

Making Choices During the Pandemic (Aug 6th)

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SPEAKERS

Lorna Silva, Scott Shepard, Sam's Aide, Priyanka Nookala, Charles' Mom, Mari-Anne Kehler, Darlene Hanson, Sam Astle, Judy Mark, David Grady, Charles Pakbak



Judy Mark 00:10

Welcome, everyone. We're gathering now while our participants and our attendees come in. And so we will. We will wait until we have everyone coming in. Thank you for joining us. Hi, everybody. Welcome to our webinar. We are going to go live on Facebook. There we go. Hi, welcome everybody on Facebook and welcome everybody on on our zoom platform. We're really happy to have you here. For our, I believe it's our 18th or 19th webinar on the Coronavirus. And we are really, really happy to have you join us. My name is Judy Mark. I'm the president of Disability Voices United. And before we get started for those of you who are calling who need Spanish interpretation, I'd like to invite Lorna Silva to explain to everyone in Spanish how you can join our backline in Spanish. Thank you, Lorna.



Lorna Silva 01:55

[Lorna describes how to access the Spanish translation]



Judy Mark 02:05

Thank you so much, Lorna. So before we get started, I'm just trying to push up my page on

on Facebook. Before we get started, I just want to tell everybody that we have, for those of you who would like to see our previous 18 webinars on Coronavirus, you can find that on our website which is DisabilityVoicesUnited.org. And right at the top it talks about our Coronavirus work. We have a Coronavirus Resources website as well that has updated information on how to first of all, it has all of our webinars and has all the handouts and PowerPoints and presentations from our speakers. But it also has our health passport, our tip sheet if you are going to the hospital or to a doctor on how to treat patients with disabilities. It has ideas for education ideas for how to keep your anxiety low. So, you know, I really encourage you to look at our website and to gain those resources in that way. I also wanted to mention that this will be our last Coronavirus webinar for the time being. We feel that we have tackled a lot of issues, from emergency preparedness to employment to special education to anxiety, this is another we've done several about anxiety, to mental health issues to we've had we've had a number of people who've had coronavirus on. So right so starting next week we're taking the week off but starting the week after next Disability Voices United is pivoting yet again. This time we're going to be focusing on the election in November. And we're going to be running a series of webinars and meetings and providing information to folks who are who are interested in the election. We're doing it in a non partisan way and in a coalition with other organizations, such as regional center service providers, mostly self advocacy and parent led organizations to ensure that our community has registered to vote, has filled out the census forms, understands the issues that are on our ballot come November and are sending in those mail in ballots. As opposed to showing up in person which I think is going to be a little scary this year. But but we are going to be informing our community and so we are really hoping that you'll join us. If you are watching and you are not on our mailing list. You can join our mailing list by going to [tinyURL.com/joinDVUmail](https://tinyurl.com/joinDVUmail). It's also in the chat. I also want to set a few ground rules on how you can ask questions to our fabulous panelists, we are having a, the way we do our webinars is that you should be asking your questions at the panels through our Q&A, which you can find at the bottom of your screen. Also, I will be monitoring our Facebook page. So if any of you who are watching on Facebook Live, want to ask a question through Facebook, I'll monitor that as well. The chat we generally use for any questions you might have that are technical in nature and our, Ed Hirtzel our program assistant will answer those questions. Or if you just like to share information with others, that's another way to do it. It's to say, I found this great resource and you can put it on the chat. So thank you so much for joining us and we're now going to get started. So this webinar is called making choices during the pandemic, increasing self advocacy to reduce anxiety and other issues. The reason that we wanted to do this webinar is because we have just heard from a lot of individuals and families that this is, that this coronavirus, like for all for everyone has been very anxiety producing. It had, all of our routines have changed. All the places that we know and love and want to go to, many of them have been closed, and that it's been really hard for us to kind of hold

it together sometimes. And we didn't want to focus this webinar in a negative way and say how do we reduce behaviors and how do we eliminate them and replace them. We're, that is not the context in which we're talking. We're talking about empowerment, we're talking about the ability to increase people's self advocacy skills in order to reduce to reduce any kind of anxiety and depression that that that can lead to some of these unfortunate incidents. So our first speaker is just an amazing human being who has worked in this field for ever. And he, and he's going to really start us off by a PowerPoint, a really great PowerPoint presentation that is talking extensively about what this all means and how we can really improve self advocacy during this time. So I now like to introduce Scott Shepard who's the Director of Avenues Supported Living. Thanks, Scott.

S

Scott Shepard 07:34

Great, thanks a lot, Judy. All right. Start my 10 minutes here, okay. Okay, so hopefully everybody can see the PowerPoint. And again, this'll, I think it'll be downloaded or uploaded onto the website as well. And so, one of the things I get asked a lot of times a lot of the time especially by a lot of our folks that that might be on the spectrum, etc is like when is COVID going to end? And my wife, Laurie, her favorite responses, you know, it's just like a chicken pox, it's going to be here forever. So we really need to, you know, help people sort of understand how are we going to cope with it, not, it not that it's ever going to be over really. And then we're going to have a lot of things a lot of guidelines that I think we're all pretty sure that we're going to need to follow for years to come. So anyhow, I want to just talk about again, increasing self advocacy and choice and how that that can be really helpful for people especially if they experience frustration or, or any, any anxiety around what's going on, which again, most people are, I've got a picture of a good friend Aaron, who's in the self determination program, which is really exciting, he's finally going to get his budget redone, but he's flying the kite in the bottom left. We just had a zoom birthday meeting because he just turned 30 today, but we had family from out of state on and so There are some good things going on about some of the ways that we can connect. And then Sharon's in the bottom right. Again, it's really important even though Sharon's in her in her 70s, we're finding that people that are older are actually having a little bit more of a difficult time staying shuttered in, they need to be out they need to be engaged safely and responsibly in some routines that are that are important to them and comfortable to them. And that's something that I'm going to talk a little bit about today about how can we empower people to reengage in essential and meaningful routines. So again, as we've seen, some people have actually responded well to changes in their essential routines. And again, we're what I'm calling we used to call essential work. We think really, that that all work and routines that are important to people are essential to them. And that's something we try to get across to everyone there's routines are labeled by us. They're not necessarily, I don't think they should be labeled by other entities about

what's what's essential and what's non essential. As we all know, we have family members and other people we support who a lot of routines are very essential for, regardless of what other people would think. And again, some people are happier with less demands on their time, which means we're going to be a little more challenged, as we put more demands on them coming out of some of the restrictions related to COVID. And some people are thriving using technology, those that have the technology available. However many other people are understandably frustrated by the changes and restrictions in their essential routines. And that includes employment and volunteering as as folks get to be adults. And one of the things that that we've seen, it's been really interesting is that people who have been able to keep their essential jobs, as essential workers have really coped the best. Although we've had some initial coaching challenges around the COVID safety guidelines, you know, everybody's got to wear a mask at first and social distancing, safety rules, things like that. In the long run, people are actually coping really well that have been able to continue those those essential jobs. David, who I support on the left, has worked at a supermarket for the last 13 years. And some of the things that we had to help him cope with that were really challenging at first was that he liked to get to work early, never, never to work late, always gets to work early, and he would hang out at Starbucks, Starbucks or the McDonald's before work. Because we sort of coached him it's not okay to hang out at Ralph's. Everybody might think you're working and then your co workers might get frustrated if you want to talk to them while you're not working. So we have him hang out at Starbucks or McDonald's but once COVID hit one of the first restrictions was people couldn't hang out in lobbies, so you can't dine in, you can't hang out anymore. And that was that was very challenging for Dave. And so we now drive him to work instead of taking the bus that was another issue, but we drive to work, so he only gets to work 10 minutes early. Otherwise, he'll want to be there an hour early. And then that led to a lot of anxiety that led him clocking out those first couple of weeks. One of the other challenges we had is that his job coaching had to change because the supported employment agency stopped providing direct supports. And that meant that David was going to lose his job if he did not have some sort of support. So we do supported living services we just jumped in and and we provided the coaching that he needs, with all the COVID changes and things like that. And now things are things are actually going really well. Some places unfortunately, not adult services for people with disabilities, but some places for example, like Target and supermarkets have actually given bonuses to their staff that worked through COVID and have taken on some some extra risks of being in public and and that's been really exciting. for them.



Judy Mark 13:00

Hey, Scott, I'm sorry that you need to interrupt. Could you press play on your slideshow so that people see the whole screen because they're seeing a layout version of it.

S Scott Shepard 13:10
There we go. All right.

J Judy Mark 13:12
Hopefully that will work.

S Scott Shepard 13:14
better?

J Judy Mark 13:16
I haven't started yet. It looks the same to me. Alright keep going. We'll figure it out. Oh, press now you'll need to share screen again.

S Scott Shepard 13:28
Yeah, okay. All right.

J Judy Mark 13:32
We were just missing part of your slides because of that. You saw on the right, the slide layout piece. See it see the whole Yeah,

S Scott Shepard 13:44
I push play it, but it didn't do anything. You can't see it different now?

J Judy Mark 13:48
I get it. Okay. I would just Yeah. All right. Let's keep going.

S Scott Shepard 13:53
All right. Well, okay, shoot. All right. Hopefully you can see some of that but all right. So again, The key thing is we've seen that work continues to be essential for people, especially people with disabilities that they've been able to continue a lot of those routines. And we've just coached them around how to do things safely and responsibly.

And, and actually, they're safer and more responsible than many of the other folks out there. Because from the very beginning, we've coached around mask usage and things like that. So this has been really exciting for a small portion of our people that we support that are able to continue to work. Person Centered supports one person, it's time if you're not sure what Person Centered supports are, instead of supporting people sort of in groups or looking at group situations, as we support people one person at a time that makes it easier to teach and promote self advocacy and choice making. It's also easier to listen to one person at a time. COVID has many, in many situations for services to become more person centered as opposed to segregated large groups. Which a lot of times our funding source has sort of led us to do. But we're fortunate in supported living and in in self determination and independent living, things like that. Most services are pretty individualized and can be Person Centered a lot easier, more easily. And that's made it a lot easier for us, certainly. And one of the things I think we need to think about moving forward is is that as services get back to more in person for a lot of those services that have gone remote, we have to think about how can we make sure that they're person centered and maybe not congregate and maybe not group things? So all right, well, self advocacy really starts with recognizing that our choices are empowering. Choice making skills are the key to empowering people. There's no quick fixes. There's no one size fits all answers. Each person. Each team and family have different needs. And different levels of comfortability. So people have sort of wanted to move forward and re engage in routines at different speeds. And that's okay. But that's what Person Centered is all about. There's some families that have a high concern over the health issues of either themselves or their family members, and they haven't wanted to move forward as quickly. That's okay. Other people have said, Wow, I need to get out, I need to do something and we say, Great, let's figure out how to do these things safely and responsibly, so that you can engage in routines and and that are meaningful to you and do some things in the community safely and responsibly. So each team is different. We just make sure that we're following our local county guidelines, the state guidelines, what the governor's saying, everybody else is saying, because the key again, is safely and responsibly. Okay. So our question has become though how can how do we and how can we re engage people in their essential routines that they need and enjoy? Okay? So one of the first things if people are even if people are sheltering at home and they're not getting out yet, okay Same thing with families. It's really important right now as we help prepare for moving forward is to make sure that people have the basics make sure people are practicing social distancing safe and responsible behavior both at home and in the community. As we engage, engage in essential and meaningful Home and Community routines, we have to learn how to follow these COVID safe guidelines. And initially for us that was helping people to identify facial coverings that they tolerate with sensory needs and various things like that. Whether it's cloth whether it's something that's a more of a pull up, or whether it's the the blue kind of masks that a lot of people wear, a lot of folks are into the Dan in the middle has a spider

man mask on he can actually pull it all the way over his head with an opening if he wants we try to get him not to because he looks like gangster so he gets a you know gets you know that part he's got another one that's Batman and we have a lot of people that have more personalized masks now and that makes it a little bit more fun when you have to wear em. Okay. We're also making sure that people are comfortable. Everybody in every household has one of those scanning infrared thermometers. So we teach people that it's their responsibility when you have family members come over when you have friends, guests, the first thing you do is you're gonna you're gonna zap them and they're gonna zap you to make sure everybody's okay. Okay, and if it comes out green, that means it's okay. You can actually see the temperature on there. And if it comes out red you ask them please step outside even if it's one of their support staff and say, you know, we'll, we need to call and get somebody to come in and replace them but we don't want that person in the same household sharing the same space that's that's coming in with a high temperature. And then the social distancing on the right even on community walks, it's good thing to practice, because as people reengage in their essential routines they need to be able to follow safe guidelines. Okay, so again, everybody's seen all this stuff, this stuff shouldn't be new. But it's important that we help people get over a lot of those fears and anxieties by practicing, actually practicing. Here's what it means we got to stand on those little red stickers in the grocery store in the bank and other places like that. We had for people first start going out into grocery stores and situations that they were most comfortable with, their favorite places. And we say let's go take a look at it and see what what has changed. We can't eat in anymore. We have to eat out unless there's an outdoor dining area. So how do we prepare people for that? For some situations, for example, we had a what we what we've been doing a lot is having what we call Person Centered zoom meetings, just one person and then their family and team. And we've sort of talked about what are they doing now? are they following guidelines or you know, what kind of things do we need to work on but then also giving some choice and saying from that person's perspective, however they communicate it, what do they want to do? What are some things that they really miss? And how can we make a plan for how we can assist people to re engage in some of these routines safely and responsibly. With Lou Jean, it was pretty easy. She says, I really miss going to the beach. But I'm told that since I'm in my late 70s, say I can't go anywhere. And it's like, well, if this is something that's really important to you and your quality of life, let's figure out how to do it. Okay, we look it up and it's still okay to go on the boardwalk. It's still okay, you got to wear a mask, you got to do social distancing. And the next week, great, boom, she's out doing it. So, again, safely and responsibly is really important because we have to make sure that that people have that dignity of risk, not that they're not following guidelines, but that they can still have a quality of life that makes life worth living. And that means things to look forward to, things we can put on the calendar. Maybe we can't go to the movie theater now, but Let's let's check in a month. And we want to be among the first people on that list and we want to

find out if and when the movie theaters open again, what are the guidelines going to be? Okay? Because there's going to be guidelines in each of those places. So, anyhow, the at the, at these zoom meetings, we try to focus on again, what's important to that person and whether they can share with us their team member their family, and we say great, how can we help them to achieve some of their, their dreams, some of the things they want to do, in spite of the covid. We want to help people to find their passion and channel that into meaningful projects or activities when faced with COVID restrictions. When when they've restricted other routines that have been essential to them. If people don't have replacement routines or things that they're doing that are meaningful to them, they are going to get depressed, they're going to get lonely, they're going to get they're gonna get frustrated, they're going to be lashing out at people. Whether it's behaviorally or verbally or what you know, with or without disability. It's really important that that people find some new hobbies activities that they can engage in and have fun. So, one of the thing that my wife Laurie shared is that while we, while we all spend more time completing chores at home, because we have a lot more time at home, it seems Let's be sure that we also look at Hobby development, interpersonal relationships, religious practices, political involvement and other ways to be more engaged. Okay, it's a good opportunity to help people figure out new essential routines. Also projects are important. This is Buddy Whitehorse. He used to work at the Japanese gardens but they are still closed down so he had does not have a job there anymore doing maintenance on their grounds that allow people to visit but due to covid that's still restricted. So it's been important for him to have other meaningful projects. He loves, you know, paintings so he's scraping some some wood and doing, he's going to put the primer on and repaint that he loves having projects, gardening, things that he gets to do with his hand, it's important that everybody have an opportunity to do things. We can't wait this thing out, we have to be engaged. So how do we help people to be engaged? This is Sharon, she feels safer at home. And one of the new meaningful essential routines that she's engaged in is writing thank you letters to first responders. And that's something that she does, she writes a few every day, and that's been important to her. And then uh, just to finish up with Melanie. Again, in order to recognize that our choices are empowering, they actually have to be empowering. If our requests and choices aren't acknowledged and nothing changes. Then we learn the methods we're using to express our choices are ineffective for change. So that leads to people us and the people we support resorting to other methods, oftentimes behaviors to express their preferences. And one of the things, Melanie has really been trying to work on a diet and she's actually figured it out during COVID. Along with her roommate, she focused on her weight during quarantines. She's lost actually over 26 pounds. Now she's up to 30. And she's doing a keto diet and planning things out. And that makes her more motivated to exercise, but she's really able to see the results. And that's something that's really empowered her and her choice making to really sort of make sense. So, finishing off something that Jose Perez taught me, who I supported for years is

that we always need to have something on the calendar to look forward to. Judy had shared earlier, she just was able to go on a COVID vacation and it was wonderful. We shouldn't stop planning things just because of COVID. We need to have things on the calendar that we look forward to. Okay, whether it's a safe and responsible eat out, zoom with family and friends, a vacation Otherwise we are going to feel sad and depressed. But we've we've got to help people get back engaged again in a safe and responsible manner. So hopefully that started off what everybody else is going to go into.

J Judy Mark 25:12
That was wonderful. Thank you so much, Scott. And I know a lot of people ask if we will be able to make your PowerPoint available and it will be on our Coronavirus website by tomorrow. So you will have that our next presenters, there's two folks who are going to present next, David Grady is from the State Council on Developmental Disabilities, regional manager of the Central Coast, as well as Priyanka Nookala, who is a self advocate who has been working with David on doing presentations around self advocacy. So I want to thank you both for presenting today and go, go right ahead.

D David Grady 25:55
Right, can you hear me?

J Judy Mark 25:57
Yes, perfectly

D David Grady 25:58
Great, let me move this, [unintelligible]. And does it look like a full size show?

S Sam Astle 26:09
it looks good.

D David Grady 26:11
Great. Okay, move this back. Thank you for that earlier presentation. I know we are busy so I want to get right to it. This is a although it's difficult time for our daily lives, it's, there are opportunities and it's a great time for education, a great time to meet with other self advocates and build the cohort and a great time to branch out. So today, Priyanka and I

are going to talk about how to focus in on the need for self advocates to gain some leadership skills. So I've been active in advocacy and quality assurance for most of my career. I've been able to visit dozens of care homes and day programs. And when talking to the folks at those programs and asking about self advocacy, I find that most advocates who meet in mostly these advocates meet in the home among themselves, they rarely Connect outside of their siloed service. Sometimes you'll see advocates on boards of directors but oftentimes I find they seem to be quiet and unsure of the issues on the that are being discussed at board meetings, unsure of what questions to ask or positions to take often just voting in the affirmative when emotion is made. An example is a group of self advocates have been very active in the Ventura region documenting some sidewalk repair needs in their in their in their near their day program. But they sent the complaints to the wrong department at City Hall and without that awareness, they weren't sure on how to follow up and so for several months into years, none of those complaints were ever acted on. So this is kind of some of the average observations I've made. Priyanka, why don't you share some of your obstacles that you've encountered as a self advocate?

P

Priyanka Nookala 28:15

Some of the obstacles that I've generally encountered, I would place them in two different types of obstacles. One would be attitudinal barriers where people's perceptions come in the way so a step to self advocacy is looking at working towards changing those perceptions. And that is a long process. But nonetheless, I think it is one of the one of the major issues that need to be worked on in terms of being able to navigate the obstacles that self advocates may be confronted with.

D

David Grady 28:56

Okay. Thank you. So as I said earlier, with, during this time of COVID, there are opportunities. And zoom has allowed us to make connections outside of our traditional boundaries. How has zoom affected your ability to be a stronger self advocate?

P

Priyanka Nookala 29:18

For me, it's been helpful because I've been able to attend more events, more activities, be more engaged, and also meet with self advocates, and individuals who might even be from different time zones, different areas. That would not have been possible if the meetings were structured in person. However, I do recognize that for some individuals, it may be difficult for the different methods of communication to be accounted for. So that's something that I try to be I try to be mindful of and think about as I attend these meetings.



David Grady 30:06

So it's a, it's helpful, but there are technical and communication needs that are kind of ongoing that we always have to address, thanks Priyanka. So it's natural for human beings to advocate for themselves. In our system, and in our developmental service system, it's endemic. All of our arrangement of services is through individual planning processes, IPPs and IEPs. The skill is from going from personal and self advo, or personal advocacy to the much more complicated community advocacy. And when shifting to community needs there'll be counterpoints, and counter arguments from those that we are trying to advocate to, that oftentimes our self advocates aren't familiar with, and are uncertain about how to respond to. And because despite the fact that these are self advocates with disabilities, those who have counterpoints might often employ typical strategy to silence self advocates, and Priyanka, have you, what are some of the pushbacks you've encountered as a self advocate? How have you dealt with being dealing with authority figures who have counterpoints or counter arguments to your needs?



Priyanka Nookala 31:27

Right. A lot of times from my personal experience, I've seen questions brought up about funding. I've seen questions brought up about, well, if, if you have a certain goal, oh, Priyanka, they would say to me, sometimes they would point to my age as the goal not being age appropriate, for instance, but sometimes some of the services and supports that an individual might need, like myself, for instance, starting those, starting to work towards those goals and those skills early on can be very helpful. But if, if the pushback is that oh well the age is not correct for the person to begin working towards the goal, then sometimes that is that is one of the major types of pushbacks that you might see or at least I have in my experience.



David Grady 32:28

Yeah,



Priyanka Nookala 32:29

Another one,



David Grady 32:30

go ahead.

P

Priyanka Nookala 32:32

Another one just relates to, because I am a person with a physical disability, sometimes the perception is that physical appearance or say, the use of certain devices the use of certain technology. Sometimes, people may form a false idea between okay if the person uses this technology Or their wheelchair is this size, that must mean that we can draw some sort of a conclusion about their ability to advocate for themselves their ability to exercise choice, and our our obligation to listen to the ideas being expressed by the self advocate.

D

David Grady 33:22

Yeah, it kind of brings up kind of one of the original points to me that it's oftentimes very subtle. One of my biggest frustrations is that passive resistive approach that authority figures might say that we'll look into it and get back to you in the future and then you never it's never gotten back to. So this needs to shift from individual advocacy to community advocacy requires the acquisition of skills. It requires instruction that includes the discovery of the issue the causes for the issue, developmental, because our developmental service system is so overly complicated and bureaucratic. The learning curve that we encounter the issues, the learning curve is often very steep. But it goes beyond just learning the issues. There's the need to improve our soft skills to motivate and influence others. This is public speaking, or message crafting and those sorts of things. And no matter what, if you're involved in self advocacy, fortunately or unfortunately, to change issues, requires changing policies and to change policies require attending committee meetings. So the basics of committee operations is needed. Robert's Rules of Order, for example, and how to speak up, how to show up and then how to speak up. And of course, no sad self advocate can work alone. And there's always a need to identify other cohorts, other members of your cohort to find support and to receive facilitation and So, Priyanka, when you as a self advocate, what are some of the issues that are you're passionate about? What is it that you've taken on as an issue of advocacy?

P

Priyanka Nookala 35:10

I'm passionate about issues related to education and help, you know. So that both in terms of the access and opportunity as well as addressing the disparities that occur in those areas, and that could be for individuals with and without disabilities, because I feel that a lot of the areas that self advocates work on part of improving self advocacy skills is being able to recognize how even for a single individual, we have multiple identities that we navigate, so to be able to understand how all those different pieces of our own lives intersect and then also hear other people's experiences to understand how we can find common ground and work with other individuals and work from a framework where it's

about transforming outcome for everyone. It matters for everyone, including people with disabilities.

D

David Grady 36:13

Great. Yeah. So not only is it the issue but also you seem to enjoy the the negotiation in the working together. That's a big part of it, too. I appreciate it. I hear that. In response to this need for education and for training and for building just the basic skills of self advocacy, Priyanka and I put together along with a few other advocates, a leadership workshop, and this leadership workshop included a program that covered five weeks of training with the intention of with at the end of the training, the intention was that each participant in the program created an advocacy action plan and the focus was on what what the person wanted to advocate on, how they plan to do that, and how much time they needed, and the supports they would put together. Some of the advocacy action plans could include joining the board of directors, or helping with fundraising, or building community awareness. Or speaking with legislators and other policy. We sent out an invitation that can be found at this link. And the invitation included this, these zoom meetings held over over five weeks. And then, so key aspects of putting this leadership series together included recruiting members, and we opened it up to not only self advocates, community and family advocates with the same expectations that they participate at the same level that self advocates, self advocates do. The training didn't end at just those five workshops. We did What we do now is we're following up with one on one interviews and helping each advocate draft their advocacy action plan. That's part two. And then Part Three is ongoing monthly advocate meetings. Now these advocate meetings are designed to, not necessarily to move forward. well, along with moving forward on advocacy issues. Other parts of these advocacy meetings are making sure that people are moving forward on their advocacy plan. And the committee itself or the community of self advocates are the ones who are encouraging folks to move forward on their advocacy action plan. So the primary message for me and Priyanka today to give to you is that we can never have too many self advocates. But in our developmental service system it truly isn't happening naturally. There's a need for leadership training and ongoing support. And what is required is our current group of self advocates need to coordinate and educate future self advocates by sharing this model with everyone. It will be a helpful guide for you during this time of COVID to maybe branch or branch outward and forward to maybe working with others to help build leadership skills, and Priyanka In conclusion, can you just share with us some of the benefits you had with participating in our leadership group?

P

Priyanka Nookala 39:18

Sure, the thing that I enjoyed most was hearing other people's stories and perspectives. And it can often be challenging or difficult for the person to describe issues that are personal to their lives or experiences that are both good and bad that they, how that helped you during advocacy workshop is, I think, being able to reflect that back onto ourselves and understand that we have some common fears and interests and hopes. There was also that aspect, but also being able to place all of the items that we're working on as advocates in a larger, you know, larger context and working on those issues as a process, understanding that it's not one solution, one answer. And maybe those those resolutions are not going to be soon or even in years or even in some of our lifetimes, but to be able to slowly work on those areas, and persist through that and be motivated to help each other.

D

David Grady 40:37

Yeah, that developing of a cohort. Thank you Priyanka. And thank you, Judy.

J

Judy Mark 40:44

Thank you so much. That was amazing. Priyanka, you were incredible. We're so happy to get to know you and hope to work with you again in the future.

D

David Grady 40:54

Definitely. She's got she's got an action plan that includes us.

J

Judy Mark 40:58

Awesome. Yay. So I would like to introduce our next panelist. Our next panelist is Charles Pakbak who is a self advocate. And we are so so happy to have you join us and I know that I've asked you to present and answer a whole bunch of questions, and we're going to let you take it away. Go ahead, Charles.

C

Charles Pakbak 41:24

My name is Charles. I am 15 years old and going into 10th grade. I want to thank you for including me today. I go to school at Excelsior Academy. It has been the best because it's helped bring more people into my life. At school friends walked up to me and talked. I liked finding news about them. The time spent there was much fun. Distance Learning has been challenging. Having mom and sister around is like an adventure day after day. Sometimes makes hometime really too much. However, my schoolwork has not changed.

We did a lot of work. I mean a lot. We finished the book Lord of the Flies, an interesting book for these times. But also I could make more comments with cabinet and just be more involved. Some teachers made all the students type their answers and that was great. Above all getting very bored being home not much contact with friends, because I cannot just call them. It is not just not going to school, but also not being able to have activities with them. We used to have four or five of us get together and go on hikes or play miniature golf and all of those activities are not happening either. Because it is not just us getting together but if parents can bring us together, I was asked to speak about advocating for myself. But it is hard to advocate when no one says what options are available for 15 year old minimally verbal person.



Judy Mark 43:19

Charles is are you Thank you, Charles. That was great. That was very, that was a really important point to make that it's hard to advocate for yourself when there are minimal choices for you. And really appreciate that point. And I'm going to move on to our next speaker who could probably address that. And that is Darlene Hansen, who is a longtime speech and language therapist working with so many people in the community for many decades to give, to help them create their own self advocates voice. And Darlene is now working with Disability Voices United and I'm so thrilled to say that. She is direct, co-directing a project for us called the Supported Decision Making California Advocacy Project which you will hear more about in the future as we move towards it. So I'm going to now introduce you, Darlene. And if you could press play on your slides so we can see just the slides that would be great. Oh, and you are muted Darlene too.



Darlene Hanson 44:24

hang on one second. Let me start over then. One second.



Judy Mark 44:27

Yeah I know sometimes when you go into zoom,



Darlene Hanson 44:29

I know it doesn't work.



Judy Mark 44:30

before you go into zoom sometimes and show

D Darlene Hanson 44:33
I'm sorry, guys. It's coming. Alright. And then I'm going to go to play from start. Yes?

S Sam Astle 44:45
Yes, that would be good.

D Darlene Hanson 44:48
I have to talk myself through this.

J Judy Mark 44:49
Thanks, everybody. And just to remind you, if you have any questions, you can put it in the q&a. And don't raise your hand because I will not be calling on you. But go ahead and put your questions in the q&a, and we will get your questions asked during that time. And I see Otto Sinc shout out from San Diego. Hi, Otto. Thanks for joining us participants in the many people who are on Facebook with us too Hello Facebook. Is it working Darlene?

D Darlene Hanson 45:26
Oh I thought it was but then I wasn't. So Hang on. Hang on. Sorry. Sorry. Sorry.

J Judy Mark 45:30
That's okay. All right.

D Darlene Hanson 45:34
I will do this.

J Judy Mark 45:39
Can you do play from start?

D Darlene Hanson 45:42
Is it right?



Judy Mark 45:43

No, no, it's click on play from start.



Darlene Hanson 45:48

Well, I thought I did.



Judy Mark 45:51

Now we're seeing everything on your screen. I



Darlene Hanson 45:53

know that I'm saying play from start. Why is it not listening to me? Sorry. Hang on one more second. Guys, I'm saying play from start right there.



Judy Mark 46:04

You were having the same issues that David had. No, it wasn't David David did it right. Yeah. David, if you have advice, I say,



Darlene Hanson 46:14

and this doesn't happen, right.



David Grady 46:16

It's time to knock on you need to. You need to stop share and reshare as a slideshow, from the from the slideshow just reshare it from the slideshow.




Judy Mark 46:31

starter slideshow.





David Grady 46:33


Okay, have a go now go to

 Darlene Hanson 46:35
bear with me.

 Judy Mark 46:36
It worked wonders

 Darlene Hanson 46:38
I don't see what you're seeing. But if you're seeing it right,

 Judy Mark 46:42
We are seeing it right.

 Darlene Hanson 46:44
Okay, cool. Hi. I'm Darlene and I want to thank Charles for joining in with us as somebody who uses AAC that's kind of my area of expertise and so you brought up some of the points I'm going to touch on here, Charles. And what I wanted to share today was thinking about the power in communication and building self advocacy because not everybody's an adult, or a young adult or even a teenager. And yet self advocacy doesn't just happen because you have your 18th birthday. And if you're specifically an AAC user, augmented communication, or someone who has limited communication skills in the first place, a lot of times we don't create that culture of communication. And so I wanted to talk about what kind of things we can do to support that as we move forward for individuals. So what am I hearing from people given this shutdown? As you mentioned, Charles, people are restless, people are bored. People are sad, people are frustrated. But then as we've been talking, it's been a time to change things up too. And so some of the things that have happened because technology is kind of I think, in some ways, neutralized situations, like you mentioned, Charles that you can chat, everybody's supposed to chat now. And you do that most easily in the chat features of the zoom meetings. So the the technology has almost neutralized things for some of the AAC users. And that's been kind of nice. The other thing, I think that's been, from my observations and opportunity for growth, not to say it's not been a struggle, but an opportunity for growth is that now the people who are closest to you, as the individual with the communication difference, are really getting to fine tune their communication partner skills, because they're spending so much time with you one on one. So that's been I think, a really Great thing for everybody that's involved, the families, the care providers and the person who does the speaking or the non speaking. So how is self advocacy important to people who do not use speech? It's the

same as it is for people who are speaking, for speaking persons. Self Advocacy is important. I'm going to, when you don't have speech though you're going to have no other option, but to use your nonverbal communication. And so if we don't create options for the limited or non speaking individuals to really fully express themselves, and to advocate for themselves, then we're going to end up with behaviors. We know that because, and I don't like I mean, I'm writing down behaviors, but I don't like the idea of behaviors really, because it's not, I don't see it as a behavior. I see it as you don't have another option you're just trying to express yourself. Um, but if I say behaviors, you know what I'm talking about. So that's why I put that word in there. So how do we build some of these self advocacy skills for for either young people or for older people who just haven't had that opportunity in the past? You can, you could and you should start building self advocacy when you start learning to communicate. I mean, that's what speaking people do. Speaking children are learning the power of No, the power of Yes, the power of wants. And not just in the sense that they make those requests, but also that they are learning what they can do for them. So what can we do to help build those self advocacy skills? We need to change our ways a little bit as the communication partner. So some of the suggestions that we give people would be things like don't rush everything. Allow some time to respond, allow some time for the person to process what is being asked of them or being proposed as an option. Not not just quick, fast, what's your answer, but let them give them that time to think about what has been said or presented their way. You want to teach yes and no, but I am not talking about yes and no in terms of is this a car? That's not what I'm talking about. Talk about yes, no, in real life. Okay. So for example, I do this a lot, where if, if you give a person Yes/No as a choice or if I'm looking at empowering communication, are you ready or you're not ready to interact with us right now? Either way, if the person says yes, which is often the case, because they're kind of prompted, they're kind of the it's not really identified for them as far as what's the difference between yes and no in their educational experience most of the time. They'll say yes. And then they'll kick you, for example, well, that's the time to step back and say, hang on that I think you mean no. And really teach that. No, that would be a no, that wouldn't be a yes. That we really do want to know. It's a real question. So you're teaching it in real life. And I don't think when when we problem solve these scenarios that come up on a daily basis, that we're really doing it any different than we do for a speaking child, okay, or speaking person who's having difficulty answering yes or no question. If they're confusing us, we say so. So teach us No in real life ways, don't teach it in just real kind of ways and it'll work it will make more sense to the person and you will get more self advocacy from it. Another thing would be choice Making Of course, we always have the choices available, but make them real choices and make the, this is one that often comes up, we oftentimes don't want to give the choice that we don't want to hear the answer to. So if your person really, really, really loves to sit on the couch and use their iPad to watch their videos, don't leave that out of the choices. Now, they may or may not be a good choice for the moment because you're all trying to

get out of the house to go, you know, to have a walk in the park or whatever. But it doesn't don't not leave them in the choices because it's going to be in their head and they need to advocate that No, I really do want to watch this video right now. And you can come back and you can say I understand that. Okay. So giving the choices but making again, real choices are a good self advocacy tool. I like to remind people not to ask so many questions, and instead use the phrase Tell me about, tell me what you think. So what's your opinion, those kinds of things, but I put it in the context of "Tell me about". When you start asking questions, you can lead a person down a path, that might not be the right option. And I'm going to talk about how to set up situations so that you can get an answer for a Tell me about, but get used to the fact that, don't ask so many questions, throw it back to the person to tell you what they're thinking. And you'll get bits and pieces of more quality information that way. Give information, a lot of times we just approach people, especially people who are using AAC with a bunch of questions, and we don't actually set it up as a context first. So that's not cheating. Set it up as a context. Gosh, you know, we've been thinking about we think it's about time we put a family weekend away on the calendar. It's not going to be for a month right now. But let's start looking at places to go. Some of us are thinking the mountains but then there's the beach. We really like that, don't we? And then maybe we want to go to the desert, you know, whatever your family's into. And so throw out all of the ideas and say so I'm wondering which one do you think would be fun? What would be your choice? So give that background information that's very different than just going. So where do you want to go on vacation? Okay? again, giving, ooh I got that in there twice. Sorry about that, time to respond. Um, provide the feedback, okay. If they say go to the desert, but they're the only person who wanted to go to the desert, then provide feedback. Oh, you want to go to the desert but, you know, the other four of us. Nobody wanted to go to the desert. So maybe we'll do that next time. Don't just walk away from the scenario. Because when you just walk away and kind of end the conversation for the person without any feedback. It's not it's not teaching or creating that culture of self advocacy. It's, it's it's kind of like Like not acknowledging that they had something to say. So provide the feedback and keep that conversation going as you would for speaking people. And then provide an opportunity to make the wrong choice and provide feedback. Sometimes your persons aren't going to make good choices. And that that's what we all do. So but provide that feedback. That's how people learn to self advocate. That's how speaking people learn to self advocate. And that's how non speaking people can learn how to self advocate as well. So when does this start? It doesn't happen overnight. Okay, you have to strive to create a culture of self advocacy, self advocacy within your daily lives. All right? So just every once in a while asking that question or asking for that input isn't really as powerful as including the person in the conversation, including the person in The discussion even or in the research part, so that they can be informed and a part of the conversation on a daily basis. So what should a what should your AAC include? Because I'm talking about people who have limited to no

speaking skills, right? You for sure why have yes to know on your choices? You want to have the choices, okay? You want to have the ability to make comments like, I think that's a great idea. You suck. I would never want to do that. No, I really want to go there. Or however the context goes for your family. You want to have questions, you got to have an opportunity to agree to disagree. And you want to put that kind of information on the communication boards. Don't sell your people short, even if they're using line drawings or photos, you can create Aa symbol that means the kinds of things that would be appropriate for the age and the conversation that you're having as a family member as a family unit rather. I tell people think of it as your opportunity to be like a screenwriter, you know, you're gonna think, Okay, what would I be saying if I was in this scenario, and then look at your displays and see if it's available. Now, sometimes you're going to bring it all the way down to two choices, or four choices, but make them important choices that allow the conversation to keep going. As a side note there, I love dry erase boards, because you can just draw out what you're talking about. Put some boundaries around it and the person can make a choice. Okay, so just including people will help with that empowerment. So what some of the things we've been having to support is anxiety. You got to in order to support someone's anxiety, you have to know your own stress. You have to acknowledge their stress, okay? If you're stressed, there's a good chance the person can be stressed for the same reason you're all living together, right? You're going to support their anxiety by providing the information, provide opportunities to engage in the conversation. And remember, your children, whether they be young or adults are listening. And if you think they don't understand, that can actually make things more difficult because that leads to confusion. So imagine if you're watching the news, or you have the news on in your home, and, and if I'm confused about what's being heard, and I only hear bits and pieces, I'm going to create some kind of other story in my head. Okay? And if we don't engage with individuals about what's going on in their environment, they're going to become stressed about that. So again, it doesn't have to be a fancy conversation, but have a conversation using whatever kind of symbol systems they can, that will help bring down everybody's anxiety. by everybody, I mean, the person in the family, people. support sadness. We're all sad. We're all bored. We're all tired. We're all wondering when will this end? And so we need to acknowledge that we need to honor it. And then we can go and talk about things like the other presenters have been talking about opportunities for some novel fun, you know, it's going to be in a different fashion, but it can be still fun. Remember that we have our own personal definitions of fun. So what's fun for you may not be fun for that person. So be a good listener. And sometimes you just have to sit and be, we're not all always happy, and that's okay. And I think we have to tell that to our persons too. Okay. Especially as a parent, you always want to fix things for your kid. But sometimes you can't and sometimes you just have to embrace the fact that this really sucks. So that's how that's supporting someone who's sad. You want to support boredom, we all can get bored even when doing things we like, after four months of the same. So

even though I like sitting on my iPad, doing my videos, I may be getting bored with this. Okay? So use some baby steps because sometimes those are like home sacred territories that people don't want us to mess with. So use some baby steps to provide some new opportunities. And for that, I would say using schedules. Just a little side note as a schedule. I don't think of a schedule as always the same thing. I think of a schedule as a place to get information about my day. I can change up what the information is, but I know I will always go to my calendar to find my day. It's not always the same. So sometimes we get confused, I think and think that people have to do everything exactly the same. And I know there are people who like things to be exactly the same. I'm not saying that's not happening. But if you use a schedule, sometimes you can get used to the fact that Oh, at 10 o'clock today that we have to change that up. At school people have been doing that. There's assemblies and things like that. So, use those kinds of schedules for that. And know that your child may have difficulty switching activities. Because initiation might be hard, so provide some support, they might not want to be doing the same thing every day. Okay? Again, these are all just ideas, baby steps may or may not work for you. But these are the kind of things I kind of throw through my head when I'm working with different teams on teaching communication so that we can get out of some scenarios that we're in. Finally take care of you. Remember, we're all in the same boat. So support yourself as well do something to feel a bit better about your day or week. And even these small opportunities, enjoy and embrace them, as they say, put your oxygen mask on first because we have to be good we have to be in good space in order to help people in a good way. And that is the end. So I'm doing this.



Judy Mark 1:03:17

Thank you so much, Darlene. That was amazing. I'm getting really great feedback on Facebook from people on this. So, once again, we will let everybody get have everybody will be able to see these presentations on our Coronavirus website at DisabilityVoicesUnited.org/CV for Coronavirus. Our next presenter is Samuel Astle. Samuel is joining us as a self advocate and he's got a really very effective screen you've got going on there. I like it. It's way fancier than the one I have. So Thank you for joining us, Samuel.



Sam Astle 1:04:03

With pleasure.



Darlene Hanson 1:04:14

Do you, you know, have something prepared ahead of time?

S Sam's Aide 1:04:16
He does sorry, we weren't sure if

D Darlene Hanson 1:04:19
you go ahead, go ahead with it, Samuel. Thanks.

S Sam Astle 1:04:24
Uh, well, home is so far the only place that was opened during the lockdown four months ago. Or should I say five? Also, I don't see my friends that often. Well, and yeah, I was doing chores such as taking out the trash cleaning dishes and vacuuming the floor.

S Sam's Aide 1:04:53
Do you manage frustration alright?

S Sam Astle 1:05:00
I also make YouTube videos and see my friends on zoom. And I've been asking my mother for favors. She teaches me how to make spaghetti. I'm speaking up the same as before March, I've always been pretty outspoken. While on zoom, I will say: I need help! I miss seeing my friends in person, and even though distance learning is necessary to keep COVID-19 cases down. I really want to see my friends back at school. Any questions?

J Judy Mark 1:06:06
That was great Samuel. Darlene, did you want to ask any questions of Samuel, I know that you had given him a bunch of prompting questions. So

D Darlene Hanson 1:06:15
yeah, hi, Samuel. So what I wanted to know from you was, how do you, do you feel? You said you spoke up all the time for yourself. And how do you kind of manage that when, with getting your other people to listen to you? How do you get people to listen to you? What do you need from us?

S Sam Astle 1:06:36

you don't talk while others are talking.

D Darlene Hanson 1:06:41
That's a good point. Are there ways, are there things that we need

S Sam Astle 1:06:45
That's a rule that I've learned in school.

D Darlene Hanson 1:06:48
Perfect. How about what do you need from us in order for you to feel heard? Can you think of anything that we can do that makes you feel heard?

S Sam Astle 1:07:01
You, you say my name, and I'll come.

D Darlene Hanson 1:07:06
perfect. Perfect. Have you had any

S Sam Astle 1:07:09
Or say, What's up?

D Darlene Hanson 1:07:11
Perfect. Have you had any examples where you really had to speak up because it just needed to change during this covid time?

S Sam Astle 1:07:20
Yes.

D Darlene Hanson 1:07:22
You want to share that? Is it appropriate to share?

S Sam Astle 1:07:25
I'm too lazy to share it.

D Darlene Hanson 1:07:27
Okay. All right, thanks. Is there anything else you want to say before we move on to the next speaker?

S Sam Astle 1:07:51
Also, I'm smart at writing stuff.

D Darlene Hanson 1:07:55
That's a good way to advocate too, perfect.

J Judy Mark 1:08:00
Thank you, Samuel. That was really wonderful. We so appreciate you joining us today. As always, we want to be led by our self advocates and use the advice that you provide us. And you were outstanding. I now want to introduce our final presenter who is amazing. This is Mari-Anne Kehler, who is a parent and the Vice President of Autism Society of Los Angeles, and has been like a role model for me on how she empowers her son to make choices from the youngest age and we use a lot of advice from her for my own son. So go ahead, Mari-Anne.

M Mari-Anne Kehler 1:08:38
Thanks so much. And I learned a lot that the best part of going last is I was jotting down a bunch of notes as I was listening to everyone and and thank you for that. As Judy said, Vice President of the Autism Society of Los Angeles board of directors. Thanks to Judy who She and I have been longtime partners in crime for all kinds of different things and and I think her group activities with DVU and all the things that you guys have been doing around self determination and other ways that we want to advocate for individuals with disabilities is one of the most important things that we have going on. There are too few organizations where I think that we put the self advocate at the center and at the core of the mission. So with Autism Society of LA what's been so exciting is that it's mission critical for us to advance self determination and a person centered life plan for individuals with disabilities. I too am a disabled adult, I have a lifelong hearing impairment. I typically read

lips for most of my life, so the mask wearing has been a little bit challenging for me and a lot of the communication has been hampered. So I very much relate to a lot of the ways that those of us that have a variety of different disabilities are challenged during this time. And I also have a chronic illness. So I share that because a lot of the physical distancing that needs to occur has been particularly impactful for us as a family and caused us to have to make certain kinds of decisions. But I think I'm here because Judy wanted a point of view on self advocacy in terms of what loved ones can do to make sure that individuals with disabilities are given the chance to self advocate. And I feel like it's important for me to say here that I'm not speaking on behalf of my son because he may have disagreement with some of the things that I'm going to share with you rightfully so he's got a, Liam disagrees with us a lot and my husband and I look at each other and say that's the outcome of raising a self advocate. he disagrees with us a lot. So we have no one to blame but ourselves for the disagreements that we have. So what I'm sharing I had about Liam I have his permission to share it, I would not share anything about him that I did not have permission to share. That's the very big point of encouraging self advocacy. But I'm sharing a point of view of my role. And and what I think is that my role not unlike my professional life, I my title in my my workaday life is Chief Strategy Officer. And I consider myself an advocate and an ally for those who have what I'll term as less power in the workplace. So just like other diversity, Equity and Inclusion issues, those who have less power in the world need allies like those of us who can to make sure that their voices are being heard. And that's a lot of what we heard on this webinar so far. I consider self advocacy to be a civil rights issue. I think that, in my experience, once you've kind of moved the veil away, and you recognize how individuals with disabilities are not allowed to self advocate, you can't help seeing all of the micro aggressions that are in you know, inflicted upon them on a daily basis, sometimes big and sometimes small. And what I have observed is that oftentimes, family members or staff members will say, Oh, you know, we're having a great day and then this behavior came out of nowhere. I don't know where it came from. But if we rolled the video tape back and we saw all the micro aggressions of ways that people's power was being taken away from them, we would see where the explosion came from. And it's kind of like a volcano where the tension is building up, and eventually it erupts. So when we say so and so has a behavior, I actually, we don't allow that terminology in our family. Because guess what, we're all having behaviors constantly. That's what we're doing when we're acting, we're behaving. And so I think it's a derogatory term that is condescending to someone who's basically doing something that you don't like. And the very act that someone is not allowed to do what they like is counter to self advocacy. So how do we fix that? I loved what Darlene said, and she said, You know, it's not like you you get the right to vote at 18 plus your self advocacy card, right? It's like, hopefully from birth, if we're doing it right for typical kids and anyone who has a disability, we're empowering those in our world to be the best they can be. That's basically all self advocacy means. So, um, when I hear loved ones say, Well, my child, you

could say that about your son or daughter, but my loved one is too disabled to be a self advocate. What I actually hear is I haven't established ways to facilitate that to flourish. So I have to take responsibility for how I can be an ally and an advocate to make sure that those around me who happened to have a disability or happen to have a gender difference or happen to have a you know, an ethnic background, that they have systemically been disempowered, that I have to figure out how I can give them that power, verbal or non verbal, physical disability or not doesn't matter. We're all having opinions, we're all having preferences. And, and self advocacy means that I have a right to express that. And I have a I have a right as a citizen, just like any other citizen, not more than the next citizen, but not less than the next citizen to have that preference provided to me. So Judy had asked, you know, what are what are some of the ways that when when Liam was young, that that we, you know, started that self advocacy journey, and that was Liam was diagnosed 22 years ago. And so I can say that my husband and I made a lot of mistakes and it you know, If we could go back we there were some very specific things that we would do differently. But we did the best we could with what we knew at the time, we got smarter, I would say as a family, but we also got smarter as a disability community. And we continue to do so in terms of, of how the civil rights of individuals are being supported. But we did Luckily, a few things right. And I'll share with you what our opinion is on a few things that we did, right. One was my husband right when Liam was diagnosed, set of family rule that no one was allowed to talk in front of Liam, about Liam without engaging Liam. So if Liam was in the room, no one got to talk about him as if he were invisible from age 2 when he was diagnosed, because there were a lot of doctor's visits and he was go into the speech and, you know, speech in this in that. So there were lots of times when there would be feedback. How did Liam do in speech? Well, he Okay, well let Liam's here. Let's get let's have a group conversation. Liam, how did you do? what, we go to a restaurant. What would Liam like? Well, I don't know. I'm not a mind reader, actually, Liam, what would you like to eat at the diner, you tell, and, and indicate and advocate and say, this may take a little longer because we're a little slow at making decisions. So if you could bear with us, or if you want to step away and come back in a few minutes, because it takes us longer to make some decisions. So how can I advocate and facilitate so that the individual with the disability is allowed the dignity of being a self advocate, and sometimes our own embarrassment, you know, if of a social or public situation causes us to disempower that individual, but I had a really great learning, which was, my elderly mom lived with us for a while. And what I discovered is that people cut her as an elderly woman a lot more slack for being slow in the community and doing certain things where it, the same, the same generosity of spirit was not always offered to Liam where we were supposed to kind of disempower him and kind of answer for him. So I thought, well, if they could be kind to my mom, they can be kind to Liam. So let's, you know, let's make this just a general family role that this is, you know, we're going to even the playing field here. The other thing and Priyanka mentioned this, which I love, which

was, how do we give choices that are real? And I think Darlene said this too. So sometimes what folks do and I think we do this as parents, if you have typical kids, you may do this as well, giving fake choices. So we'll say things like, are you ready to go to bed, which is really code for I want you to go to bed now. So if you say are you ready to go to bed and someone says no, guess what? That wasn't a choice. If you're not if you're not willing to let them stay up, so don't confuse someone by giving a fake choice. If it's a real choice, make it real. Or if you want, if you actually want a tricky parenting way, you could say, do you want to go to bed in 10 minutes or 45 minutes, it's still a choice. But you're giving some range there that can feel empowering. And the other thing is that we found that practicing choices and I think Darlene said this as well, practicing choices from a very early age. So even the most simple things like we would go drive into the store with Liam. And Liam, from almost birth has just had this very beautiful innate sense of direction. He could tell you how to get anywhere and he, he actually somehow he was born in New York, but we came here like he was one. So but somehow he knows north, south, east and west and he'll say turn West here and like no one on the planet that was any of his, you know, service providers knew what West was or east, you know, they'd be like, is it left or right? You know. But at a very, very young age, we would say to him, we're going to the store. And he would say, turn left here, turn right here. And there, you know, there were probably many ways to get to the store. And it sounds silly and it doesn't sound like a big deal. But even those small ways of empowering him to make choices from a young age, reinforced to him that he has power in the world, it reinforced to him that his voice had meaning and that when he contributed that other people were going to respond to that. Should we have chicken or beef tonight? if you don't care, you know, I mean, if that's not a choice, if it's like, Hey, you know, we have to eat the beef before it goes bad or whatever it is, you know, but if there are choices, why not engage your loved ones in that choice making? The other thing that we found and Samuel touched on this which I loved is Liam is verbal and vocal, but he has some inconsistency in his communication skills. And we discovered that writing was a really powerful way for him to express choice and express his contribution to his world in a way that vocally was a little less he was a little less confident in. So Liam started writing a blog many years ago. And and we, after he was doing it for a while we we kind of thought that we advised his support staff to not we really wanted the blog to be written by Liam and not by them and they said, Oh, no, Liam is writing it. And it was so advanced communication wise in relation to his verbal skills that we didn't realize that he had such a beautiful gift in doing that. So my point in saying that is as Darlene said, discover the mode of communication it's going to be different for everyone. Some of us are good verbal communicators. Some of us are good writers. That's just human nature. Some of us, you know, are artists and we draw, we can make a picture that beautifully depicts how we're feeling better than speaking or anything else. So during the pandemic, Judy had said, you know, can you talk a little bit about during the pandemic, what has been challenging, I mentioned that physical distancing, we I actually can't. So Liam lives

independently, and has done so for four and a half years. And he lives with 24/7 supported living staff. He lives two blocks from us, so we're very physically close to one another, but he has his own home. And so the physical distance we can, we have to remain, maintain a safe distance from one another he and I, because he has staff so his bubble's a little bit different than my bubble. And so that's created some, some difficulties. But the main signal that Liam was really having difficulty in the pandemic was that he had taken early on to sleeping all day and being up all night, consistently. So he would go to sleep about 5:30 in the morning, sleep all day, get up just in time for dinner, and stay up all night. And so folks would say, well, that's a behavior, how do we fix this behavior? And so our biggest concern was, were there, what are the practical issues? Is he getting proper sleep? Is he able to eat properly? Because if you're up from dinner to breakfast, like that's just kind of a weird thing, right? And so like, are you getting proper meals? and fitness is a problem, you know, because three in the morning, what are you doing, you know, how you working out at three in the morning, whatever. So there were certain practical things that we had to consider. But what we came to realize is Liam was a little bit ahead of the curve. Because if you're like me, the rest of us have gotten into these really weird sleep patterns during the pandemic, he was just kind of ahead of the curve. So what we realized was, there was no legitimate reason, if that was how he was coping, and what we realized was it was a coping mechanism to be awake during the least sensory intensive time of the day, and to be awake during the Did I say that right? So to be awake when it was least active in the world, and to be asleep when it was most active. And so that allowed him to better regulate his sensory system during this time of enormous disruption. And that we wanted to honor that. And so another example of you know how something is actually a coping mechanism and not a behavior is his, his service provider, his support coach, had said mentioned that Liam wanted to take a shower, you know, in the middle of the night, and she had said, No, but you know, when you get up in the morning, you could take a shower, and we said, Why? And she said, Well, I don't know. So we're like, Well, you know, sometimes when someone has a disability, we want them to do something that is conforming to what we've, we think our job is to, is to have someone conform, as opposed to really thinking about, is this a problem or not? And if that thing is not a problem, who cares? I mean, frankly, you know, my husband might take a shower at one in the morning because he has insomnia and he you know, it helps him sleep better. And no one is preventing him from doing that. And so I think, for us to step back and say, why are we really trying to change An action and is it a behavior because it's inconvenient, which is not something that doesn't need to be considered. But is it something that we can negotiate? Is it something that we can work through in a meaningful way? and tied to that, I think that what we have found is that we were very concerned, we watched the news, we, we're tracking the fact that I think it was Samuel that corrected himself and said, Oh, my gosh, it's been five months, not four months, right? Like this thing is like this endless tunnel of when is the world going back to normal, right. So my husband and I were

having this conversation and I said, What must it feel like to Liam? If he doesn't, if he's not watching the news, and staying as closely tied to the facts of the pandemic as we are? How do we need to let him know it's not an endless tunnel? That this is not you know, that he can have some control. Because what we know, if you talk to people who are experts in trauma, this is a trauma that a lot of us will have imprinted on us. The best way to address trauma is to increase control, which is why Judy is having this session today, the more we can increase an individual's control and self advocacy, the more we can lower PTSD or traumatic experience in relation to a difficult situation. So we realized that we needed to update Liam's knowledge, who what Darlene said give information, right? So what information did Liam potentially not have that we needed to give him so that he could have a framework and a context for what is going on here. Right? So we built a plain language booklet that laid out okay, it's been just like Samuel said, It's been four or five months. These are all the ways that our lives have changed. And these are some of the challenges. And then as Darlene said, honor the emotions of sadness, dread, frustration, boredom, whatever it is don't try to I heard someone call something What was it called jolly them along, you know when you give bad news and it's like just jolly them along, you know, just like well, it's if you think of you could do fitness you could go on a diet. Think of all the good things about, forget it, people. There's nothing good about this pandemic. You could jolly it along all you want. It stinks, right. So the booklet was in plain language to say to Liam, here's what's going on. We think it's going to be 2021 until this darn thing is turned around. It's the, we're looking for a vaccine. We have an election in November. You know, what are the things you can control and can't control. You can't control the virus, but you can control your health, you can control how you how you interact with friends, you can stay healthy. And so we put in the booklet all the things he can do, including vote in November. And then what will 2021 likely look like? 2021 will probably have a vaccine, we can potentially going back to a little bit of normalcy. So those are the things that I think, inject as much control as possible. Sharing bad news is scary. The intention is to protect someone that you feel like you don't want to give bad news too. But the actual outcome is that you're eliminating their ability to be self directed because you're not giving them information. And then finally, Judy had said, What about staff? And the final point that I would make on that is that it's, it's understood on Liam's team that he is The boss and that they are actually his staff members. They're, they don't, they don't report to the parents. I'm an advocate. I happen to be mom, but they support Liam. Liam is the boss. And therefore their role is not to be surrogate parents. Their role is to facilitate as advocates for him to be supported in the things that he can do. So Judy, that's, that's, that's it.



Judy Mark 1:30:26

That was amazing. That was such great advice. Everybody has given such incredible advice. People are saying they love your honesty, Mari-Anne, and everybody has been

great. And I want to get to some questions to everyone, for everyone. Um, one of our wonderful self advocate board members asked something in the chat that I want to make sure I get to before I get to the q&a. Um, Eden asks, even though we are far apart, how would you, How do you stay productive when you don't feel motivated? Because I have friends on Facebook that are beginning to feel not useful in their everyday lives. So I wanted to first ask that question to Priyanka to Charles, if you want to think about that, how do you stay productive and motivated during this really difficult time? And then we'll ask the other panelists to maybe give some suggestions as well. Priyanka, do you want to start?



Priyanka Nookala 1:31:25

One of the things I do for myself is have a schedule of each day's items but also, if I don't get to everything on the schedule, that's okay. If I did something that was not on the schedule that I still want to acknowledge myself for doing, put it on, put it on the schedule or imagine that in my mind that it was on the schedule so I can feel recognized myself for doing that accomplishment. Another thing is, for me, I find a lot of support in my family. So maybe at the end of the day, there's things that are unresolved in my mind, talk it out with the family members. Have virtual activities with friends, maybe once a week, if my schedule has availability to do that, and if they're available and just make it a purely fun activity, where there aren't any expectations other than fun.



Judy Mark 1:32:45

Great ideas, Priyanka, I believe that Charles is typing his answer, so why don't we ask Darlene, Mari-Anne, Scott, David, if you have any suggestions for remaining productive during this time and then we'll go back to Charles. David's saying no, I'm not productive at all.



David Grady 1:33:09

I just want to point out I think I read the question in the chat as well. And I kind of focus in on the motivational need.



Judy Mark 1:33:15

Yeah.

D David Grady 1:33:16
And just remember you, we have thoughts, we have feelings and we have behaviors. So if you don't feel motivated, and if you think you can't do it, you can just do it and eventually your thoughts and behaviors, your thoughts and feelings might come around to the fact that you're doing so I love a lot of the thoughts, a lot of suggestions that Scott made in his presentation and even if not feeling 100% willing or wanting to do it. Take advantage of Priyanka's idea about a schedule and then step by step do it even without wanting to

J Judy Mark 1:33:52
Good idea. Mari-Anne, or Darlene?

M Mari-Anne Kehler 1:33:55
so I was just gonna say like like Priyanka, I'm a very personally a very Schedule driven person. And I find that I can motivate myself by trying to create structure. Liam tends to be the same way, you know, like, give it a structure and then and then it goes from there. But I have to say at this point, I've, I've made my goals really modest. It's like I want to get through this pandemic, with really modest outcomes of health and happiness. And anything that has to happen between now and then, to achieve that, I think part of the the challenge comes when we think we're supposed to be doing more than we actually can during this time, because the stress comes from pretending that it's normal when it's not a normal time.

J Judy Mark 1:34:43
Exactly. Charles Have you, would you like to say something? Go ahead.

C Charles Pakbak 1:34:50
Paul's type motivation is hard. I asked for time and a schedule. I try to exercise and swim every day.

J Judy Mark 1:34:59
That's great advice. Yeah, I've been trying to tell folks that you've got to really schedule me time every day, including exercising, including taking walks. This is my backdrop from my trip to Yosemite, or Yosemite, depending on how you would like to pronounce it. But really going and trying to get away to safe places. Scott?

S

Scott Shepard 1:35:23

Yeah, I, I think that even pre COVID it's so important, especially in my area, supporting adults, to make sure that everybody has meaningful routines every day, and that they're involved in choosing them. But one of the things we let people know you say, Hey, you know, we, we care about you enough that it's, we got to let you know, it's not okay not to do anything. Okay, we've got to do something. And if we need to nudge you a little bit, you know, to get you into a healthier routine, we'll do that. But then we want you to at least experience some things so that you can, you can express your own choice then about what you want to do. I know we have one gentleman on the spectrum that his mom set up a real good plan for him that really helps set him up. For now living in his own place. He actually is a homeowner based on his job and stuff. But one of the things she told him is that you have to try things three times before you can say no, because you always say no the first time. And sometimes you just need to try a couple you need to try it a few times. And after the third time, you still don't like it great. You can say no, but you need to experience it sometimes before you can make that really educated choice about well, maybe I did like it or maybe it wasn't so bad. Great. And you Darlene, did you want to add something?

D

Darlene Hanson 1:36:40

I was just gonna add that I think it's um, my observation has been it's been helpful to keep some, because it's hard to plan for the future when everyday is kind of blending into the sameness, right? So if you can mark time in some typical fashion, so like weekdays are weekdays, and weekends are weekends or don't forget your holidays or people's birthdays like I've been doing. I'm pretty sure I'm gonna forget to decorate for Christmas. So because it's, it's, it's just hard to mark time. And so that becomes not very motivating because you think I don't know, I'm just gonna wake up tomorrow and something's gonna happen. So find some way to mark time for yourself and make things a little bit different that kind of makes it a little spicier for us. I think.

J

Judy Mark 1:37:27

That's great, spicy. I like that. Alright, I'm going to add, here's a couple more questions people have. This is for Priyanka and David, where are you doing your leadership program? What are the plans to expand?

D

David Grady 1:37:44

We're, we're, we just completed our one in at the end of July and we're actually doing our

face to face interviews and going to start setting up so we are beginning to have the conversation about when to do it again, and it's going to be online. Perhaps I can get the message to you, Judy. And you can send it out. And we'll try to get a whole bunch of folks involved. It's a model that's repeatable, we Priyanka and I, this is our first try at it, and we felt it was really successful. So now we want to repeat it.

J Judy Mark 1:38:14
That's great.

D David Grady 1:38:14
And for those so for those family and community advocates who join, you have to add to your action plans that you're going to start your own leadership training course as part of your action plan for self advocate.

J Judy Mark 1:38:29
I love it Priyanka?

P Priyanka Nookala 1:38:32
Yeah, that is one thing that I did want to add for people who had come as participants who are not self advocates, as Mr. David Grady mentioned, to make sure that as part of their action plan, they're including self advocates or even earlier than that, to be able to invite a self advocate because even if a person is not able to attend the workshops all the way from the beginning, it's structured so that each week is a topic, participants are encouraged to attend all of the sessions, because that helps with some of the connections that we had discussed and that we had developed. But even if people join later on, that is okay too.

D David Grady 1:39:29
Once you're, once we get you, we're not letting you go.

J Judy Mark 1:39:32
That's great. And one of the one of the few great things about this pandemic, and there's very few, is that you would probably be doing this leadership training in person in just your area of the Bay Area. And now really, any of us around the state can join you. So so that is

a great benefit. And what I hope comes out of this pandemic, that's a good thing is that we'll be doing more of these kinds of trainings online, so that people don't necessarily have to be in your area and can take advantage of things. Um, I there's a question for you, Charles. Um, do you feel like your friends without disabilities understand your life a little better and interact with you a little better now that they have to learn how to do everyday things a little differently?

C

Charles' Mom 1:40:20

He wrote, I get to see them not very often, they can get together but I need someone with me to get together with them. I do think they try to understand my life. Not that they can.

J

Judy Mark 1:40:35

That's That's great. Yeah, that is that is a theme I've heard before. Um, here's a general question. You know maybe this is a Priyanka question and Charles question, but I think anybody can answer it. This is from Daniel Garcia. Do you think it's important to go to local and county meetings like city council meetings Commissions on disability, I don't see enough self advocats interest in using this market of ideas to express our concerns. So how should we be getting involved in local sort of government agencies that either work specifically on disability issues or just generally a local level on accessibility and other things? David, did you want to take that?

D

David Grady 1:41:17

Well, I would say the answer to the question is yes, but come with a message. My my, I think there's a tremendous need to inform every level of, of policymakers about housing for folks. But it's a very complicated message that we need to send. And so in terms of housing, put your message together so that it is that we inform our policymakers of the needs of people with intellectual and developmental disabilities. And that I think is what's missing. Oftentimes, we do legislative visits or go to Sacramento and we say Please give us more funding. And that's when we get that answer. Yes, we're very happy to help and we'll get back to you. But that's happened for a dozen years now. And there's been very little increases in funding and a steady decline. So again, we need to be have a message and make it a little bit more thorough. And that's why you probably want to align with other people to learn the issue in more detail so that when you do go to that meeting, when you do meet with that, policymaker, you, you have a good presentation to tell them what you what's needed.



Judy Mark 1:42:33

Great. Priyanka, did you want to add anything to that?



Priyanka Nookala 1:42:38

Yeah, I would just add, if someone did make a presentation, to be able to give your feedback after the presentation, that here's how I will get in touch with you because sometimes the person who you gave the information to, um, has a difficulty getting back to you either because of time or other things that are going on in life or they don't see it as overly urgent. But if you say, Okay, here's how I'm gonna get back to you, then that many help facilitate the discussion.



Judy Mark 1:43:25

Thanks, Priyanka,



Darlene Hanson 1:43:26

I think I think for, it's important for us to be included. I mean, we've been talking inclusion for many, many years now. But so some of us, some of the discussions are separate and they're about things that we specifically need, you know, we specifically need certain kinds of votes and fundings and bills and things like that. But the reality is that when they start talking about like David and Priyanka are talking about community situations and community events and community experiences that need to be discussed for people with differences and disabilities to step up and say, and then here's how we fit into this picture, rather than making our picture separate. It's how much we're having a conversation. And we live here too.



Mari-Anne Kehler 1:44:17

Yeah, that's the view that I have too Darlene which is it's not so much what are the disability issues that we need to support, as it is How do we make sure that representation for people with disabilities are being contemplated regardless, regardless of what the issue is, and I think that representation because of the difficulty for people who are disabled, to to be present and participate, there can be so many barriers, that it tends not to be representative. I mean, when you have one in five Americans or one in four American adults being disabled, you know that the numbers are not representative in terms of the ways that that were showing up at these places that you're asking about.

J Judy Mark 1:45:05
Thank you. Lorna. Do you mind there's a question in Spanish and the q&a from Maria Rodriguez, would you be able to look at that and translate that for us? And while she's doing that, if you could all look,

L Lorna Silva 1:45:26
Judy, can you hear me? I am trying to find the question.

J Judy Mark 1:45:31
Yeah. It's, um, it's the third question in QA by Maria Rodriguez. I would say it but then I'll pronounce the word wrong and then everyone will make fun of me.

D Darlene Hanson 1:45:44
We will.

L Lorna Silva 1:45:46
I think. I think this is the question how effective is how effective are speech services by zoom when my child is not verbal and uses an AAC?

J Judy Mark 1:46:01
Thank you so much, Lorna. Look, Darlene, do you want to answer that? Maybe Charles can, too.

D Darlene Hanson 1:46:07
Yeah. I'm doing a lot of services via zoom with AAC users. And I think the thing that's coming out that I like the best I think I mentioned this is that the communication partner so you the mom, for example, assuming you're the mom are learning to use the equipment to set up the communication and how the people at school for example, are helping to teach your child how to use AAC. So now you're learning it and you're with them way more than a school system person is especially right now, but always, right? So don't discredit the zoom appointment. Now your appointment might not be an hour long. Let's say you have an hour worth of services written into the IEP, that might be too long for you and your child to stay online. Working with a device and a zoom meeting and that

kind of thing. So you might need to modify the time that you meet together. But take that opportunity to learn more about the equipment about how to communicate via communication partner, because you're gonna you guys will grow as a family that way.



Judy Mark 1:47:19

Thank you. And I can say that, you know, a lot of people started out with the with, you know, kind of being nervous about doing some of this stuff online and have found it to work better than they could have imagined. Charles, did you want to respond to that as well?



Charles' Mom 1:47:37

He wrote, zoom helps because we're all typing our answers, I think he means we're all typing our answers. And as his mom, I would just like to say, if we're actually working on speech, then you can go back and make him say those words out loud again. And that might help too, because you can mute yourself while other people are typing



Judy Mark 1:48:01

Great, that's a great suggestion. I like it. Um, so here's a question for Samuel. He had to leave. So Charles, I'm going to pose this to you, is online an easier way to communicate than in person and why do you feel that? So is online an easier way to communicate than in person? And why do you feel that? So while you're answering that, Charles, I'm going to move on. Mari-Anne, you have a couple of questions here. I love your view on the empowerment. Do you have any suggestions for how to move City County state agencies to better involve self advocates in broader decision making related to policy similar to the question that we were asked earlier, but and this could go to every one as well. But go ahead, Mari-Anne?



Mari-Anne Kehler 1:48:49

Yeah, I think you know, that's what I thought too Judy, is that it's similar to the question before, but what I would say is, I would almost toss it back to you about self determination because what I have found is that it's actually very difficult to to align with organizations that have the kind of philosophy that we're talking about that are really, most will say they are because intellectually who thinks that they're not all for empowering people with disabilities, of course, but there's unconscious bias around what we're actually doing. So I think the question is really wise, which is, how did the self advocates themselves get involved in in Policymaking to be able to change that? And who

else has a point of view on that, Judy, because I think it really ties to self determination.

J Judy Mark 1:49:44
David?

D David Grady 1:49:45
I would encourage people to look at advisory committees here in Santa Santa Clara San Jose. There is no person with an intellectual and developmental disability on the In Home Support Services Advisory Committee. You can imagine that those that that advice going up to the county doesn't include our point of view. advisory committees are somewhat informal. If you get someone who can maybe work with you as a help you with that committee, it can be very helpful. And most of these public agencies have an advisory committee to get involved. Same true with the medical or other types of services.

J Judy Mark 1:50:25
Thanks, David. Anyone else want to comment on that before? You know I, oh Priyanka? Please.

P Priyanka Nookala 1:50:32
I would just like to add that with agencies and other individuals who are involved in supporting people with disabilities and providing services, I think a lot of the things goes back to some of the ways that they open up those conversations with the assumption that the Individual that they're supporting is not actually participating in the conversation and having assumptions about what the person wants or needs. And then also saying, Wow, another individual who we worked with did this this and this and this is what our agency does, but I think recognizing that each person has, as we've talked about today a lot, needing those Person Centered supports. So there's not one answer for every person. So saying, Okay, these are the things that we do and you're asking for something that's not in that list. That kind of approach is also something that I think we need to work together to change.

D Darlene Hanson 1:51:52
Priyanka, I couldn't agree more and you made me just think of something which was, you know, I think that we have to be loud About demanding what you just suggested. And I think Unfortunately, the answer is just like David said, where this is not occurring, we need

to say that that's unacceptable. And whether it's self advocates demanding it, or whether it's allies demanding it, we have to be unified in that. And I'll just share a personal story, which was a CEO from a very prominent disabilities organization. who I think is fantastic, right? Absolutely fantastic. asked me to go out to lunch, to pick my brain on strategy for how to build on board development. We need more board members, can you help me figure that out? So we had a great lunch. I do strategy around for development and other kinds of things with nonprofits. And so I said, How many self advocates do you have on your board? And this individual said, Oh, probably at least a third of the board members are parents. And I said, Oh, no, no, that's not what I asked you how many of the board members are self advocates? And she said, Well, like a third or, you know, are parents and family members. And I said, you're not hearing me how many zero self advocates? So I said, well, you need self advocates like this is unacceptable. You have no self advocates. You're a premier organization, that is like renowned, and you have no self advocates on your board. And this person said, but how? How can we have self advocates on the board? these are like, so. So and this is not a bad person, right? This is not a bad person. But this is a person who is ignorant to the fact that that is not acceptable, and that is not factual. And so as allies, you know, we need to push the envelope and say we demand this this is not acceptable behavior.



Judy Mark 1:53:59

Yeah, you know, I would also add that I was on a call call and meeting a very, very large meeting yesterday. And Senator Tammy Duckworth was the speaker on the call who, for those of you who may not know her, she's a US senator from the state of Illinois who was lost both of her legs in a while she served in the Iraq war. And so she uses prosthetics and she also uses a wheelchair for her mobility. And she she was asked a question by a, was it was about disability by a by a self advocate that she had here. She is a self advocate and also a US senator. I've never thought about this. She was asked a question by a self advocate. It's like why don't people more people with disabilities run for public office? Whether it's school board or whether it's president or anywhere in between? Why don't people with disabilities run for office more? And she thought about it for a second and she thought about the fact That when she ran for Congress for the very first time, she, she got tremendous support from the women's community. And there's actually this women's organization that she talked about that helped her give early, got her early money, trained her in how to be a good candidate, advertised for her through to a whole bunch of traditional donors. And there's nothing like that in the disability world, which is, which means that we don't even have a voice like we don't even have that kind of political organization, regardless of the political party. And we know people with disabilities have been in office. President Roosevelt had polio, you didn't see him a lot standing up, but we know people with disabilities have been president. And we, you know, I think that that's a

really important thing that we shouldn't say, well, a person with disability just has to serve on a commission but they could also maybe run for that commission or they could run for county board, or they can run for state legislature or anything and so I think we have to start thinking in different terms that it's not just about self advocates just advocating within our own community, but also representing the broader community as much as we can

M

Mari-Anne Kehler 1:56:12

just Can I just end on a happy note with that is that while we're talking here I got a text that is part of Priyanka's Leadership Program we'd like to have her do a training for an executive director of a program just texted me and said, Could Priyanka do a training for our staff? So Priyanka we got a job number two, you and David so keep and Priyanka gets to keep David busy.

J

Judy Mark 1:56:40

All right. That's wonderful. Charles, did you want to answer the question is online and easier way to communicate that in person and why do you feel that?

C

Charles' Mom 1:56:52

When Mari-Anne was talking Charles typed to her, glad she gives her some time to be himself, so I just wanted to let you know that he wrote, yes, it's good to be able to type people are more forgiving and wait for answers longer than they would if they are in person.

J

Judy Mark 1:57:12

That is a really excellent point. I mean, we you know, not that we want to stay like this even for another minute, but there are some things that I think we've learned during this coronavirus pandemic that I think we should take with us when things finally open up. And we're almost out of time so I'm going to go with the last comment from Gabriel Douglas, who said I like when Mari-Anne talks about Liam voting, I am voting too. And that leads me to just say finally that this is at least for a while our last Coronavirus webinar, and we're going to send out an email to those of you on our mailing list and please be sure to get on our mailing list which you can do by going to Disability Voices United. org and we are really shifting as I said at the beginning, in case you weren't there, we're really shifting right now to focus on the November election to empower people with disabilities and their families to fill out the census to vote to to understand what it means to vote by

mail to understand that some very complicated issues that are on our ballot through propositions for this year, as well as to understand where the candidates fall on the issues whether it's state legislature city council up to the President, where they stand on the issues that we care about here in the disability community. So we are taking off next week for a webinar as we shift the organization over to our new priority for the rest until early November. And we will return on the 20th of August with a webinar on the census and how important the census are is, if you haven't in fact on Right now if you have not filled out the census form that you've received, we've just found out that only 65% of Californians have actually filled out their census form. And that's a very big problem because you'll learn come back in two weeks and you'll learn all about it. So I really, really want to thank all of our panelists, Scott, David, Priyanka, Charles, Darlene, Samuel and Mari-Anne, you were amazing. Thank you to all of you who've been joining us over the Oh my god, it feels like five years but it's only been like four months that we've been doing these webinars. I know more about Coronavirus than I ever ever wanted to. And I thank you all and we so appreciate you and we'll see you in a couple weeks. Take care bye bye