

Improving Social Connection Among People with Disabilities - Webinar Transcript

March 30, 2021

Kristie Kulinski (ACL): Hello everyone and good afternoon. My name is Kristie Kulinski and I am with the US Administration for Community Living and our Center for Innovation and Partnership. I am pleased to be facilitating today's webinar, titled Improving Social Connection Among People with Disabilities. On behalf of ACL, we are grateful to everyone who has joined us today for their work to engage and connect older adults, people with disabilities, and caregivers. We know that it will take all of us working together to address social isolation and loneliness. A few housekeeping items, today's webinar is being recorded and will be available within a few days at acl.gov/CommitToConnect and you can see the resources for states in the aging and disability network section. I'd also like to note that we are unfortunately experiencing technical difficulties with the Zoom captioning, but we will post a transcript with the audio recording on our website. I do sincerely apologize for the inconvenience. We will be setting aside time at the end of the webinar for Q&A with the presenters. Please type your questions into the chat box and we'll keep the phone lines muted to cut down on background noise, but we will get to your questions at the end of all of our presenter's presentations. Can I have the next slide please?

Today's presentations will highlight current research on social isolation and loneliness for people with disabilities. Attendees will also learn about replicable strategies for social engagement and connection from the Center for Independent Living network. Next slide please.

So before introducing our presenters, I'd like to highlight a couple relevant announcements. First, I want to bring your attention to ACL's Commit to Connect initiative, which is a national campaign to combat social isolation and loneliness in all communities. Please visit the Commit to Connect website to learn more. Additionally, an upcoming webinar on a National Network of Champions to Address Social Isolation is slated for mid-April. So please be on the lookout for registration information via an ACL email blast. If you haven't signed up for ACL emails, please go to [ACL.gov](https://acl.gov) and make sure you are on our mailing list. Another webinar you may be interested in will be cohosted by ACL and the FCC on the Emergency Broadband Benefit. That webinar is scheduled for April 15th at 3pm and registration information is forthcoming. Next slide please.

And now I'd like to introduce our presenters. Sean Barrett is the Team Lead for the Office of Independent Living Programs within the Administration for Community Living at the US Department of Health and Human Services. In this position, Mr. Barrett coordinates management of four hundred and eight federal grants to community based organizations and states and territories across the country. Previous to this position, he was a fiscal specialist for the Rehabilitation Services Administration and a program office in the Independent Living Unit. Before coming to the Federal Government in 2006, Mr. Barrett worked as a Director for a Center for Independent Living in Everett, Washington. He earned his MSW degree with a concentration in Administration from the University of Washington. Anne Ordway is a Program Specialist at the National Institute on Disability, Independent Living, and Rehabilitation Research or NIDILRR in the Administration for Community Living. Anne oversees disability and aging research and health policy research grant portfolios for NIDILRR. She is the program manager of the NIDILRR advanced rehabilitation research and training program, which includes 24 institutions of higher education and research, focused on preparing the next cadre of disability and rehabilitation researchers, practitioners, and policy makers. And finally, Maia Santamaria has served as the Executive Director of

the Northwest Georgia Center for Independent Living since January of 2013. She has been with the Center since 2005. Ms. Santamaria has 40 years of leadership experience service through serving on boards and working with non-profits and holds a Bachelor's of Science in Industrial Management from Georgia Tech. And with that, I'll turn it over to Sean Barrett to get us started.

Sean Barret (ACL): Great, thank you very much. I will apologize that I will have to depart after my presentation, but I will try hard to come back before you are done. If someone could—I'm sure it will be in the transcript-- document questions if there are any for me. I will get back to them. First slide please.

Okay, great. The Office of Independent Program within ACL, also known as OILP. Next slide.

What I'm going to do is try to give you an overview of what the programs are. I'm going to focus predominately on CILs – Centers for Independent Living – but first, I'm going to give you kind of a broader overall picture. Independent living involves the philosophy, the culture and some Federal programs. Next slide please.

What is the Culture? The culture is a shared identity, shaped by a common history of oppression; the lived commitment to advancing the human and civil rights of people with significant disabilities; art, music, literature, and other expressions that individuals with significant disabilities create based on their lives and culture; and the pride, identity and purpose claimed by people with disabilities. And we totally stole that from Steven Brown, Ph.D., "What is Disability Culture?" Next slide please.

What are the programs? Independent Living Services—these are typically statewide programs. They go to the states and the states decide how to spend the money. Typically, they go to what are called DSEs – Designated State Entities—which are often, but not always, the VR program. A lot of times they go to Centers for Independent Living. These go directly from ACL to Centers for Independent Living, funding the community based organizations for the purpose of providing independent living services, which we will talk more about later, to individuals with significant disabilities. Training and Technical Assistance—we have a T&TA provider: ILRU. You can go visit them if you want. ILRU.org. And Section 21—these are programs to serve typically underserved populations. We actually have one right now I think in NIDILRR – about youth from diverse backgrounds transitioning out and we have one that deals with services in Native American culture. Next slide please.

So that was pretty broad – that's all of our services. So what is the purpose of the Rehab Act – the first act enacted [indiscernible]? To promote a philosophy of independent living, including consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society. Big stuff, big goals, lots of stuff. Next slide please.

So quick historical milestones. First CIL is in Berkeley, California, Ed Roberts. The Rehab Act passes in 1973. Not putting in a plug, but if you haven't seen the movie Crip Camp yet, there are a great series of scenes in there that talk about how that happened, on Netflix. Title Seven of the Rehab Act established federal funding for independent living. A year later, the first ten states received the Title Seven funding. 1992 – that was a big year – the Rehab Act was restructured and creates the Part C CIL program and SILCs—we'll talk about that in a second—which are Statewide Independent Living Councils were

established. And then very recently in 2014, the Workforce Innovation and Opportunity Act. Next slide please.

So there you go. The philosophy, plus the culture, plus the programs, equals independent living. You need all three. Next slide please.

So what does it mean to be a CIL or work in a CIL? Consumer-controlled, cross-disability, community-based, non-residential. So basically what this means is a majority of the staff, at least 51% have to be people with disabilities. People with disabilities are always considered the primary person being served, not the family members. Family members are certainly part of the environment, but encouraged to the greatest degree possible to have the person with disabilities be the person to drive the show. Next slide.

It is on Netflix, by the way—the last question in the chat [about the Crip Camp movie]. What are the core services? CILs must provide information and referral—where do I go? Who do I talk to? Independent living skills training. This can vary dramatically. It can be bus training, it can be interview training, cooking training, whatever you need. Peer counseling – quite often groups of people with disabilities who have faced similar issues or challenges supporting each other, helping each other learn through it. Individual and systems advocacy – it is exactly what it sounds like. Sometimes you help and work with the consumer to advocate for their issues, sometimes you work on a combination of issues and approach it from a more systemic level. I'm sure we've all have had experience with those. The last one, which is the last that was added is services that facilitate the transition from institutions to community living, diversion from institutions to community living, and transition of youth from secondary education to post-secondary life. So keeping people from getting into nursing homes, helping people get out of nursing homes, and helping people transition out of public schools basically, secondary education to life after school. Next slide please.

We also recently, as part of the Part C program – and I apologize, this is part of the reason I can't be here for an hour –got a decent chunk of money to help address COVID-19 related needs. They are directed to utilize the entirety of the funds to respond to the COVID-19 pandemic and the surge of needs of individuals with disabilities to access or reconnect with the services and supports they need to remain safely in their communities. So CILs have money specifically designed to help people with disabilities meet their COVID-19 related needs. If you have any questions about that, it is super broad. There is an FAQ on our website [indiscernible]. If you are individual or consumer, I would just call your local site. There you go. The possible uses are very broad. Next slide please.

CIL CARES Act areas of emphasis are service coordination. Lots of CILs are spending a lot of time working with transportation providers and Medicaid providers and food bank to try to coordinate and make sure that their people have access. Services to increase the likelihood of people getting out of or not going into institutions, shortage of accessible housing, lots of partnerships around food, and even literally handing out food, and systems advocacy to ensure health equity in medical settings. Next slide please.

Want to let you know that this your OILP Team. Reyma McCoy-Mcdeid is our new Commissioner and she is currently the Acting Director of OILP. Me, Team Lead. The project officers are Regina Blye, Kimball Gray, Veronica Hogan, Peter Nye, and Jennifer Martin. Regina deals with the state level stuff – and the other four are all directly tied to one CIL or another. Next slide please.

I'm going to give you some quick statistics from 2018 about what the CILs are doing. Fifty-five percent of the consumers are female, 48 percent identify as a minority, 43 are 25 to 59, and 39 are 60 years or over. So it's pretty [indiscernible]. Next slide please.

Seventy-six percent of the board and 64 percent of the staff have a significant disability. Next slide.

So, we've talked a little bit about what the goals are. Goals are what the consumer needs to increase their independence, and services and what they do to accomplish them. Next slide please.

In fiscal year 2018, CILs provide 837,000 core services, almost 400,000 other services—the other services, I didn't provide a list, because it wouldn't cover everything. If you are a person with a disability looking for independence, frankly the core or other services—your goal or need will fit into one of them. 72,708 goals were met. Those should be specific, concrete increases in a person's independence. Next slide please.

Resource – our recent annual report that has a lot more statistics, graphics, and verbiage about the program. Also, anything—the disaster services FAQ I mentioned that is on the CIL page, the contact information—anything about our program, is at the CIL page on ACL.gov. Next slide please.

So that's it. Thank you very much for the time. I hope that gave you an overview of what CILs are. Frankly, the other speakers are going to give you the concrete, how it's actually fleshing out, so I need to take off. I'm hoping and planning and trying to come back as I am excited for these presentations as well. Thank you very much.

Kristie Kulinski (ACL): Terrific, thank you Sean. Jessica – could I have you go back to Anne's opening slide there. Prior to turning to turn it over to Anne—I know one of our other speakers was having some technical difficulties, but I think we have her on the phone now. Maia Santamaria, I just want to make sure we have your audio now so that when Anne wraps up we can turn it right over to you. You may be muted.

Maia Santamaria (NWGA CIL): Hi, its Maia.

Kristie Kulinski (ACL): Oh, wonderful. Welcome, Maia. Great, we wanted to make sure we had you on the line. I am going to turn it back over to Anne now and then Maia, we'll hear from you once Anne wraps up her presentation. Thank you so much.

Anne Ordway (ACL): Okay, here I am, the research sandwiched in between the two presenters on services, so here we go. Stay on this slide. Today, there is no shortage of information on social isolation and loneliness with the continuous push of information through our email and social media on the topic. This webinar on social isolation among people with disabilities is part of ACL's ongoing effort to shine a light on a very important issue that has received increased attention since the start of the COVID-19 pandemic, and to provide information and resources to keep all of us connected. In my section of this discussion, I'll give a brief overview of what we know from research about social isolation and loneliness on people with disabilities and after my discussion, we'll hear about strategies to keep us connected from the perspective of a disabilities service organization. Next slide.

We have a biological need for social connection and since the start of the COVID-19 pandemic, all of us have experienced the changing nature of social connections and have many of us have gained personal insight into what it means to be socially isolated, lonely, or both. These aren't new concepts that have

resulted from the pandemic, however the pandemic has likely made worse our experiences with social isolation and loneliness and challenged our beliefs about who is socially isolated and lonely. We have an opportunity to build on the current imperative to address the social impact of COVID-19 and to understand the experience of social isolation and loneliness for all individuals. Next slide.

Social isolation and loneliness are different concepts and don't necessarily occur together. Social isolation is objective. It is often defined as the state of having few social relationships or infrequent social contact with others. On the other hand, loneliness is subjective. It is often defined as a feeling of being alone regardless of the amount of social contact. It is our perception of both the quantity and quality of our social relationships. I can be surrounded by people, but still feel lonely. Loneliness isn't a steady state condition, which means feelings of loneliness can vary in frequency, duration, and intensity. We can't tell whether someone is lonely by looking at them. It is important to note that it is possible to make a decision to be alone. We call this solitude, or a word that I really like: "oneliness." It is a positive affirmation for being alone. We can't assume that someone who is alone, is lonely. Next slide.

It is important for researchers to focus on social isolation and loneliness. Social isolation and loneliness are not only negative experiences, but also, according to the research, are consequential to our mental and physical health. Before the COVID-19 pandemic, social isolation and loneliness had been identified as a public health concern in the US and internationally. Findings from national studies indicate that social isolation and loneliness are associated with adverse health outcomes comparable to other risk factors, such as smoking, lack of exercise, obesity, and high blood pressure. Social isolation and loneliness are also associated with increased morbidity and early mortality. The estimates of how many people in the US experience social isolation and loneliness vary. Some findings from US national surveys indicate an increase in social isolation and loneliness since the start of the pandemic. There have been reported estimates as high as two-thirds of adults having experienced social isolation, while younger people report higher levels of loneliness. Next slide.

There is still a lot that we don't know about social isolation and loneliness. And there are significant limitations to at least pre-pandemic research studies on social isolation and loneliness as they relate to disability. Most of the research studies on social isolation and loneliness before the pandemic were focused on older adults. Social isolation and loneliness were treated as issues primarily for this population. Many of these pre-pandemic studies did not have questions on disability, which isn't to say that people with disabilities weren't included in the sample of research participants. We simply don't know because the questions weren't asked. And for the studies that did include questions on disability, disability was often included as a risk factor for social and loneliness. So to drive home this point, a rapid review of about 1,600 research studies found a lack of research early in the pandemic on the impacts of COVID-19, including the social impacts, for people with disabilities. Next slide.

I guess this begs the question – what do we know about social isolation and loneliness for people with disabilities? I want to begin this part of the discussion by acknowledging that the experience of social isolation and loneliness for people with disabilities is complex given our history of social exclusion and marginalization of people with disabilities. And while I won't talk about it today, what we know about the risk and protective factors for social isolation and loneliness for people with disabilities must be considered in this context. Preliminary findings from research studies conducted before the COVID-19 pandemic indicate that some people with disabilities are at an increased risk of social isolation and loneliness. For example, individuals with traumatic brain injury, spinal cord injury, and serious mental

illness reported higher levels of loneliness pre-pandemic than those without those diagnoses. There are few published studies of social isolation and loneliness for people with disabilities in the context of COVID-19. Therefore, we know little on the current trajectory of social isolation and loneliness for people with disabilities. However, similar to people without disabilities, studies have found that younger people with disabilities are more at risk for loneliness during the pandemic. And at least one study found that urban residents with disabilities reported feeling more isolated than rural residents with disabilities. Incidentally, findings from studies on people without disabilities are similar. And while I've talked a lot about the lack of published studies on social isolation and loneliness for people with disabilities during the pandemic, we do see the tide changing as new novel surveys are developed to capture data on COVID-19 for people with disabilities and include questions on social isolation and loneliness. So, some of these surveys include the COVID-DIS from the University of Michigan, and the National Survey on Health and Disability from the NIDILRR-funded collaboration on health reform and independent living. Next slide.

Here is a twist. Whether we use the terms social participation, community living and participation, or community integration, we have been researching social isolation for decades. NIDILRR, specifically, has sponsored research on the barriers to social participation, the benefits of social participation, and interventions to promote social participation for people with disabilities. I'm not claiming that social isolation and social participation are the same concepts. The framing is different. None the less, when we discuss the next steps for research and services to address social isolation and loneliness for people with disabilities, we have a substantial knowledge base to draw from. Unfortunately, the current framing of social isolation may overlook the substantial knowledge base. I encourage disability researchers who hopefully are on this webinar today to use this current framing of social isolation and loneliness so your research gets noticed. Next slide.

As I've said many times today, there's a lot more we could know about social isolation and loneliness for people with disabilities. Since we have an immediate need to address people's connection, I'll focus on intervention research. Previous research on social isolation and loneliness for people without disabilities and social participation for people with disabilities has demonstrated that social isolation and loneliness are amenable to change. There is little research to date on the most evidenced-based interventions to address social isolation and loneliness and the related health effects. However, we need these evidence-based interventions for now and beyond this stage in the pandemic. And we know that sustainability of an intervention is a crucial factor in its long term effectiveness. Next, a range of interventions in social isolation and loneliness should be considered, including individual-centered, family-centered, and health care provider or system-centered interventions. And finally, the COVID-19 pandemic has increased the saliency of remote or digital interventions. The comparative effectiveness of in-person social connection interventions versus remote and/or digital interventions is an area for future study and will require attention to the preferences of individuals with disabilities as well as their contextual factors. Any of you who are engaged in intervention research know that the most effective intervention is typically the one most relevant to the individual. Next slide.

This concludes my section of today's webinar. Please contact me with any questions on what I have presented today, including the references for the studies cited, as well as information on the work of current NIDILRR grantees in the domains of social isolation, social participation, and loneliness. You can visit NIDILRR's online, searchable database at NARIC.com to find informational products from NIDILRR

grantees on these topics. And now, I would like to turn your attention to our main presenter, Maia Santamaria, the Executive Director of the Northwest Georgia Center for Independent Living.

Maia Santamaria (NWGA CIL): Hello and thank you so much. My presentation will definitely substantiate much of what Anne just said and you will see the direct on-the-ground approach that Sean was talking about with regards to Centers for Independent Living. So, our approach – I mean every center is different so I can't say this is what every center does, but at our center, which is in northwest Georgia, we consider peer support the foundation of all our services. So we're approaching this from the viewpoint of using peer support as the foundation for addressing social isolation among individuals who have disabilities. Next slide please.

Okay I'll tell you a little bit about our center. Our mission is not that different from everybody else's. It's "to empower people who have disabilities so that they can determine their own future and to work towards a more user-friendly accessible community." As Sean pointed out, each center is grassroots and it depends on what the community really needs. We serve 15 counties in northwest Georgia. Next slide. At our center, it says 51% or 74%, as we're cited, of people having disabilities. We currently have 100% of our center staff having disabilities – staff and management. We are a very small, experienced, and passionate team. We're able to provide peer support because each of us, I mean every one of us, could provide peer support and do. Next slide please.

Sean did a really good definition of peer support and what I will talk about with the way we do it is that we don't match a person for example, who's blind, like I am, to another person who's blind. We match what goals a consumer has with a staff person who has had the experience of either reaching that goal or working towards achieving that goal. And that's also sometimes in peer support called "peer mentoring". And we provide it – I'm sorry, I'm a little lost in my notes here – thank you. We provide peer support to consumers and always have. We've also always provided it to each other – our staff or board, our management. And we provide it to community partners who are consumer-led. We're having more and more of them in our community and we're very proud of that because we kind of started it so that's a good thing. Next slide please.

So that's how we've been doing it, that's what we believe. And then enter the COVID-19 pandemic. Here we were, building the airplane as we're flying it. Everybody across the world is doing that. So our first thing that we had to do is had to change our infrastructure. First priority, at least to me as director, was to keep our team, our staff safe and healthy. If we weren't safe and healthy, how on earth can we help anybody else? And at least where I live, people were coming down with COVID and dying from COVID right and left. It was pretty horrible. So we had to develop a remote working culture. Now this included providing equipment – thank you to the CARES fund very much. And we have learned new equipment and had to learn new platforms, digital ways of doing things that we haven't done before, such as Zoom. We had to interestingly incorporate in some funds into our budget. Now it's fabulous that we have the money – that's great. But we also had to budget for it to make sure we were using it responsibly. Getting the accommodations for staff at home. And changing policies. All of those things we were kind of doing as we were going. But, concurrently, we had to have our first response to COVID and our consumers. So focus groups, yes of course, touching base with our own consumers. Calling them, "how are you?", "what's going on?", "what do you want?", "what do you need?", you know, "do you want to hear from us?" – yes yes yes we want to hear from you. Well okay, that's cool. We set out to find accessible PPE. As I have two staff who are deaf, we had to make sure that whatever platforms we used were

accessible. And we had to make sure our community was supplied with masks, clear masks, so that people who read lips could be able to access their services they needed from our hospital. We reached out to our community partners. Sorry. We reached out to – we were the first to be able to reach our paratransit system to provide masks to them for the riders and the drivers. And there's a new day shelter for people who are housed in our community and we've been able to help them with food and PPE and sanitizing products. We're kind of ongoing with that because so many people they serve have disabilities. But if we were reaching out and touching people in the community this way and our consumers, we found that our contacts with people were taking more and more time. We could easily spend an hour or more talking to an I&R or talking to a consumer or just talking to somebody in the community. That thirst for connection grew steadily as the pandemic progressed. We also found they wanted group interaction. It wasn't just "Oh I want to talk to you", it was like "Oh you know other people like this? Yes. Can we hook up? Yes." Next slide please.

So this evolved to weekly peer check-in calls. We had to provide the technology and training to consumers and teach the accessible platform of Zoom. I'm very thrilled we were able to teach a gentleman who is deaf and blind, not completely, totally in both of those senses, but enough that he requires a lot of accommodations. We still were able to teach him how to use Zoom and he was totally thrilled. Our peer support calls, they're always safe spaces, I mean everything we do is confidential. But our peer support calls turned into Vegas. It's like what happens here stays here. We don't talk about it with other people. This is a very safe space. We even had to ask a few people to leave when they've got in inappropriately or one day were becoming too negative or derogatory to others in the group. Just because you have a disability doesn't mean necessarily, you know how to behave unfortunately. And I don't mean that in a behavioral sense, I mean just in the sense of common courtesy. So safe space is critical. We also tried to provide the most up-to-date, the most accurate scientific and medical information on COVID and the COVID virus. But I think to me, the best part really was that it really didn't matter who called in – it was interesting – community members were calling in, other organizations were calling in, consumers were calling in. Everybody was okay with that. There were no violations in confidentiality. Everybody was grateful to hear from anybody else. And we all shared everything. As staff, as management, as board members, as consumers with other community organizations. These peer calls turned into a community peer call. And we shared information, we shared our stories, we shared our fears, we shared our strategies for dealing. We all learned from these. They're still ongoing, we haven't stopped any of this. Next slide please.

Peer support, as you can see, we were using for everyone, not just for the consumers. We realize how much our team needed each other. It was kind of interesting, you know, typically we have a staff meeting – this is pre-COVID – we have a staff meeting once a week, couple hours to touch base and run ideas by, etc. Our team is small, we don't have – we have no more than nine people and most of them are part-time – well no, not most. Almost half are part-time. So we realized these weren't enough. Our staff actually asked to have more team meetings and they turned out to be fantastic. We do them twice a week now – we have a management meeting for two hours and two 2-hour staff meetings. That sounds excessive, but it's really not. We work through everything, we support each other. We – I can't emphasize to you how much we have needed peer support as much as our consumers have. We've also been left – we received peer support from other CIL directors, our state CIL directors typically meet once a month. And we're a good group. And we can reach out anytime we need to. But part of our monthly calls is focused on us peer supporting each other. We get peer support from ACL, APRIL [indiscernible] –

everybody across the country. CIL calls that we have across the country, those are awesome too. We exchange peer support with our collaborative partners. There have been a lot of new groups growing up in our community since COVID. One of the really positive aspects, if you will, of COVID is that, due to the digital platforms, we have we are able to meet more with more community partners and to strategize on how to best serve our community. Before then, there was travel time – I was shocked some people do 2-3 zones at a time. Sometimes I'm on one thing for the next all day and that's a little much, you know? I didn't know my brain could pant, but it actually does by the end of the day like I've been running. But it's a good thing because these kind of partnerships, most of us haven't had time to focus on even though they're critical. Next slide please.

So as time goes on with this, we began to recognize the impact of social isolation, not only on people who outwardly say they have mental health issues, but on people who have never considered themselves to have that. I'm thinking of a person who I know very well, it was probably one of the most mentally and emotionally balanced or stable or whatever type of term you care to use, that I've ever known. And even he, I was watching him, and it's like, you're showing signs of depression. And he was like "What?" but we went over it and he really was so he was able to get some help. So it really doesn't matter. But COVID, the isolation has affected everybody. I have not talked to a single person, my staff either, who has not been affected one way or another by social isolation. Even people who are – what was that beautiful term Anne said – [indiscernible] even they, like oh my gosh, I'm alone too much. This is too much for me. Let me out. Let me see somebody. Let me do something. It really does affect, I think, everybody at some level or another. It's far worse on those of us who have disabilities because we already have incredible challenges getting beyond now and being able to be part of society. But then you throw the pandemic on with some force – literal isolation – it's extreme. So the first thing we did was understand that our emergency preparedness obviously had to turn inwards because we were preparing in staying home. But also needs to focus on people who have mental health issues and how do you handle that. So the October APRIL conference we were honored to be chosen to present a workshop which was on rural mental health – I'm sorry – mental health emergency preparedness in rural communities. We also were really fortunate to hire a staff person with the CARES fund. Hopefully we'll be able to do a workaround and keep them after that. But she is not only a certified IL peer supporter with that training, but she's also a certified mental health peer support. And she has been able to bring us new consumers to solidify and even extend some of the relationships with other organizations and providers who help people who have mental health issues, substance abuse, other types of abuse, anything that is traumatic to your mental and emotional wellbeing. And so that's been a real, real blessing for us to have somebody who could help with that. Next slide please.

Then we ran into the holidays. Well I don't know about y'all, but holidays are very stressful, even if you have the best family and best friends and y'all are supposed to be together and it's absolutely fantastic, but holidays are stressful. When you add that on top of that, you add COVID, where all our holiday traditions are turned upside down and we're even more stressed. So in addition to our peer calls, we put on two events. The first was "Coping with the Holidays" – during that, we went forward and addressed depression, anxiety, and panic head on and we talked about recognizing the signs of it, when to seek help and where, and tips for coping, coping strategies with it to help get through a lot of events of holidays that are a little too much for a lot of people. After that, we put on a much more positive looking – the computer is behaving right now – we put on a more positive event called "Celebrating the Holidays". And during that, we concentrated mostly on food while it was a very positive event, it was

talking about “what is your favorite holiday?” – I mean all year what’s your favorite holiday. What do you think of holidays? Do you celebrate holidays? What was your favorite, most memorable favorite holiday? What was a funny thing that happened on a holiday? And we sent all of our consumers, all the staff compiled their favorite holiday recipes and sent them a little recipe book and we talked mostly about food. I think almost all that time we just talked about food and by the end we were drilling because everybody loves food. Next slide please. Now that vaccines are here, everything is just shifting again. We need to focus on different topics now. We have to educate people about vaccines. There are, there’s a lot of misconceptions, a lot of disinformation, a lot of different fears among different marginalized communities so we need to educate about that. And we understand or respect that not everybody is going to get a vaccination, but we help them think it out. Also a lot of people think, “Oh I got my vaccine, I don’t have to wear a mask.” Well think about that. Of course we also live in an area where a lot of people didn’t wear masks anyway and that was its own challenge. So we started offering our courses again via Zoom. I’ll be honest, not being attended the same way as when we offered them in person but we’re trying to put anything out there that might attract somebody to help break the social isolation. We’ll have to transition our team to working in the office. Everybody is like, “Oh yay I love working from home” except well, in this consumer contact, can we work from home and just to consumers? We have to think about what are the best practices that we’ve learned from COVID and incorporate them in.

Kristie Kulinski (ACL): Maia this is Kristie. I apologize for the interruption. I just wanted to give a two-minute warning, we’ve had some questions come in and I want to make sure we can address some of them.

Maia Santamaria (NWGA CIL): Okay. Let me just really, really quickly – I apologize – challenges we have faced is engaging staff and consumers in nursing facilities. They’re on lockdown. The digital divide – there’s been not much way to reach people who don’t have consumer – sorry – technology. Also lack of transportation, that’s chronic and it’s worse. Lack of housing or communities in crisis with housing. Lessons we’ve learned, we’ve learned a lot of cool ways to interact, we have learned more than anything. We have learned that not only does peer support work, process is the only way – it really has been getting through this crisis, getting us through this crisis, this pandemic. And I’m sorry I talked so much, I thank you.

Kristie Kulinski (ACL): Maia, please don’t apologize. That was a fantastic presentation. I want to thank all of our presenters – Maia, Sean, and Anne – for their terrific presentations. I know I learned a lot. It’s been great seeing not just the questions coming in through the chat, but you all are engaging with one another and providing additional context and information even through the chat so this is fantastic. I would like to spend a few minutes addressing some of the questions that came in. I think the first question will be for Anne – Anne, since loneliness is subjective, while social isolation is more objective, the question is should we focus on developing and testing interventions to reduce social isolation versus reducing loneliness.

Anne Ordway (ACL): Yeah, that’s a good question. I don’t think it’s a one or the other approach. Meaning because they’re different concepts, we need to develop and test interventions for both social isolation and loneliness. An intervention for social isolation may do nothing to address loneliness as I said before, they don’t necessarily co-occur together, but they can. So both routes are necessary.

Kristie Kulinski (ACL): Thanks Anne. And a quick follow-up to that one, one of the comments that you made early on in your presentation regarding urban versus rural and you know, noting that urban residents are feeling more isolated than rural residents and why is this and I noticed that some individuals had included some links to additional research in the chat, but wondering if you could touch on that.

Anne Ordway (ACL): Actually, this is a great opportunity to promote a NIDILRR grantee's work which I cited. And Catherine, if we could unmute Catherine, Catherine maybe you could address this because you did the research.

Kristie Kulinski (ACL): And Catherine I think you can unmute yourself if you like. You're not hard muted.

Catherine Ipsen: Here it goes. Can you hear me?

Kristie Kulinski (ACL): Yes.

Catherine Ipsen: Yay. Technology works. Yeah we have done some research because we're the rural center, we have looked at geography and how geography impacts experiences, one of them being social isolation and loneliness, which was pre-COVID by the way so it wasn't research that was done in the midst of COVID. And there really were these kind of odd impacts or differences between rural and urban folks, where urban folks had a much, kind of speaking to what you were saying Anne, urban folks had a broader network of social connections and yet recorded higher levels of feeling lonely. Whereas rural people had kind of these more narrow social networks that kind of more objective quantity, but then also didn't have the subjective intensity of feeling lonely. From my perspective, and this is not empirical, I think that loneliness, or not empirically based on what our paper was about I should say, loneliness is because it's subjective, I think you're always looking at a referent group in judging like, I don't know I miss the TV until everyone has a TV and I don't. Or that sort of thing. And I think that goes on a little in rural. And someone in the chat, I think it was Margaret Campbell, suggested there is a self-selection bias and that rural people kind of, by their very definition, go to places where they don't really are crowded by people and I think that makes sense too. I mean I get that. I'm pretty social and I don't like huge crowds and that's why I moved away from Seattle, like that was good. So anyway that's all I really have to share with you.

Patricia Gibson: I wonder what rural animals would play – perhaps there's more animals in the rural locations that people interact with.

Kristie Kulinski (ACL): That's an interesting question. I would like to close us out with a question that was specifically for Maia. Maia, what parts of your efforts to address social isolation and loneliness at that stem from the pandemic do you think your Center for Independent Living will maintain as you know, we will transition out of pandemic response mode and into our, and I'm using my air quotes here, our "new normal" mode? What do you think you'll continue doing that you started doing during the pandemic?

Maia Santamaria (NWGA CIL): Okay, I think we will continue offering using the Zoom platform as well as in-person. I definitely can see that continuing. As long as people want the peer support calls, we will definitely continue those. We'll slowly continue, we may even modify how we actually do partially from home, partially in the office. Different staff may have different roles to play that way. I don't want us to go back to the way we were because there are methods we definitely learned.

Kristie Kulinski (ACL): Absolutely. Thank you and I'm recognizing that we are at 3:59 east coast time and I want to be respectful of everyone's time. Thank you so much to all of our participants who joined us today, to our esteemed presenters who shared their knowledge and expertise. We really do appreciate and value your time. As we noted earlier, we'll make sure the recording, the slides, and a transcript of this webinar are posted on the [ACL.gov/CommitToConnect](https://acl.gov/CommitToConnect) website within the coming days. So thank you very much and have a wonderful rest of your day.