**Policy Forum Transcript**

July 11, 2023

>>: Okay, I think we should go ahead and get started. Thank you so much, everyone, for joining today. My name is Jessica Podesva, and I'm the director of advocacy and public policy here at NCIL, and I will be moderating today's meeting. Just a quick visual description of myself, Floridian 30-something, white woman, wearing a white blouse with flowers on it, um, with long, brown hair, pulled back into a ponytail, and glasses. Um, and I just wanted to, I want to welcome everyone for joining and, um, real quick, I'm going to do a few housekeeping details and, then, I'm going to turn it over to NCIL's President, Kent Crenshaw, who would like to say a few words before we hear from our presenters. All right, so, captions are available. To view the captions, click show subtitle in your Zoom menu bar to turn them on. We also have captions running at AI-Media. The URL is a little too long to read, but it has been put in the chat box. AI-Media will allow you to enlarge the font, change the color and contrast of the captioning. ASL interpreters are also present today and should always be visible as we're presenting. Please let me know if you cannot see the interpreters. You can go ahead and just put that in the chat. You do not need, um, to be on Zoom video to access today's meeting. We will read all of the slide content and all questions out loud, so that everything will be available to individuals calling in on the phone or who cannot see visual content. All of the materials will also be posted on our conference web page. Public chat is turned on, and we just ask that you please remain polite and aware of what you're entering into the chat. We have a zero-tolerance policy, if any instances of racism, discrimination, or hateful speech is seen. You will be immediately removed from the meeting and not able to re-join. We will be answering all questions as time permits. You're welcome to submit questions throughout the webinar, um, but please note that they will be held till the end of the meeting during the Q & A portion. There are a number of easy and accessible ways to submit questions to presenters. If you're joining us on Zoom, you can simply type your question into the chat. You're also welcome to e-mail your question to me at Jessica@NCIL.org and, finally, um, if you're joining us on the telephone today, you may press star 9 to indicate you have a question and star 6 to un-mute yourself. We'll also be utilizing the hand-raise feature and calling on folks in the order of which, um, they raise their hand. To utilize the hand-raise feature, you just go to the reactions button at the bottom of your screen and click raise hand. All right, without further ado, I'd like to turn it over to NCIL's board President, Kent Crenshaw, who would like to say a few words. Kent?

>>: Hello, everyone. My name is Kent Crenshaw. I'm NCIL board President and, um, first of all, I want to welcome you all, um, for being in attendance of this advocacy and policy forum. We're very excited about the NCIL conference and the job that we're seeking to do while we go on Hill visits, but as just a part of the NCIL staff and board, we want to extend our warm welcome and, um, we have a lot of confidence in the work of our legislative and advocacy subcommittee and getting this information to you all and, hopefully, it will be very helpful during the NCIL rally. Again, thank you. Um, appreciate you cutting out some time out of your busy schedules to spend this time with us. So, thank you, thank you , thank you.

>>: Thank you so much, Kent. Um, next up, well, first up, we're going to hear from Marty Musser, who is the incoming chair of our Rehab Act subcommittee and IL funding subcommittee, who's going to talk a little bit about our five for five campaign and our funding ask for centers for independent living. Marty?

>>: Thank you, Jessica. Hi, everyone.

>>: We just got to spotlight you.

>>: Okay.

>>: All right, you're good to go.

>>: Okay, thank you. Um, as Jessica said, I'm Marty Musser. I am, um, your region 4 representative on the NCIL board, current chair of the ADA and Civil Rights Committee. I work at Disability Rights and Resources, which is the Center for Independent Living in Charlotte, North Carolina. Quick image description, I'm a white woman in my 30s. I have light, long, brown hair. It's kind of wavy today, and I'm wearing a black top. I am presenting to you from my home office, so you can see some bookcases behind me, and I use she/her pronouns. So, I'm going to talk to you a little bit today about the five for five campaign. Hopefully, this is familiar already to some of you, but there is information in the legislative and advocacy booklet, um, that is available, as well as on the NCIL website, so you can get this information that I'm going to go over with you. Um, it's a good idea to, kind of, study it a little bit in preparation for your legislative visits, so that you can be comfortable talking about this with our elected officials. So, the five for five campaign, um, what we're asking for is $500 million, so, make sure you're really clear on that, it's not $5 million, it's $500 million, and it will fund the five core services that we are doing at all centers for independent living. Currently, um, IL funding is around $128 million and, so, $500 million is a big ask. It's a lot more money than what we're getting right now, um, but the reason that this campaign was created, um, last year, at the conference, it was very important to all of us on the board, um, as well as Jessica, as the policy director, to really listen and hear what you, our membership, had to say in terms of, um, you know, what you're struggling with and what you need, so that the work that we do at NCIL reflects that and, so, funding is a huge need that we all have in all of our centers for many, many, many different reasons. Um, it will help us to provide the services that we currently do at a higher and better level, as well as serve more people in our communities, um, and, also, take better care of our CIL staff. You know, this is something that varies from center to center, but, at a lot of our centers, we need to take better care of our people. Most of us are not in this line of work for the money, but it is important that anybody who works at a center, um, earns a living wage. So, that's a big part of it, as well as providing better benefits, and this is important for a couple reasons. One, so that we can retain the very talented, hard-working people we already have, as well as be able to recruit new people into our movement as we, hopefully, grow and are expanding our impact in the community. So, I'm just going to run through some of this information that I sent. You can find it in the booklet, as well as on the website. So, why invest in centers for independent living? Hopefully, a lot of these concepts are going to feel very natural to you to talk about when you're meeting with legislators, but keep it simple, because, to many of them, they're not super familiar with the work that we're doing and, so, it's important for us to help, sorry, apologies, there's a cat walking. Okay, it's important to really, um, you know, make a good sale and make a compelling argument for why we need this funding. It's very common that legislators have lots of people come into their offices to ask for more funding -- speaker froze --

>>: It looks like Marty has frozen. Marty?

>>: To remember who we are and how important -- speaker frozen --

>>: Marty, you froze. It looks like you're back now.

>>: Is it okay?

>>: Yep. So, um, you left off, um, you left off, funding, it's very common that legislators have a lot of people coming into their offices to ask for more funding. Aren't transcripts great?

(Laughing.)

>>: Thank you for that, and if it happens again, because there is some, um, bad weather where I'm at, please jump in and pick up wherever I leave off.

>>: Okay.

>>: Okay, but, so, yeah, it's, um, very important that we make a strong impression when we are having these legislative visits, because it's very common for people to come and ask for more funding and, so, we really want them to remember us, as well as to understand how important and valuable the work is that is being done at centers. So, there are a couple ways to go about that. My personal favorite and what I recommend you think about, um, is to tell your own story. Talk about the work that you are doing at your center, um, the consumers in your community, just, you know, whatever stands out to you and why you feel like your center is so important. You can think about it in terms of, you know, what would be missing from your community, if your center wasn't there, but personal stories, I think, tend to be a little more memorable and stick in peoples' minds. So, that's one angle that I encourage you to use, but you also can use numbers. Those are really powerful and, so, we have a lot of really good statistics in the L & A booklet that you can refer to. I'll share some of those with you. In 2020, so, this is our most recent year that we have this information from, more than 1 million services were provided.

>>: Can you pause for one second, Marty?

>>: Yes.

>>: Sorry. I just have to, there we go. Go ahead.

>>: All right. Um, so, the specific number, which you'll find in the booklet, is 121-6970 services provided. What does that mean, though, the services provided? Hopefully, you're all familiar with the five core services that we're all mandated to be providing at our centers. Just to run through, excuse me, to run through those real quickly, that is information and referral services, I & R, independent living skills training, efficacy, both individual and systems, peer support and peer mentoring and, then, transition, institutional transition and diversion. So, take the time to go through and explain what each of those things are. Sorry. My cat. Okay, um, so, remember, you know, five core services, that's an important number, our two fives that we're working with, $500 million and five core services. It's also helpful, I think, to talk about it from the fiscal perspective. There is a lot of really good information about how people with disabilities living in their communities, um, is very cost-effective. There's a really, really great return on investment when we invest in centers for independent living and, so, you can pull out some of those numbers and explain on an individual level, um, you know, how many taxpayer dollars we use to keep someone in a facility compared, um, to the much, much lower costs of providing, um, home and community-based services, and you can also talk about how our five core services support peoples' ability to live in their community. Another big thing to think about, you can talk about our current level of coverage when it comes to centers for independent living, and this is something that's going to be different for state to state, so, absolutely, personalize it for what it looks like in your state, but, I can tell you, in North Carolina, we have a little less than half of our state covered, if you're looking at a map by county and, so, you can talk about all of those people in unserved counties, who are not able to make use of a local Center for Independent Living, and talk about how increased funding will help us to expand the amazing work that we're already doing to reach more people. That can be a very compelling argument to make. When we're thinking about staff, um, at centers and how we can, um, you know, do a little better in terms of CIL staff, it's helpful to know that there are almost 5,000 individuals who work at centers for independent living. As you all know, um, most of us are people with disabilities, so, um, emphasize, you know, how some of the unique, um, special, sort of, different approach that we're doing at CILs, um, is based on this idea that we, disabled people, are the best experts on what we need and what's going to help us and, so, sharing that lived experience with other people with disabilities is a very powerful thing. So, drive that point home as much as you can. Jessica, am I leaving anything out? Oh, so, when you're talking about how many centers there are and the fact that we need more centers in our country, just a few numbers that you might want to use. There are 403 centers for independent living right now. This includes 330 branch offices, or that's in addition? Jessica?

>>: Um, 403 centers with 333 branch offices.

>>: Okay. Thank you.

>>: So, the total, like, 700 locations.

>>: That's a good way to say it. I'm going to write that down to use it when I am in my legislative meeting. Um, then, you can also talk about, um, state-wide Independent Living Counciller and how they are part of, kind of, our IL structure. There are 56SILCs across the country.

>>: Marty, it looks like you've frozen again. Um, I'm just going to pick up, kind of, where she left off. So, you know, there's 700 and change locations throughout the country, which, for disability-led services, which independent living is the only disability-led arm of the aging and disability network. That's really not enough, and we really need more. That really comes to the heart of this ask. We do not have enough centers to serve people with disabilities that need services. Marty, are you back? Looks like you're back. Maybe, turn your camera off, and that'll help with the weather.

>>: Sure. I'm happy to try.

>>: That might help.

>>: Okay, um, I'm not quite sure where it dropped.

>>: I picked up and said about not enough in the country and that we really need more centers to serve. So, after that.

>>: Okay. Um, did you hear me start to talk about SILCs?

>>: Um, I think it dropped off right as you were getting there.

>>: Okay, yeah. So, just also, when you're, um, you know, kind of, giving this overview of what independent living is, make sure that you include SILCs, our state-wide independent living councils, because they are a very important piece of the work we do in IL and, so, just for your information, there are 56 state-wide independent living councils across the country and, then, finally, just, kind of, last little piece of information, you can explain the channels that our funding comes through. So, we are funded through the Department of Health and Human Services, specifically the Administration for Community Living, ACL, as you're probably used to hearing and, then, within that is the Office of Independent Living Programs. So, like I said in the beginning, all of this information is available for you to reference, you don't have to memorize all of this, um, but, you know, be prepared, spend some time thinking about how you are going to make the case, um, that centers for independent living need to be funded at a higher level and, you know, think about it almost as making a sales pitch. You want to make a really compelling argument with legislators. So, that is all I have, Jessica, unless you would like to add anything else.

>>: Um, yeah, just one other big point, and thank you, Ann, I also, um, had flagged this to jump in on. Um, the other big important piece is that, you know, back when the fifth core service was added, the transition, we were never actually funded to provide that service. We received no increase in funding. They tacked on, um, another core service, which is actually three significant services, and very expensive to provide, transitioning, um, the transition piece, so, we really need, um, this big increase of funding in order to adequately provide all five core services, which is why our motto is $500 million to support the five core services. So, five for five. So, thank you very much to Ann McDaniel for throwing that in the chat. All right, does anyone have any questions on our five for five campaign? It looks like we have one in the Q & A. Um, for the five for five campaign question, what is the projected real cost of the services, if they were fully funded versus the requested ask? So, honestly, $500 million is, probably, not enough to fully fund all of our centers, but we came up with that number, because it was a big enough jump that didn't seem totally unreasonable, but it, and that would make a significant difference, but it was small enough that we wouldn't be totally dismissed by the ask, but I think Ann McDaniel, maybe, correct me, if I'm wrong, we had talked about really needing $800 million plus. Is that the number that was come up with? Sorry to put you on the spot, Ann.

>>: That's okay. Yes, that is what we talked about based on those most recent studies done by April and NCIL for what it takes to run a center and, then, if you really think about adding three significant services, it's not just money, it's people. You know, Marty was talking about taking care of the staff of centers, which is really critical, but we need more of them. So, having the additional funding to not only hire people, but to provide the wages and benefits that is going to attract good people is really important to being able to really dig into those three transition services on top of all the other core services, plus all the other things that centers do in and for their communities.

>>: Thank you, Ann. Yeah, it really is critical and, you know, this is my first year here at NCIL. Prior to this, I worked at a center in Boston, and I was working three jobs, um, and only able to put a very little amount away in savings. So, um, you know, I understand the barriers that you center staff are facing, I've lived it very recently, um, and I heard it loud and clear at last year's NCIL conference. So, this campaign really reflected of all of that feedback and, also, hearing from executive directors on struggles with staffing, etc. So, you know, first and foremost, um, you know, our job is to help and promote centers for independent living, so this campaign is really reflective to support center staff.

>>: And another piece of that to consider, Jessica, is the centers had not received great, big cost of living increases over the years either. So, many centers have had very little increases to their grants from the feds, let alone being able to keep up with the cost of actually operating. Many centers have reduced their staff, because they can't afford to keep all the staff and cover all the rest of their expenses.

>>: Yep, and, also, this is an equity issue. We are the only disability-led arm of the Aging and Disability Network under ACL, and we are significantly underfunded to our counterparts with aging and with developmental disability services. So, that's also a good piece, um, to bring up. You know, we're not fighting anyone for money, but we are asking to be paid accordingly, and this really is also an equity issue. Um, another question, for the congressional meetings, do you think it would be helpful to have information on your CIL, like a summary sheet? For sure. Noting your services, along with business cards and related to policy budget information, yes, absolutely, and I'm going to talk a little bit more about that towards the end of the presentation. So, I will circle back to you on that. All right, any other questions? I don't see any hands raised. Jenny, do we have any hands raised?

>>: Nope.

>>: So, next up, we're going to hear from Lisa Hayes, who's going to talk about our second advocacy ask, ending the institutional bias, so, asking Congress to pass the HCBS Access Act and Better Care Better Jobs. Lisa?

>>: Thanks, Jessica. Hello, NCIL.

>>: Let me get your power point up for you Hayes. I have auburn-colored hair. Floridian wheelchair-user. Today, I am wearing a, um, black and white dress with, sort of, chevron type stripes, and I wear glasses, and it's great to be able to share something that I am extraordinarily passionate about. Anybody who knows me knows my previous career, um, I spent 23 years working for managed care organizations, and I currently am the Executive Director for Rolling Start. So, I am super excited to share with you two really important bills, um, that, and I'm so excited that NCIL has selected these as priorities, because they really absolutely need to be priorities and, as many times as the centers, the independent living movement has stayed away from managed care, stayed away from medical issues, this is time where we need to be in, we need to be at the table, we need to be having conversations with our states, with our managed care organizations, because as these pass, and I have every confidence that they're going to, there's such tremendous opportunity for the centers for independent living to do what you do now and actually get paid for it. So, without further ado, I'll go ahead and talk about Better Care Better Jobs, which is also identified as BCBJ, and it's Senate Bill 100 and HR547, and its companion bill, which is the HCBS Access Act, um, which I'll, kind of, tell you how they all intertwine at the end of this. So, this is, hopefully, exciting to you as much as it is to me, and let's see. Can we, are we going to display the slides?

>>: The slides are up.

>>: Oh, okay. I'm sorry, I can't tell.

>>: Just say next slide when you're ready, and Mary-Kate will advance them for you. Thank you, Mary-Kate.

>>: I'm not seeing it, so, hold on just a moment. I apologize, I don't see the slides. I'm going to just pull up the ones that were sent, and I'll try to, kind of, follow.

>>: Does everyone else see the slides?

>>: I can see them.

>>: Okay.

>>: Okay. So, the first slide, title I, expanding access to Medicaid home and community-based services. So, what Better Care Better Jobs has in it is enhancing Medicaid funding for home and community-based services, and what that includes is expanding financial eligibility criteria for HCBS to federal limits, requiring coverage for personal care assistant services, expanding supports for family caregivers, adopting programs that help people navigate enrollment and eligibility, expanding access to behavioral healthcare, improving coordination with housing, transportation, and employment supports, developing or improving programs to allow working people with disabilities to access home and community-based services, and we'll go to the next slide. Really big piece of this is strengthening and expanding the HCBS workforce. I think, probably, all of us, and throughout the nation, have experienced challenges with personal care assistant services and obtaining, um, a personal care assistant. So, this is going to address rates and ensuring that they are passed through to direct care workers. It'll off training opportunities and be inclusive of family caregivers. I know some of your states don't allow that, and I think, sometimes, a family caregiver might be a better option, someone that you can trust to help you and support your needs. Um, show improvement over time. There will be a lot of data gathering on this. Improved availability of services, reducing disparities and accessing and using home and community-based services, and evidence of competitive wages and benefits for workers. Complying with a strong maintenance of effort for home and community-based eligibility and benefit standards to ensure that additional federal dollars go towards growing and improving HCBS programs. Encourage innovative models that benefit direct care workers and care recipients, support quality and accountability, facilitate state planning. So, a lot of this that you're going to see, that you'll be able to talk about, what BCBJ is is building the infrastructure around home and community-based services. That, in a nutshell, if I could summarize, that's exactly what it does, and if we can go to the next slide, title II of this act is the Medicaid and CHIP payment and access commission report. Leveraging innovative practices learned through COVID-19 through the pandemic, permanent spousal impoverishment protections, this will permanently authorize protections against impoverishment for individuals whose spouses are receiving Medicaid HCBS and, also, making permanent money follows the person. So, that's pretty much the infrastructure around BCBJ, and we're going to go to the next slide and talk about the HCBS Access Act. I am, I told Jessica when I saw this, a few of us at NCIL got the opportunity to review this in draft form and offer some suggestions to it, which we were excited to do, and I told her, as soon as I read this, I just started crying, just because I've never seen anything so comprehensive and something that really had teeth that could help us with Olmstead. How many of you wish that you could, you know, possibly sue your states for lack of homestead implementation? This provides something that, I hope, is as exciting to you as it is to me. We'll go to the next slide. To outline the current challenges, Olmstead, envisions that states will provide appropriate services through home and community-based services and end forced segregation in institutions. What is so exciting about this is that, if you have to go to the hospital for any reason whatsoever, um, the only thing that hospitals think about for rehab is putting you right into a skilled nursing facility. If you're an individual who's had an accident, the first thing after hospital they do is move you into a, um, rehab facility or skilled nursing facility. Getting you into a home is not even on the, it's not even on the table. Nobody's talking about that. What this does is it changes that whole landscape. It will end that institutional bias that we've all, um, have been so frustrated with. Most states have failed Olmstead miserably. There's that instability of money follows the person or funding that supports transitions. The workforce challenges that we had, and the challenges that we saw with COVID-19, I think a lot of the, um, issues really became apparent with COVID-19, with people in nursing facilities, how many people, of our people died, um, it, kind of, shined a light on things that, you know, the challenges that we have as individuals with disabilities, as individuals with immune deficiencies and not being able to go out, um, and not having the supports and services, to get the services that we need and stay protected. Title I of the HCBS Access Act, requiring and expanding access to home and community-based coverage under Medicaid. So, the goals of this is to eliminate the wait list on HCBS, ensure that all people receive the services needed to independently, in their community, ending the institutional bias, eliminating the need for state waivers, wouldn't that be kind of groovy? Support for family caregivers, improving capacity and quality of the direct care workforce, and eliminating the race, gender, and other disparities. We all know people of color, people with different, um, that are lower-income, don't have access to these needs, and they are more vulnerable to the challenges that people have, um, with their disabilities and not getting the services to support them. Let's go to the next slide. This creates HCBS as a mandatory benefit. Yes, I said that, a mandatory benefit. This is equal to other long-term supports and services, to skilled nursing facilities or any other institutional care. It increases the Medicaid FMAP to 100 percent. States must enhance, expand, or strengthen HCBS services. The Health and Human Services Secretary will convene a panel. This will mean the development of person-centered care plans. This is something we do, right? Medicaid eligibility modifications, this adds home and community-based services as a required option of services. HCBS implementation plan grant programs, this provides planning grants for states to implement the requirement to expand access to Medicaid HCBS. It includes quality measures, the development of quality measures, and the enhancement of them and, um, technical assistance, and it also, in there, has language to make money follows the person permanent, which is in section 109 and, on the next slide, I'm going to talk about title II, which is recognizing the role of direct support professionals. So, it defines direct support professionals, means an individual who, in exchange for compensation, provides services to an individual with a disability and defined, as defined in the Americans with Disabilities Act. Services that enhance independence and community inclusion and includes travel while visiting friends, family, shopping, socializing, life in general. Um, it involves having them assist us in coaching, communicating needs, achieving self-expression, pursuing personal goals, living independently, participating in employment, or volunteer work. So, if you don't go to work because you need personal assistant services at work, this would change that. Assistance with your activities of daily living and tasks, such as meal prep, shopping, light housekeeping, laundry. Services that support every individual that at home, work, school, or any other community setting. We can go to the next slide. Title III is support for the direct care workforce. It involves having a technical assistance center for building the direct care workforce, gives states the authority to award grands for projects aimed at recruiting, retaining, and providing training and career advancement to direct care professionals, managers, self-directed care professionals, and family caregivers, and provides funding for planning, technical assistance, evaluation, and reporting. On the next slide, title IV is the evaluation piece of it. It gives CMS the authority to conduct national surveys to determine the effects of the HCBS Access Act on the availability of Medicaid HCBS services. It offers direct care workforce improvements and, this is kind of cool, senses, it's going to demand that the census bureio add a question on long-term supports and services needs to the monthly American Community Survey, so that we can continually get information and data on those that need these services. I know this probably all sounds to be good to be true, but this is why this act is so beautiful, um, and just what we needed and why both bills are important on the next slide. So, Better Care Better Jobs is going to create a robust infrastructure for the recruitment and retention of workers. HCBS access considers, is considered a companion bill that will establish a permanent funding stream to keep the infrastructure strong and to make sure we're able to continue to pay direct care professionals at a rate that ensures qualified, reliable services in a qualified, reliable workforce into the future. These are transformative pieces of legislation. There's been persistent underfunding and bias in federal Medicaid laws, funneling more money into institutional care than to in-home care. This provides the roadmap and funding to enable people with disabilities, regardless of age, race, disability, or location to live at home and remain connected to their communities.So, that, I hope, um, it's a lot of information, I know, and I hope you have time to review that before your Hill visits. These are such critical, um, pieces of legislation that we really, really, um, are due to pass and, if you have any questions or, Jessica, if you want to add anything, please feel free to do so.

>>: Yeah. So, we do have some questions. Can we take down the slides and, maybe, spotlight Lisa and I? Then we'll go through some questions, and I see we have a couple hands. Um, I'm just going to quickly run through the questions in the Q & A and, then, um, we'll turn to the raised hands. So, the first question, um, from Jamie, Medicare does not cover the cost of P & As for elderly, and there are many who don't qualify for Medicaid due to income. Are any of these bills seeking to include HCBS for Medicare participants? And, no, these are funding increases for people with disabilities in, um, Medicaid. HCBS questions, will updated ADLs be adopted nationally? Um, that, I believe, is an unknown, but I will, certainly, take that one back.

>>: I can say that they did list, in the HCBS Access Act, those activities of daily living.

>>: I'm just not sure how they would handle the enforcement, but I would definitely prompt that conversation, but I will take that back and, kind of, find out how that will work. Um, are elected officials, what are the costs associated with these bills? Will NCIL provide leave-behinds we can use? Yes, or you can leave behind the advocacy and policy booklet with them. It has been written, both, to help all of you, as well as for legislators. So, um, contact info for questions and, kind of, the overarching information is all in those booklets, and you can pick up those booklets at your regional caucuses at the conference, which we'll talk about in a bit.

>>: So, Jess, I did, also, on the power point, I don't know if it's in the notes section, I actually listed the costs, because they were definitely by sections and what those costs were.

>>: Yep, and the power points are available on our conference page as well, so you can pull that information there. All right, um, looks like we have a hand raised. Michai? Is that the right way to pronounce your name?

>>: That's correct.

>>: Great.

>>: So, black and brown hair, wearing glasses. I am in front of a green screen, and my pronouns are she/her. I'm the new systems change advocate at the Berkeley CIL and, um, I think it's a great bill. However -- indiscernible -- in our community and, to get people care, we need to also mandate for states to understand and, also, prioritize accessible, affordable housing, because one will not happen without the other. Also, many people with disabilities like to work, so, also, putting in their access to childcare, health services and, um, pregnancy-assisted supports. We want a full life that actually helps us to live and -- indiscernible -- in order to go to work -- indiscernible -- protections to care for the children. So, I just feel that this will could do just a little bit more. That's part of the reason why people don't seek employment, because they're worried about losing benefits. I just would like to make a systems change going forward. Thank you.

>>: Thank you, Michai. We know this bill will not solve all the issues affecting the disability community, nor will the priorities that we've, um, kind of, identified for this advocacy day, and it's important to note that these are not the only priorities of NCIL, these are just our priorities for this Hill day and that NCIL subcommittees are working on a lot of those other issues you mentioned, including access to reproductive healthcare. We have a group that will be starting to really develop a policy position on that, as well as we have a housing subcommittee that's been doing a lot of work, and I also would like to, not to throw it back to five for five, but, you know, centers play a vital role in being able to do the systems change advocacy to help provide the services that you're talking about and that culture shift that you're talking about and, so, I really encourage everyone to think about this like a big wheel, right? They all influence another and, if we can really rally around centers for independent living and communities to have the funding they need to thrive and have, employ systems change advocates, like yourself, we really will slowly whittle away at a lot of those barriers, um, locally on up. So, just another thing to keep in mind. Lisa, do you have anything else to add?

>>: Only, um, Michai, you had so many really great things, things that are challenges for people with disabilities. A lot to unpack there, and I hope my enthusiasm for this act, um, isn't, you know, trying to think it is the be all end all to fix everything, because it's not, as Jessica said. Um, it's just working, um, in managed care for as long as I have and not really being able to see how a path to really, um, being able to achieve what Olmstead said, um, and this is the first thing that we've seen that actually would make that change, and it is, you're right, there's so many other issues, um, the housing crisis is, really, a big challenge, and all of these things go hand in hand. I think, though, the whole idea that we would be able to have personal care assistant services at work, personal care assistant services in every other aspect of our lives is really transformative. It reduces some of the barriers that we've experienced over time and, so --

>>: Yeah, and that's what, I do agree -- indiscernible -- supports who don't know the laws, um, can't fight -- indiscernible -- program for community. Thank you.

>>: Thank you so much. Um, I'm looking at the time, and I want to make sure we have time to also talk about our third advocacy act. So, I think we're going to go ahead and shift now, um, to Shari. So, I'm going to, now, I'd like to introduce Shari Myers, who will be the incoming co-chair leading our work on disability and disasters. Shari?

>>: Thank you, Jessica. Um, I am not on camera today, but I do want to, kind of, hit the high points on the REAADI, and what we know is that, um, we, as disabled people, are two to four times more likely to be injured or die in a disaster. This is why it is so important that we advocate for these laws. Um, this piece of legislation has been introduced now several times, re-introduced just recently. It is a bipartisan bill, is sponsored, or it was introduced in the Senate by Senator Casey, Democrat of Pennsylvania and in the House of Representatives by Congresswoman Dinggold, District 6, and Congressman Fitzpatrick, Republican of Pennsylvania, District 1. Um, what we're looking for here is whole community resilience. What we're focused on is providing opportunities for people with disabilities and older adults and disability-led organizations to provide guidance, technical assistance, and training for disaster preparedness, for recovery, and for response at those local, regional and, um, national levels. My experience is in disaster response and, um, making certain that, um, facilities, programs, and services are accessible, and it is, it's, certainly, my passion, and I'm so honored to be leading the new, this committee on disability and disaster. Grateful to be able to move ahead with these things and advocate for, not just the laws, but for making emergency management and emergency responders, like, um, Red Cross, the larger organizations that provide shelter and feeding and other mass care services, um, educating them on bringing us to the table or, better still, coming to ours and including us in these plans. Nothing about us without us is for us, and this has been, you know, messaging that many of us have been working on for years and years now. I actually, um, lived in southeast Louisiana during Katrina, I've lived in other areas that were affected by mass floods and, um, a number of different disasters. No, I promise, I don't bring them with me when I move from one place to another, but, um, we know that disasters are happening more and more often and, um, the infrastructure fails the 61 million adults with disabilities. There are more than 55.8 million adults age 65 or older living in the United States and territories, and these disproportionate deaths and injuries are a result of barriers, um, where we're left out of critical evacuation information. We don't receive notifications. They are not accessible. They're not, um, you know, effective communication is not provided in these circumstances and, so, when you are talking with your representatives, um, it's important to remember these numbers, for one, but, also, to, um, to let them know, we have lived experience, we're the experts on how we go through a disaster and what we need in a disaster. There are so many more challenges coming up every day. With each disaster, we realize how little affordable accessible housing is out there and, when you lose your home, um, whether you're a renter or homeowner, it's so difficult to find that accessible housing, to find another place to live. So, as part of the subcommittee, I'm really looking forward to talking about how we work with organizations that are focused on these things and become a much larger part of these processes for responding and recovering from disasters and for preparedness as well. Um, I did want to quickly, um, mention that parts of the REAADI Act are being considered for incorporation into the, um, I lost my place here, um, into the, um, pandemic and all hazards preparation act and, um, we're advocating, um, for those pieces to, um, actually remain as they are within REAADI, but for REAADI to, perhaps, become, um, I did it again. Sorry. To become, um, a title within, um, this pandemic and all hazards preparedness act. I don't want to take up anymore time, because I know we're running long, but thank you, Jessica, so much.

>>: Thank you, Shari. Um, Jenny, are we okay to go a little bit over?

>>: No, the captioner actually has to log off.

>>: Okay. Um, so, we're going to wrap this up really quickly. Thank you, I know we're at time, I wanted to make sure we got through, um, all of our presenters. If you have any questions on how to prepare for the Hill or, um, how to schedule your meetings, etc., all of that information can be found in the conference booklet, as well as, um, prepping for the Hill guide that we have posted on the conference web page as well. I'm also happy to chat with anyone who has any questions or who is unsure. You can feel free to reach out to me by e-mail, Jessica@NCIL.org. Thank you all so much for coming. We really appreciated you taking time out of your day and, yeah, if you have any further questions, please feel free to reach out to me by e-mail. Thank you.