



Build Back Better: Striving for a Post-Pandemic World that is Inclusive for All

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SPEAKERS

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Alixé Bonardi 00:25

Hello and welcome to this webinar build back better. We have a number of people still joining so we will get started in just one minute.

Alixé Bonardi 01:08

As people are continuing to join, I am going to get started because we have a full session today. My name is Alixe Bonardi, I am a white woman, I have shoulder length, brownish gray hair, and I am wearing a black shirt, and I'm standing in front of a bookshelf with several pictures of birds arranged on the shelf. I'll continue on with the session just as we understand it as we sort out who's on mute. And we'll go to the next slide please.

Alixé Bonardi 02:06

So, as I said, welcome to today's webinar. I am Alixe Bonardi, and I am joined also by the co-director of the National Center on Advancing Person-Centered Practices and Systems. My co-director, Bevin Croft, thank you for joining us to learn about how the new normal can be inclusive of people with disabilities. This webinar series is sponsored by the National Center on Advancing Person-Centered Practices and Systems and our center's funded by the Administration for Community Living and the Centers for Medicare and Medicaid Services. All webinars are free and open to the public. Next slide, please.

Alixé Bonardi 02:51

A brief background. The goal of NCAPPS is to promote systems change that makes person centered principles not just an aspiration, but a reality in the lives of people across the lifespan. Those of you who are regulars on our webinar, see the slide regularly. And we keep reflecting on it. Next slide, please.

Alixé Bonardi 03:13

I will do just a few logistics as we get started. We have all participants on mute. You see, we have the chat feature open. And I'm delighted to see that people are starting to engage in the chat section. I just want to note that we are also in the chat. The chat feature is open for questions, and toward the end of the webinar, our speaker speakers will have an opportunity to respond to those questions. You'll notice



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in the platform that you may be seeing that there's a Q&A pod. This is something that Zoom has inadvertently inserted for us, and we're not, we don't really use it. So please, if you have questions or comments, please go ahead, and put them in directly into the chat pod. This live webinar has polls and evaluation questions. So please be prepared to interact during the polling times. And ones coming up soon. Next slide please.

Alixé Bonardi 04:10

So, after this webinar, you can send follow up questions and feedback about the webinar to the to the link which is included here. Please know this is actually there's an email address that will be put in chat that you can access as well. You'll see in chat there also there's information about the recorded webinar, how you can access the recording after the fact along with PDF version of the slides. We will have a plain language summary available as well. And that will be available up on the website ncapps.acl.gov. Next slide please.

Alixé Bonardi 04:57

So, let's get started, our panelists are always interested in learning about who's here as we start this conversation. So, in what role do you self-identify the poll has been opened, and please feel free to, to respond. You can, you can add as many options as you choose. And I see a number of people are starting to respond, and we'll give it another few minutes for people to enter their responses. Currently, we have approximately approaching 400 people on this, this webinar. And we really appreciate each and every one of you who is joining today. I see answers still continuing to stream in. And when we get up over about 300 people who've responded, which is just now we will give about five more seconds, and then we will. Okay, now let's see. So, we have a mix of people joining us today, which is tremendous. We have people with disabilities, who used Long Term Support Services, family members, self-advocates, peer specialists joining us, thank you for joining us, social workers, counselors, care managers, we have people who are researchers. And the majority of people I guess, the largest portion, not the majority are people who identify as government employees. So, we've got a real mix of people joining here today, and this leads to rich conversations. So, thank you all for being here. Perfect. All right, next slide please.

Alixé Bonardi 06:59

So, we're here to talk about build back better. This COVID-19 pandemic has led to dramatic changes in the way people with disabilities engage with an excess their communities. The title of this webinar is build back better. And in many corners, the phrase build back better is being used to as a shorthand for the build back better act, which has written provides substantial provisions and funding to expand the availability of home and community-based services, as well as health, housing, and other social and environmental supports that are critical to people with disabilities. What I want to make clear is that we're not focusing on the specifics of the proposed Build Back Better Act, which has been passed by the House of Representatives being considered in the United States Senate. What we are focusing on very much is the spirit of the act to build back better from where we were in 2019. We're using this opportunity to bring together and amplify the voice and wisdom of people who have had the most direct knowledge of the experiences of people with disability prior to and living through these pandemic years.



This webinar features a panel of people with disabilities, family members, direct support professionals and advocates reflecting on the lessons they've learned during the pandemic. And we hope that this collective insight and wisdom from this conversation will provide inspiration and feel the ongoing work to use this moment in history as an opportunity for positive change. And kicking us off we have this quote from Emily Ladau, "The idea of normal that we seem to hold in our minds doesn't really include disabled people, we have an understanding of normal as something that works for people who are non-disabled, who don't have to take health precautions and excess needs into consideration on a day-to-day basis. Are we talking about returning to a world that takes into consideration the lessons we've learned from the pandemic, or going right back to excluding disabled pure people?" And that's what we're here to talk about. Next slide please.

Alix Bonardi 09:27

This is the exciting part of the session; this is where we get to meet our speakers and begin to hear from them. I'm going to briefly introduce our speakers and so that we can move through and get into actual session. So first, next slide please.

Alix Bonardi 09:44

We will hear from Nicole LeBlanc, LeBlanc who has a keen ability and interest in public policy and excels at communicating the needs of people with developmental disabilities to public official officials. She currently works as the person centered advisory and leadership group coordinator for NCAPPS, and her motto is control your own destiny or someone else will. Next slide please.

Alix Bonardi 10:08

We will then hear from Susan Yuan, who is the mother of Andreas Yuan, who's 47 years old, and Andreas doesn't speak but communicates by supported typing. Susan retired from the University of Vermont but continues to train in advocacy and leadership and does parenting skills assessments of parents with IDD to help them keep custody of her children. Next slide please.

Alix Bonardi 10:37

We will then hear from Deyanelin Galvez, who is a direct support professional mentor from the Center for Family Support. And as a member of the agency's Workforce Committee, Deyanelin wears many hats, and is proud to wear everyone every one of them she says her mission is to advocate for and assist those we support so that way they can live their best lives. Next slide, please.

Alix Bonardi 11:05

We also will hear from Sarah Blahovec, who's a disability rights activist, advocate, and activist. She currently works as the voting rights and civil engagement organizer for the National Council on Independent Living, where she advocates for greater accessibility in elections, educates the disability community on voting rights and works to energize a disability voting bloc, and addresses barriers to running for office for people with disability. She's the creator of Elevate campaign training for people with disabilities. Next slide please.

**Alixé Bonardi 11:44**

And finally, we will hear from Finn Gardiner who is a disability rights advocate with interests in educational equity intersectional justice, comparative policy, and inclusive technology. Finn holds a Master of Public Policy from the Heller School for Social Policy and Management at Brandeis University. And he's currently the communication specialist at the Lurie Institute for Disability Policy at Brandeis University. And we are delighted to have each and every one of you with us. So, with that, I would like for us to turn to our first panelist, our panelists are all going to join us and in answering the questions that we're putting to them. And essentially, there are three questions that each person is going to be responding to. First, we will turn to Nicole LeBlanc. And Nicole will be answering questions about a couple aspects in her life in which in which she can speak to whether things are better or more person centered than they were before the biggest concerns that she has. And what's better about life currently. So, with that, I'm going to turn it over to Nicole.

Nicole LeBlanc 13:00

Well, done on the introduction. Good afternoon, everyone. Well, my answers for the first question. The pandemic has opened up the door to more remote work, events activity options. Telehealth allows us to see doctors for, say blood test results, for instance, and therapist without having to pay money to travel to an office, which is nice given how Uber and Lyft is expensive and virtual conferences allowed disability groups to reach a wider audience given that not everyone has the money to travel, to allow us to use Zoom and other platforms for meetings that can save money. It's sparked interest in exploring new hobbies like nature therapy via hiking. As someone who has become a bigger fan of the outdoors, I've done more hiking in the past year than at any other time. From a research perspective is a perfect time to test out new technological innovations. For instance, I took part in a study with the World Institute on Disability testing out a MYDOC app that allows people to access doctors 24/7 from wherever they are.

Alixé Bonardi 14:15

Can I ask you a question? We're getting something in chat. And this is just for accessibility. If you, can you tip your sit up a little higher or tip your camera down so people can see your lips because people who are lipreading would prefer that or need that. Awesome. Thank you very much.

Nicole LeBlanc 14:31

Wherever they are by paying a small app fee. In some ways, the world has become slower pace. And then of course it's nice not having a nice not having to wear dress clothes. I will say do I keep going on are you or do you read the next question?

Alixé Bonardi 14:53

I can keep going Nicole, I'm sorry for interrupting earlier.

Nicole LeBlanc 14:58

Next question is what biggest concerns during this period overall as I look back from day one to the present, I would say all the virus confusion, questionable decisions by the CDC, and those in charge on



things like masking, boosters, how the virus spreads, have been the most mind-boggling unpredictability of the world and the economic and mental costs. For instance, CDC should never have rolled back its mass gains back late last spring. Right now, it seems like no one is doing enough to end this pandemic, when it looks so simple vaccines masking hygiene theater, given that the same way you stop this virus is pandemic viruses the same way you stop norovirus. Just the general mismanagement of this crisis, society's lack of empathy, outrage for the needs of the disability community and our nation's most vulnerable essential workers! Crisis management comes down to effective communication, this pandemic says the consequences for failure to communicate the facts during a crisis. The panic buying and utter disregard for disadvantaged populations. Our virtual world has shined a light on how inaccessible many websites are, like vaccine website signups given, that in the beginning, people couldn't just sign up for vaccines at a doctor's office or walk in at a pharmacy. Many of us have had to jump through hoops and call around to folks in our social network. All the uncertainty of this crisis has made many of us aware of how much low tolerance we have for uncertainty in general, not just in the Autism world, but in society as a whole. Lastly, I would say just the mental grind. One major issue is people are getting overpayment notices from Social Security right now, and we need to have rules to limit the length of time they can go back. We need SSI to accept all documents IRWE stuff via email instead of just mail. Slow mail service has been a major inconvenience especially for things like checks, essential items.

Alixé Bonardi 17:00

Thank you. So those were your concerns. And finally, what was better about your life when we had to make pandemic changes and what was worse?

Nicole LeBlanc 17:09

It was nice working from home 100% of the time not having to deal with paratransit, not having to deal with traffic. It allows for a more relaxed dress code. I see that given up a DC region is very conservative, big on business attire based on experience. Speaking engagements at virtual conferences and other events without having to deal with the hassle of airport security, getting patted down at the same time. Using telehealth because it saves money on transit when it comes to simple things like blood tests. Lastly, as far as what was worse, I would say you know burnout, zoom fatigue, having to have an arm and a leg and dental work done during this pandemic like wisdom teeth removal, just the day-to-day grind. On top of that moving two times, in the summer of 2020 when my friend Tia Nelis from TASH moved back to Illinois, I ended up moving into a month to month 3-bedroom 1 bath, which you know ended up not turning out to be the greatest arrangement. I ended up having unstable housemates and having to chase them, roommate replacements, and cover other people's rent. Pandemic became an excuse for people not giving 60 - 90 days' notice. This pandemic has felt like Mother Earth sending us to our rooms for timeout grounding us or destroying the planet by telling us we need to change our race as a society. take climate change seriously. As Greta Thunberg says, "Act like your house is on fire." Also getting comfortable with being uncomfortable by addressing our issues with racism ableism climate change and so forth. Intersectionality there are no single right issues. We don't live single lives, single issue lives.

**Alixé Bonardi 19:07**

Thank you. Thanks, Nicole. I mean, in your answer to those questions, you've provided an awful lot of content. I was just trying to scribble down a few notes which we might be able to drop into chat to one of the last things he said was we don't leave simply single-issue lives. So true. And, and I also was I took a little note to write down the mental grind. That's a pretty universal experience, but I think a lot of people are talking about so. So, we will we'll pick this up. And we'll keep going. We're going to move on to our next panelist. And the next panelist we are going to be joined with who's going to join us will be Susan Yuan and I'll be asking Susan, what has been the experience of the pandemic for your family? And we'll move our way through, I guess we'll go through each of these questions. And let me turn it over to you, Susan, with a brief reminder that if you can provide a description of yourself, for people who are getting their information, not visually, please go ahead.

Susan Yuan 20:27

Thank you. I am a white woman. And I have shoulder length hair, which I like to think of as blonde. But really, it's white hair. I just, I'm getting older, I'd say one of the aging family members. Now, would you like me to begin to answer some of the questions?

Alixé Bonardi 20:57

Yeah. So, let's get started with the first question what has been the experience of the pandemic for your family?

Susan Yuan 21:06

The experience of the pandemic for our family was influenced by the characteristics of my son, as well as, as our family. And I think that our experience certainly can't be generalized, for a lot of families. But some people may find something similar in it. First, I'd like to say a little bit about our family. And first about my son Andreas, who has given me permission to talk about him. He's 47 years old. He is non-speaking. But he understands everything, and he can type. But it's difficult for him to type. So, a lot of his communication is just natural communication. Now a little bit about our family, we were dealing during this pandemic, with the fact that I had a deteriorating heart condition, which made it very dangerous for any possibility of exposure to the pandemic. And since then, just to tell my friends who are on here, I've had a heart procedure, I'm much better. But this was the background with which we face the pandemic was the need to try to keep as much health as possible. So that was one of our biggest concerns all along, was how to keep Andreas in the mainstream of life as much as possible, but at the same time, to keep him safe enough so that he wouldn't be able to pass anything to me. And I didn't want to cut off all contact with him, just to protect myself. So, it was a constant balancing act, between his exposure to things in the community, and his getting a full life in the community versus my being safe. And another factor involved with Andreas, is that he's very tactile defensive; and what that means is that, in his case, he can't stand having anything on his face. He can't stand being touched around his head or face, and we thought about trying to desensitize him to try to get him to be able to wear a mask and it became evident pretty early, that we were just causing more problems. So, I think one of the things that this pandemic has taught us is to choose our battles. And to listen more to what is Andrea says, reality of his experience, and not try to force him into hours, even though it also added to



the limitations during the pandemic. Andreas is very affectionate and outgoing. But since he won't wear a mask, and since everyone is afraid of exposure, that limited his ability to have his kind of interaction in the community, which was part of his daily life. And it really fell to his care provider, who's a man who's a year older than Andreas and a wonderful care provider, but it fell to him and to me to try to keep Andreas as exposed to the world as possible, at the same time that he couldn't really be in the world as much as he wanted to.

Susan Yuan 25:12

Another thing that affected our family is that very early, Andrea speaking began to show very strong signs of anxiety. And he always was, you know, he'd gotten to a point of quite a lot of independence. But he suddenly couldn't sleep without me being with him, or at least my lying down with him for a period of time. And I saw this at the beginning as sliding backward, because he had achieved a lot of independence in his life. But then, with typing, I asked him, I said, "Andreas, why do you suddenly want me to lie down with you? You know, is this going backwards?" And he said, "I'm afraid." And I said, "What are you afraid of?" And he said, "I'm afraid of, you're getting sicker, and my losing you. And I don't want to be without you. So, I want you with me more." And I realized that this was a very real fear that he had, because he understands everything. But because he can't speak about it a lot, we often just assume that he just goes with the flow. And we realized that I couldn't require him to go back to the way he was. Because that wasn't where he is right now. So, I had to give into the fact that he needed to spend more direct contact time with me, even though well, partly because he wasn't having as much contact to the rest of the world, but also partly because of his anxiety. Also, oh, I was able to get very good support from the agency that supported him. When it came time for vaccination, he didn't have to go anywhere to get vaccinated, people came directly to him, still didn't make it any easier. I mean, any vaccination would be a bad experience for him. But at least he didn't have to go out into the world to get it, people could come into his world. And I would say that the agency that supports him, and his direct support provider, really was very conscious of trying to keep him in the world as much as possible, and at the same time, safe from the world. But what we learned was that we have to have a balance of what we can expect him to tolerate. And we have to listen to him. And let Him guide us in what he can tolerate in this new world.

Alixé Bonardi 28:15

Thank you. And I heard a lot about what you were talking about already, Susan, was some of what was some of the challenges, your experiences, your family's experience. But I also want to ask, were there things that you would say were better about your experience when we had to make pandemic changes or specific things that jumped out that were worse that you wanted to address?

Susan Yuan 28:40

Well, the things that were better is that it made me more aware of what he was thinking. We had to become aware of what he was thinking so we could figure out how he could adjust to the new situation. And that meant that I couldn't just assume that I knew what he was thinking. Because we know each other so well, a lot of the time, I do assume that I can know what he's thinking. But I needed to force myself to use his communication system, which is not easy for him or for anybody else, but to really



struggle to find out what he was thinking. And I think that this, this raised my awareness of the fact that I need to listen to him. So, I'd say that was positive. It also gave me more confidence in the agency serving Him because they really thought about his needs. So, it wasn't just me trying to think about his needs or his direct support provider, but the agency itself was trying to think about those needs. And that's given me more confidence for the future. Especially as I get older, because I know that they can think about what he needs as, as well as his Family.

Alixé Bonardi 30:05

That's powerful. And thank you for all of those reflections, Susan, what I what I heard and what really jumped out with me was the value placed on needing to listen is something that that we've been really trying to struggle through. And honestly, that takes a lot of mental energy and just enter energy generally to be to be doing the work that it takes to listen. And thank you for sharing about the trust in in support providers as well. This is a this is a great segue, I would say I guess to a support provider who's going to be joining us next. Next, I would like to invite Deyanelin Galvez to join us. Thank you, Susan, and Deyanelin Galvez, is going to be joining us in our role as a direct support provider. So, thank you for joining. And I would like to start the first question for you is what were the biggest shifts that you saw in how you supported people as a direct support professional.

Deyanelin Galvez 31:22

And afternoon, everyone, I am a Hispanic female with shorter shoulder length hair, black hair, with a blonde stripe on my right side. Thanks for having me. Some of the biggest shift that I saw in how I supported people as a direct support professional, was the decrease in hours and days of services provided also changes in our daily routine that not only affected the person I supported, but also myself as the person providing the support. Getting ready to go out into the community gloves, masks, and hand sanitizer, and emotionally and mentally preparing the person I support was now our new team, reminding her that she may not see the store owner she will go say good morning to every day or talk to the ladies at the bakery where she would get her favorite oatmeal. I myself have fears of going out with her and running into someone who would give us bad news on someone we knew from the neighborhood dying due to COVID. On the days I was in face to face with her, we will do telehealth after a few weeks, she decided it will be best to do telehealth full time. And sort of having face to face pays for our safety. Telehealth helped us get closer because now she was viewing a part of my life, which she will have never gotten a chance to do. So, speaking to my dog and seeing her through video will bring a smile to her face. The second question?

Alixé Bonardi 32:52

So, you've touched on that already, Deyanelin and about some of your concerns. But what were the biggest concerns you had in this period?

Deyanelin Galvez 33:00

So, the biggest concern I had during this time was the fear of many people contracting the virus, the impact that will have on so many of the people that we supported learning that their friends were no longer here and had passed its COVID How will we support or provide some sort of comfort with all



these low losses when us ourselves, we're dealing with losses as well. It was very trapped, troubling time and still is. But it was mostly just trying to remind them that each day that we were getting, and we're alive, you know, we're getting the opportunity to push forward. And because of those people that are no longer with us, we had to continue fighting and continue to keep safe. So, we will constantly remind them, you know, we have to follow guidelines where your max, use your hand sanitizer, keep your distance. So um, that was one of the biggest concerns, mostly, you know, having to tell them that a friend was no longer with us.

Alixé Bonardi 34:00

That's a really challenging, challenging thing. I'm sure. As, as you work through this this time, and you're right, you said it, we're still in it, right. We're also trying to learn what was better about your life and the work you were doing when we had to make pandemic changes. And then what was worse? So, so we're reflecting on that a little bit.

Deyanelin Galvez 34:29

Yeah. What was better about my life when we had to make pandemic changes was that I was given the opportunity to be a part of the agency's innovative team and we create a virtual student support. We quickly put together virtual supports of wellness, learning activities and club groups, workshops with special guest presenter and it has truly been a great outlet for us all. We have all virtually bonded create new friendships, and throughout all of New York and New Jersey, so soon so far has helped us do If the changes and emotional effects of the pandemic, we have lifted each other up on difficult days, and giving each other hopes for the future, we hope to one day be able to gather face to face and actually meet face to face. And the worst part, one of the pandemic changes has been not being able to actually be present with the person, even though we are having that bond virtually, is not the same. You know, we were so used to having activities, especially now around the holiday seasons where we have so many plans, I myself have created a group for my agency for ladies' group, where they create a fun, like friendships and support one another as woman going through a lot of troubling things that we face on a daily basis. And now we will go on trips every week, we will hang go, they would like to go out to dinner together. And we couldn't no longer do that. So, it kind of put us in that bag. So that kind of has been the worst part not being able to continue with that bonding of friendship building and memories creating. Thank you.

Alixé Bonardi 36:06

Thank you, Deyanelin. And you know, it's so you, you've touched on the relationship part, which has been such a critical thing and the two sides, right. One part is the loss of the ability to maintain some of the relationships in the community. Because of us not having as many opportunities to connect in person, you also touched on a relationship that that you were you built as a result of creating a virtual group and a virtual work setting together. And this is something that that we're all trying to figure out how best to keep the good and make up for some of the losses that people have experienced. So, I really appreciate you bringing forward all of these are my thoughts and perspectives. Okay, so now I'd like to turn to thank you for that Deyanelin. And, and I'm now going to turn us to our next panelist,



Sarah Blahovec, who is going to be describing, again, some of her own experience and knowledge. And the first question that I have for you, Sarah, is because of the pandemic, are there one or two aspects or experiences for people with disabilities that you think is more person centered than it was before? And then we'll go from there.

Sarah Blahovec 37:42

Yeah, um, so to start, I'm a white woman with brown hair pulled back in a ponytail wearing glasses, I have a colorful shawl on, and I am sitting in my, my condo, there's a large Christmas tree on behind me. So yeah, I come to this with kind of two perspectives as a disabled person who is chronically ill, and immune compromised. And also, as someone who works at a disability rights organization, although I'm just representing myself today, I'm not here to represent them. There are several aspects that I feel are more person centered than they were before. I'm someone who's worked from home for five years, as I have a complex chronic illness, that is always an accommodation I needed. And prior to the pandemic, getting remote accommodations was really difficult. We were told by education, institutions, and workplaces that you can't work from home, it's not a reasonable accommodation. So suddenly, to our surprise, in March 2020, that that change, we saw, everyone had to kind of scrambled to work at home, to educate at home. There were, of course, so many challenges with that, and adapting to that environment, because in many cases, it was just figuring out how to do that. So, you know, we suddenly saw that people who needed to work from home for reasons other than the pandemic, or, you know, take schooling from home due to reasons other than the pandemic finally had those accommodations. And, yeah, along with that we saw, you know, I work in voting rights as it was mentioned earlier, we saw a renewed focus in the 2020 election on voting by mail, and remote voting options and even access to events. Obviously, the way we held different events, whether it be conferences or concerts drastically changed and we lost that very important in person component of it. But as we get into where we're going through the second year of the pandemic, we're starting to see a lot more innovation in the area of virtual events. My organization has held a virtual conference for two years now. And even when we are quote unquote, post COVID, which we're not at this point, we're just in COVID. We're gonna we have realized that there's a need to have virtual options. So, I would say that the expansion of remote options has really been a welcome thing and a relief for many people with disabilities.

Alix Bonardi 40:36

And thank you, Sara. And, you know, I've reflected on this as well. And it gives us an opportunity to for remote participation that also allows for people from a wide range across the country and around the world, frankly, to participate and connect in ways that we've not maybe thought of. It's a great point. So, I want to turn next to the next question we have for you. And that is, what are the biggest concerns you've had in this period?

Sarah Blahovec 41:06

Yeah. So how, honestly, I wanted to leave more time for this question, then then for the first one. As someone as Brooke mentioned in the comments with COVID, quote, unquote, winding down, we've seen that work from home, reasonable accommodations are off the table yet again. That is, you know,



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we're seeing that across the board. And I hadn't mentioned access to telehealth previously that had been mentioned. But that has made a radical difference. For me, as someone who's on controlled medications, where I need to see my doctor every month, I can see my doctor from home and not have to take two, three hours off work, take public transit to go see my doctor. So those remote accommodations, in education, medical accommodations, employment, those are all being taken off the table. Because it's post COVID, which it really isn't. I've seen some really distressing things with people who were able to get their required and there needed accommodations for the first time ever. Now being told that these institutions can't do it. I know it's really frustrating, because first thing we know that it isn't true. And we know that these are reasonable accommodations for people now the excuse that this is not a reasonable kind of accommodation under the ADA has really gone away. And we're starting to see you know, the great flight from in person work to remote jobs, I have people in my family who have switched from a job that was going to require them to go back into the office to one that is at home, not just because of safety, because we are you know, I'm still high risk, and my family members are still high risk. But because it's more convenient, and it works better for them. So, we need to see a renewed focus on making sure that these accommodations stay that we meet the needs of people who are better served having access at home, whether it's through telehealth appointments, because traveling to a doctor's office can be burdensome, and even painful. And you know, people don't have access to quality, accessible, reliable public transportation, or even private transportation. It's expensive. But, you know, we were starting to see these taken away. And it's really heartbreaking because people are having their access needs denied yet again, and we're just trying to that we're seeing renewed focus from people who kind of have a stake in seeing people in the office, saying that this is the way that it needs to be done. And it's that's truly not the case. I would also say that, you know, there's also challenges with the belief that everyone's served well by remote accommodations. Obviously, we don't have it to where people are only beginning being offered remote accommodations in some cases at this point. But there's obviously some folks who really struggled with it, they need the in-person components. We have a massive digital divide in this country where poor people of color, may not have the same quality access to internet to technology to accessible technology, that they are able to take equal or equal part in these accommodations that they are being made. And so, we're seeing students who are lower income from lower income families suffer we saw people who just didn't have the access to be able to participate in these accommodations. So, we need to be able to address the digital divide in a way that is really effective and starts to address the societal issues. And then there's also the fact that just you know, remote accommodations don't work for people based on different needs and, you know, there, there are some people who really do benefit from being in person, there are access needs massive access needs, through internet technologies that we still need to address. So, people may have a much harder time having equal participation or maybe denied equal access due to accessibility needs. So, we need to be able to work on this, those issues, kind of address the whole societal issue to make sure that, you know, people have the access, we're providing them with the supports they need, especially if they need remote accommodations so that they have the proper, you know, technologies that there and reliable access to be able to take advantage of that. And then as we maybe someday move to a post COVID world, whatever that looks like, making sure that we preserve, you know, the maximum range of options available. So having hybrid opportunities where have remote components and in person components so that everyone can benefit.

**Alixé Bonardi 46:09**

Thank you, Sara. And you've touched on some really important things. And I think there's also a lot coming through in chat as well, specifically about accommodations related to work. And then also civic engagement, community engagement opportunities, just to include everyone you've brought to, you've brought forward so many important topics, and we're going to have some opportunities to follow up during our panel discussion. Is there anything else you wanted to add? No, I think that's it. All right. Thank you. Thank you for these remarks. And, again, it's sparking the conversation. And with that, I would like to turn it to our final panelist, Finn Gardiner. And thank you, Finn for joining us.

Finn Gardiner 46:57

Thank you.

Alixé Bonardi 46:58

With this, I'd like to start with the first question to you, then. So, what shifts have you seen since the pandemic began that made life more or less person centered?

Finn Gardiner 47:12

Okay, so let's start with my description, I am a 30, something black man wearing glasses. And I have some facial hair and very little hair on my head. Anyway, so how has Okay, so I kind of want to echo what Sarah said earlier about remote working. I've worked remotely before, on and off, but I'm at my current job management was very insistent that we come in that we come to work in person before the pandemic, because they really valued that social connection that we had when we saw each other in person, because we often had, we often met in person, and we had this very lively atmosphere, people would bring in snacks, and people would pop into each other's offices, there was a lot of socializing going on, it was good was good. But of course, that couldn't happen during the pandemic. So, we started working from home. And as someone who kind of lives a little far from my job, who doesn't have a car, um, remote work did help me in some ways, I was able to do work on a more flexible schedule, I was able to not I was able to avoid commuting, I wasn't spending money on Uber and Lyft as much, or the commuter rail. And that really helped. And, but on the other hand, um, everyone, not everyone, but I think a lot of people benefit from in person socialization, including me. And it was more difficult to work in isolation, especially when I was living in a less than ideal environment, which was the case during the pandemic, at least for the first year. Because I was living in an extremely toxic, I was in an extremely toxic relationship. And so, I was dealing with that and trying to focus on my job as well. And that was, that was a challenge to say the least. Um, now I live by myself. So that's not as much of a problem but that means I don't get to see people very much. So, I think that it's been kind of hit or miss. I've also noticed that as the pandemic continues, I think that there are some policies that for example, a Sarah also meant to telehealth and certain other programs that have allowed us to avoid commuting, avoid



exposing ourselves to the virus if you're high if we're high risk or have mobility difficulties, etc. And on the other hand, I feel as though with everything shifted toward COVID There's less energy being spent on other distant other important social factors, there's less energy being spent on our needs outside the pandemic. And often the pandemic is, because the pandemic is so urgent, there are other needs falling by the wayside. And it's also been harder for a lot of people to get the support, they need to get to stay at home rather than going rather than going into an institution. So, some colleagues of mine did some research last year, and they noticed that people with disabilities who are getting home and community-based support, were less likely to have workers come over, or they'd had to tell their workers to stop coming. Because every time a worker visits a client, bear coming into contact with people who may be spreading COVID. And if you need a lot of support at home, you have people coming over all the time. And a lot of these people who need in home support are also high risks, they're also immunocompromised. So, it's "Oh, go without help", or "have people come over", and every single person you have coming over to your house could bring the virus over. So, you have a lot of people who were in a double bind. And if you and it's harder to get services if you don't already have them. And I think the COVID has also exposed or at least drawn more attention to some of the gaps that we experience. Um, and there's been little change in certain areas, for example, getting home and community-based services is based on a lot of that is means tested. A lot of that. Um, if you make too much money to qualify for Medicaid, you don't qualify for home and community-based services, or you have to pay a large deductible for a buying program, you're not getting the support you need.

Finn Gardiner 52:10

But on the other hand, if you're middle class, you can't afford to just hire people yourself. So, a lot of people who are not poor enough to qualify for Medicaid, and not rich enough to hire a maid, or housekeeper personal organizer. A lot of people who are kind of in the middle are stuck. And this and the pandemic has done and this issue of sorry. And although we have learned a lot about the support that people need, we haven't addressed the systemic problem in which people with disabilities are still in a poverty trap. Because it's the only way they can get services. Or a lot of disabled people get taken advantage of by abusive parents or partners or relatives or friends' housemates, who provide them support, but they also kind of, they provide them support, but it's on the condition that you do whatever the abuser wants. And that's incredibly dangerous because people with disabilities are at higher risk of domestic violence. We are at higher risk of sexual psychological financial abuse. And that means we are at even higher risk during this pandemic, when you can't get when the government will not cover your supports. And you are not rich enough to hire somebody to come over and help you with taking help you with cleaning and cooking. And errands. either have to do everything yourself, or you're dependent on somebody who does not have your best interests at heart. And that's dangerous. That's dangerous. Because we have the right or should have the right to have support in our house in our homes. That is not tied to poverty or tolerating the intolerable. I had to deal with the latter I was in an abusive relationship. And I was dependent on people who were taking advantage of me. And I had to deal with this for about a year. And it was extremely difficult to deal with this personal exploitation along



with the stress of the pandemic itself. And I was also isolated from my social circle. I was isolated from my friends. I didn't have the same social outlets that I needed to get away from that and I had to, I struggled a lot it's a wonder that I managed get anything done under those circumstances. So, I think that, as advocates, as researchers, as care providers, we need to understand how all these interplane factors affect us how these gaps in our policies, put people at risk, not just for COVID-19, but for domestic violence, for abuse, for exploitation, for being stuck in relationships that are unhealthy, that are degrading and toxic and dehumanizing. And that is, it's astonishing that we still don't understand how these things play out. Even though we spent a lot of time thinking about supports support during this pandemic. We haven't done enough thinking I don't think. But I think we can do better. I think that, you know, I think we can do better, I hope we can do better. And it's simply a miscarriage of justice not to notice these depths.

Alixé Bonardi 56:20

Well, thank you, Finn, you take us to you take us to a place of hope. And I really appreciate you having you bringing this whole discussion forward. You've talked a lot about what's important to people and the importance of making sure that we remember what's important, both to and for people to make sure that people are in a position to have their own human rights protected and to be free of the abuse, neglect, exploitation. And thank you. What we're gonna do now is we're going to turn the conversation, actually, you know what, Finn, I have I have one other question, which we were going to ask, and I can turn it back to you if you're willing to pick this this up.

Finn Gardiner 57:16

Go right ahead.

Alixé Bonardi 57:17

And that is? Yeah, it's not a little, little question. That is, do you see us being on a path towards more equitable access to supports for people with disability? Why or why not?

Finn Gardiner 57:33

Man? That's a tough one. Honestly, I don't know. Because I feel so we're going in the right direction, some places, and then in the wrong direction others. So, I think that we could go either way. I don't I think it's too early to tell. Because the pandemic is still going on. We have this omicron variant that has started to spread in this country. We have not gotten rid of COVID, we are still socially distancing. We are still masking; we are still following all the protocols. So, it's hard to tell right now. Others on this panel may notice may have noticed and things. But I think that we're still it's still too early to tell.

Alixé Bonardi 58:16

Well, actually Finn, you know what, and that's perfect you out for a bit of our panel discussion, because the whole the purpose of having this conversation at this point in this moment is because we know there are so many changes happening, that this is a moment in which we need to be really, really mindful paying attention listening to people's experiences, for the purpose of influencing the shifts that



are just going to happen anyway, we are in a time of a lot of change. So, let's bring all of the panelists together. This, this is we're gonna move to the section of a panel discussion in which Nicole is going to be facilitating the conversation. And we will have Sarah, Deyanelin, Finn, and Susan, answering questions, two questions that Nicole is going to ask. So, if everyone can come back on video, we will have everybody for this part of the conversation. And as we go through the conversation, for the purposes of accessibility and for our F our transcript afterwards, I will try to remember to do this as well. If you identify yourself just to get started, so I will start with this is Alex and with this. With that, I'm going to turn it over to Nicole to ask the first panel question and two, and the first person who answered will be Sarah, so the first panel question is over to you,

Nicole LeBlanc 59:58

Nicole. This is an opportunity for change, how do we keep the good and avoid going back to the status quo? If it wasn't person centered? Sarah, Deyanelin, Finn, and Susan in that order.

Sarah Blahovec 1:00:12

Yes, this is Sarah. Um, so I think when you people with disabilities, as decision makers at the table, we're seeing again, a lot of the options that were extended to us being rolled back. And a lot of times that is being done by decision makers who don't have disabilities don't have aren't high risk for COVID who are making business decisions and not considering how those business decisions impact the people, you know, the most marginalized people, whether that's, you know, people with disabilities, but there's, there's other factors there as well, other demographic factors. So, we need people with disabilities, and multi marginalized people with disabilities at the table to be able to give their lived experience and share their input. And we mean to hear people listen to that. We are sorry, I'm having trouble with words today. But we need to have people actually listen to it not just, oh, you know, "we're gonna humor you". And we're still going to do things the way we would like to and the way they were. So, you know, I think that that is really the most important thing. And again, we need to not be viewing this time as post COVID We still don't know so many things. We've been going through this for two years. But also, it looks like we're going to be going through this for years more and the push to rush back to the way things were is leaving people behind and putting people in danger. So, we need to kind of slow down this this desire to get back to the way things were and make sure that we're doing it in a way that prioritizes safety

Nicole LeBlanc 1:02:04

awesome answers

Alixé Bonardi 1:02:12

Do you want to turn it over to the next person, Nicole?

Nicole LeBlanc 1:02:15

Next, let whoever's in line.

Alixé Bonardi 1:02:24



I think it's Deyanelin, who's next

Nicole LeBlanc 1:02:26

Deyanelin, your next.

Deyanelin Galvez 1:02:29

Alright, so um, in regards for us to keep the good. I can say we can keep the good by spreading hope on a daily basis, reminding those that we support, that this is all temporary and that we may carry on with the goals and dreams we have prior to the pandemic, as well as new goals and dreams, we now have to ensure that we are taking a step forward each day. And by keeping those who we support motivated, excited, and committed to reaching these goals and making these dreams a reality. The way to avoid going back to the status quo, if it wasn't Person Centered is to keep in mind that now more than ever, we must ensure those who we support are living their lives to the fullest. The past two years have been an eye opener for us all. And if we are here today, we need to make the best of it. We advocate for those who need us. We support those who need us. It's our duty to make sure we are listening to what they want and need to ensure we do all we can and more so that they can achieve and live their life to the fullest striving each and everything. Thank you.

Nicole LeBlanc 1:03:44

Finn, you're up next.

Finn Gardiner 1:03:46

Okay, so how can we restore hope? How can we make sure that things that we do bring back better? That's a very good question. I think that it's important for us to keep the heat on keep the pressure on our policymakers to make changes, to remind our employers to remind our senators and representatives and program directors and anyone else in our life who has the power or to make changes, that these accommodations that we're getting during COVID help that it would be unfair to go back to the way things were because the way things were was not acceptable. Before it was not acceptable before. And for example. And we can talk, and we can go back to history to consider how things change. important changes important positive changes during an extreme circumstance led to long term changes. For example, during World War Two women were the went into the workplace while men Were fighting in the war. And after the war, women were told, "oh, you have to go back home, you have to be in the kitchen." They weren't gonna have that, women were not going to have that. They proved that they were able to work just as well as any man could during the war. And so about, you know, 15, 20 years after the war, women got up. And they started organizing, they started, they started to make, they started to make changes. And women were more visible in the workplace, they became more visible in politics, they became more visible in the media. And you had, you know, about 30 years of the war, you had women like Shirley Chisholm running for president. And now we have a woman as vice president, very first woman in the White House. And she's a black woman and Asian woman. And so often, some of these changes that we make under stress can lead to bigger changes. And I think that can happen with disability, just as it happened with the civil rights movement, you had black soldiers coming back from the war, they had fought for their country. And now you're being told white



only get out of here, you're black, you're, um, we're going to make, we're going to keep you in your place, even though you went out there and fought for the United States and defeated the Nazis, were going to do the same thing that the Nazis did to you. And you're not supposed to make waves know, the civil rights movement. Same thing, black people and allies got together. And we fought for our civil rights, we fought for the right to be treated as human beings, as real as full members of this society, not just second-class citizens who, oh, yeah, you can fight for our country. But once you get back, but to get back in your place, no, we're not going to do that. And we're not going to do that after COVID. Either. Or at least I'm not. And I hope you won't either.

Nicole LeBlanc 1:07:22

Awesome, well said. You should be you should run for office.

Finn Gardiner 1:07:29

Oh, man. Oh, man, I don't know, I could do that. The scrutiny.

Nicole LeBlanc 1:07:39

Next, Susan,

Susan Yuan 1:07:41

All right. Sometimes crisis causes us to see new ways of doing things. I see a combination of COVID. And the direct support workforce crisis, as has coming together, at least in our experience here in our state, that we have both the COVID restrictions, and the difficulties. But we also have a real direct support workforce crisis, that there are shortages everywhere in terms of workers. And I think it's at times like that, when the system isn't working, that we sometimes come up with more creative solutions. And it shakes us loose from doing things the same way. We've always done them. Now some of us feel we worked very hard to build the system that we have. But I think that we have to face the fact that if it isn't working, we've got to figure out new ways to make it work. We've got to figure out ways in which people can support one another. We're relying more on peer support, relying more on Well, it's hard to say natural supports in the community because we're all stressed at this point. But I think that it's at this point, that we have the best chance to come up to shake loose of the way we've always done things and to come up with new ways. So that's what I see as a possibility out of this. And I haven't got answers yet. I just see a possibility of shaking things loose.

Alix Bonardi 1:09:53

And thank you all and to your point, Susan, we don't have the answers yet either. But we are working together to crowdsource them. Perhaps we're working on this as a group. All right, so Nicole, we're moving to the next and final question that we have for the panel. Before we move to Q&A?

Nicole LeBlanc 1:10:18

Are there any tools or supports that you can suggest? Use to help keep supporters focused on what is important to the person or the person who is receiving support? So, starting with Susan.

**Susan Yuan 1:10:36**

Yes, this is Susan. Because my son doesn't communicate conventionally. Communication is, I think, the most essential support to make sure that we don't lose out on our way of supporting people. Because we don't want to lose the voices of the people who can't communicate conventionally. So, I think supports for communication are continuing to be essential at this point.

Alixé Bonardi 1:11:22

And Nicole, do you want to queue up the next at the end of one? Oh, yes.

Deyanelin Galvez 1:11:30

So, tools are supports that I can suggest to us to help our supporters focus on what is most important to the person who is receiving support is to always remember it is their lives, we must find ways to ensure they're safe, happy, and satisfied with the life they're living. We need to put aside the ways we view things from our perspective, and always do the best to understand those we support views, listen, and communicate clearly. I always say DSPs are sidekicks to some pretty cool superheroes. So, let's ensure to use all the resources available to assist with anything and everything they may need support with. Always reach out to your mentors or supervisors for guidance, or advice when feeling stuck. And don't forget to have fun in the process. Learn to approach and take every opportunity presented to guide those who we support. Let's work on keeping them up to date with technology, setting up emails, learning to use Zoom, learning how to use self-checkout at the stores, ordering food from kiosk, overreates Door Dash, ordering from their groceries, ordering their groceries from Instacart. That's all-new stuff that we are facing now. Being able to use their food stamps on Amazon, just to make sure that they are feeling confident when going back into out into the community that is now more than ever, technology focus. Thank you for your time. Stay safe everyone.

Nicole LeBlanc 1:12:59

Next, Finn.

Finn Gardiner 1:13:03

Okay, so there, there's a lot. I agree with what everyone else has said. Um, I also think that we should continue to have support for people who experience multiple forms of discrimination or marginalization, things like support hotlines, and ways to stay in touch with others, especially if you live alone, or you're isolated, or you're institutionalized, or there's something else going on in your life, it's disconnecting from other people even more, even more so than we all are during this pandemic. And even afterward, especially for folks who are, you know, isolated and would be isolated, regardless of what's going on with the pandemic. I also think that having access to technology is important. Making sure that people have access to the internet, they have access to transportation, that they have access to communication devices, phones, etc. So that we're able to maintain these connections that we've created during the pandemic. And afterward. I also think that we should continue to ensure that workplaces are accessible, we shouldn't just throw that out after it's so after the pandemic is over, and several other folks in the panel have been emphatic about that and I agree, we should not go back to



the way we were. Just the way we were. We weren't doing too well. We weren't doing too well, but we can do better. And I think that everyone here has can see that pretty clearly.

Nicole LeBlanc 1:14:58

Sarah, your last

Sarah Blahovec 1:15:01

Yeah, I agree with what everyone else has said, um, one tool in particular I want to highlight is the Job Accommodation Network. They are a fantastic resource, and I will put their link in the chat. But they are a, an organization that helps employers, employees, and others, including rehab and medical professionals learn about what is required of employers with regard to accommodating people under the Americans with Disabilities Act. They help employees and job seekers understand their rights as job seekers and employees. So, they even have a free hotline to help people with any questions that you may have with regard to requesting reasonable accommodations or disclosing your disability to an employer. So, they're a really fantastic resource. That again, I'll put their link in the chat. It's ask J n.org. And yeah, I would say definitely look to them. Again, multiple perspectives here on helping employers understand what your responsibilities are to employee. So, I certainly would suggest to folks in that position to check it out. So that you really do have an understanding of the legal requirements. And then for, of course, employees, and those who will help people find jobs. It's a really great opportunity to learn what your rights are under the law as employees.

Alixé Bonardi 1:16:42

Tremendous for every, every one of you, thank you very much for your insight. Thank you, Nicole, for taking us through this section of this discussion today. We have just a few minutes to, to put some questions that have come through in chat to the panelists. And I don't think we're going to get to all of them. So, for that, I apologize. But I will say that we always collect all the questions and send them over to the panelists with an opportunity to respond, their responses can get will get posted along with the web, then our materials on our website afterwards. So, I would like to start with the first question that I'm going to put to the panel. And this one is, what are examples of ways that the disability community can profit from the post pandemic world? For example, what are some opportunities in business or employment that we should take advantage of? So are there particular opportunities that that those of you that that come to mind for anyone, and I I'll put it to, to anyone here?

Alixé Bonardi 1:18:16

And I will, I'll, Susan, I was just about to put it to you. So, Susan, please?

Susan Yuan 1:18:22

Well, I'm thinking, I don't know about other states. But I know that our state has been flooded with new federal money that came along with the COVID crisis. And we have lots of opportunity, I think, to think about projects that we haven't been able to fund before, or new ways to reorganize ourselves. Anytime that there is an influx of money. If we have good enough planning around it, we can use it. before it



disappears, we can at least put out some time limited one-time projects that could move us forward in terms of what's available to people.

Alixé Bonardi 1:19:17

Thank you, Susan. I'm going to put another question to the group and, and this is specifically to personal assistant or direct support professionals. And here's Well, this is a two-part question. The first question is, could we share could the panelists share which state they're from to provide a little context? So that's probably an easy one. The second one is what has been your experience with or knowledge of personal systems and DSPS receiving emergency response and recovery services. So, including getting information about service versus for accessing personal protective equipment, or vaccinations. And have you witnessed personal assistants and DSPS, or the people that they serve, paying directly for personal protective equipment supplies out of pocket. So, I'm going to put this to you Deyanelin. First, cause this is a question directly around direct support professionals. But I think that many others may also have some insight.

Deyanelin Galvez 1:20:29

Hi, everyone, good afternoon is Deyanelin, so I'm, I'm from New York. And, yes, we have been provided PPE, from the very beginning, in all of our people that we support houses, and they were mailed and shipped to us. Um, they're still available, we can always pick them up at the office, thank God, there was a point, of course, when we ran low, and we were afraid like what we're gonna do, but luckily, we managed to get some on time we even had someone donate handmade masks, which was amazing. From one of the parents, she sold them. And I think that was beautiful. The pandemic has shown like how people have managed to come closer and support one another. Um, so yeah, that's pretty much it, we have been provided, thankfully, with all the things required for us to continue to stay safe, and those who we support.

Alixé Bonardi 1:21:29

Thank you. I'm going to squeeze in just one more, one or two more questions. And this one I'm going to go ask is, we started talking about this post COVID How can we balance the needs of those who need or prefer virtual alternatives, or accommodations, with those who struggle with it, and really thrive on in person contact. This is the sort of a classic balancing act that that many have been struggling with through all of this, but we'd love to hear a little bit more about your perspective.

Nicole LeBlanc 1:22:15

Make everything hybrid, and have classes that can you know, teach people you know, how to use technology as a way to code you know, basic computers basic iPad and what have you. And I say this is somebody who doesn't consider themselves a computer genius.

Finn Gardiner 1:22:37

I agree hybrid but...

Nicole LeBlanc 1:22:38



and you know, push tech industry, you know, make your more platforms accessible, easy to use. Keep it short, sweet, simple, to the point less complicated. The less complicated it is for us, the better it is for anyone, especially when we look at, you know, we have generation millennials and Generation Z generation, the next generation. And then we have, you know, the baby boomers Generation X and the silent generation, the grandparent's generation. So having a bounce, I can meet the full spectrum is ideal. Like, for instance, nowadays people, like, I know, nobody's using checks anymore. It's like everybody's, you know, Cash App. And like that stuff. More complicated me if like, you know, direct deposit or cheque is the easiest, for instance.

Alixé Bonardi 1:23:38

So, lots of tools and tricks, right? Yeah. Thank you. and I were going, I promise, I think this might be one. We've got many questions coming in, but I want to make sure that we get to this one. This is a question directed to your fan, but also for anyone who would like to answer based on your insights and experiences. Why does is a big one, why does abuse in the disability community, especially in the disability community, continue to be an ignored issue? And how can allies support survivors without discrediting or gaslighting them?

Finn Gardiner 1:24:22

Well, oh man, that is that is a toughie. Um, I do think that I think the reason why there's so many abuses that disabled people's lives are devalued, and a lot of abuse gets framed his care. Now, I'm going to content warning here. Um, there are certain kinds of abuse that are very easy to mask his care. I won't go into details, but there are certain kinds of abuse that are easy to mask his care and also if you're vulnerable, it's very easy for somebody to, if they're a carer, if they're a caretaker or a family, caretaker, or a partner, they could control your finances. I'm disabled, it happens a lot to older adults, the whole elder abuse like that's financial abuse of older adults is a huge problem. And not just older adults, but adults with disabilities who are under guardianship or conservatorship or other. For example, let's look at Britney Spears, Britney Spears, Britney Spears, his father, what had her under guardianship and took in financial took advantage of her financially. So that's an example right there. And it's very easy to just credit people with disabilities. Because there's this idea that if you have a disability, you're not a reliable knower of yourself, or the situation in which you you're living. And that's especially the case with people with developmental cognitive disabilities and psychiatric disabilities. So, oh, they're autistic, they have bipolar disorder. They have an intellectual disability, so they don't know what they're talking about. But that's not abuse. That's just care. Oh, no, they're just making sure that you're managing your money correctly. Oh, they're just making sure that you're safe when they are not. These people are not acting in disabled people's best interests. Because although most people mean, well, you know, there are going to be some people who don't. And I think that, and I think that there's also this idea that if you're caring for somebody with a disability, then you're a saint. And, in general, yes, if you're caring for disabled people, then you are doing a good thing. But there are some unscrupulous people, there are people with questionable morals, who take advantage of others, and use their position as a caregiver to abuse the people they're supposedly taking care of. And, oh, and so they'll take, they'll, oh, they'll take care of you. But it's just a way for you to stay dependent on them and not talk to anyone else. Or to get all your needs from this one person or group of people. And so, you



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can't, so it strips you of yourself determination. I'll do everything for you. Everything will be okay, as long as you do whatever I say. And then you're stuck. And because people just credit people, people just credit disabled folks, it's hard to say, hey, look, something's wrong here. And it's easy to and how to rally support. First thing to do is listen, ask if people are okay, if you see someone withdrawing, from, if you see people withdrawing from their friend group and start spending all their time with their new partner, or if they're spending all their time with their parents and not their friends anymore, then it's time to make sure they're okay. Because although things could be going well, they could not be because a common abuse tactic is to isolate. Isolate the victim from other people who could support them as they look, something's not okay here. So, the first thing to do is to listen and read up, read about different kinds of abuse. And, and not just the not just the classic ones. I mean, when you think people when people think about abuse, the first the first things to think about are physical and sexual abuse. But those are not the only kinds of abuse. There's emotional abuse, psychological abuse, financial abuse, which I've already mentioned, there are several different kinds of reporting to recognize the signs. And there and no one demographic has a monopoly on being abusive. It doesn't just happen in working class families. It doesn't just happen in low-income houses, it doesn't just happen among people of color, domestic violence, and abuse have can happen anywhere. So, it's important to keep an eye out for it because we are especially

Alixé Bonardi 1:29:20

vulnerable to you speak the truth fan. Absolutely. And I really very much appreciate you. And I appreciate each of our panelists who have joined us for this far-reaching conversation, and this has taken us to the very end of our session. What I would like to do is first apologize because we have not been able to get to all the questions but as I mentioned, we will this has been a fantastic conversation and fills me with hope for work that we can do together to continue to learn as we move through this experience and frankly craft a society that is better and more for equitable there is a post webinar evaluation that is up. And please go ahead and you can scroll, there's a little gray bar that you need to scroll down to be able to find all six questions. And we really appreciate people's response to these panels or to, to these questions. Finally, I think I've said it and I'm going to say it again, so much appreciation for each of you as our panelists who've come and really spoken very much your own experience, and also your own vision for what will be a future but that we can all make better. So, with that, thank you all for joining us. Thank you to all the participants who are who were active in chat. Lots of information shared very good thinking and we look forward to you on future webinars through NCAPPS and through our future NCAPPS activities. Thanks everyone.

Nicole LeBlanc 1:31:11

Adios! Happy holidays.