



Staying Social Inside and Staying Safe Outside: Ideas for Ac...

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SPEAKERS

Lorna Silva, Amy Westling, Isita Tripathi, Kavita Sreedhar, Judy Mark, Ann Turner, Joseph Meadours, Brianna Doherty, Ed Hirtzel



Judy Mark 00:02

Welcome, everybody to our webinar. We're just going to get started and allow the participants to come in as well as we're going to get started on Facebook Live. So hold tight and we'll be with you in a moment. Welcome, everybody, we're just assembling so please hold tight while everyone gathers. Hi, everybody, welcome. We're streaming live now on Facebook as well as on zoom. And just to let everybody know we will be recording this particular webinar. We're gonna get started. We're gonna continue to allow people to follow us and then we will get started in about 30 seconds. Thanks, everyone. Welcome everybody. My name is Judy Mark. I'm the president of Disability Voices United, which is an organization directed by and for people with disabilities and family members. We have been holding weekly webinars since March 19th. So this is like our 1,000,000th webinar, or at least it feels like our 1,000,000th webinar. We have been quite active in this space of representing the disability community in, around Coronavirus advocacy and really want to welcome everyone. This webinar will be recorded, and it will give everyone a chance to ask questions through the chat. But before we move forward, I want to let those people who need Spanish interpretation know how you can access that Spanish interpretation through an outside line. So I'd like to introduce Lorna Silva, our fabulous Spanish interpreter to speak in Spanish and let folks know. Go ahead, Lorna.



Lorna Silva 02:44

But unless personas que necesita interpreter Susie Moulton espanol jamming and cinco cincuenta you know those cuarenta UNICEF anti-trade Yes Then well, cinco cincuenta uno dos quarantined into you know sis antitrust DS no se necesita codexes graphes Thank you.



Judy Mark 03:01

Thank you. So welcome everyone. Today's topic is called, um it's part of our series that we're holding. This is our third one, around opening up in a pandemic, the perils for people with disabilities. This particular topic is called staying social inside and staying safe outside: ideas for activities and human connection during the pandemic. Two weeks ago, we had a town hall meeting of individuals and families telling us how they feel about the re entering the reopening the re engagement. These are all things that DDS has been calling the the reinstatement of group programs and how people can start accessing services and I've been very frustrated hearing the discussion about it because they keep saying, oh, we're re entering them. People want to restart their services. But there's been a whole bunch of providers, some of whom are on the call today who've been providing services all the time, particularly those in supported living services, who have had to take a huge amount of additional work, because many of the individuals they support, go to day programs or to employment during the day. And so we want to do a major shout out to those those workers who have been out there on the front lines every single day. We have some really amazing presenters. But before we do that, I wanted to tell everyone how you'll be able to engage with us on the webinar today. There's going to be two ways. The first way is that if you have any questions about the technical issues around zoom, you can put that in the chat and our wonderful program assistant Ed Hirtzel will respond to you. Or if you have ideas that you just want to share with people, put that in the chat. If you have a question or a comment that you would like me to read to the presenters today, you should put that in the Q&A. And the way you find Q&A is by going to the bottom of your screen and clicking on Q&A. And that is a way that I can really focus on what your questions are. And once they're answered, I put them into the answered section. And it's a way that I can make sure your questions are answered or comments are read. If you put it in the chat, it goes by too quickly. And I will probably not catch it. So please make sure to put it in the Q&A. We're going to be discussing a lot of things today that you might have questions on. I've already I actually just got one a whole set of questions about participant directed services emailed to me right before this call, so we we are already getting started with that. So let's get started with our webinar and I want to introduce our amazing intern yes we have a lot of amazing people today I keep using these these superlatives. Our amazing intern Isita Tripathi who is a just recent few weeks old graduate of UCLA and she took my class at UCLA and is now interning with Disability

Voices United. She's on her way to medical school next year and is working with us on a number of projects in particular how people with developmental disabilities interact with the healthcare system. And she and our organization have produced a tip sheet that we will make available to everyone through our Coronavirus website, which we will put in the chat if you don't know it, but it's DisabilityVoicesUnited.org/cv CV for Coronavirus, and we will have it up there. But we wanted to share this, this tip sheet with you that you can print out and bring with you to doctor's appointments to the hospital to emergency rooms if needed on how to treat patients with developmental disabilities from the perspective of people with developmental disabilities and their family members. So Isita take it away and I know she's gonna show you something on her screen.

I Isita Tripathi 07:40
Okay, so can you can you see this alright?

J Judy Mark 07:42
We sure can.

I Isita Tripathi 07:43
Okay, awesome. So I'm very excited to share this resource with everyone today. So as Judy mentioned, we've created a tip sheet for healthcare providers that encompasses general practices for interacting with people with intellectual and developmental disabilities. And this was created based on input from self advocates and family members in our organization. So I'm not going to go over the specific tips here. But it generally includes topics like presuming competence, making accommodations, adapting communication styles, and many more. But a lot of healthcare providers don't specifically get training in working with the population. So this is a really quick resource for them in emergency situations, surgery centers, or even in regular health care visits that we're hoping will help improve the quality of interactions. So on our end, we're going to be sharing this with--

J Judy Mark 08:27
Isata? Yeah, I'm sorry to interrupt First of all, can you just slow down a little bit for our interpreter? I'm the, I'm the worst. I talk very fast. And could you make that your full screen by clicking the right, the green button? And that way, we'll be able to see a little bit bigger possibly green button on the left.

I Isita Tripathi 08:49
I'm gonna have to drag, oh this. Yes, yes.

J Judy Mark 08:53
I think that might be a little bigger. Well, maybe not. Maybe you can zoom in. I just think it'll be easier for people to see. There we go. Perfect. Thank you.

I Isita Tripathi 09:02
No problem. All right, so, um, where was I? So we will be sharing this with hospitals, doctors, and administrative staff and working on increasing training and awareness from our standpoint. But in the meantime, we really recommend that all of you bring this with you to any of your health care visits and give it as a preliminary document when you're checking in, you can just say something along the lines of I have some materials here that I would like the doctor and other healthcare staff interacting with me or my child to quickly review and this might help them better understand my preferences for communication and care. So we also recommend attaching this to the healthcare passport. And I'm going to switch over and show you guys that. This is already on our Coronavirus website but will re upload it attached to this webinar for you guys as well. So this is a quick resource that you can fill out that just shares your preferences for communication, your medical history, what medications you're taking. And so there's many different versions of this online. But we believe that this is the one that's most person centered and empowering. So this is going to be uploaded on our website as well. So if you bring this along with the support document that we've created, we're really hoping that that will help the staff better accommodate you and support you throughout the visit. So yeah, these are just really some quick resources. And if you have any questions, let us know and we can answer any concerns you may have about these tools.

J Judy Mark 10:30
Thanks, Isita. That's great. And so we want people to understand as you are interacting with the healthcare system, and I we know that that's not what this whole topic today is about. But because this resource has just become available, we wanted to talk about it, especially as coronavirus cases are radically and rapidly increasing in the state of California. We wanted to make this resource available to everyone and that you have these, this health passport filled out in advance, do it while nobody's sick, do it while everybody's okay, so that if you were in an emergency, you can have literally have it printed out. It's part of anything that is in your purse, in your pocket in your backpack and

you can bring it with you into a healthcare setting, whether it's a doctor's office, an emergency room or a hospital. And so speaking of hospitals, I want to introduce our next presenter, Brianna Doherty, who is a PhD in something really smart like neuroscience that I can barely understand. So we already worship you, Brianna, but she's also a medical student at UC San Francisco, a really incredible med school, where she's focusing on developmental disabilities and mental health and she's also created a really great tool that you all could use as well as has some general advice from a medical perspective. So thank you and welcome Brianna.

- B** Brianna Doherty 12:08
Hi, thank you for having me. I first wanted to say I apologize for wearing a mask. I'm actually working in the hospital right now. And so I'm required to wear a mask at all times. So I hope that doesn't, I hope that you can still hear me and understand me okay. So let me share my screen. All right, can you see that full screen?
- J** Judy Mark 12:40
Yes, we can.
- B** Brianna Doherty 12:42
Great.
- J** Judy Mark 12:44
Well, actually, we're seeing you if you could start the slideshow, it's probably best.
- B** Brianna Doherty 12:49
Start the slideshow.
- J** Judy Mark 12:51
Yeah.
- B** Brianna Doherty 12:53
Is it not happening?



Judy Mark 12:54

Yeah because we're just basically seeing the presenters view, so go up to slideshow and then click down to start. And then say from beginning



Brianna Doherty 13:09

that's what I had then.



Judy Mark 13:12

For some reason we're seeing it or you might because you probably are doing it through presenter, but it's okay. We can still see it. It'll work.



Ed Hirtzel 13:18

Brianna, you may need to this is Ed Sorry, I'm the admin sort of this. I helped Judy, with the that side of things. If you could go to the share screen, but you may have to Yeah, there may be the full screen view somewhere in there that you can select would be my best guess.



Brianna Doherty 13:38

Okay, I apologize. I haven't done this before. So maybe if I just do the screen, share the whole screen like that. You can see my whole screen.



13:53

And then that's not it.



Judy Mark 13:55

Yeah, perfect. Got it.



Brianna Doherty 13:57

Does that work? Okay. I apologize for that. Okay, um, so I'm going to be talking about the state of the pandemic and where we can go from here. So I have to say upfront that I borrowed some material from Dr. Clarissa Kripke, who has spoken on other webinars. So some of this material may look familiar. So how does a pandemic end? So the first option,

and to be very blunt is it continues until everyone susceptible is infected. If getting infected makes people die or become immune, it will eventually peter out. And the problem with this option is that there are 8 billion people in the world and that's a lot of infections and millions of people will die. Additionally, if getting infected doesn't make people immune, it won't peter out even if everyone is exposed, and more research needs to be done. But recent data is suggesting that immunity after infection is not lasting as long as we would hope. So we clearly shouldn't rely on this option. For the second option, we contain it with testing, contact tracing and quarantine. So this is what many countries are doing at the moment. Getting the numbers very low, so that it is practical to find every case and make sure it doesn't spread. However, in the US, we currently don't have enough political will or leadership to make this happen outside of a few communities. And the third option is it becomes endemic, like the flu and we learn to coexist with this virus in the long term. So where are we in the US? As you can see from this image, we are not on the path to control. We're on a path to having to adjust our lives to living with community spread at COVID because it's not being contained. The direction that the US is heading now will not only, will, we will not be able to go back to our old lives for the foreseeable future. So we're going to have to figure out how to make our lives manageable and productive without getting exposed to COVID. And this is going to go on until there's a vaccine or a widespread treatment, which some people are predicting may take years. So what did the data show about the intellectual and developmental disability community? Again, there's much more work that needs to be done. But the data that we have suggests that people with intellectual and developmental disabilities are getting infected and dying at higher rates. And those living in large group settings and institutions are at more risk. And there are many structural factors at play here that will be important to unpack moving forward. So given the state of the pandemic, assessing the risk level of everyday activities is going to be a daily reality for all of us. So it's important to understand what are considered low, moderate and high risk activities. So I will outline general guidelines. But it is important to note that risk assessment is by nature a personalized process and must take into account each person's individual circumstances. So, sometimes there are extenuating circumstances that require engaging in higher risk activities, and if so, we should be thinking about how to minimize that risk as much as possible. So, with that caveat generally speaking, low risk activities include virtual programs in your home, packets of materials sent to your home, hiring people who are already within your household to be a service provider, or adding an aid to your household if you can offer them housing so they can become a part of your household. And moderate risk activities include having one to two staff come into your home on a daily basis and take you out into the community via private transportation. And to minimize risk in this situation, it's important to give staff as many hours as possible to make it as close to a full time job as possible. Because the more clients that staff have, the more risk is involved. So try for as much staff continuity as possible and use precautions

such as masks, distancing, disinfection, ventilation, and utilizing outdoor space. It's also important to make emergency plans when engaging in moderate and higher risk activities. And for more information about that the DVUs excellent webinar on emergency preparedness planning has great resources around that. And then higher risk activities include having transportation come and, outside transportation come and pick you up and take you to a day program where there are groups that congregate indoors. So when thinking about risk, it's important to keep two things in mind. So first indoor activities are higher risk than outdoor activities. And if you have to be indoors, ventilating this space as much as possible by opening windows and doors helps reduce the risk. Second, the number of close contacts you have is important. So a close contact is someone you come within six feet of for 15 minutes or more. And close contacts include people you live with, the staff in your home, transportation assistance, and aids. So higher number of close contacts, increased time in close contact with any one person, and closer interaction with any one person including bathing, grooming, toileting, transferring, all increase your risk. Additionally masks, symptom screens, temperature checks, and disinfection definitely help but do not eliminate the risk. And then the last step of any risk assessment is thinking about the consequences. So what happens if I'm exposed to COVID-19? This is an important question to ask because per the CDC, most people with intellectual and developmental disabilities are at higher risk of becoming infected. And if you become exposed, you will be told to quarantine yourself for 14 days. You may also get sick or you may infect your family, your peers and the support people that you rely on. And if you have underlying medical conditions, or are older, you're at increased risk of severe illness. Given this information, I'm sure a lot of you are wondering, Well, what can I do with minimal or no risk? And this is a question that all of us are asking ourselves right now. And many people are coming up with incredibly creative ideas. So these are just some ideas here. But there are many more. So setting up a regular FaceTime call, making treats and art to deliver to friends, having a dinner party where each household cooks one course and delivers it to the other, and there are many, many more ideas. And then another question you may be asking are what are safer alternatives to group settings, and some of these I already mentioned, but this includes hiring household members to provide services and having a single consistent aid or a small team of people to provide services in your home with precautions, meeting one to one outside and uncrowded place with precautions, taking drives, doing window and drive by visits. So these are all, these are all lower risk activities. And then finally, since it isn't realistic to think that we'll be going back to our lives as they were for the foreseeable future, I think now is an opportunity to imagine something more individualized and included. So don't forget this can be a time to participate in disability advocacy or political activities, build new skills, such as educational, vocational, service, and or volunteer activities and engage in inclusion and participate in activities with non disabled people. And importantly, you shouldn't have to settle and you don't have to stick with the same providers if they're not adapting to your

needs. So programs should adapt to your needs, not the other way around. So I look forward to seeing the creative inclusive solutions we come up with as a community. Thank you.



Judy Mark 23:04

That was wonderful. Thank you. That was really, really great. So, there's a few questions that have come in specifically for you, Brianna. And I know that Brianna is right now on call at the hospital. So there's a chance she's going to need to run off and hopefully, I don't know which which service you're on right now. But you're delivering babies or what are you doing today?



Brianna Doherty 23:28

I'm in the neonatal ICU.



Judy Mark 23:31

I knew there were babies. Yeah, yes, you're gonna go hang out with cute babies that need your help. So, I'm going to, I want to ask you a couple of these questions now. But then if you're able to stay on or come back, please do because generally, what we found in our previous webinars is that whoever the doctor is on our webinars always gets a huge amount of questions. So let me ask you a few right now. There, is there a way, is there a way to get a printed list of measures to minimize risk like more hours for one staff member hiring someone already in a household? I do not know of that list, although that's a really great idea that maybe we can work with you on Brianna? Have you seen a list like that?



Brianna Doherty 24:23

I have not. But that's a really great idea. And I'd be happy to brainstorm some things and put together something. Yeah.



Judy Mark 24:30

Okay. That's great. Um, Irene is asking, Is it really safe to share cooked food between households?



Brianna Doherty 24:40

That is a great question. And, you know, a lot of this you know, we don't have the data

that's specifically asking that question. And, but from what I have seen, I feel like that is a safe activity. If you you go and you leave it you know, it's cooked. It's been cooked. You know, you can kind of some some people have recommended disinfecting kind of the outside or anything that you might be touching. But I haven't seen anything that's advised specifically against that.

J

Judy Mark 25:15

The research that I've seen and maybe you can verify it, um, when it comes to food, is that zapping it in a microwave for even like 30 seconds destroys any kind of bug that exists on food. And so I probably not salmonella, but but this kind of fish. Um, so. So certainly if you're taking food from another source, transferring it into your own cooking equipment or your own plate and then putting it in the microwave for a minute is certainly very, very safe. Wouldn't you say? That it's the same as getting takeout food.

B

Brianna Doherty 25:52

You know, and with most things, I can't tell you that there is zero risk, right? And that with many activities that we're going to be engaging in I can't say that there is zero risk, but you know, there's low risk. Yeah, yeah.

J

Judy Mark 26:08

Um, Arianna's asking and I don't know if you know anything about this, but that Japan has, has been keeping numbers very low on COVID. And do you know what it is they're doing? I mean, they're not the only country, there's a number of countries that have been able to keep their, their numbers low. What are they doing that we're not doing?

B

Brianna Doherty 26:30

Sure. And, you know, I can't say for any one country in particular, but I think in general, like I mentioned, the countries that have been doing particularly well have been those that you know, that had shelter in place or quarantine early and had people who sustained that practice, and then also instituted early contact tracing, to to get a handle on like early testing and contact tracing to get get a handle on who was infected and who their close contacts were to try and minimize the spread. And so those are the general principles that countries have been using, but specifically for Japan.



Judy Mark 27:10

Yeah, you know, and just for me to comment on what's going on in LA County, which is really driving the numbers in the state of California up is that things are completely out of control here. I can just tell you living here, there is absolutely no contact tracing happening. My friend got COVID two weeks ago and never got a contact tracing call. There is also no enforcement of masks, there's no enforcement of on restaurants who are incorrectly, you know, their masks are down to here. And they're not wearing the face shields which they're required to do. So you know, we cannot count on other people doing the right thing right now, which is scary and sad. And that means that we have to do the right thing. And this is not going to go away anytime soon as Brianna said, and so we don't want to scare people, but we want you to be in reality based in reality, which is why we're here to offer ideas. Because this is an idea for the long term, things are not going to reopen in the way they were for a very long time. Certainly not till next year and maybe beyond. And so we need to come up with ways to stay connected to each other and to stay happy as happy as we can be. Um, so what I'm going to do is I want to go on to our next speaker Brianna, I think you may have another half hour with us. So I might come back to you with a few more questions.



Brianna Doherty 28:40

Sure.



Judy Mark 28:41

Um, thanks so much. So now I'd like to introduce our next presenter Amy Westling. Amy is the executive director of the Association of regional centers and a multi multi time presenter for us and we so appreciate your time with us. And I've asked you to really talk about all the opportunities that exist through the state that regional centers are given a lot of flexibility in providing services to folks, and particularly around participant directed service. So go ahead Amy.



Amy Westling 29:13

Yeah, thank you so much. And every time I hear Judy, or someone else give a realistic point of view about how long it's going to be before we get back to life as normal, I it kind of makes me reconsider everything I am going to say. I think, you know, when these webinars started, what, three, four months ago now? You know, it was okay, what are we going to do in the short term? What are we going to do to kind of bridge some gaps while we wait for life to get back to the way it was? And we're beginning to see through the

comments that Judy made but also through what Brianna was discussing, that there's going to be some permanent changes in our lives. And so things are starting to pivot to think about more: what are those permanent changes going to look like? And how are we going to continue serving people? One of the great things that happened as a result of the pandemic was that the Department of Developmental Services issued a lot of guidance that gave regional centers a pretty wide amount of discretion in terms of the services and supports they could provide. Pretty early on regional centers began to say, Okay, if people are no longer going to day program or work or school or daycare, then you know, I think the initial response was let's see what we have in our toolbox now and offer people more respite or personal assistance. And then we got to a place where we started thinking about, how can you know some of the non residential services be provided in a different way. So you started seeing more remote service delivery, or you started seeing perhaps some day service providers bringing people food from food banks and doing those kinds of things. But what we heard from families and really just want to commend all the family advocacy that goes on in our state, was that there was still the need for another solution. And part of that came from as Brianna was discussing, you know, one of the ways that we know that we can help to keep people the safest is to limit the number of people they interact with. And so even though service providers may have been willing to come into people's homes, there were a lot of families that said, You know, I really at this time, want to make sure that I'm keeping myself and my family kind of in a closed network, not in a negative way. But in terms of I want to control, you know, certainly the degree of social access that that I have, that my child or family member with a disability has, just trying to keep that network pretty tight. And if you think about it, these are things that we all kind of did or the people that were being responsible about this, right? You know, I have lots of friends that I haven't seen in months and months, I haven't seen my grandma in for months, those kinds of things, because we made those decisions about how to make everyone's social network, particularly for those people who are vulnerable, smaller. And one of the things that we heard from families was that they wanted an option to have services continue to be provided. But they wanted the provider to be someone that was either in their family or in their close social network. So a very close family friend or an extended family member, maybe who lives with them even. And so the way that this was addressed by the department was through what's called a directive. And basically what that means is that Nancy Bargman, as Director of the Department of Developmental Services, has the authority to make some temporary rules to allow people to have greater levels of health and safety and to allow people to have greater access to services during this time. And one of the rules that she issued in her directive, dated March 30, I believe, was around participant directed services. If you think about our system and kind of where we are, many of you, I'm sure are familiar with the concept of the self determination program. And you're familiar. Thank you, Judy. And you're familiar with the concept of the traditional service model, where you know, where you access services through the

regional center who contracts with service providers who provide staff to provide your services. Participant directed is sort of in the middle of these two. And it really is, provides the opportunity for families and for self advocates to access services, defined services based on their needs, but to plug in friends or family members or somebody else that is well known to the family into actually providing the service. And this isn't a new concept in our world. In fact, in every day, just kind of the lanterman Act and the regulations, we operate under this, there are ways to do this for respite, daycare, transportation, nursing, and day services to a degree already, but there's lots of rules about how each of those works. So for example, in nursing, you can self direct or participant direct nursing services, but the person still has to be a nurse. It just allows you to hire someone who's outside of a nursing agency to provide a nursing service. So there's lots of rules about how these things work. But for three more services during the pandemic, the department has said that you can use participant directed services and those are independent living services, personal assistance, and supported employment. And so that allowed people to access these services by selecting someone who was over the age of 18 and say, and that they believe could do the job and connecting them with what's called a fiscal management service. So somebody that's going to make sure that the payroll and the workers compensation and all those things are handled. And then that person can provide the service that maybe you would have had an outside person providing to you previously. And some of this is being driven by like I said, families wanting to kind of tighten up that social network a little bit. But some of it is also being driven by in the early days of the pandemic, there maybe were times were, particularly in the supported employment world where we had People being supported by regional centers, who worked in essential functions, essential jobs. So they worked at grocery stores or they worked at Target. And what we saw happening to some degree was that, at times their support workers who had worked with them on the job site, weren't able to go do that with them. Maybe they had their own children at home, who all of a sudden didn't have school, or maybe they didn't feel safe going into those work settings. But we didn't want people to lose jobs. So we wanted to make sure that there was a mechanism to make sure that they could still get the support they need, because nothing would be worse than during a pandemic that then leads to a recession for someone to lose their job and their well paying job at a grocery store, because they didn't have the support they needed. So that was really the intent. And we've seen that through this time, I think one of the things that we've talked about for a long time in this system is that services need to be flexible, and they need to be built around each person's needs and the needs of their family. And we've really seen through participant directed and remote service delivery and some of the deliveries of activity packets and some of the food delivery and all those kinds of things. we've really seen how true that is that each person's needs are going to ultimately drive what services look like. But we also understand that each person's needs aren't going to be the same today as next year or six months from now or even next week. And so as those needs change, we need for people

to let us know, let the regional centers know what the need is now, what's the new emerging need? Like I said, in my family, I thought, Oh, we can ride this out for a couple months. And now we're starting to see in, you know, in our own lives, the changes that are going to be needed because it appears this is going to be a much longer term situation.

J Judy Mark 39:24

Thank you, Amy. There's like 20 questions for you already. Brianna, I just want to I just want to go to you real quick, to see what your time that you need to leave, do you need to leave by three?

B Brianna Doherty 39:38

I'm going to leave at three and then and just make sure that everything's okay. And then I might come back.

J Judy Mark 39:43

Okay. So, there's been a couple of questions that have come in that I'm just going to throw to you and then I'm going to go to Amy for the questions that she's gotten. Um, okay. So um, would you say that there are, Are there any preventive measures that you've seen that people can take like types of food that they consume or hot tea that is proven to combat COVID?

B Brianna Doherty 40:13

That's a, that's a great question. And not that I have seen, you know, there is no, ther,. There's only one FDA approved medication for COVID. And it's just recently been FDA approved and it's for very, very severe illness. There's no preventative medications or anything like that, that I've seen that's been FDA approved.

J Judy Mark 40:36

I'm glad that this person asked this because I have seen on Facebook the same kind of myth that keeps recirculating where people say if you rinse with saltwater if you take this specific set of vitamins, supplements, I mean they have this whole cocktail of things, you will definitely not get COVID and I would love for you to just explain how not true that is.



Brianna Doherty 41:07

well, I mean, for for those sorts of things, you know, usually to have the standard of evidence that we need to be able to do those things you have to go through trials you have to do and to be able to prove that something has had that kind of benefit or that has that kind of effect did not none of those trials, none of none of those things that I am aware of have been studied. And, and off the top of my head. I can't think mechanistically of how that might, how that might help. But, but yeah, the at the end of the day, there's no FDA approved or no studies that I am aware of that have have shown anything that has any preventative measures like that.



Judy Mark 41:50

So I'm going to say that's not to say that people should not be doing things that can help boost their immune system, and to not be in, if it's possible, the categories that make you more likely to have a poor outcome things like controlling your, you know, we know that people who are morbidly obese have poor outcomes. So maybe this is a good time to eat super healthy, and to exercise which boosts your immune system. So, so I mean, would you agree that people should be focusing sort of in those areas? Quit Smoking is a good one.



Brianna Doherty 42:26

Absolutely. I mean, you know, the CDC has said that there are, you know, they have a list of chronic medical conditions that they say, you know, make make individuals more prone to getting really sick when they get COVID. And so it's really important to manage those medical conditions and make and talk to your doctor and, and make sure that you you are managing those medical conditions to the best that you can. And for many of those medical conditions, just the general advice of, you know, eating well and exercising, helps your health in general and, you know, I think most doctors would recommend that for anyone and everyone. Yeah.



Judy Mark 43:04

Great. All right, thank you. And then somebody's questioning whether it's safe for them to send their son to a one on one swim class, where the instructor is wearing a shield.



Brianna Doherty 43:17

I saw that question and that's a great question. And to be honest, I I'm not sure about

swimming. I know that most I think public all public swimming facilities that I'm aware of have been closed. And and and I'm not sure if that's just because you know, they don't want people congregating or if there's something about swimming in the water in particular that could be, that could be dangerous. I I don't know. I haven't heard anything to that effect. I'm not aware. I can look it up. But off the top of my head, I'm not aware.

J

Judy Mark 43:47

Yeah, um, you know, I, I, I can tell everybody so I have a son who's a 23 year old with autism and we, my son does not have swimming lessons but he has a trainer. It used to be in a group setting but now it's a one on one who comes to our backyard once a week, who is has a mask on and stays six feet away from my son outdoors. And so I believe that that is safe. I've read I've heard from others that that is a safe activity. You know, the swimming, I would say if if the child who's in the pool is safe, if somebody is six feet away from them, then that is a safe activity. But if it requires that swim instructor to be on top of them, it becomes less safe. So the closer you are, the less safe it is. So you have to take those into account.

B

Brianna Doherty 44:38

Now again, it's a matter of like I mentioned that kind of general principles of outside is better than inside. And and you know, distancing, minimizing your close contacts is really important. So if you can participate in activities that are outdoors and minimize your close contacts then that that's a lower risk activity.

J

Judy Mark 45:01

So um, for those a number of people joined us late and so we I want to let everyone know that Brianna has done this really incredible risk chart. It's kind of an infographic that is a really good thing and that we will also make available we make her whole presentation available on our Coronavirus website starting probably tomorrow. And but that particular document I, we're gonna have, you know, get out in our social media as well so that people can understand what it means to be in a high risk activity versus a low risk. But sort of the last question for you, is it a little bit of a repeat of what you said in your presentation. Is a person with intellectual disability and hydrocephalus and higher risk to get affected and any recommendations to prevent risks of getting infected with COVID-19 when going out in the community? so Mario is asking that, that was covered and we are recording this, this webinar so you can go back and watch That, but just to quickly answer that question.

B

Brianna Doherty 46:03

It's really interesting. So when you look at the CDC website, you know, they say having an intellectual or developmental disability in and of itself does not make you higher risk. But then they do they do then kind of go through and list different things that might make you higher risk that really overlap pretty pretty closely with intellectual and developmental disabilities, which includes having mobility issues, or having, having difficulty communicating. And so the CDC hasn't gone so far as to say, you know, intellectual and developmental disability in and of itself is a high risk category. But many of the things that associated that are associated with intellectual and developmental disabilities, makes people at high risk, and that's why I said most people with intellectual and developmental disabilities.

J

Judy Mark 46:53

Absolutely. And I'm gonna I'm going to go to a bunch of questions that came in for Amy, and then we're going to move on to our next presenter. Um, so, Amy, Rachel asks that some people who are not yet able to use virtual services remotely, yet might be able to do so if they have the right training/app/hardware supported program, you could access it, what assessment services are available or support services are available to help people figure out what works for an individual. Have you been hearing anything that regional centers or are funding for this? This is this I actually just heard this come up last night at another meeting I was in.

A

Amy Westling 47:38

Yeah, I haven't heard anything about assessment for devices. I imagine that it would be kind of the same type of assessment that's done for for adaptive devices in general. I do know that in terms of the cost of the devices and the internet access because we also recognize that that's a barrier for some people, that there are some communities that have lending libraries. And I've heard that there's talk of finding a way to perhaps incorporate into our waiver, which enables regional centers to purchase things with federal dollars attached, some capacity to help people with that. One, you know, that would be based on income levels is what I've heard, but I don't have a lot of details.

J

Judy Mark 48:43

Right. And I, I do believe that the organizations that are doing the AAC assessments, which stands for augmentative and alternative communication assessments, and every Regional Center has contract has a contract with at least one of those kinds of agencies.

They, at least on the meeting that I was at last night, in Westside Regional Center, the agency that has that contract says we are absolutely available to assist with training on accessing remote learning and remote opportunities. So that's definitely something you should ask your regional center about. The, another question comes in around overtime. So the regional center is restricting 40 hours per week per service provider. And they're forcing the client to find another service provider to distribute the hours when they exceed 40 per week. The regional centers are not considering the extraordinary situation and are not making exceptions so that these hours can be increased. So that the same service provider offers a services which would make contact with fewer people. It's a great question. And that's and that's a tough situation. What do you think Amy?

A

Amy Westling 49:55

Um, I'd be interested what service we're talking about. Because I think that in--

J

Judy Mark 50:02

personal assistance hours would be my guess.

A

Amy Westling 50:04

personal assistance. Okay. Um, I don't. I'm trying to think through how that would work. I don't know that...I don't know the answer. I will be honest. You know, when we look at personal assistance, and if it's being done through the participant directed, there is a set hourly rate. And so whether you can afford to do that, for the set hourly rate, even if it runs into overtime is a question. So I don't know if it's that agencies can't afford to do the overtime,

J

Judy Mark 50:52

They're not getting reimbursed. So what I've been hearing is that the financial management service agencies that are providing the, that are paid for these services do not get the time and a half rate when somebody exceeds 40 hours, and therefore, because of that, so so here's what I know, This is this is coming from the lack of funding that exists in our system, and that there is no authority that regional centers have to say yes, we will pay time and a half there's, that funding does not exist. I think this is a really important advocacy area. And one of the things that I can recommend is that you can request what's called a health and safety waiver, and I'm going to let Amy explain health and safety waivers but to tell you that there's been additional flexibility offered where you usually had to get this approved at the state level. And now you can get it approved by

your regional center. So I don't know if you want to explain what that is Amy?

A

Amy Westling 52:08

Yeah. So when I was talking earlier about the directives that Director Bargman has issued, one of them took the authority for issuing what are called health and safety waivers, which are the one of the few tools we have in our toolbox to get around certain rate limitations. So you have to show that a higher rate is needed to accommodate someone's health or safety. And in normal times, that's kind of hard to do in certain instances. But what the department saw was that they were going to get a lot of requests for finding ways to creatively meet people's needs that might cost more during this time. And so they allowed regional centers to approve health and safety waivers, they still have to be approved based on the needs of the person. So it can't just be a blanket here you go have a health and safety waiver for the whole system. But traditionally, these waiver requests have to be originated by the service provider. They go to the regional center, who then looks at it and analyzes it, and then they're ultimately approved at the department. What this did was it took that final layer of approval off but the rules in terms of what could be approved didn't change.

J

Judy Mark 53:51

So but but I do believe that you could potentially make that case. One more question. There's just a ton of them, but I want to move on to our next speaker. People are there's a lot of questions people have asked their service coordinator for participant direction, their service coordinator's never heard of it. They've been denied participant direction when requesting it. They want to know can it be used actually for children under 18? And not just for adults? So how do we even request it? So what would you, sort of give advice? First of all, yes, it's available to all ages in the regional center. Let me just get that out there. And you can use it for for personal assistance and not just on respite for children to go out in the community. But if people if their service coordinators Never heard of it, if they're getting denied, what are their options?

A

Amy Westling 54:47

Oh, gosh, um, the thing I would really recommend is that people look at the guidance that DDS has issued on this. It is available in English and Spanish as well as in a more accessible format. I think they've got it in. Let's see, they have it in English, they have a summary. You can listen to it verbally in English, you can watch it in ASL, they have it in Spanish. You can listen to it in Spanish and it's in Tagalog. And so I would take that piece of paper. Well, if this was normal times I take the piece of paper and hand it to a service

coordinator. But I would take the link and send it to your service coordinator and it's got the nice official DDS logo and that will help start the conversation. Because if you are working with a service coordinator who hasn't had this request come forward before they may not know that this is an option and they may not know what you're asking for, but those pieces that are on the DDS website, and maybe we can ensure that, you know, we get those links out to folks, those pieces explain not only what participant directed is, but what the rules are. So for instance, for a child. So there are rules about that for personal assistance and for iOS. The guidance says that it can't be a parent who's providing the service or a spouse. And so you know, it provides not only in not only that the service exists, but it also provides a good summary of the rules and that'll help your service coordinator get started, because that's probably the biggest challenge. It's not that people don't want to help. It's the maybe they, this is their first opportunity to work with participant directed services. And it really is an opportunity for us all to learn together.



Judy Mark 57:09

Right. Wonderful. All right, there's 20 more questions, but we're going to move on and we can always come back to this for sure. Um, so our next speaker, hold on, let me get my speaker's list out. is Melissa Crisp-Cooper, if my memory serves me, Yes, that's correct. Melissa Crisp-Cooper is a writer and a disability advocate. And she also serves, are you the chair? Are you I know you serve on the Golden Gate regional centers self determination local Advisory Committee, she's, she's the chair of that. And she her communication partner is usually her husband who's at work today. So I have I will be reading her statement and then she if you have questions for Melissa, she will type out the responses. Okay, so this is Melissa' statement: Before COVID I was super active in the community. I she lives in San Francisco just for people to know. I would hop on BART to go to meetings, go shopping or meet my husband for dinner. Honestly, I miss seeing other people in three dimensions and being able to venture out alone. I have been lucky enough to have a project for work to keep me occupied. But I feel like I live on planet zoom. I love that I'm going to have to use that phrase, Melissa. Our adapted yoga classes are on Zoom now. These classes are fun and a great way to exercise with a kind, knowledgeable instructor and a friendly group of classmates. I can pass along information about these classes if anyone is interested. I've also attended many webinars meetings and joined various online groups. In some ways having everything online has made participation easier for many people with disabilities. It's definitely easier to attend events on the east coast. I'm pretty excited about attending a chat with Judy Heumann for AEC users on July 17. Again, let me know if you want more info, then perhaps Melissa, you can put that in the chat because I think a lot of people would really be interested. We do weekly zoom sessions with my husband's family. So lots of quality time with my in laws, happy face. I've been texting and emailing my friends and family. We also go for walks/rolls around our

neighborhood to stay connected to our community. I think it would be fun to start an online book club or host a modified game night. So those are really great, great ideas. And I just want to mention, I just want to give a little more details for Melissa talking about her. This one particular event that's going on with Judy Heumann Judy Heumanns sits on a board with Melissa called communication first, Judy Heumann's also one of the stars I guess you would put it, of Crip Camp on Netflix. Many of you have seen that film. It's amazing. And so this will be an opportunity if you're interested in being on this event on July 17, to to interact with her personally. And she's just an extraordinary human being. So I really recommend that. So thank you, Melissa. And once again, if people have questions, you can put it in the q&a, and she can type her response or put it in the chat and she can type her response. Thank you, Melissa. So we're going to move on now to our next presenter. And that is, Kavita Sreedhar, Kavita, you are, she is the pair, a parent, most importantly a parent, but also the co founder and CEO of Pragnya, which is a really wonderful organization in San Jose that provides really great social interactions for children, primarily children with autism, but all different developmental disabilities. So thank you Kavita. And, and we look forward to hearing your ideas.

K

Kavita Sreedhar 1:01:07

Thank you, Judy. And I really appreciate the opportunity to be able to share here because, as we all know, unprecedented is a word that we've been hearing all along and for the incredible service that DVU is offering the community as well and putting this webinar together. So I'm really excited to share what we sort of did. My daughter's name is Pragnya. She's 14 years old, going on maybe 50, I would say so she's one of the reasons why I do what I do even as a presenter, I mean, even as the co founder of Pragnya, so can you all see my screen?

J

Judy Mark 1:01:51

We sure can. It's best if you start Yeah, there you go. Perfect. That's perfect, thanks.

K

Kavita Sreedhar 1:01:56

Yes. So what we do at Pragnya, This, what I'm going to be talking about today is about working with Pragnya. Incidentally, Pragnya is also the name of the organization. And for those who are not familiar, it's a Sanskrit term that actually means mindfulness and staying mindful so and how to stay connected. So one of the biggest things that I found that COVID-19 did for us is it kind of induced a disconnect from every single thing that she was used to: schools, her neurotypical peers, you know, every other inclusive activity that I was trying to get involved in, and one of the biggest things that almost every parent on

this call can probably relate to is that it brought on anxiety, that feeling of isolation, that claustrophobia and that stir craziness, it happens to the best of us ourselves. And you know, this was something that happened with them of course, the change of the comfort zone of home going into a work zone where she's expected to, you know, comply with all the restrictions of sitting and attending school classes or virtual zoom classes and things like that. So, and of course, obviously, that translated into some really, really maladaptive and disruptive behaviors, sadness, depression, and you know, non compliance with a lot of the tasks. Didn't want to do anything because she couldn't adjust to the change. And then of course, health complications, because she's not able to do the usual activities of swimming, which she really enjoys, which helps regulate her temperament and you know, keeps her on task and going out and working out at the gym and things like that. So there's a whole lot of other issues and of course, eating to compensate and we all know how ice cream and cookies and chips kind of sort of are the go to foods when you're sad and you're lonely. Even if you have mom and dad around dad on a call mom's on a, you know, on webinars and presentations, so it's and then you have to do what you have to do with regard to work when you're not necessarily at school. So those are some of the things that we felt was a big disconnect when it came to, you know, especially my child Pragnya. And what when I said, thinking with Pragnya, what I meant was, yeah, had to come up with a creative solution. But, you know, at pragnya the organization as well, we believe that creativity is more about not just thinking outside the box, but also being able to perceive the world in you know, and identify different patterns and then make connections between these seemingly unrelated things that are happening around us and then try to generate solutions that are, you know, that are driven by more like Mindfulness like for instance, in my case, I felt, my daughter started having a lot of aggressive behaviors, a lot of disruptive behavior, self injurious behaviors, which we had never seen. So I had to come to the point where I had to come to terms with my own and you know, reactions to her behaviors in terms of, you know, accepting that the sorrow, that helplessness that I was feeling as to how to be able to help her and then being in the present moment with her every single step of the way. And then, of course, empathy and compassion. So, if I would explain this, I had to literally put myself in her shoes to figure out what are the possible challenges that she's facing and she's minimally verbal. She has language but she does not use it functionally. So it was difficult for her to express her angst. Obviously, home is a safe zone that was one of the biggest things that I felt, at the moment identified that that really helped me along the path with Pragnya as my daughter. So what we noticed was that I had to understand that, you know, I had to still maintain that balance between her safe zone and comfort zone. And again, try to see how I could get her to work along the different other expectations of hers, like, you know, attending to school or do teletherapy or speech therapy. And then, of course, the humility to understand that what I perceive as enjoyable was not necessarily what she was deeming as enjoyable in this current moment, and the ego transcendence to accept that

not everything that I was thinking was going to be working. So one of the things that what I did as soon as we started this COVID sheltering in place was I tried to get in all the in person services and keep them in place the ABA therapy, we made sure that the company was screening their employees who was able to offer ABA therapy, we have a behavior therapist coming we kept that going. So she had interaction with one other person a safe interactions. During service, we made sure that she got to go to a tutor where it was a safe, you know, physical distancing and everything was being followed with masking, and they were constantly being tested and at the same time, temperatures were being taken. We also advocated for in person lessons because she has screen fatigue, she cannot actually connect through a computer. So those things and then this is where the regional center really came in handy where we asked for behavioral respite and you know, there were a few you know, loops to jump through but we did get that approved with some personal assistance services as well. And of course, crisis intervention which I was never aware of, we had really not used it, but You know, to try to use some tools with regard to how to deal with the maladaptive behaviors. And then the next thing, of course, we can explore technology to get the Virtual Learning going. And then of course, and get her whatever direct intervention services we could through teletherapy through the school district. And this was the biggest thing, which was Pragnya, the organization and it's keeping her Pragnya connection. So this helped us in reconnecting her. So what is the Pragnya connection? Well, one of the biggest things that we do at pragnya is we train neurotypical children and adults to be allies of individuals who are neurodiverse through a specific ally support program that I talked about before. So one of the biggest things that we did was, we took technology and we used it and we talked to our allies and we built something called a pragnya social, where the kids get to meet, spend time together, laugh, share jokes. You know, also sing dance, whatever they were doing. They were able to continue with that particular aspect every single week they meet every Friday and it became something for her to look forward to. And something that was a continuity of her comfort, comfortable activities that you really enjoy doing just singing and dancing. We added something called an online skills Academy where I'll show you towards the end, I'll show you some small snippets of videos and photographs where they all learn to sit down and all the allies and they're the neurodiverse peers, all of them sit down and they draw something like a pikachu or a teddy bear or whatever make Father's Day cards and different things every single Sunday they meet that's another opportunity for them to meet. We are Zoom, the planet zoom, which I really liked what Melissa shared, and we also established something called a Pragnya Connect Call. Now many of us have the liberty and the luxury of being able to FaceTime a friend FaceTime somebody, a lot of our neurodiverse friends don't really understand how to FaceTime and my daughter doesn't know how to use a phone and call somebody, she really doesn't engage. But through the Pragnya Connect calls what we did was during the week midweek, we make sure that our neurotypical allies, their peers, very close in age will, will be facilitated on our call to be

able to connect with their neurodiverse friends, so they get to spend five to 10 minutes every week talking about something that's of interest to them how their week went, and they share and it's just an absolutely beautiful feeling to see individual sharing and of course, one of the in person that we have now started is the my pack, which went zoom as well, which went online too where we have our young adults program. This is called the pragnya allies circle of kindness, and basically in this particular thing we go out, physically distancing. We go out on hikes. We try to do walks, we go to the beach, we do different things as part of the pragnya My pack. Did I face bandwidth issues? Yes. One of the biggest issues that we faced was with the school district. That's a never ending situation where we finally I'm very proud to say that we did at our school district, managed to lobby and I get some hybrid in person sessions, which are socially distanced and with one to one time with the teacher, where they get to work on their IEP goals, and they'll get to work on that regional centers. What were the bandwidth issues? Well, again, I still have some questions for Amy probably at the end of this, but I was you know, with some escalation of the matters to supervisory levels. We were able to get Pragnya the behavioral respite as well as the person assistance and it was it has been really, really helpful to have even the crisis intervention in place. Now, that being said, the crisis, support services, some bandwidth issues is crisis intervention, the Start program that we have, we don't know how really it works, but the fact that it is in place, and I have somebody to call, and they gave me some tools like you know, making her visual schedule and things like that, that really helped at the end of it all. And one thing that I did realize is how to deal with these bandwidth issues is using wisdom skills, that empathy, the fact that I have to be mindful and compassionate. And also using advocacy skills constantly advocating at every level, not just for my child, but also the kids in the Pragnya program or her peers in school. And also being resilient, not giving up. So we have a saying at Pragnya that we literally have to go to War to maintain the peace for our kids. So and you know, the whole thing is I've we wouldn't have been able to do any of this had it not been for all the wonderful allies, the families and neurodiverse families and all our allies in every front. So we say together is always better. So get Pragnya, get mindful, get awakened, is what we say. I just want to share these three small little clips with you before we go. This is a I want to call what's your social? This is a three and a half year old autistic kiddo who was connecting on the virtual call in dancing. And I did this already. The next one is this is them singing together. They're singing the song count on me with their allies. And then, and then of course, and this is the skills Academy, which I talked about where these are the different kids. And this is of course, my daughter Pragnya and somebody who never connects on a computer lesson. When you have a compassion and you have something that engages them and they see their other peers, they're able to do what needs to be done. So that's pretty much what I wanted to share about what we do at pragnya and how we've been able to support Pragnya.



Judy Mark 1:14:49

That's so amazing. Um, you know, there's a bunch of questions. I'm going to go to our last presenter that I'll get to you but it's so amazing because we had on a on a webinar a few weeks ago, an organization in Southern California called the friendship Foundation, which has their version of allies. And we know there's Best Buddies out there, we know that there are ways to connect with neurotypical peers for for our children. And so I think it's really important, important that all of these resources are available now, because we don't have to be in San Jose, to take advantage of pragnya. We don't have to be in Los Angeles to take advantage of the friendship foundation. And so we have put some of these resources up on our Coronavirus website. But I'm actually going to talk to Ed after this and realize that we should have a whole set of resources 'cause Kavita you would be very open to anyone from around the state to join in your program. Right?



Kavita Sreedhar 1:15:51

Absolutely. We in fact have two allies who join us from New Jersey and also we have neurodiverse individuals joining us from Ohio. And also from Chicago. So you know, we're able to, that's one thing good that's come off COVID. Yeah.



Judy Mark 1:16:08

the one thing. That's great thank you Kavita. Alright, now I'd like to present our last presenter. It's two presenters. I first want to introduce you to Joseph Meadours, who is a self advocate who's going to talk to us about some of the ways he has stayed connected with the world. And working with him who's from the step agency in the Sacramento area. Thank you, Joseph and Annfor joining us. Go ahead.



Joseph Meadours 1:16:44

Thank you. Anntthere?



Judy Mark 1:16:50

Ann, you're still muted Ann.



Ann Turner 1:16:55

Here we go. Can you hear me okay everyone?



Judy Mark 1:16:58

We sure can. Go ahead.



Ann Turner 1:17:01

Thank you so much for having me. I'm with you, Joe.



Joseph Meadours 1:17:06

Yeah, I'm here.



Ann Turner 1:17:07

Want to talk a little bit?



Joseph Meadours 1:17:09

Okay. I want to talk about a couple things. I'm Shane Shane with talk to talk. I'm going to talk about how I stay in contact with my family who got an aunt who lives in Colorado. I talk to her at least twice or twice a month. Check in with her. To share lives to take in and is looking forward to see you at Christmas time. So talk with her and keep the peace, she's worried about my nephew, so But before this all happened, we had a good relationship already. I think this has made us even stronger since she's in Colorado and I talk to her quite a bit, checking in with her. And I got a brother who lives in Texas. And we talk at least two or three times a month just contracting in sometimes we just shoot a bow. She says no. She says no, no major sports on. It's hard to find something to talk about. And we will be talking about the news but who wants to listen to news if you go hear the same old same old stuff. So we compare notes, how is Texas doing and he asks how is California doing So, I know we're both in competition, and both states are doing pretty bad.



Ann Turner 1:19:10

I want to tell everyone too in the background with Joe is John Lindell, who is one of my, my job coaches. Since this all started, we've not had apps and services we moved forward, obviously, in various fashions. And how we started that was kind of looked at the person holistically made sure absolutely that everybody had and I mean, everybody needs. We call them employers, but actually what we mean is, the people we support we made sure that they all had masks. They all knew how to take care of those masks. We had staff individually trained, each person how to use the mask how to take care of the mask, in

most cases gave them more than two or three because sometimes our masks just don't make it. We had one person accidentally microwave theirs, for instance, hand sanitizer. We just continue to do educational, not only zoom meetings, but put it in plain language to make it a little less frightening, because everybody was high anxiety. Lots of different things were coming out. There seemed to be a new directive every other day in the very beginning. I unfortunately think people are becoming acquainted with the new normal of trying to get less acquainted with frantic and more educated on covid 19. The other thing with family and friends is each person that we've worked with, we absolutely worked with them on how to utilize zoom. Not everybody has a laptop. So we really had to get creative with even doing phone calls, and how to teach people how to do group phone calls on their phones. I'll put myself in that I had to learn how to do zoom and I had to learn how to be more technically competent. That was not my wheelhouse either. So it's been a journey in both those venues. One of the things we started was we do a weekly zoom meeting for different things. And Joe, you could talk a little bit about that too. And I'd like you to jump in in a second. But what we do now is zoom. We have a zoom exercise class that is led by a professional trainer. We also take in account, of course, everyone's overall health and wellness, making sure that medically they are able to participate. And if we're not, we have ILS and or TDs instructors that are with that person that needs to be supported on how to safely do that. Joe, do you want to jump in a little bit on some of those zoom meetings, you're absolutely fabulous in those



Joseph Meadours 1:21:58

shows step by step by Maybe two times a week with us. And, for example, on Tuesdays, it's almost like peer to peer, we talk about a bunch of us looking forward until we're talking about what's gonna happen after this is all over and how to, we each give us some advice and some tips, how to be safe. And be sure that we are healthy if we, if we're going back to work because we want everybody to be safe and healthy. If you go, head to knee, page in life. So that's on Tuesdays, peer to peer. I can chat with you doing exercise group and I've been involved a little bit exercise is almost like peer to peer in that is still exercises. How to stay healthy through this process? I mean, for me, I do. I do a walk twice a day once in the morning before it gets too hot in evenings when after dinner, when it's cooler out so different you should have it in church works without pace, she doesn't go too fast or too slow. She knows if we need help or assistance, she worked with us somehow somehow prone spot about five of us on on that. nerja is not a support group that everybody just everybody talking about people talking again just find out how everybody's doing what they're doing, trying to stay safe and healthy. It's not a joking matter back and back with Shane contract with crunchy palate, calm come I got a large network print so I am constantly chatting with them. Do Facebook, email or text with my friends tell em I'm still alive so kicking so you don't have to worry about me and I don't have to worry about

them. So we keep the dialogue going.

A

Ann Turner 1:25:06

That's right. Thank you, Joe. And what it is, is it's a creation of a safe place to even talk about things other than COVID. So we also talk sometimes about politics. It really is governed and driven by the people we support. Sometimes behind the scenes, especially Joe, who does a lot of advocacy work behind the scenes. He works this job coach or myself, and we do a lot of zoom meetings. And I think that we've gotten pretty competent at zoom meetings other than we're on our phones today. Right, Joe? We're both on, our laptops are not working too well. The other thing I wanted to tell people too is we also had I had three of my staff who had to dial back some of their job coaching duties because, of course COVID impacted our ability to support People who had jobs in the courthouses. So then we had to get creative about what I was here to utilize job coaches, and effectively to support other people that they weren't familiar with in ILS because they were doing tedious stuff. So what we did is we took the entire caseload, divided it up by three, and then they were to call those people every day, just whoever I assigned them to, just to do a check in, ask how they were doing anything that they needed to help to bridge them to supports and services with doctors or dentists or family members, just to kind of be in a safe place to debrief and we could get a pulse on how people were doing through all of this. And that was in addition to ILS going out and giving them supportive services. and Joe might go to number two, which is the safety precautions that we took. We've had ongoing training with staff and the people we support Again, because sometimes COVID-19 languages and guidelines would change so routinely, that we had to keep people as educated as possible and up to speed and also put it in plain language. We also always kept a line on what's happening with how many masks were needed. We also did dissemination of foods and and I don't know, I don't know if everyone remembers the the grand toilet paper barrage that people did not have. But we had a we had a big storage of toilet paper and actually, I know myself personally drove some toilet paper and provisions and even diapers out to a woman and her three children. Steph also even provided housing for a couple of weeks during this covid time she's in between housing. So those are the kinds of things that we kind of disseminated in services. The other thing that sometimes is the Forgotten is pets. You know, making sure that pets had supplies They weren't going to the veterinarian. They were being safe. You know, pets are a big lifeline to a lot of people we support. And so we had to really make sure we included all of that. And out on one zoom meeting, we everybody who participated, you know, had we had a pet day so everybody could bring their pet and kind of introduce their pets. The other thing we have to we have to be mindful of is because people were home more and as they got more competent on using their computers or their phones and had less to do. There was an overspending that started to occur. So people were doing the the Amazon thing or

doordash and really overspending and we found that also, the scams started to increase. So we really had to get staff educated on being mindful and spotting scams on the internet or on the phone. Again, just to be more protective and supportive and educational with the people we support. And a lot of people lost their jobs and were getting scammed on not only their money, but that there were jobs for them or they could go back there was a lot of confusion. So we really had to make sure that we also had good communication going on with other advocates in the area. And Joe, do you did you have any experience of that as well?



Joseph Meadours 1:29:20

Yes. I guess the first two three weeks, I got about two different phone calls to, and email this and that. Of course, I knew what to do, but then they just didn't the first time they didn't really buy it, the second time when they call I guess they got the right into the wrong person. So I knew what I knew and knew how to know knew how to handle it in in our Did I report it to my I LS seeking chair with rest of my peers, I should be aware that people are making phone calls and scams out there. So when I get them I'll be sure record to work, she can share with her contacts in there, we'll have to get this message to people out in the area. So in any way, shape or form was, oh, I take my numbers. And what I mean by taking my numbers, I checked my blood pressure, a fever, but I should be with my blood sugar at least three times a day. Be sure everything's normal. Yep. Since I've done beers and doing a shot, I need to keep an eye on it. Things have changed a little bit. Now I'm wearing a meter on me that tracks my sugar in five minutes. I know how to cook myself, but I still have to keep an eye on it because it just takes just one spike. So and I have a good relationship with my doctor. Same as with my ILS worker or the AC and with that they go with me to my medical appointments and be sure that I understand the terms right it comes back I got a boy and she she's a little concerned about my health yet but quite a bit and when my ILS worker goes with me, at least she has somewhat understanding and when we contact my ayunt or email my aunt once a month to give her report how well I'm doing it makes her feel better than "I'm, all right, I'm taking care." He's taking care of himself, everything's going to be okay



Judy Mark 1:32:31

Thank you. Great. Thank you Ann and Joseph. Those are really important suggestions. I like that check in your numbers. Checking your numbers every day is superduper important.



1:32:49

We can waking me up. I mean, they should get a sham with me. is working. And we're just the servers to put out around me. And so it's crucial to have the right kind of support around you. You got support, but not the right kind of support, you will fail. And so I'm thankful for step, I'm thankful for my two workers honest job coach, because we have, I believe we have a good relationship. They can talk to me, I can talk to them. And so that has helped me carry me through. And I have a roommate too. There's only one problem with him but he said he's a Giants fan. So I give him a hard time about it. issue the precipices to baseball Same as me. But I mean, we, and we, and we talk. It's important for us. Really should we talk? And she doesn't get out as much as I do. And when I'm out, I do practice, and we're a mess. Especially if I'm on a city bus, or if I'm going to the local mall. I try to wear Converse, on my side of the house. Mm hmm.



Judy Mark 1:34:32

Thank you, Joseph. Thank you. And we have a bunch of questions that have come in and I want to turn to them before we run out of time. This one I'm going to throw to Kavita, um, as a parent. One of one of the questions asked, my daughter has a lot of needs, but so do I. Do I have to sacrifice my needs for hers? What are other options? Are there any tools for figuring out a new plan for our family? And I've heard that a lot. parent, you know, this is a very, very stressful time for everyone in a family, not just for the people with developmental disabilities and parents need support, they need a support in their home, they need to be able to stay healthy themselves both physically and mentally. So maybe you could have some advice for her Kavita?



Kavita Sreedhar 1:35:25

Um, well, it's absolutely true. Every one of us has our own unique needs. One thing that I do I encourage the parent to ask that question is to reach out and connect with the different support systems that are in place and that's what I did. I expressed my inability to be able to engage my daughter on a computer screen and you know, for her to not you know, the district had by Default had worked your learning for all students, what about the ones with your basic needs? What about the ones who will pick up the keyboard and throw it at you? What about the ones that just will sit there and not engage? Absolutely. And what do you need to do? And if there are no solutions, or if the district is not giving you the solutions come up with solutions is what I figured out. We tried, tried kept going at it. And eventually, you know, I guess it did succeed so we did succeed to an extent because we have been able to pull that, especially for students I'm talking about if the child is in school, and outside of that, I wouldn't have known about the different services

at the regional center had I not written to my case coordinator and copied the regional center. I copied the AD, of course, and I asked, I said, I'm in this situation, I really don't know what to do. Try to Reach out to as many people as possible. At Pragmya we also have a parent support group where we, you know, you can always come into those parent support groups, share, there are other parents and you know, there's a wealth of resources, I'm sure DVU and I'm, you know, one of our Pragnya parents is part of DVU. And you have such wonderful coronavirus resource information on your website. So the most important thing is ask, and, you know, I guess you try to figure things out. And when it comes to our needs, yeah, at the end of the day, you have to be able to that's one thing that we always insist that if you're happy, you're able to make another person happy and self care is extremely important. Thank you, Christian for putting that on the chat. We that's why we do this parent support group every Sunday, where we talk about, it's hard on the parents too and it's hard on the caregivers. Connect and find out what we can do. We play games. We try to do a walk outside, each of us having our zoom cameras and walking and then showing people in the community what we're doing just staying connected, I think. I hope that answered your question. But at the end of the day, just dig away and ask away and reach out more than anything else rather than secluding yourself.

J

Judy Mark 1:38:20

Yeah. And ask for support from your regional center. Yeah, um, speaking of that, a couple questions for you, Amy continuing on the road of participant directed services. So can a client access participant directed services if they're also receiving respite? Can an additional participant directed service provider be brought on as a personal assistant that is different than the respite provider?

A

Amy Westling 1:38:50

Yeah, I mean, I think that you know, the, what you have to look at is the function of respite versus personal assistance. So respite is to give the primary caregiver a break. And then personal assistance is sort of like IHSS. So if you're, if you've applied for IHSS, and you have been given a certain number of hours, and you need more than that to meet someone's personal care needs, that usually is for personal assistance. So, you know, the most important thing is to be really clear about the function of each service and how they are different.

J

Judy Mark 1:39:37

So to be clear, respite is actually fully called in home respite, and personal assistance, you can leave the home and go into the community. So that's why if you're getting if you're a

parent of a child, and you're getting respite, but you want the child to be able to go to the local park, or you want them to be able to take walks in the neighborhood, that is really it's important for you to go in and ask for those personal assistant hours. I have another question that came in on participant direction. Could you explain the difference between participant directed daycare services, participant directed respite services, participants directed personal assistance services and participant directed community based training services?

A Amy Westling 1:40:25
Sure. Um, so the first one was daycare?

J Judy Mark 1:40:30
Yeah.

A Amy Westling 1:40:31
Okay. So daycare is defined in the lanterman. act as care that's needed for a person to enable the parents to go to work or to you know, I guess in these times, to work remotely. So it really is tied to periods of time when the parents are engaged in work activity. What was the other one?

J Judy Mark 1:40:59
The next one was respite,.

A Amy Westling 1:41:03
Respite is, and backing up with daycare. With daycare, one of the considerations is what's the cost of daycare for a typically developing child. So if you have a five year old, the expectation is that the family would be paying something for daycare. So the regional center can pay an additional supplement if it's required because of the child's disability, but the family unless there's, I think a financial hardship is expected to pay the traditional cost of daycare. respite, as we've discussed, is to allow the family member to get a break from the care and supervision needs. So if you want to go grocery shopping and have your child stay at home with a paid caregiver, that would probably be respite.



Judy Mark 1:41:58

Great. And then the next one is community based training service.



Amy Westling 1:42:03

community based training service. So I mentioned that the DDS directive said that in even in normal circumstances, there are participant directed services. One of them is a what's called community based training service. And the challenge with this service it came along in during the last recession. And the challenge with it is that it is very much like it sounds like it lets you select a provider that will do some sort of individualized day service with your loved one. The challenge with it is that the rate is exceptionally low. And most of the rates in the regional center system are set are set by the department or the regional centers have some ability to negotiate them. But there's a limited number of services where the rate is in statute. So that means the rate is the rate and that's the law. And the all end rate for the community based training is 1499, inclusive of transportation. So it's really hard to use that service because that's lower than minimum wage in most areas. And that's supposed to be an all in rate. But that really is kind of if you know what it's intended to be, is if you think about, and, Judy, I've heard you describe this kind of what your son does. If you have someone that goes into the community, one on one with a staff person. This would be a staff person that you selected probably from your immediate network, to go access parks and in traditional times museums and libraries and those kinds of things. But the real challenge with it is the rate.



Judy Mark 1:44:05

Mm hmm. Got it. Okay um another question for Melissa that they've asked again about this yoga program would you mind putting it back into the chat again I know it scrolls up there but people are very excited about this potential exercise opportunity. Absence billing as is literally asked about every single one of our webinars, and I don't always have someone and sometimes when DDS is on I make them answer it but I don't know Amy if you even want to answer but but the basic question is Will absence billing continue to be effect past July 31? So first of all, most people have no idea what absence billing is explain that and then explain whether you think it'll go past July 31?



Amy Westling 1:44:57

Sure. So absence billing Really is there's a place in title 17, which is our regulations that allows regional centers to pay service providers of non residential services. So those are things not where places where people live. So like day programs and respite and ILS

services, those kinds of things. It allows regional centers to pay those providers for their average attendance during times when there's a state of emergency, because we recognize that, that not as many people are going to use those services maybe when there's a forest fire or there's an earthquake because people's lives have been upended. And so during the pandemic, because there's a declared state of emergency this has been an allowable process for the last few months, on June 18th the Department issued more guidance that said that they expect this process to come to an end on July 31. And that's the latest we've heard on that.



Judy Mark 1:46:16

Yeah, I hear that some of the congregate setting providers are arguing that it should be extended. I'm hearing though, that it's unlikely to happen since they wanted it to the governor of the state wanted it to end in the end of June. So if that's in fact, the case, you know, we are really strongly urging families who utilize these congregate settings like a day program, to go to their day program provider and say, I want to get services from you, but on an individualized basis, or in a group of two people where we trust the other person and the family that they live in or the place that they live in, that they're not going to spread COVID to my child or to me and so It is really important for us to think about this long term solution because group big group programs where people are going to a to a center where there's 40,60, 100 people that ain't coming back, possibly ever, possibly ever. And so we need to look at alternatives now for the kinds of services we need to support us during this time and into the long term future. Um, so people are asking, there's a couple people with kind of similar questions where they're asking like, my son is doing virtual classes that he loves, but we're having to pay out of pocket for them, could particularly participant directed services, pay for it? Someone else is asking about virtual classes that consumers can take, would that be covered by participant directed services? Since nothing is really in the community now it's community based. So you know, here's my take on me, correct me if I'm wrong, but participant directed services are based on one on one assistance, it's not based on a program that you're involved in. So if you're doing like a class online, that's exercise to regional centers, that would be equal to you taking an in person exercise class, which is not covered by regional center services. Unless it is inherently part of a program, you're already in like a day program, maybe be providing that. But if you're a child, you're not going to be in a day program, you're in school. And so therefore, participant director services are not going to pay for that group program. What participant directed services will pay for is an individual to come into your home to do those exercises or to meet you at the park or to take you for a walk through the community. So there's lots of opportunities that exist to give the family a break, to give the person the opportunity to get out of the freaking house and to do it safely. So So I, you know, I really encourage people pick up the phone or send an email to your service

coordinator today asking for participant directed services. You saw in the chat that we gave you the link for the participant directed services, guidance on the DDS website. We can put it again there. For those who are who didn't see it. I printed out it's written in really plain language. as Amy said earlier, DDS has done a very good job on that. And you can present this to your service coordinator, if they've never heard of it. You should know that DVU In addition, organization is advocating and begging actually DDS the State Department to train regional centers and their service coordinators on participant directed services so that they when they get these phone calls from families and individuals, they can answer Yes, of course I know about that. And I know how it works. So I don't know if you want to add anything Amy or did that work for you?

A

Amy Westling 1:50:04

There we go. Um, yeah. And the other thing that I would explore if you find that kind of these remote classes are working well for you is or for your loved one is that a lot of traditional service providers are doing these kinds of things now as well. And so that may also be an option. If you're interested in some sort of remote classes, there are a lot being offered by traditional service providers now to

J

Judy Mark 1:50:42

so, thank you. It's, okay so we have a question right now I think it's for Kavita, um, you had mentioned that you were able to access behavioral respite This is not something this participant or this person has heard of Could you explain what that is and how that's different from regular rack respite? And also, what is crisis intervention? You've kind of mentioned all these things. Yeah.

K

Kavita Sreedhar 1:51:09

So regular respite is where somebody comes in and works with your child or your neurodiverse loved one, right? In behavior respite Sometimes your loved one is going to be having maladaptive and disruptive behaviors and you need somebody who is more trained to be able to work with them. So this was something that I specifically requested for and the associate director at our regional center suggested that I get behavioral respite for her as I was asking for personal assistance, but she suggested that behavioral respite would probably work better because we needed somebody who was more behaviorally trained. So the respite caregivers are given, I think They have to go through a behavioral training module to be able to handle different types of maladaptive and disruptive behaviors, you know how to get them to how to keep themselves safe and keep the individual that they're caring for safe as well. crisis intervention is, you know, it's

when you're at, in a situation of crisis, like if your child or your the person that you're caring for is going after you or they start indulging in self injurious behavior or in very aggressive behaviors, they run away. These are different types of crisis that come up and I had to reach out for crisis intervention services because we were having we'd never seen that happen ever before. I'm sure Amy would be in a better position to explain what crisis intervention services are. But there is there is a company that we work with which is start and they work With the different systems and supports that are available around us, and they actually provide training and tools, we developed something called the communication chart to talk about what are the what are the tells, so to speak, or what are the antecedents to certain maladaptive behaviors that come in, and how to, what could it possibly mean? And what we did did as part of Pragnya's Person Centered plan, and also what we do for all our individuals who are enrolled at pragnya. The organization also is we develop a one page profile, which basically talks about how to be able to de escalate and how to redirect their behavior or how to address it more acknowledging how their behavior is, and that's something that crisis intervention with start, we work with them to be able to provide them that support like, you know, they gave us stim toys they gave us, they asked us, one thing that I did ask for us If Is it possible for them to pay for a pool because she likes enjoying swimming, but not really, that didn't come through, but we did. She likes painting so they sent me some or coloring so they sent some coloring paper and, you know, pens and things like that. So and they also document and keep data on the individual. So in the event there is any you know, there's unfortunate situation where the police need to get involved. So the crisis intervention comes in really handy at that point.



Judy Mark 1:54:32

Thank you. Briana, welcome back. Did we deliver any babies while you were gone? No. Okay, good. Um, so did here's a couple questions I saved for you. Um, people, a lot of people with developmental disabilities live in apartments, and apartment buildings, and so do a lot of families and they're really worried about those complex hallways. The narrow staircases, the elevators, where people are not wearing masks. And it's impossible to keep a six feet distance in a predictable way. What are your suggestions for people I know that public health the public health guidelines, I've never seen any guidelines addressing that, that private apartment buildings should say only, you know, one part one party, one family, one co living unit should be on an elevator at a time and I don't know if you guys have heard the story that just happened in the last few days. here in California. I have a woman who was asking people on her apartment building elevator to put on a mask and she and she started getting hate stuff and there was a swastika in the elevator because they put up a noticing saying you must wear a mask and, and so people are getting a lot of hate when you have to call people out to wear masks. So any kind of

advice, I mean, we're not expecting you to answer the hate stuff. But um, you know, any sort of advice for people who are living in these apartment buildings to stay safe?

B

Brianna Doherty 1:56:11

Yeah, that that's really difficult and I know that there you know, our spaces have not been necessarily built for with COVID in mind, right and so it's so it is going to there are going to be spaces that are it's difficult to maintain distance. And but but again it you know, it is important to try and maintain at least six feet of distance as much as possible and to wear masks. So with regards to elevators, like in the elevators in the hospital, they have big signs on them that say four people Max and they have little dots in the elevators where everybody stands so we can be as distanced as possible. And so I think as much as possible, and to you know, to ride elevators, and it's, I think it's okay to say hey, there are already three people in the elevator. I don't think any more people should be in the elevator and, and and to try and you know if it's a narrow staircase go one person at a time. You know, I think it is pretty important to try and maintain as much distance as possible within, you know within the structures within the spaces we've been given.

J

Judy Mark 1:57:18

Thank you, Briana. Um, here's a question that anyone can answer Melissa, Kavita Joseph, or maybe Briana, you've seen it as well. Are there any styles of masks that might be more easily tolerated by people with disabilities? We have tried several masks that attach on the ears. We have tried plastic face shields and they have not worked. So I'm just going to start by saying First of all, that the governor's order statewide order requiring mandatory mask wearing in public has an exception for people with developmental disabilities. Um, it's very specifically says developmental disability. With that being said, we still want to try to get people with developmental disabilities to wear masks if it is safe for them to do so, because it keeps them safe as well. I mean, part of mask wearing is to not infect others, but it also has some even small measure of protection for you not to get sick yourself. And so we do need to figure out ways to do that. However, if you are an individual or you are the parent of an individual who absolutely will not wear a mask, you do have that out by and I would honestly i'd print out the governor's order and carry it with you in case you are going into a store or into any kind of place where somebody stops you and you should be able to show them the order. But I'm wondering Kavita Briana, Melissa, if anybody has seen a mask or something that is available to people that maybe makes them want to wear it more, go ahead Kavita.

K

Kavita Sreedhar 1:58:58

So there is Like a scarf kind of thing that comes up and that you can, it's a cloth thing a if you could make it more like a fashion accessory and express, you know, that's what we try with our daughter. So that's something that you can put on and it goes on like a collar and then you just put it up so it automatically stays up. That's one of the other things if they cannot tolerate the thing going around the ear.



Judy Mark 1:59:26

Great. Any other ideas? Joseph or Melissa? Joseph, are you are you okay? You're okay with wearing a mask?



Joseph Meadours 1:59:38

Yeah, I have no problem. I have no problem wearing one. I mean, I did. I dropped to my chin every so often just to get some air, but No problems with it.



Judy Mark 1:59:57

That's a really great point when you're at home When you're in the car with your family, I, it's shocking to me how many people I see driving down the street with their masks full on, and they're the only people in the car. You don't need to do that. If you're out for a walk and you're nowhere near anyone else, you don't need to have the mask on. So you should. So one idea is if your child is unwilling to wear a mask, is to try to stay in places that are really low populated. To go out at times with low populace where people are not out early morning, mid afternoon, like if you walk around my neighborhood at 10 o'clock in the morning, it's empty. You walk around sort of 6pm It is packed, like the pre or post dinner family walk time and we're constantly crossing the street to stay away from people. Um, so um, so anyway, one of my I other idea I have I was hoping it actually physically showed you but I don't have it anywhere near me. Is that why son's aid, made masks for my son with his favorite characters on it. So she, so we have one. He has one with SpongeBob SquarePants on it. She made me one with Mickey Mouse on it, which is my favorite character and one. Each of our family members has a mask with a with a character that my son might be interested in, which makes it like a fun thing to wear it, it becomes you know, like, it's amazing when you go to Disneyland. You know, a person who hates wearing a hat all of a sudden is wearing Mickey Mouse ears. So let's have it so that people you know, think it's kind of fun. But I also think that there needs to be a behavioral approach. I'm not a big behaviorist advocate. But I do believe that you can create a protocol for someone to start by wearing a mask at home for 30 seconds and then let them get to take it off and then an hour later they have to wear it for a minute that you can work your way up. And time them so that they can say, Alright, now we're going to go

out for a five minute walk with your mask on and you can't take it off, and then come home after five minutes and say, See, you did great in five minutes, instead of saying, you know, forcing the mask on a person and then throwing them out into the world and saying, Oh, you can't wear it, and then we're punishing you by coming back home. I think there's really a way to think of it in the context. And I mean, that in the best of the way of APA, that you can work slowly up to that, and I don't think that families are thinking about they're just, my kid won't wear a mask and we're done. Of course, there are those people who won't wear a mask and it's unsafe. It's unsafe for them to wear a mask, but go ahead, Briana.



Brianna Doherty 2:02:45

Yeah, I was just hoping Can I revisit some previous questions that were asked really quickly?



Judy Mark 2:02:50

Sure.



Brianna Doherty 2:02:50

judOkay. So um, so I wanted to confirm that there is no evidence that coronavirus is spread through recreational water. So, so Similar to what I was saying before, it's not the water in and of itself or this thing in and of itself. It's swimming in close contact with people. So again, if we keep kind of the big principles in mind, it's staying at least six feet away from people and and minimizing that close contact. And similarly with regard to that has been prepared either by a restaurant or somebody else. There is no evidence that coronavirus can be spread through food, as long as it's been prepared with those principles in mind so that the people preparing the food or wearing masks have washed their hands have disinfected the surfaces. There's no evidence that Corona virus can be spread through food. So again, it's you know, there's a lot of these questions and it's just important to keep the big principles in mind, right that, you know, as long as you are maintaining distance, wearing your masks, washing your hands and following these simple principles. You know, it's it's easy to kind of Just sort of what activities are okay, and not and when in doubt, just google CDC and your question, and there's a lot of information out there. And also ask your doctor.



Judy Mark 2:04:10

Great. Thank you, Briana. Um, Amy, I just want to tell you, there's a couple of people in the

q&a who are dying to send you an email. So you can either send them private things or put it on there. So I don't know. I generally don't give out my email on these webinars, but you're welcome to.

A

Amy Westling 2:04:30

I'm happy to it's on the internet anyway. So I'll be happy to find one of those questions and throw it in the response.

J

Judy Mark 2:04:38

Perfect, great. Oh, I just put one of them into answered. So go into answered. I got it live. Um, and another quick answer question, if we're in a day program, but we found another program that we like better and they are offering things like online that we'd like to do. Can we change? You can change at any time. Absolutely can change at any time just because in COVID we're not in like a standstill. In fact, this is a really good time to think about what, it what are the services we're getting. I mean, I know that there are some people are unbelievably creative and are doing some very cool with people are providing one on one assistance in the home. Um, and then there are others who have closed shop completely. So you want to be able to find the services that are working for you. Um, so here's a question for you, Briana, is a face shield sufficient by itself or should it be worn with a mask?

B

Brianna Doherty 2:05:42

That's another great question. And and i think i think you know, as much as possible mask is is the is the first way to go a face shield is definitely an alternative both is even better. And so so. Yeah, as long as that But the mask is kind of the main thing that the CDC recommends.

J

Judy Mark 2:06:04

Okay, great. Um, let's see. Um, I'm just trying to see if there's any more questions we receive. Oh, here's a basic question for you, Amy, who receives and manages the funds and payments for participant directed services. Is it direct between the Regional Center and the person providing the services?

A

Amy Westling 2:06:28

No, it goes through a financial management service. So very similar to the self

determination program. The money goes directly from the regional center to the Financial Management Service and the financial management service pays the provider

J Judy Mark 2:06:47
can they negotiate the rates on any of these services or are they set rates

A Amy Westling 2:06:54
for the three that were added to the thanks to the departments directive. It is a set rate. And I think I mentioned earlier that the, the community based activity is also a set rate.

J Judy Mark 2:07:12
Great. this is a real I'm only gonna ask for one or two more because we're running over time. This is a really technical question, but I was asked yesterday on our call on our SDP Connect call and I want to ask you, Amy to answer this. If a consumers on the HCVA nursing labor, can they still access to participant directed nursing services or do they need to change the waiver?

A Amy Westling 2:07:44
I actually don't know the answer to that. Because the HCVA nursing waiver is actually administered by the Department of Healthcare Services. But everyone should have a caseworker who receives that waiver service. And it would be like your CCS caseworker, or there's some new agencies that are managing that. Now, I would ask them for clarity on that.

J Judy Mark 2:08:22
We acquired this is this is the artist Mackenzie, who created this Oh, here we go this super cool mask with SpongeBob on it. So that's one way. Thank you, Mackenzie. She's the artist of the household. Um, okay. 'ml think that there's probably only one other, people are asking a bunch of questions about the self determination program, which is not the subject of this, of this webinar, but I'll just tell you that at this point, DDS did not decide to expand in the budget to expand the substitution. program to people who are on the waiting list, we you should know that they can do it at any time. And so we haven't given up and we're continuing to advocate with them. So keep sending your emails to Nancy Bargman on that one. Um, and just I guess a final question I'm going to give to you Briana. Because we have to have hope. It's just this is it's very we're, I mean, when people ask me how we're

doing in our family, I say, it all sucks. We're all screwed. But other than that, we're fine. Because I really believe that is that things are not great. I mean, they're not great for my son who loves Disneyland. They're not great for my daughter who is in college and is not being able to not cannot go back to college in the fall because they're not doing it in person for her. The, it sucks for our vacation that we were supposed to be on right now. So yeah, it all kind of sucks, but We're also kind of all screwed because people aren't doing what they need to do. So we have to have some kind of hope and one of them is a vaccine. And we know that that is not your specialty. You're not it you're not Anthony Fauci and we can certainly ask him. But do you think that there's even a chance of a vaccine at all? And what would be the timing that you would say?

B

Brianna Doherty 2:10:23

Yeah, you know, as you mentioned, I'm a medical student, I'm not a doctor. And so I can't give advice from that perspective

J

Judy Mark 2:10:30

to play a doctor on TV.

B

Brianna Doherty 2:10:33

And, but you know, I will say that there is immense pressure and and immense desire for a vaccine. Right? And, and with that, with that amount of drive, you know, people can do really amazing things. And I know, I know that there are many labs out there that are working on a vaccine and are working really hard and there's a lot of money being funneled into a vaccine, because because everybody wants it right. And that's a really big driver. And so I am hopeful that there will be a vaccine as to timing, you know, I can't say for sure. And numbers that I have heard has been, you know, within a year or a year or two. And those are numbers that I have heard. I can't predict much more than that. But I'm very hopeful that there will be a vaccine. Well, that, you know, will that mean that life can go back to exactly how it was? I'm not sure. You know, I'm not sure about that. That but it will definitely, it will definitely help and, and move us forward along the trajectory that we're on.

J

Judy Mark 2:11:40

Great. Thank you, Briana. And thank you to all of our amazing panelists, Joseph kevita, Amy and Brianna, and Isita thank you all for being part of this webinar. Once again, we've recorded it. It's available it will be available by tomorrow on our Coronavirus Resources

website. You could also look on YouTube, we have a YouTube channel, Disability Voices United. And you can check on YouTube, we have all the webinars we've ever had, plus all of our self determination program Connect calls, as well as a couple of little videos that I did about how to make a homemade mask and you get to see lots of fun things on our YouTube channel. We are not doing Tick Tock videos or anything like that. It's all informational. But I want to think of all of our panelists. Next week, we are not having a webinar because I'm going on a mini vacation to Yosemite National Park where we will stay physically distinct from as many people as humanly possible, and go on lots of hikes and get lots of fresh air and we will be back in two weeks with another webinar of subject matter to be determined by tomorrow. So thank you all for joining us and please stay safe out there. Thanks, everybody. Bye