages, what we're going to have is a shortage of attendants, meaning less people to support people with disabilities in the community, forcing more people with disabilities into a facility. So it is now, under The Disability Integration Act, prohibited for insurance providers, either public or private, to pay inadequate wages. They have to provide adequate payment to support the workforce. That means you have to attract our attendants here to come to the workforce and to stay to be our attendants. Otherwise, we're going to end up in a facility.

Failure to provide intermittent supports and services. Sometimes people with disabilities only have intermittent needs, and so they'll say, well, we're not going to provide you your community-based support, because

you don't need them all the time. If you have intermittent needs and without supports and services you would end up in a facility, because you didn't get that help when you needed it intermittently, then you are eligible for that under the disability integration act and you can't be denied.

Another one we see a lot is requiring people to use informal supports. So I mean, what I've seen is you've got a 16-year-old guy. He needs attendant services. He comes and gets evaluated by his consumer-directed program and they say, well, we're only going to approve you for ten hours of service, because you have your mom here to help you has an informal support. I don't know about you. I've never been a 16-year-old boy, but I've got to imagine there are probably things in your life that you don't want your mom around for as your informal support when you're 16, that you would rather have an attendant there that you get to choose. It's probably a guy that you can relate to. Do you really want to go to the mall with your mom to try to pick up girls? I don't know. I've never been a 16-year-old boy, but I would imagine that me, as a 16-year-old girl, probably wasn't going to go and date the guy who is at the mall with his mom. Maybe I'm just terrible 16-year-old girl, but maybe I'm not. So that requiring informal supports is where the problems have been. So insurance providers can't require that anymore. If you don't want to have informal support or your mom doesn't want to be your informal support, they cannot require it.

Then moving on to the last three of the prohibitions. Insurance providers can't fail to offer community-based services before institutionalization. So they can't say, oh, you need this help, so you have to go to the institution. They have to first offer community-based services. They have to first say, hey, we see you need assistance. So how about we provide that in your home, in the community? And then beyond that, we still have the issue of people who are currently in institutions. So insurance providers cannot fail to notify people in institutions of their right to live in the communities. So if you're paying for that person to live in that institution, you must notify them of their right to live in the community. Go in there and say, hey, did you know that you could live in your own home in the community if you wanted to? Because the scary part of it all is I've gone into institutions and said, why aren't you

living at home? And people will say, I can't. They put me here. Like I need help, so I have to live here. And I say, no. There are programs. You could live in the community. We can help you apply and they literally had no idea that they even had the option to live in the community. And this happened a lot even when I was in Florida. I was litigating in Florida and Florida has a way of systematically institutionalizing children with significant disabilities. And parents don't even realize that they have the right to bring their kid home. So we have kids who are paraplegics, quadriplegics lying in bed at 3:00 o'clock on a Friday afternoon and they could be at home and their parents don't even know, that because the state didn't tell them. The state just said put your kid here.

And then the last prohibition is the failure to make accommodations to allow people to live in the community. So if all of these other prohibition don't work and that's still something else you need, then that last prohibition says you've got to make those reasonable accommodations as well.

So we're getting towards the end, but there's some other fun things that I just think are important to know. What about informal caregivers? I already said DIA says you cannot require people to use informal supports and you can't require people to provide those informal supports. But in addition to that, we know that informal caregivers are an important resource. So The Disability Integration Act does require the insurance provider to assure the federal government that it supports the I know formal caregivers who are providing services to people with long-term services supports and needs.

>> Alexandra Bennewith: I'm sorry. This is Alex. I want to remind people to do the poll, the second poll? You want to do that?

>> Stephanie Woodward: Thank you. And that question is do you feel that there is enough accessible, affordable, integrated housing in your area? It's going to come up on your screen, and I just click yes or no. Do you feel that there is enough accessible, affordable integrated housing in your area? We'll relay the results in a couple minutes. Bill, do you see some results popping up yet?

>> Bill Fertig: I do. The results are, and I was talking to you, but muted, the results are 99% feel there is enough integrated housing in the area. Do you feel

there is enough integrated housing in your area? 99% say no, there is not.

>> Stephanie Woodward: And I think that that's valid. And we agree and so that's why the act has a very specific prohibition, mobile public entities. This is only for state and local governments. This is not for private insurers. These private insurers don't pay to build housing. But your state and local governments do. So this prohibition is specifically for them. Public entities can't fail to ensure that there is sufficient affordable, accessible, and integrated housing.

So what does that mean? Public entities have to ensure that there's enough accessible housing in the communities. Quite frankly, there's no point ever transitioning someone out of a facility if there's nowhere for them to move into. But what's also important is the housing has to be affordable and integrated in the community. A lot of the things we're seeing is great, new buildings are being built that are accessible, but new often means expensive. So people with low income cannot afford them. And integrated. What we don't want to see is what I like to lovingly called the crip get owes. You have these areas where it's all elderly and disabled people grouped together in housing areas. No. We want to be integrated. I want to be your neighbor. I want to be in the neighborhood. And I don't want all of my neighbors to look just like me and to have disabilities just like me, because that's not integration. Quite frankly, that might just develop and still be the nursing facility. So the States have to ensure that.

So you might be wondering how does this work? How does The Disability Integration Act make this happen? So once passed, the regulations for the disability integration act will have to be released within 18 months of the bill signed into law. So that means there's 18 months for the regulations to be written and released. And then there's also self-assessments. So the public entities and the private insurers have to complete a self-assessment on where they are currently within 12 months. How are they at providing these supports in the community? Where are they on this housing issue?

And then there is a ten-year transition period. So I know that we would all like this to happen today. I would like this to happen today. In order to get a law passed, we have to give some time to help states and private

insurers come into compliance. There's a ten-year transition period, but with that transition period, they also have to submit transition plans to make it happen.

And then the last thing is there is an incentive for the public, 5% FMAP, which is federal matching money, and it's only for certain costs that are identified in the transition plan. So what additional cost would there be to help people get in the community? And so those things would be covered with a 5% additional match. And it's really just incentive to say, hey, we'll help you financially a little bit to help people live in the community, because the federal government is looking at it like this: It is cheap for people with disabilities to live in the community, so to put in the money up front, to save the money in the long run is really helpful for everyone.

And then how does it work? DIA specifies what to do and not how to do it. And I think the best way to analogize that. The ADA said businesses have to be accessible. They didn't tell businesses where they were going to get the money, how to fund the money, how to build the ramp. They gave some facts on what the ramp should be. The slope shouldn't be too much. But they didn't get into the details. They just said be accessible. So the States get to decide how they will get there, but the DIA just tells them what they have to do, not how to do it. And then the federal government will review what the states and the private insurers are doing to ensure that they are complying.

Enforcement is through the Department of Justice. They can bring cases against both the States and insurance companies. I think it's also important to remember that individuals can bring cases. If your insurer has forced you into a facility or isn't providing services and you're about to be forced into a facility, you can bring your own case and what's beautiful is the courts can award punitive damages, which I think is incredibly important for this bill, because it's not under the ADA and I think damages are a great motivator for compliance.

So after hearing all of this, what can you do to help this out? Call your senator. Get them to sign on to the disability integration act. Call your representative. Tell them that it's going to be in the house and we want support. And the capitol switchboard number is (202) 224-3121. And there's also a link so that you can

find your representative.

And then here are just a few resources if you want to learn more about The Disability Integration Act. And I hope you do. The Disability Integration Act has its own website. ADAPT has a great info page on the disability integration act. And you can even contact us.

and so I guess it's time for questions.

>> Bill Fertig: Stephanie and Alex, great content. A lot of content. We have a lot of questions and comments. Let's get to them. First question is if you have sufficient funds to be know able you to live in subsidized housing and have insurance, how could they possibly force you into a nursing home? Stephanie?

>> Stephanie Woodward: Well, because if you have insurance, but your insurance provider won't provide the assistance you need in your own home and there's a lot of insurance providers that say, we'll provide this assistance, but only in a nursing facility. So a lot of Medicaid programs, if you need say ten amount of assistance, you are automatically approximate pushed into a facility. It doesn't matter if you own your own home, if you're having your own public housing. It doesn't the matter. They'll just take you and put you into that facility, because they won't provide the attendant services that you need. They won't provide the cooking or the help with showering and transfer and go they say the only way we'll give you this help is if you go to a facility.

>> Bill Fertig: It's not that they're paying for it. They're just paying for it in a facility or not at all?

>> Stephanie Woodward: Right. There's where the problem and is and the DIA is trying to address it.

>> Bill Fertig: You address this had in your presentation early on, but would you address this previously again? How is community defined in this particular bill?

>> Stephanie Woodward: Community, it's really important, community is something that is your own home. It's not any institutional grounds. It's your dwelling, a home of someone in your family that you choose to live in or the place that you rent. And the rental agreement is the same as any other person would have. It's not going to be a rental agreement that has any specification due to your disability. And should you choose to live in a group setting with other people with disabilities, its only community, it's four or less people with disabilities in

that setting, so it can't be some huge amount of warehoused people with disabilities. You have the right to come and go as you please. You have the right to eat whatever you want. You get to control the lock on the door. Things like that. And that your rental agreement is the same that you would have if you lived on your own in an apartment. It can not be based on your disability. So that's what the essentials of community is.

>> Bill Fertig: Thank you, that makes it more clear for me, and I listened to the earlier part as well. I appreciate that. This is from Candy in Texas. It's a little bit long. My friend would qualify for nursing home placement. She is paralyzed from the breast point down. She has to have someone to help dress her, turn while in bed, help getting in and out of bed, bathing, personal hygiene, help with bowel programs. She was in a car wreck and lost her two girls. Her husband is blind and has other health issues. She has insurance, but doesn't cover the help with the assistance that we're talking about. She has an electric wheel chair and a van that she can drive. She's been moved to the first floor of the building, isolating her from fellow colleagues unless they have staff that are there that can get her down. She is having such a hard time. It is costing most of what she makes to even get part-time care. Any suggestions for her to stay in her home?

>> Stephanie Woodward: I mean, suggestions for right now, if she lives in a state where the Medicaid buy-in program is affordable to her, Medicaid would then be able -- Texas? I do believe Texas has the Medicaid buy-in. I don't know what their buy-in rate is in Texas. I do know in places like New York if you make less than \$50,000, the buy-in rate is free and then Medicaid is able to pay for those attendant services. The great long-term solution for this is to have her and everyone else advocate for the disability integration act so we can insure people who are eligible for nursing facility placement like this are able to get it.

>> Bill Fertig: Thank you for that. A comment on ADLs. This is more of a comment. I assume that the basic ADLs are included in the IADLs inclusively. Right?

>> Stephanie Woodward: Well, they are a different definition, so ADLs are all under just ADLs. IADLs are a different definition. IADLs are instrumental activities of daily living. So they're different from activities of

daily living, because activities of daily living are those very fundamental things that we do, bathing, eating. Instrumental activities are things that help us to live independently, like money management, care of others, prompt and go reminding to take pills or things like that.

>> Bill Fertig: A comment followed by a question. Real life problems. Client directed care cannot find someone. In other words, someone to do the care for the amount of money that's lot by the state. And then a question. Same person. How are states able to get away with this? What are we doing to stop it? Actually two questions.

>> Stephanie Woodward: All right. So states get away with it, because states set the Medicaid rate that they reimburse for attendant services. How do we stop this? The Disability Integration Act. It addresses this, because The Disability Integration Act says that they cannot pay inadequate rates so that the workforce is not there. I mean, that does not mean the same rate across the nation, because maybe in New York City you need a higher rate than you need in Kansas to keep people in the workforce. But what it does mean is that it would then be illegal for both public and private insurers to pay such low rates that nobody even wants to work has an attendant. So that's how weigh dress it. We address it by advocating for The Disability Integration Act.

>> Bill Fertig: Exactly. Next question, who decides what are adequate wages? You sort of did address that in your last portion.

>> Stephanie Woodward: Right. So adequate wages is something that you look around the area. What are other people making in the industry? And what we would probably say is they shouldn't be making the same amount as any other entry level job because some entry level jobs are a lot easier. An entry level job is a salesperson lifting a phone, but you have to lift a human being. I would say that that entails a little bit more work, so advocates would be a part of this, but also looking at the area wages and looking at what it would be comparable in that area to keep attracting people. So if minimum wage is going up in your state, but your rate has been the same for the last ten years for attendants, then we're not at adequate rate. So that's how you would look at it.

>> Bill Fertig: Thank you for that assessment. Next question, would will be evaluating these people to assess

how much and what type of services will be provided?

>> Stephanie Woodward: It's the same that are evaluating them now. Whoever is evaluating you, and again, it's different by state, sometimes different by region or different if you're in managed care versus Medicaid or private insurer. Whoever is assessing you now for your needs to be the same people assessing you. If they're assessing that you need nursing facility placement, they need to also say what you would need to live in the community. Same assessors. Just different options in the end.

>> Bill Fertig: Okay. Next question, and this refers to your section on accommodations and who would be required to pay for the accommodations.

>> Stephanie Woodward: So the accommodations would be whoever is the provider right now. So your local Medicaid, are we talking about accommodations as in regional accommodations or housing accommodations? I'm sorry.

>> Bill Fertig: Yeah, that would be the question.

>> Stephanie Woodward: So housing, you can find your housing through other -- if you own your own home, then you stay in your own home. Sometimes you receive social security disability. Sometimes there's other low income housing options for you. Or there's plenty of people who own their own homes and just want to stay there. They can pay their mortgage. They just need their attendant services. So that would be the housing part of the accommodation. Reasonable accommodations? Just like every other regional accommodation, even under the ADA. Providing the basic service. Must also provide reasonable accommodations to individuals with disability has an equal opportunity to access that service.

>> Bill Fertig: Quick comment that I think is an important one, and then another question. The comment, I need help with all the ADLs, however, I can certainly handle my finances, et cetera, by myself. You must know that, and this is a person who is quadriplegic and living with mechanical ventilation. So important to know that someone certainly is capable of making their own decisions and they just need more, you know, physical help.

>> Stephanie Woodward: Right. So that's the beauty of the disability integration act. You can need help with only ADLs. There are some people who don't need help with ADL and his only need help with IADLs. You don't need to

necessarily needs the help in every category. We just want to be clear that every category is covered so that any person with any disability is eligible to receive the assistance they need. Maybe they had the wrong disability.

>> Bill Fertig: Thank you for that. Next question, and we're getting towards the end, there are many, many more questions. Please, in your questions weren't asked and answered during our presentation today, do not hesitate to reach out to Stephanie or Alex directly for further guidance. The final question from the attendees, what can we do to get this important information out to everyone that needs to hear this?

>> Stephanie Woodward: I would strongly suggest not only calling your Senators and your representatives, but getting this out on social media. Educating the public about how important this is. Social media has such a strong presence, so I would really encourage you all to educate others. And as if you know other groups who would like to support this, go on the disability integration act.org and have those groups sign up on our supporter list. We have over 00:001111 supporters, but the more groups that support, the better we have a chance of getting this passed if we can show how many organizations are really in favor of this.

>> Alexandra Bennewith: and I just wanted to make sure that folks had Stephanie's e-mail. Stephanie, would you find going to the final slide so if people have other questions, they can also reach out to you?

>> Stephanie Woodward: Absolutely.

>> Bill Fertig: We have a question not from one of the other attendees, but I jotted this down earlier in your presentation, Stephanie. Who and what are the primary opponents of DIA? What are the arguments against DIA and who are the opponents?

>> Stephanie Woodward: Well, the main things we've heard so far is that it is too expensive or that it takes away states' rights to choose how to run their programs and we're saying, no, that's not it. And so some of our opponents have come from the conservative side, but we've been able to explain that it's not too expensive. It's actually much cheaper. And it doesn't take away the States rights on how to run their program. They still can run it however they want. They just have to offer those equal services. So it helps to talk with our opponents about

being fiscally conservative with this, and also about family values. You don't have to send grandma to a nursing facility. She can stay at home. Or if you have a disabled child or if you don't want to and leave your family and be forced into an institution four hours away, it helps keep families together, and those are some talking points that have been really helpful with our opponents, because they do truly value fiscal responsibility and family values 6789

>> Bill Fertig: Great examples. We're just a few minutes over at this point. There are a number of questions. So for folks still attending, wish to post your specific questions to Stephanie or to Alex, their contact information is on screen now. On behalf of United Spinal Association, I'd like to thank Stephanie Woodward so much for sharing her wealth of professional knowledge and personal insights with us today about The Disability Integration Act and why it matters to you. Also, thanks are due Alex for shepherding this presentation to fruition today. Thank you both, Stephanie and Alex.

>> Alexandra Bennewith: thank you Bill. Thanks, Stephanie.

>> Stephanie Woodward: Thank you.

>> Alexandra Bennewith: okay. Have a good day, everyone.

>> Bill Fertig: Sign up and receive your news webinars. Visit us at spinalcord.org or visit our publication site, newmobility.com, for coverage active wheelchair users need to know. This will conclude today's presentation. Thank you for your time and attentions to this important remember topic.

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