



Disability Voiced United Webinar: Coping with the Coronaviru...

Fri, 4/3 5:51PM 1:50:31

SUMMARY KEYWORDS

people, regional center, disability, home, services, judy, important, parents, life, mindfulness, directive, webinar, feel, anxiety, routine, family, hector, learning, provide, exercise

SPEAKERS

Allison Buchner, Victor Lira, Ed, Emma Erenmark, Nina Patel, Judy Mark, Hector Ramirez, Ben Russell



Judy Mark 00:07

All right, participants are joining. Welcome everybody to our third webinar in responding to the Corona virus outbreak for the disability community. We're really happy that all of you are joining us. And it looks as if we have over 200 people on so far to our panelists, and we have a really amazing group of folks. So, first, let me introduce myself. My name is Judy Mark. I'm the president of Disability Voices United which is an organization directed by and for people with developmental disabilities and family members. I'm also the parent of a 23 year old who is served by a regional center and who is very frustrated at this stay-at-home rule. So, we are going to learn a lot for our family as well from this webinar. Before we get started, I know that all of you are here specifically for the topic at hand. But we wanted to just take a few minutes to talk about something that's been very important. First of all, wait before I get started, for those of you are needing Spanish translation. It is really important that you get in a different system for the Spanish translation. And I'm going to ask our program assistant, Ed, to put on the chat, the calling number for everyone. So you're going to have to go to a separate line and you'll be able to watch the Zoom presentation on your computer or on your phone, where you can listen to the simultaneous translation done by the amazing Lorna Silva. If anybody is having any technical problems with your Zoom, with your with your simultaneous translation in either Spanish or English, please write something in the chat and Ed will respond. The other

thing that I should mention before we get started about how this is working: This webinar is being recorded and will be available within a few hours this evening on Corona Risk Resources website. Maybe Ed while we're speaking you could get up and share screen after Victor on the thing you sent me because it will have our will have our website as well as ways for you to be part of this process. But before we get to that, I just wanted to take a few moments and Introduce Victor Lira. Victor Lira is the Senior Vice President of Premier Healthcare. And he's here to explain to us a directive that came out on Friday, which I think will impact a lot of families and individuals who receive services from a regional center, because there was a directive that's providing a lot of flexibility for people to be able to hire individuals to support them who are close to them, whether it's family or friends. And so Victor, I'm gonna have you take it away and just try to explain some things.



Victor Lira 03:34

Okay, thanks, Judy. I hope everybody is safe right now and in good health and, you know, maintaining as best you can in all the kind of trying times that we're in. But as far as our folks and the clients in all the, the, you know, participants that are being served by the regional center. What we've seen in our experience is that the regional centers are actually opening up their checkbooks, for lack of a better word, to be able to give people more services. Normally, we see an increase in services during the summer when all the kids are out of school anyway. But now all the kids have suddenly been dropped on their parents doorstep with very little to no notice. And so, you know, there's a lot of support that's needed right now. So there's two main ways that families can get extra hours of service for personal care in the home to be able to help them out. The first, which is becoming readily apparent, and depending on the regional center, you know, this is going to be greater or lesser degrees. And if you have specific regional center questions, I can try to address those too. But the first is, through traditional services, if they're already receiving traditional, you know, respite services or personal assistance services, then the easiest thing for them to do would be just to petition for more hours. We've seen some regional centers just sort of open up the floodgates and say, You know what, we know everybody's at home right now. We know it's a very trying time. We're authorizing eight hours a day, five days a week. We've seen others that will do four hours a day, five days a week. And then it sort of, you know, scales back from there. That's usually with personal assistance services. However, since there's no more respite cap (yay) they can actually authorize more respite services as well to get more personal care in the home. So you can actually go to your regional center and ask for more respite care as well. If you already have that service, and try to get increased hours that way, as well. So that's the first way I would say that's already in place and already happening around the state, with families going back and saying, hey, I need help, you know, can I get an increase in either respite or personal assistance? So the directive that came out yesterday from DDS per Nancy

Barkman, the director, that Judy was referencing. There you go, case in point. Is essentially expanding access to services that currently exist. But what they're calling in a participant directed manner, meaning that the client, the participant gets to choose whomever they want to provide the service. So this is similar to some of the current respite and personal assistance services around the state in that, you know, clients and families can choose their own personal care worker, which is great. So now with this directive, they can do the exact same thing across the state for personal assistance. Also for Independent Living services, as well as supported employment programs. So now it's not limited to just respite or just personal assistance. Personal assistance is basically available to everybody across the state, because not all regional centers use that program. But now they all have access to use that program per the directive. As well as independent living services. You can go out and choose somebody to provide your own independent living services if you want. And you can hire your family member, your cousin, your brother, your grandmother, your neighbor, your church member. Whomever you feel is best suited to provide that service. You can go nominate them and say, you know, would you be willing to help us out during this time, during this crisis. If they say yes, great, then they can become that provider for that specific service. And the last service is the supported employment program service. And interestingly enough, in the directive, that was the only one not mentioned, that spouse or parents were not allowed to provide, so it is entirely possible that a parent might be able to provide that. Now how you access those services, you go to the regional center, you make the request for those specific services. Say that and let them know that you have somebody to provide those services. And then they can refer you to a financial management service or FMS agency. And then the FMS agency brings them onto their books, and essentially issues them their paycheck based on the authorization for the number of hours as well as withhold all the taxes and all the insurances and all that kind of good stuff. So essentially, you become a co employer. So the family is in the home managing the worker for their personal assistance, independent living or supported employment program service. And the FMS is there to issue them their check. They made it straightforward. There's one standard rate, black and white, that's in the directive for the whole of the state. So we're not going to get all of this well, we kind of do it here. We pay this much there and all this. It's set. So that is that part is easy for the regional centers to understand. So the directive basically says, Yes, we've opened it up, you know, this component type service where you can go pick your own worker, and you can do it for one of these three services. And you know, families will be able to get more care at home that way.



Judy Mark 08:52

Wonderful, thank you. So, Victor if you can hold on for a few minutes. So we're moving on to a totally different subject. And so if anybody has any questions about this new

guidance, now would be the time to put it in your Q&A. So if you go into the bottom of the screen, and you look under Q&A, you can type a question in there. We prefer that you type it there, than in the chat, because the chat is having lots of things on it, like I'm having problems hearing, or all those kinds of things. If I could also asked my friends with my personal number not to text me during this webinar, I'd really appreciate it. Because I'm getting a lot of them. Thank you. I will not be able to respond to your text during this webinar. So if you have a question, I'm going to try to look to the chats now. But if you have a question, please try to put it in Q&A so that I can know when it's resolved. So here comes a question for you. Is what Victor was saying also apply to individuals with medical needs. So I'm assuming, nursing services?



Victor Lira 10:08

Yes, I would say that it does. I mean, if you're already getting nursing services, you know, where you have an LVN or an RN coming to your home to help you and you need more hours, you could definitely petition the regional center to give you more hours for that. Yeah, and we've got a whole nother conversation about that. But the short answer is, yes. Any kind of care service that you receive right now, to help you, you can ask the regional center for more hours. And as I kind of understand it, I mean, there's not much in the way of a budget limit or any of that kind of stuff that usually goes on, you know, during the year during, in a traditional type of service environment. Like right now. I mean, I've been overwhelmed by the response that I've seen from some, especially some specific regional centers and sort of them just rising to the occasion and trying to get more hours in people's hands. So that's actually been good.



Judy Mark 11:00

So what this means in in the real life of families is that if you have lost your care provider or you're concerned about your care provider coming into your home because they may be, they may be spreading the Coronavirus, you can hire someone within your own immediate life. So it could be a close friend. It could be a brother or sister, an aunt and uncle, a grandparen. It cannot be the parents providing respite. And it cannot be the spouse of an individual served by a regional center, but it can be an aunt, an uncle. The person has to be over the age of 18 to be able to provide this service. I know that this is something that a lot of people asked for. So there are many services that you can do this for currently. The three additional services somebody just asked are personal assistance, independent living and supported employment.



Victor Lira 12:12

Oh, sorry, I was gonna say, if you've not had these services before, it doesn't mean you can't ask for them now, by the way. So I mean, if you're in a, in a specific situation where you need help, and so you would benefit from one of those services, ask for it. I mean, this is the time because, I mean, in, in a medical crisis or in like the environment that we're in, there's no such thing as being, you know, too polite in this kind of environment if you have needs that need to be met. So just ask for it. And then I was giving some online advice to some guests in the self determination forum, where this mom had tried and she got denied and if she tried again, got denied. So she ended up I told her, just run it up the chain because at the end of the day, if you need the care, and you need the help and the service, hopefully somebody realizes that at the regional center, and then she ended up getting, you know, more hours authorized, which was great. So, you know, and even to the point where, if you feel strongly enough, and you feel that it's justified, you could even appeal to DDS directly. I mean, they're being really responsive and, and really trying to manage it from a crisis management perspective and trying to get out in people's hands. Because they know that, you know, they don't want any kind of negative impact on anybody that we serve.

J

Judy Mark 13:35

So I want to just clarify something. This is not self determination. Those of you who are in the self determination program already have this authority to hire and supervise staff. This is for people in the traditional system who are not in self determination, who have ability on these specific services. And these services include respite, daycare, transportation, nursing, day services, personal assistance, independent living skills, and supported employment. And let me just see if there's any other questions. Okay. Yes. Somebody asked if a sibling can provide the service. If they are over the age of 18, Yes. Somebody asked, Is this directive for all regional center consumers? Yes. All regional centers consumers, not self determination. Can my respite worker do the extra hours through the agency they have now? Yes, yeah. You know what I'm going to do because I want to move on to our next thing. Victor you have the power to be able to answer the questions in the q&a. So if you go into zoom into your q&a, you can start to type the answers and all of you who are participants can go into the q&a and look to see what's been answered because a lot of these questions are relatively similar. Okay. And we're going to move on to our main topic right now because a lot of people have joined us to hear about coping with Coronavirus in isolation and I want to move on. But for those core people that we serve who are regional center clients, we will get your questions answered directly by Victor.

V

Victor Lira 15:23

Yeah, I'll go through, and bang them out one by one. And I just put the link in the chat for the directive because there's been a few requests for the actual you know, language. So you can check, and you can click the link and go pull it down yourself. So I'll go ahead and get answering them.

J

Judy Mark 15:43

Alright, thank you. Okay, so we're going to move forward. And there's a couple of other things I want to mention before we really get started that are related. The first one is that Disability Voices United is doing a survey of people with disabilities and their families to see what their needs are during this time and whether their needs are being met by school districts, by regional centers, by counties. Whether you have fear of not being able to make your rent, have a fear of not having food, we want to hear from you. And so Ed, if you could share your screen, where I'm going to show you the links, and we'll put them in both the q&a and in the chat. We really need to hear from you on the concerns that you may have. This is a this is primarily for people in California, however, people from outside California can also answer the survey. So Ed are you able to get that up on the screen?

E

Ed 16:41

It is asking me to quit Zoom.

J

Judy Mark 16:47

We'll get it up in the chat. And then at the very end, we'll put it up on the screen. The second thing that I wanted to just relate to folks in the latest news is that it does appear the CDC is going to come out and say that people should be wearing masks when they go out even if they have not been affected by the Coronavirus. That it does provide, whereas not a perfect protection, it does provide some additional protection. We're not recommending, they are not recommending that you go out and buy the N-95 masks that are in desperate need by healthcare providers. But to use a scarf or to use material to make your own mask. I found a website that shows how to easily in two minutes make a mask out of women's hair ties or men's hair ties too. Hair ties and a bandana. And I'm going to be making a video of it this afternoon and putting it up on our YouTube channel and on our website and we'll email it out to all of you as well. If those of you who are on this are not on our mailing list and want to join you will see that in the chat, a direct link to be able to join our mailing list so that you are given the most updated information. Okay, so moving on to the most important issues that we're talking about today, and that is people's mental health during this very difficult time. We know that a lot of folks, that everyone is really struggling right now. That everyone is really suffering right now. And it's

particularly profound for people with disabilities, who, you know often have underlying issues that make them more susceptible to a more severe case of Coronavirus. So there's a lot of fear, but also often our circles of support are much smaller than people without disabilities. And so we have some really fantastic folks to speak to you today to offer some very clear suggestions about how we can cope. Hector is putting on a scarf for this as well. The first person I want to introduce is Dr. Ben Russell, a clinical psychologist, and runs his own agency, which is called Real Connections Institute. And he is going to be sharing some of his suggestions. Thank you Dr. Russell for being on. Welcome.

B

Ben Russell 19:05

Thank you, Judy. I work with mostly families with children on the autism spectrum. And a number of adults as well. And the amount of need right now and the different kinds of struggles and stresses that families are going through is really unprecedented. And so I have been able to work with families with a lot of remote services and helping kind of build a new routine. And we're realizing that there's some really helpful tools that Judy wanted me to share but just wanted to start out by saying that the amount of anxiety and stress that you're going through and your loved ones are going through... Just we're all in this together, we're all feeling it in various ways, and it's just hitting everybody in surprising ways and, and differently. But I think it's really helpful for us all to just keep remembering that. In isolation, one of the things that we're seeing is just a change in the routines of our lives. And your family system is experiencing, or, you know, some people's family systems are experiencing a big change and being around one another all the time in itself can be a stress. And other people are just completely in isolation. So, really being flexible to figure out okay, how do we, how do we apply some of these tools in a variety of ways. So as I share all the tools, just keeping in mind that, you know, they apply in different situations, different ways. All right, I'm going to share my screen. So this hopefully will go smoothly for us here. So a few things I want to highlight for us to think about self care and mental health during isolation. It is really helpful to have a routine to write it down, to post it in your home. And when you're considering this routine, to think about doing it together, if you're somebody who's really isolated and by yourself, you can have other people that maybe participate in some aspects of the routine that are aware of, you know what your routine is, and have scheduled time with you. But if there's other people - it can be support staff or family in your home - to be in it together by knowing what the routine is. And then that way you can be making sure that you're using some of these tools everyday to manage the anxiety. And coming from, you know, research in neurobiology, and understanding anxiety, I really want to stress that the managing anxiety starts in your body. We are a body, we're people that are living in a body and that are living in relationships. And managing the anxiety through movement and through body awareness is really what you're gonna hear me focusing on. And we're also social beings, we're

embodied social beings. And so really being aware of how we're relating to others, and that we're having opportunities to relate to others and to relate to ourselves, making sure that we create those opportunities. I know working with families, I realized that there is a lot going on, and families are concerned that their children aren't continuing their education. They're trying to work from home. You know, they're trying to get meals on the table, they're trying to keep the house clean. And there is a lot going on in our lives right now. And so one of the things that you know, can become overwhelming is when we start to put expectations on ourselves that are beyond what we can realistically manage right now. So just really encouraging everybody that I'm talking to and working with to prioritize connecting, and be realistic about what you can do. And as you as you develop a new routine, you know you can, you're going to need to get your work done, you're you're going to need, you know, your children to keep learning. But take it slow, develop routines that are going to support that. And be realistic with your expectations as you're building those. This is something that I feel really strongly about and comes from a lot of the research in neurobiology and some of the cognitive behavioral therapies out there...is working with the suffering itself, to find acceptance of the suffering. So give yourself a chance to feel your feelings. If you're struggling with anxiety and you're struggling with, you know, well, I don't want to feel this way. It actually intensifies the suffering. So accepting the suffering actually leads to more peace and ease. So again, slowing down, prioritizing, connecting, feeling your feelings, and then sharing kindness with one another whenever possible. So I want to get into some specific tools to think about in managing the isolation. The research on exercise and health and anxiety is incredibly powerful if you're interested in learning more about this. John Ratey has a couple of books out that describe the importance of exercise, and I can put that link in the chat later. But I really encourage you to look into the book Spark by John Ratey if you're interested. But in particular getting your heart rate to increase has profound benefits in terms of anxiety and depression and sleep and health. So start off with prioritizing that. Connecting with the outdoors if you have a chance to just sit outside, take your dog for a walk. If you don't, finding a way to sit by the window or you know, getting some fresh air, getting some sunlight, being able to see trees in the neighborhood. As I said earlier, where we're embodied and relational beings. And so the relational, our nervous system responds to one another through face to face interaction, and we get an automatic unconscious sense of calm and ease from being with other people that are showing empathy and are also calm. And so one of the most helpful things that you can do is to be able to see somebody's face to be able to hear their voice, feel that sense of connection with other people. So using video chat to reach out to friends and loved ones to support one another. You know, my own children are finding all kinds of creative and fun ways to do this. We're working on building all kinds of remote resources and connections with our staff and the families that we work with. It's really a lot of inspiring ideas out there. So get creative and and try to have some fun together, laugh together, cry together. And the video part of it

can be really helpful and looking at one another, feeling the sense of connection through the video chat. So, practicing mindfulness. One of the best ways to manage anxiety that's always available to you is with your breath. Slowing down your breath and particularly what's effective is taking a longer out breath and in breath. So I've been practicing this myself when I feel my anxiety coming up. In the last week, it's just being aware that my out breath is longer than my in breath and counting. Having the breath just come in and out evenly and bring awareness to movement and the diaphragm just has a profound effect on the nervous system. Loving, kindness, prayers. If you have religious traditions that have prayers or mindfulness practices, going to those, sharing those with other people in your community. And every activity can be done with mindfulness. And this is a profound way to manage anxiety, whether you're washing the dishes or you're doing your work, you can do it with an approach of mindfulness in your movement, mindfulness in where your thoughts. And you're engaging the higher parts of your brain, the non-reactive, more integrated parts of your brain whenever using mindfulness and it calms their reactivity and a lot of difficult feelings. So balancing alone time if you're managing kids and people and relationships in the home, make sure you have time for yourself, which is also a great time to practice mindfulness or maybe to get exercise. And then time together and time for social connections, you know, with people that are not in your home through video chat. And then keeping your mind active, learn something new, follow your interests. You know, remember, find the things that you've wanted to do, have a chance to really do things that make you feel good. So that's gonna atop the share. And I am available to answer questions. I'll post the link to John Ratey book in the chat.



Judy Mark 30:59

Thank you, Dr. Russell. That was wonderful and really helpful. Are you able to post, send us the PowerPoint so we can post it?



Ben Russell 31:25

Yes I can. Do you want me to send that to you?



Judy Mark 31:48

We're going to move on now to Hector Manuel Ramirez who works for the health task force for the California Health and Human Services Agency, as well as on every possible stakeholders groups in the universe. And I have known Hector for many years because he and I served on the Disability Rights California Board and I love him. So thank you for joining us, Hector.

H

Hector Ramirez 32:09

Buenas tardes. Thank you very much for having me today. I really appreciate the space and everybody here today. My name is Hector Ramirez. I am Chihuahua, Apache, and Mexican. I live in this tiny little city called LA. And I am a person with a disability. I have autism and lived experience. And I've known Judy for a long time as a self advocate. It's really interesting the times for everybody, family members and service providers, but also for people with disabilities like myself. You know, it's kind of interesting to see the news and hear people's thoughts and perspectives. And I think one of the things that I had to realize is that a lot of the ways in which people are feeling right now with anxiety and fear. Those are some of the things that me as a person with a disability, I have been dealing with all of my life. And I'm very fortunate that I have along the way, developed a variety of coping skills and learned some great techniques like the ones that were mentioning. The breathing, I do it constantly, the mindfulness, I'm very active in it. Because I've known that they've helped me in the past. And now it's a pretty good time to use them. And the people around me are recognizing. My family asked me to teach them how to breathe. I actually did a Zoom this morning for my siblings, and we did a little bit of breathing just for a minute and we checked in with each other. You know, I've been just talking around to the people, because some of us feel very helpless. There's a lot of uncertainty. Not sure what we're going to do or what we can do, but, you know, there's a lot of things that we can do, especially as people with disabilities. So I think the perspective that I'm taking in this is, you know that in a time like this, I am trying not to come from a place of fear, even though there's fear and anxiety. But I think I made the choice to come from a place of love and power and compassion, especially to myself, and then to others. When I say in coming from a place of love, is understanding, you know that I am scared and so is other people, and not be ashamed to tell other people. I live in a community with 118 seniors and I'm the youngest person, I'm 45. I live with my mom. And last night when I was walking my dog, you know, I talked to two senior men who were very angry, very upset, and we just chatted with each other. And I told them, you know that I'm autistic but one of the things that I do is I run a food pantry down the street. And for the past couple of days, while everybody's here isolating, and I'm at home doing Zoom, with my extra time I am volunteering at my food pantry. And we fed 600 people, you know, this week. And they were like, but you're disabled. And I go, yeah, but I am able to do this right now. And I think just allowing that conversation, made folks a little bit easier to talk about how they're struggling. And it certainly allowed me an opportunity to talk to them about how I was struggling. So it gave me another, another venue, another soundboard for me to really go for help. Because I think what I want everybody to know is that you're not alone. You know, you might feel like you're alone or isolated. But there's all of us, all of us literally, just about every person in the city, in the state of California, 40 million people. Everybody in the country, everybody in the world is having similar thoughts and anxieties. So talking about it is good, but also sharing, sharing good positive things. And I think that's why I

also say, you know, coming from a place of power, and knowing that I am not hopeless or powerless to this. That I can make choices. I wake up in the morning and I have a routine that I follow even though I'm not going to work. I still make my bed, I still take a shower, I shave because this grows fast. And I realized that I still have power, so that I don't feel so powerless to everything that is going on. You know, and I shared with my family, you know, do little things like that, go for a walk like you were doing. I have a service dog. So that's my routine. I have to go for a walk at least twice a day. So that helps me, you know, but I think the other thing that I was saying is that instead of coming from a place of fear, I think this is a really good time to also come from a place of compassion. And this is perhaps an important one, especially with family, you know. I am Native American Mexican, so very, very close to my family. And we can't see each other right now because we're maintaining, you know, physical distancing, for their sake, and for mine. And it's hard to tell you the truth, even though sometimes my sisters bug me, but I love them. And I love my nieces and my nephews, those are like my kids, and it's hard not to see them. But I know it's also hard for them. So I have to be compassionate, and, you know, find ways of supporting them as they're supporting me. And that means doing little things like having a little Zoom meeting this morning because it's free. And I came up with that idea. They didn't realize they could use it. So just sharing information, sharing resources. You know, it's important, just letting people know that they have probably more power than they realize, to stay safe and to stay stronger. We're all in this together. You know, as our California Governor says we have to lean in together and, you know, look out for one another neighbor to neighbor, even if it's just sometimes walking and saying hello to...walking to people behind their windows, which I do a lot. And like I said, I live with seniors, a lot of them are shut ins right now. And doing whatever we can. I've been bringing them boxes of food with my extra time, which is good for helping them out. But it's also given me a workout. And exercise is really, really good. But I wanted to share three resources that I'm finding at least very, very useful for me. And this is if you live in LA county or California or other parts, you know, because they can really, really have a lot of things to contribute. And these resources are all free. And they're available in Spanish and additional languages. And so for the first one for mental health is definitely the link to the Los Angeles County Department of Mental Health. And they have this amazing collaboration of resources that they've been putting together. Because here in California, we have been getting ready for this for quite a while. And so in this particular nice big page that is available in a variety of traditional languages, because advocates like me make sure that we have those. You know, so you know, things that you could do for a family member, if you're a person with a disability. If you're a service provider, if you're a community member, you know, things that you can access for free and find information. I used to be at regional center, I couldn't get my mental health services. So I had to go to Departmental of Mental Health. But now you know these things can be correlated. So they're available to all of you. There's a link of some really good apps that you can

download, to help you with mindfulness, with meditation, with planning. We have a variety of apps that they have let us provide them for free. So there's some really good things as well as resources for parents with children. It's very important, as well as resources for adults. Because people with disabilities, we come in all shapes and sizes and ages. And so it's really good to have a variety of resources. Especially, it gets hard being at home sometimes. I know my mom, I've had my mom for a long time. And even she needed a break the other day, because I was feeling a little bit stressed out. And so she downloaded this, you know, walking app, and she went for a nice walk and she came back. And I said, Sorry, I say sorry, all the time. I can't help it. I have blowups even still, you know, so there's there's a lot of really neat things there for folks. Our department is really, really good. And it has some reliable, consistent, free information. The other resource that I want to share, and I think that my mental health falls under the perspective of love. The next resource comes, I think, from perspective of power, and it's the issue of protection and advocacy. Part of feeling vulnerable is not knowing what's going to happen. There's a lot of different conversations. We're very fortunate to be in Los Angeles in California, you know, but there's still a lot of news that I hear of around medical rationing and beds, that is completely frightening. And I think more now than ever, knowing that we have an agency like Disability Rights California, that provides protection and advocacy for free to all Californians with disabilities is so important for all of us who have. They are the people that are going to really go and fight for us. And they do and the governor listens to them. And so I include there their hotline, right. Everybody's working from home. I'm on their board of directors so I know this. You know, but these are people that are pretty much unsung heroes. They're the ones fighting right now for some of these new benefits like the ones we're just mentioning, you know, the food, the medical rationing, a lot of these issues, you know, we're working together literally nonstop to make sure that folks realize that we matter. We're one of the two highest risk populations, the elderly and people with disabilities, and some of us are elderly and have a disability. And so they are there, they're still fighting from home. The other resource that I wanted to share also falls within the perspective of compassion. And that's about peer support. As a person with a disability, it's really important for me sometimes to just have other peers, other people with disabilities that I can talk to that explain things to me in a way that makes sense for me. And I've been looking around for a lot of peer resources. And the one that I really, really highlight is the one from our friends at Mental Health America. And it is all staffed by peers and they have a line for family members and they provide some really good information on mental health, sometimes they're just there to listen, you know, when I'm frustrated, or if you're frustrated, if you're scared. It's just somebody that you never will never know, so don't feel ashamed or scared, you can tell them anything. And it's a really, really good resource to have, you know. All you need is a phone or a computer. And I think the last one that I didn't put in a category just because I know it's important to have is, you know, the National Suicide Prevention Lifeline, and they are free and confidential, you

know, crisis counseling in a variety of languages. And it's also available in text. And what's important about them is that you don't need to be feeling suicidal to call, you could be feeling frustrated, and they'll help you de-escalate or calm down. They'll breathe with you, I've called them and they help me breathe, you know, when I'm feeling overwhelmed. Sometimes they give you options. So these are some of the resources you know that I have been using for myself. So I know that they work, you know, and I really wanted to share them with everybody out there. You know, as a person with a disability, these are the things that I'm doing to deal with this. And, you know, just listening to my peers, you know, listening to their fears, listening to their parents. I also get, like, a lot of conversation with parents, because parents also have disabilities. And so I once again wanted to thank Judy and this organization for inviting me. And I just want to remind everybody that you're not alone. You're not alone. Thank you.

J

Judy Mark 44:35

Thank you. That was amazing. Thank you, Hector. Hector also prepared this handout in Spanish. And we will have this handout also available. I'm just leaving it up on the screen for a minute here because I wanted to make sure that when this recording comes on YouTube that you'll be able to see these resources as well. Okay, I'm going to stop sharing the screen now. And we're going to move on to...both of you, both Ben and Hector, you were amazing. And now we're going to move on to another amazing person, Allison Buckner. Allison is also a friend who is the mom of an amazing young woman named Sammy, who's served by regional center and has, I've just noticed that she's just had an incredibly wonderful perspective about the crap that we're living in right now. And so I invited her to come on. So Allison, take it away.

A

Allison Buchner 45:37

Thank you, Judy. So I have two daughters. One is eight and one is 11. My 11 year old has a disability. She has a movement disorder, presents much like cerebral palsy. We've only learned in the last year that there's a genetic cause for that. And also all of this sort of coming, you know, Coronavirus is coming on the heels for us of what was one of our most challenging years last year. She was in the hospital, we had no idea why, we won't get into all of what we what we learned through all of that. But we had one of our greatest health scares of her life and of my life and it fundamentally changed us, I think, as a result. And so then we have this virus and we don't know how it would impact her. I mean, I'm we're encouraged by the data on kids, right and that's encouraging, but we just don't know. So there's this sort of anxiety that's living in the background, in addition to all the other things, with just regular life. So my eight year old and 11 year old and then I am a full time working attorney and primary breadwinner for my family. And my husband works for the

city of Los Angeles in homelessness policy. And his job right now is to get all of the individuals in LA experiencing homelessness off the streets if we can, and to set up quarantine places, to set up the infrastructure that can handle that issue as well. And so to say that our lives are stressful right now is very much an understatement. And the first week when the kids came, you know, were home from school and doing remote learning, we actually have a charter school, it's doing a phenomenal job with remote learning. Their teachers are online every day, teaching them live. But that said, we still have a child who went from having a whole lot of supports in the classroom to, Here's the computer, let's do remote learning now. And so the whole landscape of our lives has changed. Someone recently said to me, and I thought this was very true. It was another working mom who said, who said that we're having a public health crisis, but for most families, we're also having a huge logistical crisis. And that really spoke to me because that's 100% true. We were having to sort of redo and figure out everything and switch things around. And so in all of this, How do I and I actually was having a rough morning when Judy called and asked me if I would do this. So it's perfect timing to sort of be real honest and authentic about how hard it is, but what's keeping us going. What is helping me stay mostly sane, which I think I am staying mostly sane. And in mostly frankly, I'm staying like happy and pleasant most of the time. Hector, lots of apologies still happening in my household too. And, you know, what are the things that are keeping me going and I think that a lot of it is stuff I've drawn on from prior experiences, whether it's from Sammy being in hospital last year, or just the experiences, life experiences of having a child with a disability. We learn coping systems and things as we go and then those translate into other areas of our life. But I will also share a few of the sort of driving principles that I think are keeping me sane. To be decided. And maybe they'll be helpful to you, and I certainly can't take credit for them because they're tidbits that I've picked up through all of these other experiences. One of which I shared with Judy on the phone the other day. Right after Sammy got out of her hospital stay last year, I was in a in a rough spot. I mean, there were so many questions. And several friends had been talking about Renee Brown's Netflix special. So late one night I couldn't sleep, that's when I tend to do my worrying, I decided to watch Renee Brown's Netflix special with ice cream, and wine. But one of the things that Renee Brown talks about which just spoke to me was what defines resilient people. And in my life, that's something that I call it grit. And I always say that I aspire, I wear a bracelet that says grit and grace that my girls got me for my 40th birthday, actually two days before that hospital stay that Sammy had. And so grit and grace are something that I aspire to daily. And really, when Renee Brown talks about resiliency, I think of that as grit. And she's done lots of research over the course of her career. And I'm probably oversimplifying, and in fact, I know I am. But we, you know, A) I'm not her, and B) we don't have that much time. But essentially, as she's researched resiliency over time, and she's talked to people who've been, you know, part of mass tragedies and terrorist attacks, and just trauma beyond what thankfully most of us can imagine. And the one thing that comes out in interviews of

people that have sort of survived those things in a way that we would think of as being very resilient, is gratitude. And that's something that's just been a common theme. And when she talks about that, that spoke to me because if I look at my life, and I think about when I'm doing well versus when I'm not. When I'm doing well as a special needs mom, working attorney, all of these other things. When I'm doing well as a daughter caring for a mom who's having some medical issues. Whenever I'm doing well, it's always because I'm looking for what's good. It's not easy. And whenever I'm not doing well, it's because I'm losing sight of those things. And I had to over that summer after Sammy's hospital stay, I had to keep reminding myself, she's here. She's home with us, like there were nights that we didn't know that that would happen. And so rather than getting lost in all the questions and the worry and the wonder, I had to just keep re-centering myself and so that Renee Brown Netflix special at probably like 1am was life changing for me in that regard. Because I do keep taking myself back to that and even now that's been a kind of a constant force in the last few weeks, which have been really hard. I also have a dear friend who is a photographer. He also has a child who's very medically complex and she has her own worries as a mom. And we often text each other just when we're having a hard moment or a hard day, and one of the things we always talk about is how do we not get lost in that worry about tomorrow or the next day or 10 years from now? And she said, that's why she loves photography. Because for her when she's taking pictures, the only thing that matters is what's in front of the camera right then. And to me, that is the definition of mindfulness. It's being in the moment, right. And so, in any event these last few weeks, I've been thinking a lot about both this notion of gratitude, or sort of even more generally just finding finding the bright spots, which is something I always try to help my girls do. Each day. My eight year old is naturally a really big complainer. She finds, if you asked her how her day was, she could have had a...I see Emma smiling, she knows my eight year old. If you ask her how her day was, she could have had 300 wonderful moments and one bad moment. And she'll always define her day by the bad moment in how she describes it. And it's something we've worked on a lot with her and we play this game over dinner, like, Can you give me one rose of your day and one thorn of your day. And that's helped her because now she goes on in her day, and she's looking for the roses. And so I've had to put that in action in my own life. And then kind of combining that with what my photographer friend told me, I've been trying to take a picture. When I see the moment that I'm feeling it's a rose, I just snap a picture with my phone, and I'm posting on Instagram, because I'm also a very social creature. And that part of me is like really missing interaction in this world of isolation. And so it's sort of feeding me in a lot of different ways. Each day I'm posting, you know. And I make jokes about it, like day 592 of quarantine. But each day I'm posting the moments that were my bright spots that day, and sometimes it's hard to find them and other days they're plentiful. And that's sort of like life. We're not guaranteed easiness, right. And I just kind of keep reminding myself of that. And then, just really making purposeful efforts for me. Like I said, posting, that's one

of them. Posting those shared moments or sharing the moments of gratitude. But really purposeful efforts not to isolate. And I go back to what helped me early on in my early experience as a special needs mom, which was finding communities of people. And I have people who...our girls were all born around the same time, we've never even met each other in real life. And they are my lifeblood when I'm having a hard moment. And so going to those communities, and finding that shared experience is something that has also really helped me. Social media, you know, that's kind of...We now have that as this gift to connect with people like us. Whatever like us means in that moment, and it changes over time, but finding our community and obviously that comes with pluses and minuses. There are days when I read social media, and scrolling through my feed, and there's too much about Coronavirus and too much data. Then there are days that the data can comfort me. And sort of checking in with myself on like, is this comforting me? Or is this making me spiral and feel anxious and worry about what this virus means for me and my family? And the harder part obviously, is once you check in with yourself is sort of taking action, right. And like, It's not helping me today, so I'm just scrolling by. But those are things that I'm having to do sort of constantly. And then as a mom, I think remembering with my kids. And in particular, my eight year old, who's the child who is you know, a typically developing eight year old, is to remember that behavior is communication. Because it's been a really...It's been challenging, it's been really challenging. I mean, I think she and I forgive each other, like 500 times a day right now. But her whole world got turned upside down too. I mean, she was at school on a Thursday and we kind of talked about not going, you know, maybe school will be canceled. And now all of a sudden, it looks like she's not going to go back to second grade at school. And recognizing that that is just a lot of change. And then the moments that are really hard, in my better moments, I'm able to remember that behavior is communication. And also just, sort of, and I think this was something that Ben said, is just being realistic with yourself. I am someone who gets a lot done at work. I mean, I am very efficient. I am like, I get in there, I get it done and I get home to my family. So I tend to keep things very separate. Like at work, I'm this litigator. I'm an intellectual property litigator. And so I get in there and I do my work. And I'm pretty hardcore about it. And then I come home and I'm mom. And then I go back to work if I need to in the evenings. But suddenly, it's all supposed to happen at the same time. And so really just showing myself some grace, which is one of the hardest things, I think. And so I'm working on that. I was on a call with a professional organization last week of all women who are intellectual property litigators. And someone said that they went from realizing this isn't like a day where I'm working at home for some reason, and everybody else is in the office. And she said she kept finding herself, you know, as her kids walked in, and as far as I know, she has typically developing kids, doesn't even have the extra layer of complication that many of our families have. Said as her kids would walk in while she was on speaker call or conference call, she'd give him the Death Stare, like leave me alone. And she had to sort of recalibrate and say, we're in this for the long haul. And we're

all in this together. You know, it's not just me that's working at home, and just kind of continually recalibrating expectations for myself, expectations for my kids. And just taking breaks. And I think, you know, mindfulness is probably... I'm always 100 steps ahead of myself. I think that's been something that's helped me succeed in life. It's something that helped me be a good mom, I'm always researching things and thinking about what will help. But I think right now, the best thing I can do for myself and my family is work on mindfulness. And I'm learning from my kids in that respect. I mean, like my eight year old, she's working on some mindfulness stuff, and we went for a walk the other day, and she's like, Mom, let's make this a mindfulness walk where we just listen and feel our feet touching the ground. And we look around at what's around us in that very moment. And to me, that's not how I normally walk, I'm thinking about what I have to do, what I should be doing. And I'm also learning from my kids. And I think, you know, those are sort of just my very anecdotal things. I'm certainly not an expert, certainly not doing it perfectly every day or any day. But also just that notion of, you know, I talked about resiliency or grit, but also that notion of grace. And I say that in a very, you know, non religious way, just grace for myself of forgiving myself and those around me. I think the other big part of it for me is at night even on the bad days, I go to sleep thinking what were the moments that were my roses today. And yeah, those thorns kind of sucked, but at least I get another shot at this tomorrow. And so yeah, that's how we're getting by. It's day by day.



Judy Mark 1:00:10

Yeah for us, sometimes it's hour by hour and even minute by minute. Thank you, Allison. That was really, really wonderful. I'm going to now turn to Emma Erenmark who has developed a set of materials that we can email people. We will email it out to everyone. We will also put it on our DV website, our Coronavirus website, as well as make it available to all of those of you who registered for this. Not registered for this, who signed into this webinar using your email. You'll receive an email from us this evening. So I'm going to...Let me know when you want me to do share screen and I'll get it up.



Emma Erenmark 1:00:50

Okay. So my name is Emma. I am Judy's daughter and I am really passionate about mental health because I struggle with mental health issues as well. And I put together a lot of resources and tools that I use to get by in life, but also now during the Coronavirus outbreak. And I made a series of resources based off of my own experiences and what I felt, I know that other people around me are feeling now and other times. And so you can put it in share screen. Okay. Yeah, good. So the first worksheet that I thought was really important was focusing and separating what's in your control versus what's out of your control. And a lot of times in life, there's a lot of experiences that we go through that are

out of our control, and it's especially true right now. During the Coronavirus time that there's so much in the news, sharing on social media, and other people telling us things that are way out of our control. So to first focus on what's in your control. So hopefully all of you will be able to get these forms and that you can have space to fill out what kind of things are in your control and there actually is a lot that that if you really think about it is in our control during this time. For example, I have some examples, your thoughts and are you choosing to be positive are you choosing to be negative? And this is a choice that is in your control. Your feelings and your actions and really importantly, your daily routine. What do you choose to do and who do you choose to spend time with is totally in your control. And if you are choosing to spend your time doing things that you love, and spending time with people that you love, whether it be on the phone or in real life. And that is something that we can all do to kind of survive this time. And another part is what are some things that are stressing you out? Because there are things that may be in your control and out of your control that are stressing you or making you upset or sad or anxious. And that recognizing that is a really important and hard skill too. Sometimes when I'm upset, I'm just upset and I'm not sure what exactly I'm upset about. And sometimes it takes a little digging to figure it out. And once you've kind of identified it, it's a really good thing so that you can work on, Okay, now I know what it is, I'm concerned about getting the Coronavirus or whatever that is. So for that example, there's a lot that's in your control and a lot that's out of your control. What's in your control is staying home and minimizing the amount of time that you could be exposed. And there's a lot of things that are out of your control as well, how other people are acting and how other people are choosing to leave their house or not leave their house. So in every kind of worry there are definitely both sides. And just trying to just focus on what is in your control is a really great way to to make you feel more calm. Okay, so the next form is achieving balance. So this I feel is really, really important. That spending your day, if you are a caregiver, that it's sometimes really hard to spend time with doing things that you love and what you want to do because a lot of your time is working or helping other people in your family or your friends. But that every single day you should be doing some activities that you love and that you want to do. And do different kinds of activities every single day. So starting with...



Judy Mark 1:05:19

Emma, can I interrupt for a second? The interpreter, the Spanish interpreter wants you to speak a little bit more slowly please.



Emma Erenmark 1:05:28

Okay, sorry, sorry. So, first, I'll go over back a little bit and repeat myself. But sometimes, for especially for caregivers and as well for people with disabilities, it's difficult to prioritize

yourself because you have so many other responsibilities that you have to do in a day. But it's really really important and possible for you to have balance and for you to incorporate a lot of really important activities into your day. So, for example, first of all identifying what you enjoy and what brings you life and what makes you happy and that there are for me personally, a lot of activities I enjoy that I cannot do right now. For example, traveling, going to restaurants, even going to Disneyland. Both my brother and I as well. We love doing those activities, and we're not able to do that. But there are a lot of activities that I like to do, that I can do. For example, exercising is something that is the third bullet point that is something that Dr. Russell talked about, is something that helps me with my anxiety. And really, I think if you're someone who doesn't exercise, this can be a great opportunity to start. You have a lot of time now to exercise every day in little amounts, and every day you can increase how much you're exercising. So for example, I like running so I can still do that. And I run around my neighborhood and I make sure I don't get near anyone else. I stay six feet away from everyone else. And so that is something that you can still do and you can try, Okay, let me do two push ups today or one mile. And there are a lot of things, a lot of exercises you can do in your house as well. So I've been finding a lot of YouTube videos that have exercise routines, and things like that. Another really critical part of your day that you should be having in every day so that you can have a balanced day is bringing in support from others. So videochatting or talking on the phone with friends and family that you're not living with. That you can continue to maintain those relationships in this time is super, super important and makes you feel less alone. As well, bringing relaxation in is something maybe that most of us don't really do usually. But this can be a good opportunity to bring relaxation and calmness into our lives. And that can be... whatever relaxes you can be in this space and that is all up to you to choose. Okay, next. Am I going at a good pace now? Next is similarly creating a daily routine, because so much is changing right now. And so much we feel is...we're losing what we used to have and what routine filled up our days. But it is possible to bring a lot of routine into your life and this can be a great way of having kind of some stability. Because everything is uncertain and everything is unstable. But if we have our today, that we're going to do X, Y and Z today, and we know that that's going to happen, then that can make us feel better. And especially if those x, y and z are things that you like to do and you love to do. And doing it with others that you love can make you really happy right now. Um, so first focusing on what was your life like before the Coronavirus outbreak? And especially what did you like to do? And then thinking about how can we continue a lot of these activities and adapt them to a stay-at-home lifestyle. So for example, maybe we can't eat at restaurants, but we can go and get takeout or we can go through drive thrus. And we can still go out and eat different food. Maybe we like to spend time with friends. And that was something that we like to do. Now, we can't physically be with them, but we can video chat them and make sure that we're doing that a lot and, and making a routine out of it. Not just doing it once, but doing it a lot of times and doing it every single week or

every single day. And even traveling, maybe you can't travel right now, but you can look up virtual tours. I know that some museums are putting up virtual tours, if you like museums, or different kinds of activities like that. And it's still possible. Okay, continue. And another point is, even if there are activities that you usually don't every day, you can do them now.... Like exercising is something I did not do every day, because I didn't have time. But now I have time. So there are different activities that you like to do. But maybe you didn't have time. Or maybe watching TV is something that you really like to do. But before you didn't have time to do it every day. Or walking around your neighborhood. And there are ways to actually learn new things, and do new activities in this time. So you can continue. What is really important to me, and I also think is really hard. I've been very negative and sad this week. And sometimes it's really hard to reframe your minds and to think positively. But as long as we're trying that's important. And what's really important is to be patient and to be kind to yourself right now. Because we may not be positive all the time and that's okay. And that as long as we're going to get to it eventually and we're going to be positive eventually, that's what's important. And that we're just being nice to ourselves. Because there's so much that is sad, and that is out of our control. So we try to be nice and kind to ourselves right now. So first, like I said before, it's really important to really identify what is making you upset or making you anxious or making you sad. And you can write that down. That really helps you identify problem-solving and feeling better if you know what's going on and you know what's making you upset. And there is always, always a way to change a negative thought to a positive thought. Sometimes it's hard to do this, but there's always a way. So for example, being in quarantine is really hard. That is a thought I've had and a lot of people have had. But there is a positive spin to every thought, which is I am strong, I'm more strong and I'm a more resilient person now that I've dealt with this and that I have had this experience. Another example is it's so hard to not see my friends or my family, or my extended family if you don't live with your family. Another thought, a positive spin is that I can FaceTime them for now. And I know that's not as good as seeing them in person. But once we are allowed to see them in person, it will be even extra special. It will be so special to see them in person. So there's always a way to change a negative thought to a positive one. Now, here are some in-the-moment skills that I use that also Dr. Russell and Hector talked about, which is how to deal with anxiety or stress or sadness in the moment that it's happening. And sometimes it's really hard to do these things in the moment. I found that sometimes it's hard but that there are definitely resources that you can do. So for example breathing, we've all been talking about that. And breathing in through your nose and out through your mouth. And trying to focus when you close your eyes, when you're breathing, you're focusing on a place or on a person. Or on something that you are super happy. And that gives you a lot of happiness, and is your favorite place to go or your favorite food or your favorite person, whatever it is. That's what's in your head instead of the negative or the worries that you have. Another way, Dr. Russell talked about this, was your body and having physical exercises that can

really help you calm your body in that moment. For example, what I use when I'm really anxious, is that I clench and release different parts of my body. So that, for example, you start...there's instructions here... But you start with your bottom of the body. You start with your feet, and you clench them for five seconds and you release. And you do this with all different parts of your body and that can first of all distract you and second of all actually make your body less tense and less kind of bunched together. Another advice I have is to listen to your favorite music or watch your favorite movie. And watch especially music or movies or something that is familiar to you, and that you can rely on that you like and you know that you like. For example, going through your favorite memories. Maybe something's not making happy right now, but maybe something in the past made you happy, and you can look at pictures or look at videos. And there's a lot of meditation apps and even apps like Thought Diary that you can write down or journal. Or you can just write it down on paper, some of the things that you're feeling. Or also talking about it with someone can be really helpful. And lastly, what Allison was talking about, which is being grateful. And that's sometimes really hard for me as well too. But it's really important to focus on what you have. It makes you happy and it makes you more able to live your life if you're focused. Because we all have things and we all don't have things. So might as well focus on what we have. So these are the kind of the three main components that I believe can really be helpful and make you happy during the day, which is I've already kind of gone through this. But social time. Social time, relaxation time, and exercise time are all I think really important components to your day to make you happy. So first, social time is... A lot of this is kind of a worksheet that you can use to really put down into your life instead of just thinking, oh, maybe I'll call this person later. Okay, no, you're actually going to call this person. And that's going to make you really happy and that you're going to create a schedule where, Okay, every Monday at 6pm, I'm going to call my cousin, or Every Tuesday, I'm going to call my best friends. And these aren't just going to be things that maybe you are thinking about, but you're actually doing. As well, exercise is another really important way to incorporate and you can start with exercise that you already like to do. And you can incorporate new ways to exercise. So this is the perfect time to learn new ways. I haven't even realized how many online resources there are for exercising. There's a lot of really great YouTube channels that are free, that offer yoga classes, offer Zumba, and dance classes, and offer cardio exercise classes. So I think that it's important for - really scientifically - it actually gives you happiness. And that exercise... And especially now that we're not naturally moving our body because we don't have anywhere to go, we need to try even harder to move our body in this time. And this also has number three as a very concrete way to incorporate and to add in exercise into your daily life. And lastly, it's a similar thing but with relaxation. That if you're not someone that really takes time to relax, this is a time to start. You can experiment with different ways to relax: you can take a bath, you can meditate, you can sleep, whatever it is. You can try different things to do. And relaxation is not selfish and relaxation is really important, especially

when we're all anxious and stressed. And lastly, I just wanted to say that validating your feelings and feeling your feelings is really important and that you're not alone right now. And whatever feeling that you're feeling is normal and okay, and everyone else is feeling that way as well. And if you're feeling lonely or isolated, that is super natural, because we're all forced to be isolated right now. But that doesn't mean that you have to be socially isolated, even if you live alone or you're living with...maybe you're not living with one of your friends or family that you love. Looking at social time workshee can really help incorporate social time. But also validating that feeling lonely is really hard. And all of us have felt lonely, and that this is definitely a heightened, or a more intense time of loneliness than usual. And feeling sad and missing your old routine is okay. And I miss my old routine. I was in Spain before I came here. I was studying abroad and I had to come back. And that has been really hard to deal with and we all have, most of us have plans that we didn't get to see through because of this time. And it's a really...we all miss some parts of our life. And also the third thing is not having an end date is really hard. Especially people with disabilities, if they have anxiety or if they want or kind of need an end date, which I also need. And my brother I know, is upset about not having a day where this is all going to be over. And the nature of this outbreak is that there's no end date and that's really hard to deal with. And we all can validate that. And we all know that that's hard. And so hopefully these resources will help you. They're hopefully very practical and concrete so that you can really implement these into your life. And they have helped me over the years with different struggles that I've gone through. And I think that will be sent to you. So yeah, that's it.



Judy Mark 1:21:29

Thank you, Emma. And I just want to mention to everybody that these are fillable PDFs. So you can, when you get the PDF, you can put it...That this is the one for relaxation. We're going to meditate on Monday. And so they will be fillable so that you can use it on your computer or you can print it out and handwrite it. We also have it already translated into Spanish. And so we will have all of these available within a few hours of this webinar in both English and Espanol. So I'm going to stop sharing. Thank you, Emma. And now we're going to move to our final presenter, Nina Patel. We know on our webinars we get a lot of wonderful providers. She is the managing director of Friendship Foundation, which is a really outstanding organization in the Manhattan Beach, South Bay Area of Southern California. And they have just done a really great job of making sure that their participants are continuing to be connected even during this difficult time. And we wanted to share some ideas for all of you. Go ahead, Nina.



Nina Patel 1:22:38

Hi, thank you. Thank you for everyone who's on the webinar today. Thank you Judy for including me. We are facing extraordinary times and our team has decided to focus on community and connectedness. We think that's the most important thing we can do at this time. It's something that we have specialized in for 15 years and we thought, let's translate this as quickly as possible online. For those of you who don't know us, we've been providing access to enrichment activities and socialization activities for our students with special needs in a very socially integrated manner so that they're engaging with their peers with and without disabilities. We are in our third week from working from home. And in the very first week, we started Skype Pals, which is a buddy to buddy program where we're encouraging our student volunteers to connect with one of our buddies, one of our children, that they're assigned to, to have a quick conversation. And we are encouraging this to happen every single day. Another program that we've started - and the rest of them are really through zoom - is a yoga meditation class. We have one tomorrow, Friday, and then we have storytime. Friends storytime developed by our one of our team members with props and puppets, and a really sweet program with question and answers at the end. And then we have Zumba actually at four o'clock. Soon as we get off here, we'll have a Zumba class for our kids. I think the most important thing about all of these online classes that we started... First, we're learning we're improving day by day on how to present it so that we have less glitches, because technology can be difficult. But what we found is when our kids see each other on Zoom, they're starting to say hello. We're giving them 5 to 10 minutes to kind of communicate and chat with each other. I think our biggest joy as our team goes through these online classes is just seeing the kids communicate with each other. A lot of our friendship community members see each other every day in person at our activities, and now they can't see each other and they can't physically be there together, but they're socially there through Zoom. And you know, just the cutest things they say to our yoga instructor, like you are great, you know, and giving our team support when we finished a program. And then saying hi to each other and one checking in with the other. And I think at this time, I've talked to a lot of our parents in preparation for this webinar and asking them, you know, what's been difficult for them? What are their challenges? And I think most of you listening today, know that this is a challenge. There used to be a structure. As parents, you're also used to help. Some of our parents are choosing not to have respite because they're afraid to let people in. They're opting not to have maybe a behavior therapy or any of the other therapies inside of their home to protect the people in their home. So this leaves a lot of burden on parents. And so I asked them, What can we do, what more can we do? And of course, they've been thankful for the fact that we're connecting their kids to their friends. They're connecting to our team members that they know really well. And you know, that already is a blessing to them. The other is, they use it as a carrot, right. Let's get through our schoolwork. We'll have a Friendship Foundation Storytime at four o'clock Friday. Let's get through this. And they have something. Parents said even having half an hour to 15 minutes of time where

they're engaged with friendship communities programs allows them to have just a second to themselves. So that's been extremely helpful. We also started a friendship community Whatsapp group. And really this group is about parents communicating inspirational videos, information. A lot of great information was shared today that I'm going to go ahead and share on our WhatsApp community so that parents can access that information. The other is asking for help. Anybody in that community can post something like I need groceries or, you know, I've run out of Tylenol and my child needs some if anybody can drop that off. So we're using this as a support system as well. And then the other thing we're doing tomorrow at four o'clock, which is Thursdays at four o'clock, we're providing a parent coffee and conversation. I've invited a local therapist who does family therapy as well as child therapy. And she'll be joining the chat group and providing extra support. And other means, maybe, you know, just behavioral tools or skills. And it's just a chance for parents to exchange information. I've heard some really great things, talking one on one to our parents, like one of them said that she takes her son to do one course work online, maybe in their living room, and then the next coursework online into their bedroom, and then maybe into the front yard or the back yard. Just keeping things moving and keeping it new. I know there's a mom who just wrote in to us saying that the online isn't working for her child. You know, she's always had support. So how can we do that? So I'm hoping this parent chat that we have tomorrow will be an opportunity for other parents who are in the same boat, having the same experiences, understand what it's like for our community, and give each other tips and tools that can really be effective. So those are things that we've put together. Of course, because everything's online and moving super, super quick, we are talking to our website developer and trying to get all our classes onto our Friendship Foundation website. So anyone on this call and anyone else that you know can access our zoom events. We're providing them free of charge. And anyone can, you know, Zoom in. Parents, you know, can do yoga with us as well. We have Zumba this afternoon. You can do that as well. So it's not just for our kiddos, but it's also for our parents, and maybe parents and children can do it together or the family can do it together. So I hope all of these tools are helpful to all of you. I think it is a time for compassion. It is a time to forgive ourselves when we are anxious. And when we are stressed. I think mindfulness is probably the most important thing for us. And I listened to a TED talk yesterday and what I walked away with was, forgive yourself. And we all do the best we can on the day that we wake up, and you know, and then that's the best we can do. I'm happy to take questions...That Judy at this time, I feel like I can just provide a lot of the Zoom links to you that maybe you can post. We will continue to look at new ways to interact with our kids. And so for those parents who are just looking for 15 to 20 to 30 minutes of reprieve, please use that. I know that we're really good at providing respite when there is a physical distance restriction. But we're trying to do our best to do it online. And I...my happiest moment is when I see the kids all smiling and saying hello to each other. Doesn't even matter that it's Zumba or yoga or friends storytime, it's just the

connection. It's just pure joy to see. So if we can add a little more joy and laughter to all of you, we're happy to do it.



Judy Mark 1:30:32

Thank you so much, Nina. That was really wonderful. A lot of people are asking for your website. Could you just say it and then also type it into both the q&a and the chat?



Nina Patel 1:30:45

Sure. Absolutely. So we're at friendshipfoundation.com. And I think it should be pretty easy to google. There it is. Somebody just wrote it in. Thank you, Ed. So if you go Friendshipfoundation.com today you won't find those links on Zoon. But as of today, we've started to work with our website developer. We're hoping by Monday morning that it will be up and running. I encourage you to check in maybe tomorrow. We never know, it could be done today. And if it is, I urge you to join us for storytime at four o'clock. John and his mom are doing the readings. And it's a super cute program. And really darling. So please don't miss that if you have that opportunity. And hopefully, Judy will be putting something out as well, where I can provide those links immediately via email through Judy.



Judy Mark 1:31:44

Perfect, thank you Nina



Nina Patel 1:31:46

Any other ideas, any other ideas that parents may have that would be helpful, we will take them. And we'll see if we can implement them.



Judy Mark 1:31:56

How wonderful. So some, a lot of parents are, you know, really trying to...I think a lot of parents are feeling stressed, particularly parents of children who maybe are non or minimally speaking or who, you know, maybe they're very active. And sometimes these classes are not going to work for them. My son is now 23 years old and is much more chill. But when he was eight or nine, it is hard for me to imagine that he could have sat and looked at a computer screen and participated in activities. What are - this is to everybody - what are suggestions that you may have, you know, to keep children who are probably pretty anxious because their routines are broken up, but maybe they're too young to really understand how to think with positive thoughts or thinking...You know, some of the

worksheets, they maybe can't ask access that stuff because they're young. What kinds of ways do you think that we could help younger children to sort of deal with this disruption of their routine? I don't know Ben if you have any ideas, or Allison.

N

Nina Patel 1:33:17

I had a mom who said that you know, her son kept saying I'd really like you to call Easter Seals because that's his day program. And please, mom, just call them up. Tell them, Can I come? Can I come? Can I come? And you know, that was on repeat. Can I, can I come? And one of the parents said, what she finally did to make him understand the situation was actually get in a car and take a car ride, and actually visually show what is happening. So look, no one's on the playground and no one's on the beach. No one's on the sand. So she said using visuals helped communicate what is happening without instilling more fear. Right. Sometimes we have to be careful about instilling fear at the same time when explaining things. So I don't know if visuals help, but it did help this parent, make her son understand what is going on.

B

Ben Russell 1:34:13

We have been able to work with some younger children with remote services, as well as all ages of nonverbal clients that we work with. And you know, at first, a lot of people said, Well, this isn't going to work with my child or with my client. But we've been creative. And a lot of what's meaningful is just to be present. So one of the things you know, initially it was like, Well, let's think of activities like, try to do arts and crafts or stuff that takes preparation. And actually, that's not necessarily as helpful as just whatever somebody is doing being there with them. So if you can, you know, set up an iPad or phone or computer. And it can be mobile and go with them. Then you can put on music together, you can, you know, kind of parallel play together. Finding ways to be together to connect has been really meaningful. And, you know, we have some of our professional therapists spending hours over remote services with kids, and finding that it's been really meaningful. And they've been able to have interactions, they're able to see each other's face. Some of the kids are really interested in the screen, so they almost feel like they're getting more eye contact than usual. And you can also, if you're using zoom and you practice sharing screen, you can do things together with shared screens. We have kids that play Minecraft on the speakerphone, and then they're on Minecraft portal together and they're playing hide and seek in Minecraft. So, you know, depending on somebody's interests, you can go with their interests to find ways to use those possibly with shared screens. Music and movement are great for little kids. So going with their interests, thinking outside the box, being creative, and just being yourself.



Judy Mark 1:36:34

Allison, do you have any ideas of how you've gotten...how you've entertained your kids through their anxiety who maybe wouldn't fill out a sheet or?



Allison Buchner 1:36:44

A lot. They've watched a lot of TV. I mean, the reality is we also still do have to sort of have a little bit of survival mode in this time. But we've tried to watch movies and you know, there are like Disney Plus released movies early. There are all of these movies now that were in theaters, but that now you can see at home. And so we've been really playing up that that's something that's fun that we get to do because there were movies they were looking forward to seeing. So we've watched movies together, and we have done Zoom playdates with friends, and it's gone well. I mean, it's, you know, sometimes they're focused, sometimes they're not. And I think just letting them be super honest. And like, if they're not, and they just keep putting the phone down or walking away. Then it's, you know, they're just being honest. We also, we are fortunate that we have a pool so that has been like a saving grace for us. They've gotten to swim. But exercise during the week has been a struggle, because we see a lot of extra energy. And so I've been doing like, some cosmic kids, which is a fun yoga thing online. We've been doing that with, at least with my eight year old. And then just kind of minute-by-minute figuring out something else.



Judy Mark 1:38:01

Yeah, I know we're taking it minute by minute. If those of you who have questions, please put them in the Q&A or in the chat. While we're waiting for more questions to come in, I wanted to share the information that we are looking forward to get from all of you. So Disability Voices United is doing a survey and it's already been published. So at this time, these are the questions we're asking. If you look on your screen, we also can send you directly the link. You go to tinyurl.com/dvucvsurvey. DVU is Disability Voices United, CV is coronavirus. We have surveys in both English and Spanish. This is for people with disabilities. of all ages, all disabilities. And we are really trying to get thousands of answers not just hundreds of answers, but thousands of answers so that we can really get a sense of what is happening on the ground. And then we as an advocacy organization will bring that information to the state agency, or the National Agency that cares about this stuff or that's supposed to care about this stuff. We ask questions about school, education, we ask questions about support. We ask questions about whether you feel like you are not going to be able to feed your family or you're not going to be able to keep your job or make your rent. Or if you face discrimination based on your disability or your ethnicity or race in receiving health care. So we really want to know - this is an anonymous survey. Although you at the end are able to get onto our mailing list, but we're not going to release any

individual answers. We also have created a Coronavirus resource website that we've talked about. So you will see the survey, you will see there are previous two webinars, as well as all of our...Every time we get a new set of information, we immediately put it up on that. I feel like we're keeping it up to date on a regular daily basis, so keep looking at it. And then if you want to join our mailing list, visit tinyurl.com/joinmail to get on our mailing list. Or click on the link - or copy and paste from the link that's in the chat. You can't actually click on any links in our chat. So I'm now going to go to some...I'm going to keep this up on the screen for just another second and go into and see if we have any more questions coming from folks. How do we prove that we were part of this webinar was a question. I would suggest that you join our mailing list. And that is the best way to ensure that you receive this and make sure that you get your Constant Contact emails, just what our mailing program, so it doesn't go to your spam. Let me go to some of the q&a because a lot of folks asked some questions there. Um, there were a lot of questions for Victor. Victor was had to pop off the call, but he did actually answer a lot of the questions that you posed to him. So my suggestion to all of you is to go to the Q&A, which I believe you will be able to do, even when you see this recording. But we, you know, we want to make sure that the people know that you have people to call. You should not feel alone in this. I mean, if it's in mental health, you saw the resources that Hector gave you. If you were not able to get services that you need for your school district, you should be advocating with your elected officials. Elected school board members are there to represent you. And you should be calling their office and saying, my child has an IEP and and is supposed to receive services, and he or she is not. And you should be asking for these services from your elected officials. With your regional center, as Victor was saying, if you are not getting the services you need to support you because your services have been interrupted. Let's say your day program shut down, you should be able to get these services from your regional center. And if they are not giving it to you, then you can go to the Department of Developmental Services, the state agency, DDS. And they are providing what they're calling technical assistance, which means they'll help advocate to get you what you need to keep you safe. The other point that I really wanted to make today is that particularly for those adults who are receiving services through a day program, we are hearing that many day programs are closing up shop, because obviously being in a kind of congregate setting with a lot of people together is not the safest thing to do. So we understand that. However, that day program is is required to to continue to provide you with services and to provide that adult with supports. That could be anywhere from coming into their home and providing one on one services. It could be if you choose not to have somebody in your home, it might be to do your grocery shopping for you. I mean, you would have to pay for it but they could pick it up for you. To pick up your prescriptions, to create social stories ,or fill out some of these worksheets with you that Emma presented. To fill out - last week at our webinar, we talked about health care, sorry, emergency planning in case somebody in the household becomes sick with

Coronavirus. They can help you fill out your health passport, your emergency plans. You should be demanding that your service providers continue to provide you with services even in a remote way. By the way, they can also take you on physical distance walks. You can meet them outside and be six feet apart and walk through your neighborhood. So there's a lot of services that you can continue to get even if you don't want them to come directly into your home. And just providing that little bit of routine to the adult to see a familiar place face, I think is really critically important. I'm looking for more questions. And I am not seeing.... Oh, somebody who's working for a day program is trying to provide remote services. I mean people should also be in a remote - I mean, they can be providing one-on-one services, and I can promise you that regional centers will approve that. I'm just looking to see if there's any more questions. People are suggesting that you sing songs to learn how to wash hands. I believe that we've really tried to answer all the questions and if you feel your question wasn't answered, go into your into the q&a and go up to answered. And the questions were answered probably by Victor Lira. So I just want to give our - first of all thank our panelists for their incredible presentations and just wanted to see if any of them have any kind of last words of wisdom for our incredible amounts of people. We still have over 340 - we have 342 people still on this webinar, so that that shows that there's a lot of interest and you've obviously kept their interest up. So does anybody have any kind of finals to make people understand that we're not in this alone? Go ahead, Hector.

H

Hector Ramirez 1:46:42

So this is Hector. So thank you for having me and everybody here today. One of the things that I want people to know as we deal with healthcare and take care of ourselves: advocacy is also part of healthcare. And a lot of you might have a little bit more time at home. Some of you not as much as others. This is a pretty good time to pick up the phone. And really like Judy said, call up your city, your council, your state and federal representatives. And you know, demand more action, especially for the disability community, for your family. Right now more the ever, I think this is a time where those elected officials that are making policy decisions need to hear from us. Need to hear from you as providers. They're so flooded by a lot of demands right now to make decisions. And I worry sometimes that they're not really listening, especially in this crisis, to the needs of our disability community. So I think more than ever, literally, this is where we have to speak up for our lives and for the lives of our loved ones. And that - that's also part of my routine. So part of what I do in the morning is I send my governor an email, I send my mayor an email, I send my Counsel Member an email. And they've gotten to know me, and I let them know what my concerns are. You know, it's important, you know, for people in a variety of localities to hear us now more than ever. And that's something else that is keeping me going. You know, it's given me an extra purpose, and a sense of power. And I

really want folks to empower and realize that they have more than ever at this particular platform. And I just, I wish everybody you know, love and take care. In Native American community, we have a saying, Mitakuye Oyasin. And that means that we are all related. In the disability community more than anything, that's really the case right now. So thank you.



Judy Mark 1:48:46

Thank you. Anyone else want to have any parting words before we sign off? Alison?



Allison Buchner 1:48:54

Just saying thank you. I'm happy to have been a part of this. And thanks for all the great resources and thank you for putting together



Judy Mark 1:49:02

Thanks, Allison. The kind of final thing that I said about the day programs people are asking about. You all should know that you should call your regional centers, and your regional centers truly understand that day programs should still be providing these services. I know that they do. We had a session last week about this, or webinar last week where the head of the Association of Regional Centers specifically laid this out. And so if your regional centers are not advocating for you to continue to receive services from your day program, then please contact DDS. If you go to the DDS website, it's DDS, like Department of Developmental Services: dds.ca.gov. They have a whole section on Coronavirus. They have been really up to date on the latest information. And there was an email address and a phone number that you can call and ask them questions directly and get their support. So thank you all again for participating. And once again, we will make this available to everybody online, both the Spanish translation as well as the main video webinar. Thank you all again. Take care and love yourself and love everyone around. Bye



Ben Russell 1:50:28

Thank you. Bye bye.