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# **Peer Support for SILCs**

## **Sandra Breitengross Bitter, Presenter**

## **Sidna Madden Trimmell ‑ Host**

>> Hello everyone and welcome. I am Sidna Trimmell, I'm the APRIL Board Treasurer and I'm going to be moderating your meeting today. Thank you for joining us, you're here to listen to the session called Peer Support for SILC. I want of I have a little script to lead because you haven't been here before. I want to be the first one.

I want to mention a few housekeeping items before we get started today. First when you scroll over the screen a menu bar will pop up. Depending what device you're on, you can find that menu bar at the top or the bottom of your screen. This is where you'll find the closed captioning for today's session. You can view the captions by selecting the CC tab on the menu bar.

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To ask a question or make a comment, you can also select the hand option on the menu bar as that allows us to know you have a question. For you who are on the phone or using key strokes we ask that you press star or the asterisk sign 9, and the alt key on the key pad to raise your hand. We can let you know if you can unmute. You can select the unmute option by selecting alt and the letter A if you're using key strokes.

Also if you join in the conversation, please be sure and keep the background noise down so help you here more clearly.

As a last reminder, app is a safe place tor marginalized an (indiscernible) communities. We ask that everyone in the session treat everyone with respect and that you enter this and every session with good intentions. This means respecting names, pronouns and other personal identifiers and avoid using the derogatory or abusive language.

I also want to let you no he this session is being recorded but it's not going to be posted on the site so that makes it a more safe, more personal place for you to ask any questions that you want to ask. And it's not going to go out onto the Webb sight. But any material or resources that are going to be shared that are going to be put in the chat, that material and those resources, any links and so on, will be on the website, so that you can go back and find them. But the actual content of sharing your stories or asking your questions today will not be shared with anybody else outside of this meeting.

So, I would like to turn it over to our presenter, my good friend Sandra.

>> Hi everyone. My name is Sandra Breitengross Bitter. Thank you Sidna for the introduction and the housekeeping.

I am going to quickly introduce myself and then kind of turn it over to the group here. But like I said my name is Sandra. I am currently the Director of Training at ILRU. I recently transferred into that position but previously I was the Executive Director for the Texas SILC. And I was there for almost ten years. And so, I feel like this is very much still my peer group. And so I'm excited to be here with you today.

I think, I think it would be great if we had a chance to talk as a group, and share what's going on in our states and if there are issues that are coming up in your council, this is a great opportunity to also hear from your peers, because there is a good chance one of us has experienced a similar situation. And if not, we can definitely collectively point you in a particular direction to get more information or additional support from those additional resources.

So, real quick on a visual description, I am a Hispanic female with dark curly hair, I wear glasses and I'm sitting in my home office. And my dog is behind me. So if you hear any snoring or barking, that's his participation. So, bear with me on that one.

You're welcome to put questions in the chat. And Sidna will be helping me voice those questions. I'll try to grab them as well. But this is really a time for us to share together. So what I would encourage you to turn on your videos if you're comfortable. And feel free to unmute yourselves as you would like to interject into a conversation. Of Course you're welcome to raise your hand. Actually I don't, do we have the raise your hand feature? I don't even see it on here. But if you have the raise your hand feature.

>> We do. For me it's under reactions down on my lower menu bar.

>> Oh, okay. Then feel free to do that and we can call on you. Whoever sees it. But also feel free to just come off of mute and let's have a conversation and a discussion, because that's really, really what it's all about.

So, let me see. Before we get started, I do want to make a quick announcement and it's something that's coming up with ILRU and ACL is there will be a webinar session on October 19th. So this coming Wednesday, in which the relationship between SILCs (indiscernible) and the DSE will be discussed. And some clarifying information will be available from our friends at ACL. So what I would encourage you all the attend that session. It is free.

I'm going to put the link in the chat where you can find out more information and register for that session. You do have to register in advance. ASL and CART will be provided. But hopefully if there is any DSE questions today, hopefully they'll be answered there.

So, to kick us off, who would like to go first? I know, I can tell by the names, this is a very lively group. I've seen you on other sessions. And there are some names that I'm not so familiar with.

So, if we, I think we have a mix of SILC Executive Directors. Maybe you could wave if you're comfortable. SILC staff. I'm sure. And if we have any SILC board members. Do we have any SILC board members in this group? I'm hoping so. They always love it when we have that perspective as a group too.

Okay, looks like we have a little bit of everything here. We have responses from SILC board members, SILC staff, and SILC executive directors. So I'm excited about this conversation.

So, what's the first thing we should talk about? Does anybody have a pressing issue or topic that they would like to bring up?

Tyler.

>> Yeah. This is Tyler. I'm going to bring up the elephant in the room. This whole thing with the SPIL being put off a year.

>> Yes.

>> I don't know how much information everyone has. I got a little bit more today about it. And I'm just kind of wondering how everyone feels about it, what everyone is thinking. Because, I don't know. I'm kind of going back a little bit. I'm frustrated mostly, I think, but maybe I'm mistaken about that and I'm trying to see if there is another perspective or if I'm missing something.

>> That's a really good question. And I know there was some discussion, it might have been as part of the SILC ED's group about this too. Is this impacting anyone else with regards to their SPIL schedule or plans?

>> Sandra, this is Sidna, I can say that for NASA, we received some feedback from people that are very happy that it's happening and feedback from people who are not very happy it's happening. And that's a mix of people who are really fairly in the process and trying to get down to the finish line to get their SPIL out, down to people who have no cooperation whatsoever other than they're centers and the they're really starting to sweat it.

The feedback we're getting is mixed, where some people are happy and some aren't so happy. That's what we're hearing.

>> Tyler, do you want to talk, if you're comfortable sharing, a little bit more information about the concerns that you had?

>> I, well, I had worked really hard to kind of set up, what I think was working pretty well for SPIL development. And now I have a lot of questions from the people on that committee, because I actually managed to gather like SILC staff and SILC directors and our DSC was in place. It's a group of like 20 people. And now they're all kind of watching the CO, you know, uncertainty, because they're thinking, you know, well if it's not due for a year, why are we doing all this work? So I'm kind of losing, we had really good momentum, I'm kind of losing that steam.

Part of that retreat is we had a network. And we have been in the planning of that, and one of the things that I came up with was, you know what, we all have to sign that SPIL when it's due anyway, so everything that we've been planning around that, around that, has been focused on implementation and signatures of the new SPIL. Our entire planning process has been, let's, let's make this about, hey, we've got this new thing coming out, let's start it off with a bang. And now that's kind of, admittedly, it's probably, it is probably only affecting my state in this way but that's where the frustrating is coming. All of that was centered around that date and they just kind of pushed it back because, well, I'm not exactly sure why. It's just there wasn't any, there wasn't any communication that it was even a possibility until it was actually what was going to happen. So it kind of came out of nowhere.

>> Got you.

>> Where it was.

>> So, they've done this before, I think it was 19, fiscal year 19/20. Where the new SPIL instrument was being shepherded through the official process, through OMB which goes through a multimonth process of getting approval and public comment. And so they had delayed the process as part of that.

And at that time, I was kind of along with you, Tyler, in the sense that we had created a lot of momentum within our state to kind of move forward. And one of the things is, is that you can always make a decision as a state too, to continue that momentum and move forward. And do a substantial amendment for your SPIL; instead of just doing a technical amendment and going ahead and move forward with significant changes, if that's decide, if you decide that works for you.

But I'm sure ACL will provide some additional clarifications about that amendment process, but just know that that was an option last time. And so, it might be possible this go around.

Esther, you have your hand up.

>> Hi, I'm Esther Ratajeski. I'm Coordinator of the SILC in Kentucky. I am a middle‑aged lady with a blue sweater eating my lunch.

I just, you already said what I was just about to say. I had talked to someone from a different state yesterday and they're going to just continue with their new SPIL, but just file it as a substantive amendment and then they'll already be a head start next year where it will be very easy to repackage that for the new SPIL because they have all these ideas and programs they're starting. So I think we might go ahead and do that as well, if that's okay with ACL. So that way you don't feel like you have to just wait around for a year before you can do anything new.

Yeah. That's all I wanted to say. Thanks.

>> Great idea. And that looks like Grace T, has their name up, or hand up.

>> Hi. I wanted to introduce myself.

>> Great.

>> I'm a part time youth specialist, just because I have to work part time because of some of my disabilities. I have a severe heart condition. But I work in both north. I work for paid work in South Carolina and then I do a lot of volunteer work in North Carolina. I'm wearing my Youth Lead T‑shirt. I don't know if Kay is here, Kay from the NCYOF. I was volunteer staff on the NCYOF.

So, I, yeah, that's just me, do I need a visual description?

>> If you would like to provide a visual description, you're welcome to.

>> Okay. I am kind of like an androgynous looking white person with short brown hair. I usually wear glasses because I'm legally blind but unfortunately they broke. Very sad. I have a land yard on, just because it's my work lanyard. I also think I'm usually smiling most of the time. Yeah. I don't know if this is offensive or not, but I'm a lesbian and I look very much like a stereotypical lesbian just to sort of put that image in your head for any of our blind friends.

I don't mind saying that about myself. Thank you for having me.

>> Thanks Grace.

Looks like Jami has her hand up. Hey, Jami.

>> So, this is Jami from Idaho. And, Tyler, like you, we definitely had the frustration just because we had done, we put our, started working on our SPIL in January and had it open through October ‑‑ or excuse me, the middle of the September. And we did 631 meetings, did 31 townhall meetings around the state and did two virtual meetings. So we had a lot of information that it was just kind of hurry up and halt.

But after, after you know, going through the emotions, it actually is kind of going to work out nicely, because like Sandra has said. This isn't the first time they've done this. But we captured a lot of stuff that was not what we were expecting. And so, we're really going to take the time. We still, our SPIL planning team is going to meet every month and meet and go through with everything but it's going to give us a little more time to kind of fine tune. But what we heard from around IDAHO. But we totally feel you, Tyler. Then again it could be a good thing.

>> So, I have a follow‑up question for you, Jami. I would like to know how you managed to do 31 town halls? Is that what you said, 31?

>> Yes.

>> Please share your process. Because I would love to see how you organized this, and handled it.

>> It was exhausting. So, Mel our Executive Director took the earn part of the Idaho, I took northern Idaho. And we were gone about a week each. Sometimes we would do two town halls a day in various locations. There were about three hours, we scheduled three hours.

We worked, our SILC did a lot of work. As far as they found the locations, they really marketed this. But yeah, and then we had our local area, it was within a four hour drive, we would go there, do a Town Hall and come back. And that was about two months worth of drives. So, but we hit senior centers at lunch. We thought that was a really good place.

>> Ah.

>> It was kind of funny because they don't say they have a disability necessarily. Because and I would sit there and like I got a hearing aid, you've got a walker. You know but they don't have a disability but they talked about their kids and their grandkids.

>> Right. 12346 so we got some really good lunches at senior centers too.

>> Can you identify that plan, that older generation, I've noticed, because disability is just a natural part of aging. And people don't like to consider themselves disabled because of ableism. And internalize ableism. So that's why we don't get a lot of elderly reaching out to our organizations.

So, when I offer, if I see an elderly person that looks like they might be a good candidate, I say, I work for an organization that helps disabled people and the elderly. Because they're not going to, the elderly are disabled people, but they don't like that one.

>> Yep. That's a problem too. And I asked my mom. I said what do you think. We can't hear, we can't walk. And okay. That's what we found too.

>> AARP is like, they don't talk about disability, they just say aging. So if I see an elderly person and they tell me, because I love to talk to old people, because I feel like I relate to them because I've had all those problems that they have since I was two years old. So I love to talk to old people. And old people love to talk to me because I've been the same way they are since I was two years old. But I say, I work for an organization that helps disabled people and the elderly. By the way, you can drop my name a little bit and they, if that gets them connected with the organization because they're, sometimes people just don't want to identify that way. A lot of people in the disability community don't like the term special needs. But that's term was actually invented by people with intellectual disabilities before parent grow up. So they say, oh you're not allowed to say special needs and people with the intellectual disability, say no, that's their term. We know it's sad now because parents could opted it but why is their fault. You can't tell people they're not allowed to identify a certain way. So even though I'm not supposed to, I say elderly, disabled, special needs. We have different I had fee work. I don't like when parents use it but if I'm talking to an intellectually disabled person, that's their history. So that's not offensive as people think it is. Some people think it is because parents adopted it, but women with DID. DID was diagnosed a severe autism as a child and I was referred to as special needs.

So, yeah, no, that was my first disability community. So don't tell me I'm not allowed to say that. If I want to, you know.

>> Correct, and there is a lot of other communities that don't use the term disabled or disability. So, you are correct.

>> Awesome. Thanks so much Jami. That sounds exhausting, like you said, but it sounds like you really did get some good feedback, especially if it wasn't what you were expecting. Always think that's a sign of success in the sense of that you're possibly reach ago population that you might not have reached before so that's pretty neat.

Let's see, I am trying to see if we have any other hands up.

>> I didn't see any.

>> Okay. All right. So, I know SPILs are a big topic. There was so much to do with them. And Tyler had a really great session with Doctor Anderson earlier this week on SILCs and spills, so if you missed that, I think it would be really awesome to go back and to catch that on the recording, because I think they had some great conversations as well.

Let's see. Anybody like to jump in on a particular topic?

>> Sandra, what about what people are doing in various aspects of peer support?

>> This is Grace. I, with that, I shouldn't call them my kids because that's condescending, but with my young people we have been doing a discord, it's an app that a lot of young people use. Got a lot of interaction out of that. We've been doing game nights.

Because (indiscernible) I started out when I was 15. So you have to (indiscernible) (Breaking up). So we do discord. You do game night. (indiscernible) so we can learn from the young people. We do accessible dungeons and dragons. Just whatever tracts young people and the best way to find that out is to ask young people. It's not super cheesy and old person would be like, hey what are the kids doing these days. But yeah, what are the kids doing these days, that's the key.

So, like, yeah, so I always ask my kids that like at the end of a session, because they don't know that it's related to their disability. It's probably more accommodating to them and their disability and their youth. So we always do that at the end of our more formal sessions. It's like, let's chat for a little bit about what you're doing these days. And they think it's just fun. But we're actually learning something from them, secretly, because you kind of trick teenagers sometimes because they can be a little bit surly sometimes. But yeah. So you just got to really get with the kids.

And I want to go even younger, because I feel like by the time they get to me, they have so much internalized ableism and it's much easier to teach a good habit than it is to undo a bad habit. So right now we don't have the funding, but I would love to like have a job that was like just like really, really little kids, because, because of my autism I feel connected to my inner child. I have PTSD and kind of like DID type symptoms and so I quite literally have an inner child that comes out sometimes. And so I think I would do very well with like really, really young children, like four years old. That's about when my PTSD triggers, that's about the age I go to is about four years old. So I think I would do very well with them.

And I'm actually going to talk to the Executive Director about basically creating a new position for myself, because I can only work part time. And so I'm hoping I'm going to leave my position where I'm at now and create a part‑time position with myself, just work with the baby babies. So if I wasn't in disability, I would probably be a preschool teacher. So I want to kind of do that, but disability related because I love all that stuff. Like (indiscernible) stuff. And I'll do it ironically. That's where I think we need to go if we have the funding.

>> Cool. That sounds awesome. Definitely a youth focus is something a lot of SILCs are, working on right now. And so, some others would like to jump in to the conversation and kind of tell us what's going on in their states, that would be awesome. We, it looks like we have some folks that were active in the chat.

Andy, if I could say that you introduce yourself as being a new member of the Utah SILC. Would you like to come off mute and introduce yourself?

>> Okay. So, yeah. I got, I just got in last month. I have to confirm on that. Yeah, it's going really good. So, plus I've been also the chairman in my YLC for Utah. So it's been really helpful to know, sorry, I'm scatter brain today. Know what I can do to help my peers and know what's going on in the new SILC. And collaborate.

>> Awesome. Well welcome. Thanks for sharing.

It looks like I got a question through Messenger. And it is our SILC is looking to increase our membership and we're considering more ex‑officio members is there a set number that each SILC should have besides DORS and DOD? I'm assuming those are state acronyms for some providers. And other agencies would be of benefit. Interested in hearing what other states do.

Would anybody like to talk about how they're ex‑officios are structured? And this was from Rose from Maryland.

>> Tyler has raised his hand.

>> Oh, go for it, Tyler.

>> I don't know if there is a specific number, but the way that we kind of do it in Wisconsin, is we have Department of Health services who is our DSE they have a representative that is an ex‑officio. And the Department of Vocational rehabilitation.

The other thing we'll do is every three years, we set up advisory committees across the network which are kind of advocacy groups. And if there is, so right now, two of them are kind of healthcare related, but one of them is transportation. So the DOT representative also sits as an ex‑officio, because we're kind of talking about transportation issues with the whole network.

So, whatever kind of advocacy things we're doing, we'll try to pull someone in from the state that represents that department so that we have a little bit better ability to communicate with them and kind of a direct line. So when something happens at DOT, we kind of know about it pretty quickly, which has been really helpful.

>> Thanks Tyler. I appreciate that. I enjoyed your webinar the other day too.

We have, in our state, we have a lot of transportation and housing issues. And we don't have representatives from those, those agencies. We do have one from the Department of Disabilities and the rehabilitation, but that's why I was wondering what other states did. If they had representatives from, or ex‑officio members or if they just did advisory committees. So I appreciate your answer. Yes, thank you.

>> Something to remember when do you add official, ex‑officio members that are appointed by the governor to your SILC, is to really look at that rehab act language and what it says about your ratios for people with disabilities. So that would potentially impact your ratio numbers, because it increases the total number of individuals serving on your board.

So, really, that's something that in Texas, we were paying attention too that we wanted to add additional ex‑officios to bring in that stakeholder involvement and those agency involvement. We also ran into an issue where if we put too many ex‑officios in, then our ratios were no longer acceptable to be in compliance with the rehab act.

So another option you could do is create liaison positions where you have liaisons from specific state agencies or groups that aren't official ex‑officios and aren't appointed by the governor. That's another work around.

I would love to hear what other states are doing on this as well. Anyone has anything to chime in or another topic.

All right. Well, let's see. So something that we hear a lot about is the work folks are doing to make sure their SILCs are in compliance with their, their indicators. And one of those things is board training. And trying to, kind of make sure that your boards have access, your board members have access to the training they need.

Does anyone have like a really great training program or protocol that they would like to share that they kind of, they create either for on‑boarding new members, or if they have it as like a regular process throughout the year for their board members as you go.

Oh, Dora. You can go ahead and unmute.

>> Hi Sandra.

>> Hay.

>> This is Dora, with the SILC of Tennessee. My pronouns are she and her. My visual is a black screen with my name on it because I'm having a really bad hair day. (Laughter).

>> That's okay.

>> I turned that on and saw my hair, and nope, off went the camera.

I just wanted to say that boy, as far as training, of course I got with Ann McDaniel at the beginning and she was gracious enough to send me her new member orientation. So we Tennessee‑fied that for all new members when they come on. And we offer them a mentor.

>> Hmm.

>> Especially when you have someone that may be coming aboard that's never served on a board or council before. That kind of helps put them at ease. And I usually always invite one of my council members to join us to give a council perspective there.

And then after that, we have individual training plans where I meet with them manually and discuss what it is they would like to train on. Of course we use that handy dandy ILRU tool as well to see what it is that they are and are not familiar with.

And then we go from there. I try to bring in providers of different types or agencies into each of the quarterly meetings to present to the council to widen their perspective or knowledge, you know, within Tennessee. And that's a training too as well.

So, we do quite a few things. I also put out a monthly newsletter, if you will, to the council, that always reminds them of the dates, tells them what the SILC is up to, what national focus it is, you know, for the month. You know, October is, you know, employment awareness or whatever.

And then I always plug ILRU trainings on there, because there are some fantastic trainings on there for board members to go through.

So I think we try to really come at them from every angle that we can, from a local perspective to a national one. And I would be happy to hear any other ideas that you can add to what we're doing.

>> Sorry, I was on mute. That sounds great. I like that.

Amy? You have your hand up.

>> How do I put my hand down? Lower hand. Okay.

I'm sorry. I'm here, I'm trying to start my video. I'm having a bad hair day too, but there I am. I am a white 50 something lady with brown hair and a gray sweatshirt on. I look like it's my day off and in my home office and my background says New York state Disability Rights Hall of Fame. Which is one of the things that we've been doing for the past six years. And finding peers who have really kind of made a mark in the disability rights community and inducting them into a Hall of Fame every year.

But what I wanted to mention is we engage in diversity, equity and inclusion training this past year. And invited as many members of SILCs as wanted to attend and also our SILC board. And we have 42 centers in New York. So that was a lot.

It was a six week training and, so it was four people to learn what's needed to be more inclusive in general. And also how to be more respectful during meetings. We had some bullying going on. I won't be specific about it. But we had some issues that we had to address. And also you know, find a way to move forward and focus on the future.

At the end of the training, we actually developed a diversity, equity, and inclusion committee that monitors and facilitates change in equity all the time.

So it's something that's new and we're not really certain how well it's going to work in the long term, but short term I think things are really changing for the better.

>> That sounds awesome. How was the, when you went through that training, because it sounds like it was pretty extensive, right, six weeks.

>> It was.

>> With your SILC and your CILs. So how many CILs participate paid?

>> It wasn't, sometimes there were a couple people from one CIL and sometimes there was nobody. So it's hard to say.

>> Yeah.

>> But I think you know, it was really board training. And we opened it up to CIL. So it was more focused on the SILC members.

>> Got it.

>> But I think it could be go across CILs. The only problem was, the bully did not attend any of the trainings which was very frustrating. (Laughter). So, luckily, this person is not going to be on the council much longer. But it was very frustrating to sit there and be trained in something that you know that the person that most needs the training is not even there.

>> Yeah. That is hard.

>> I don't know if you've had that situation but that's what happened.

>> Yeah. Understandable.

Let's see. Grace, do you have your hand up or was that, was that still left over from before? That might be.

>> Hi. What I was going to say is like what we did to make sure we're keeping on top of things that I really like that we did at my supervisor came up with. We do like biweekly staff meetings that are optional for like the general staff. So you don't have to come if you can't. And then as the youth team, I like the youngest youth team with actual youth on it, we meet once a week. And it's mandatory.

So, because we have a youth (indiscernible) that's not actually made up of youth but the team that I work for, like we have a youth team that works with you and then the team that I work for is the one that's made up of youth. If that makes sense.

>> Got it. I think so. Awesome.

So, I see a lot of new names here on the screen. And I would love to hear from some other areas of the country that might be embarking on some new activities or if there is some problem solving that we can help as a group. Feel free to jump in. Like I said, this group is pretty diverse. And we, you know, we have been able to share some of the issues that we've been dealing with as individual states and had great, great direction provided by our peers.

So, don't hesitate to either reach out here in this session today, or of course, follow up with folks that are participating. That's always a good way of getting some additional information.

So, we heard a little bit from Tyler about SPIL. Now, how are things going with your current SPIL? Because you're in your last and final year. Of the current SPIL much and I know some folks have already embarked on the process of drafting your new SPIL. But how are things going? How did monitoring the progress on those objectives, the consumer satisfaction. How did that go with regards to partnership with the centers? I would love to hear anything that you all have.

>> This is Sidna, I'll speak up.

>> Sure.

>> There is a question for you or anybody in regards to the current SPIL or moving forward. When you have centers that don't participate whatsoever. So in a current SPIL if you have centers who aren't following through how would that be rectified. Going forward if you have centers that don't want to participate in the writing of the new SPIL, how would that be rectified?

>> That's a good question. Does anybody have any great advice for Sidna? I know for us we've struggled with that. And I can't say for us anymore, but in Texas, they previously struggled with that, with regards to reporting on activities. For example, you know, the SILC always in a tough position knowing that your network, the IL network is doing some incredible things, but getting down to the process of reporting those things in order to show progress ton the plan or to show even progress as you move forward with other advocacy issues with your legislature or something like that. Sometimes that can be difficult if folks aren't participating.

So, one thing I know that is really helped in the past and I think Jami is a good example of this, is making sure that when some of that initial outreach or needs assessment and things like that are going out, is making sure that those centers are involved in those events. That creates a level of almost an ownership of the process, realizing that their community, their constituents are the ones that are providing input on the statewide plan. And showing that the value of their community he's voice.

So I think that's really great that some SILCs have gotten centers involved in those town halls or official hearings. I think that's a good practice.

Sarah, did you have, circle back, did you have something to add to this?

>> Yeah. Hi, this is Sarah with the Florida SILC. We have weekly IRS calls for all of our centers here in Florida. It's a good way for them to catch up on different issues that they're having and collaborating with one another. So it's a good way for our SILC to stay involved with the network.

We also have just recently completed our needs assessment, send it out to Ben, but we posted four different town halls last year that were virtual and we hosted them through each of the Center for Independent Living in our state. So we're including our centers with our town halls, kind of virtual forums is what we're calling them. It's a way to connect with them if they need assess many. So they can be in tune and having consumers learn about the state plan and what our SILC does.

>> Hi. What's the name of your SILC?

>> Are you talking to me, Grace?

>> Yes. I just have to find Florida and I was wondering the names of different SILCs.

>> Yeah. I can DM you with the Florida Independent Living Council.

>> Okay. Thank you.

>> You're welcome.

>> So, in the chat, it was asked by Susie, an individual CILs, what kinds of reasons are there for not signing onto the state plan? If that question is for me, because I had asked the other question, the answer to that is because they don't want to engage with SILC at all.

You know, to try to include them in anything. And anything in the process from the Town Hall meetings to virtually anything, there is just a complete disconnect. And therein lies the problem.

Dora, you're muted.

>> I'm going to lower my hand while I'm thinking about it too or I'll just keep it up.

Anyway, the, I'm very fortunate in Tennessee and I've mentioned this before that the centers that we're running are very involved with the SILC. And like Florida, we do our community conversations through the CILs. You know, they kind of host them whether it be in person or virtually. And that helps us and then a few years ago before I was with the SILC I was with the center. We developed a statewide consumer needs assessment. And so all of the centers in Tennessee utilize the same consumer needs assessment.

So on a quarterly basis they kind of send me that snapshot of what that looks like. So quarterly, we're able to see what is trending in the state as far as what is a success, right, or what is not working. And so that's helped us too and.

And then I really do try very hard to make as many in‑person or virtual events that the centers are having, because that gives me a great time to talk with the consumers and hear them out. Or listen to what it is that's going on in their world. And then that kind of brings it to a statewide focus.

An again, that's because my center, my centers, Tennessee centers started working very well together and I'm very proud of that. And I'm just, where I have to tell you, you've got to be in between a rock and hard spot if that's not going well for you.

>> Thank you. So, Dora, if I can ask a follow‑up question. I'm sorry, Kathy, you just unmuted go ahead Kathy.

>> Sorry. I'm not good at the whole hands thing. I was trying to find it but anyway.

>> No, no, no, you're nine.

>> I wonder if a situation that Oklahoma has and I know some other SILCs have had it too. The first SPIL that I had to do, there was a little bit of tension. Not anything like Oklahoma faces, but we brought in a consultant to help us do our SPIL. And he came in for, well, he worked with us for, before he came down and did like a one‑day meeting with us. And he looked over what we had. And we were kind of stuck in a rut where we thought we had to do things the same old same old way and it had to be written the same. And all that kind of BS.

But he helped us to understand that we could do whatever we wanted with that SPIL. And we could really change things up and we could really get away from how it had been. But he also helped us come together on that CIL SILC aspect of it where it didn't have to be, you know, like a fight the entire time. And he kind of helped us come together and have ownership by everybody. So we had all of the directors in the room. And we had myself and the SILC chair in the rom.

And I'll tell you, that helped tremendously. And then we were able to move on the next SPIL and not have to have a Facilitator. But I highly recommend that to anybody. And I would say it cost us, it was less than 3,000 dollars total and that was with his travel expense and his fee. So it's David Hancock. I highly recommend him. If anyone wants his information, I can give it to you. It has changed recently. But he's not the only one. There are probably way, there is probably more out there that can come in and help. But David had experience with being a SILC member and also being the Director of A center. So he could see both perspectives and sides. And the break down and understand what each side was really like, you know, what their, maybe preconceived notions were of why they were tense going into it or if there were conflicts already.

So, you know, doesn't have to be him. But you know, maybe a nonprofit, a nonprofit trainer, there is usually nonprofit organizations throughout the nation. Usually each state has one. If not your region would have one. But that would be another excellent idea to come in and just help you like figure out how to even get moving on that, just my thought.

>> That's a really good idea. Having kind of a neutral third party that everyone can agree to; just to get folks talking, might be a good way to start.

>> We've got about eight minutes. Seven minutes left, Sandra.

>> Okay. All right. What other kind of issues are you all facing as we, as we wind down from the calendar year, start up a new fiscal year? How is advocacy going within your individual states? Are you working on specific issues? How is that balance between advocacy and lobbying? It's always a (indiscernible).

>> We're working on vaccination because we live in a very conservative state. And that's why I can really say about that. And COVID is, so affecting people with disabilities and causing people to become people with disabilities. Although people with long COVID usually don't identify with disabilities yet. So we can say that we can help with long COVID too.

So, we just again use those different identity words. But, because it's very stigmatized. Especially if you never had a disability before and you're not used to have having a disability. And then you get long COVID. And especially if you're (indiscernible) then people are oh, well you put the disability community in danger for not getting a vaccine. So now we're not going to help you. But they're still part of the disability community. So we still have to, we still owe it to them to help them even though they don't help us.

So, that's been kind of tricky dynamic. So we've been doing a lot with vaccination. You can't really convince anybody. You can't be too pushy. We are just putting the facts out there and distributing this information. We can't force anybody to do anything they don't want to do.

Our vaccine clinics, free accessible vaccine drives have been very, very successful. Because a lot of the times vaccination isn't fully accessible for people that have anxiety and like intellectual disabilities. They can't go to like the pharmacy and get one. So, because they just don't are the time. So accommodate and they're not willing to accommodate. They just get very unwilling to accommodate if people with IDD get a vaccine. Someone with IDD, sometimes they have to move a little bit slow and think a little slower. And people don't always like that. I don't have intellectual disability but I have autism which is kind of a co‑community. So I took my neighbors that have intellectual disabilities to the vaccine drive. And yeah.

So, that's how we did the family thing we're doing right now.

>> Awesome. Are any other SILCs doing COVID activities? COVID related outreach or accessibility?

>> It looks like Susie has her hand up.

>> Sorry, Susie. I missed you. Go ahead.

>> Hi.

>> Unmute.

>> Hi.

>> There we go.

>> Thank you. I started thinking when a couple minutes ago somebody mentioned needs assessments. And I have a real problem with the way needs assessments are done. Not the methodology as much as the categories. I work with people with chemical and electrical hyper sensitivities. A lot of us live out in the rural high desert areas in Arizona. And there are a few dozen in Tucson and some of the cities always.

When I've taken an active part in helping with needs assessments, it's always been, I've always wound up with an odd outcome in that if 20 or 25 or 30 people with this kind of disability answer lots of questions and think, oh good, this year we're going to be included. We're not. I mean our specific access needs are not. Where we get put is other. And I'm unable to make the point so far that this community is not well served and I think that we need emphasis on it.

And now, you know, when disabilities come up that I'm not used to working with, like people with long COVID, I think that's really critical. And at the same time, I have this really childish feeling, like, hey, wait a minute, now we're going to pay attention to them and the chemically and electrically poison people still can't get into the SILC stuff or the CIL.

>> I understand.

>> And I don't respect my attitude there, but I do, I do want us to be included in the cross disability movement. But I want us to have our own little box to fill.

>> So, yeah. I totally understand that. And you're right, you often don't see that as a, as a demographic box to check or that it's a, an accessibility issue or inclusive issue that is discussed all that often. So you bring up a really good point.

And one that I think we should all really think hard about as we're trying to reach new communities or underserved communities, how are we approaching them. And making their voice heard.

Thank you, Susie.

>> I'm really stumped about it. I was our SILC chair a couple years ago. And I actually had a real tough time signing off on our plan. And I had to resign from that position right after having done it because we weren't in there. You know. It felt like saying, well people with all disabilities have all these rights and I keep thinking, well, yeah, ours aren't spelled out, you know, anyplace.

>> Yeah, just when it's a rare condition like that, I have a very rare genetic disease. There are only six cases in the world. It's not that they don't want to accommodate you, it's just they don't know how to accommodate you. And sometimes you have to accommodate yourself like you do by living way out in the boon he's. I have a lot of chemical sensitivities too. So, I don't think it's that they don't want to accommodate you, but like people like us, if that's just hard to codify that into law, because it's so rare.

But I think usually most people are willing to do it, but I really relate to what you're saying, because I work in a CIL and they deal with their class disability and they are a class disability and they really believe in that. But the way it's set up is a little bit inaccessible to me, because again I have a condition that only sick people in the world. So I'm actually meeting with the Executive Director to talk about accommodation for people with like rare illnesses. And chronic illnesses. Because sometimes I just need to talk to the person in charge. It's not that they don't want to do it, it's that they're busy and they, they need to be told out right, because they don't have that experience.

So I'm meeting with our Executive Director next week. And I bet all of my ideas are the same as all of your ideas. But just like solidarity, like I definitely know where you're coming from with the chemical sensitivity and stuff.

That wasn't even recognized as a disease it was so rare until like five years ago. So you got to keep that in mind. People were just saying that was made up until like five years ago. So and that gas lighting too is really hard. So, I just really emphasize with that and traditional medical system and traditional disability systems. You know, it's hard sometimes. And I just wanted to say that I really hear you on that.

>> Thank you Grace. So, Sandra, this is, we're out of time. So any last words before I close us out of here?

>> No, I just want to thank everyone for a fantastic discussion. Feel free to reach out at any time. And I'm excited that we had some good topics today. And I'm sure everyone will have a fantastic weekend after a long week of talking, right? So you have another session at the end. But you all had some great input and I really appreciate your time an effort today.

>> Yes. I appreciate it from everybody too. I wish the session could have been longer to answer more questions. But we do look forward to seeing all of you back at the next session. They start up again at 1:30 Eastern Time. So thank you guys.

>> Thank you.

(End of session).