Welcome, everybody, to the Disability Voices United townhall for self advocates and family members to give your voice to the prospects of reopening group programs and other kinds of programs in the Developmental Services system in the state of California. My name is Judy mark. I’m president of Disability Voices United and also a parent of a 23 year old son with autism who is in the self determination program. Yay, and served by Westside regional center. We have a really amazing group of people to start our conversation today. But this is really about you. This is about all of you who are family members and self advocates who I have the right to have your voice heard on what’s going on around you today. And your willingness or your worry or your concerns about moving back into the community as California reopens many segments. So just a little bit of background.
because of the governor's order to not have people in groups congregate together. Um, and I you know, so just like restaurants were closed or stores were closed we, the these group programs have to be closed. Many of you might have been personally affected by that. And whether your program was shut down or whether your your family members program was shut down. We are. We are now entering a stage where we’re reopening a great deal of California, you can have your opinion about whether that is a wise thing to do or not. I certainly have my opinion. But regardless of whether we’re opposed to or not, it is happening. We’re seeing it deep in our communities. We’re also seeing a lot of people being really irresponsible by going to restaurants without masks or going to malls without masks or, or, you know, walking down the street. And, obviously, we strongly urge you and we’ll talk to you a lot about the fact that we all need to remain safe and we all need to stay at home as much as possible. And but we know that people want to go out there in the efforts to move forward and the efforts to figure out how these programs can reopen on the Department of Developmental service. It’s been in discussions with a lot of providers, regional centers. And now they’ve been really asking us to add self advocates and family members what our thoughts are. You should know that some of these group programs have been getting paid, even though they haven’t been able to provide the trade the services, as they traditionally have done. It’s a little bit complicated. It’s called they’re getting paid for absences. I think as families and self advocates, we don’t have to know all the details. However, that ability to continue to get paid, even though they’re not providing the regular types of services is going to end it was supposed to end on June 30. And now it’s going to end at the end of July. They’ve extended it one more month. So service providers are obviously extraordinarily worried that they’re not going to continue to get paid. And they’re wondering how they can go back to providing services. At the same time. There’s a whole lot of us who are really worried about going into any kind of setting that is congregate and kind of group setting. And so we’re, we’re really worried about that. So this this town hall as part of our effort to get that information from you on what your concerns are, what your beliefs are, and get that information back to the regional centers, and I’m sorry, back to the Department of Developmental Services, so that DDS can hear from you directly. So just a couple of ways we’re going to hear from you. And I’ll repeat this again, after our presentations, is that you’re going to be able to give your comments in in the chat. But you will also going to be able to give your comments in the q&a. So if you go down to QA, you’ll be able to see that at the bottom of your screen. It’s really for me the best way to ask a question, because I’ll be able to monitor that. And when that question is asked, I click that it’s answered and I’ll be able to tell that I’ve that I’ve gotten to all of your questions. The chat is constantly moving. So that was will be a little bit harder for me to monitor but I do have people who are doing that for us. The final way that it is very different than we've ever done before is that we’re going to allow you to speak on this webinar. And you’re going to do that by raising your hand raising, you’re not physically raising your hand because I can’t see you. You are
going to go down to participants, click on participants, then you’re given an opportunity to raise hand and I will see your hand raised and I will call on you and then add our fabulous program assistant is going to make you a presenter so that you can ask your question or give your comment. You do not you could absolutely have a very strong opinion. We’re interested in that. And then after you provide your comment or question, we will put you back in as an attendee. I will repeat all that. But before we move on, I want to introduce our amazing Spanish Language Interpreter Lorna Silva, who will explore For those of you who need Spanish interpretation, we have a different phone line for you to get that interpretation. So go ahead Lorna.

Lorna Silva  06:09
Better left personas Kia Lang espanol Estonian soon. Willing damar ile cinco cinco into you know dos cuarenta you gnosis antitrust vs. But as we travel interpreters to simultaneous manual dinner we know Mary’s cinco cinco Quinta, you know, dos cuarenta you know, Sisson, Piper is the ES necesita Codex. So gracias.

Judy Mark  06:30
Thank you. Thank you so much. All right, so we’re gonna get started with the presentations. We’re really lucky to have our three presenters today. They’re all experts in different ways, and also really, really amazing human beings. And and love working with all of you. So our first presenter is Dr. Clarissa krupke, who first and foremost is a mom of an amazing daughter who has actually been doing some pretty amazing things during the code. been shut down. And you’re welcome to talk about better not know if you have our permission or not. But, but it’s also a developmental physician at the University of California, San Francisco, Office of developmental primary care and has, I think, a pretty extraordinary presentation for you. And I hope you’ll all pay careful attention. So go ahead, Clarissa, thank you for joining us.

07:25
Thank you so much. I’m gonna share my screen now.

07:34
There we go. How does that look?
I'm going to talk about reopening programs that bring people with developmental disabilities together for in person, indoor group activities. Site based programs and I'm talking about are things like day programs AMS, sheltered workshops, indoor group employment or social skills groups. I'm going to speak bluntly, because there's so much missing information out there. It's very easy for people to be confused. And frankly, this is life or death. The decisions that we make as individuals and as a community are going to save or cost thousands of lives. It's important that we have our facts right. And I recognize that some of what I'm going to talk about may be quite hard to hear. I have no financial interest to disclose. Although I'm a family physician who takes care of people with developmental disabilities and I'm a parent. We all want to support people with disabilities to direct their own lives. Anyone who provides or fun Services has a competing interests with the person served The needs and perspectives of all people who provide and fund services are critically important but they need to be considered separately. competing interests need to be acknowledged and managed. We're in this together for the long term. The needs of families are important. The needs of service providers important. Laws, regulation, and limited resources are important. And the needs of people with disabilities are important. We need to find solutions that meet everyone's needs. decisions about services should be person centered and uncoerced. But in this unprecedented pandemic, all of our individual freedoms and choices have been restricted, because we realize it's necessary for the common good. We are interdependent. A community that leaves even one person behind is no community at all. Regional center clients are at high risk of severe disease or hospitalization, even if they don't have any underlying Heart, Lung, kidney or liver diseases. However, most people with developmental disabilities have additional risk factors such as older age or chronic illnesses. In addition to their disability related risk. their caregivers are also at higher risk of COVID-19 due to their close contact. In this slide, you see the CDC definition of high risk for disability. And on the right side, you see the definition of developmental disability per the lanterman Act. And you see that they're basically identical that if you meet the criteria for developmental disability, per the lanterman Act of your regional center client,
then you also meet the CDC definition of someone who is at high risk of severe disease from COVID-19? What is the data show? reporting is incomplete. But there is enough data now to know that people with developmental disabilities are not just theoretically at higher risk, but they are getting sick and dying at more than twice the rate of the general population. In New York, it was five times five times the infections and five times the death rate. Is it safe to return to our previous life? there's currently no specific Food and Drug Administration approved treatments for COVID-19. there's currently no vaccine to prevent COVID-19 treatment is currently supportive. That means basically, we take care of you till your body body fights it off, and the best way to prevent illness is to avoid being exposed to the virus. We haven't contained the virus and loosening stay at home orders has increased infections in California and across the country.

12:19

How do pandemics end?

12:22

Well, they continue until everyone susceptible is infected. If getting infected makes people either die or become immune, it'll eventually peter out. The problem with letting everyone susceptible get infected is that right now everyone is susceptible aside from a very small percentage of the population, and there are 8 billion people in the world. That's a lot of infections. It'll take many years for everyone susceptible to become infected. Millions of people will die and if The if getting infected doesn't mean make people immune for the long term, then it won't peter out, even if everyone is exposed. Another way that pandemics end is that we contain it with testing, contact tracing and quarantine. This is what most countries are doing, getting the numbers very low. So it's practical to find every single case and make sure it doesn't spread. However, in the US, we don't currently have enough political will or leadership to make this happen outside of a few communities, San Francisco is trying but most of the Bay Area in California is a long way from being able to do this. Another way that pandemics end is that they become endemic like the flu, and we learn to coexist with the virus for the long term. Governor Newsom's plan for reopening is basically a version of the third option. Except that we can't contain the virus and let most people get infected, but try to protect those who are vulnerable. Also make it happen slowly enough so that it doesn't overwhelm the healthcare system. I think we should also be concerned about slowing it down enough that it doesn't overwhelm the regional the regional center system. It won't take much to do that because it really isn't set up to be proactive or to respond quickly to this kind of problem. What are the high risk protocols for PR the Centers for Disease Control? caregivers for people with disabilities are at high
risk of getting exposed on the job. Direct support professionals and family members who provide care are considered to be in the same general risk category as health care professionals, when they're providing care for someone who's been exposed or diagnosed to COVID. Caregivers are essential for the health and well-being of the people they serve. If there's a potential that a caregiver may be splashed or sprayed with bodily fluids, use a face mask, eye protection, disposable gloves and gown. Wear gloves when touching a client or a family member, launder clothes and hot water and practice every day prevention actions with clients, even if they don't have suspected or confirmed COVID. Reopening plans for reopening programs should be based on high-risk protocols. Not on the stages and protocols designed for the general population, the Department of Developmental Services and the regional centers. Proposed plans are based on guidelines for the general population rather than for those who are at high risk.

16:01

So what are these everyday prevention actions that we should be doing? Even, that we should be doing even if the people we’re serving have not been exposed to, to COVID as far as we know or don't don't have any symptoms, you’re probably all aware by now that the best ways to prevent COVID-19 and what's recommended is physical distancing, and isolating, wearing cloth face coverings, covering your mouth and nose with a cough or sneeze throwing it. The the cover with in the trash and washing cans and cleaning and disinfecting and hand washing and using sanitizers. The Centers for Disease Control has put out recommendations that acknowledge that people with developmental disabilities have difficulty with all of these of the things physical distancing, they may need reminders and supervision cloth face masks, they may need exceptions covering their mouth. When they sneeze, visual and verbal reminders may be needed. Cleaning and disinfection may not may be a challenge. If there are sensory or respiratory issues like lung issues, people having reactions to the cleaning fumes, and hand washing and sanitizer may need assistance or supervision.

17:31

In terms of made face masks,

17:34

this these may be difficult for people with sensory cognitive or behavioral issues. Cloth face coverings are not recommended for children under two or anyone who has breathing, trouble breathing or is unconscious, incapacitated, or can't remove the
covering without help. Cloth face coverings are not personal protective equipment for use with someone who’s sick. They should not be worn in place of the appropriate medical masks, gowns, gloves and eye protection that are necessary for people who have known or suspected COVID. So in a nutshell, the CDC high risk guidelines are, are this, don’t get sick, you’re at high risk, and so are the people who serve you. There’s not much we can do if you get sick. People with developmental disabilities aren’t necessarily at higher risk than others, unless they have the characteristics of people with developmental disabilities. People who serve people with developmental disabilities should follow all the guidelines except we recognize that many of them can’t, but don’t get sick. The guidelines are confusing because they recommend people with developmental disabilities do things to protect themselves and caregivers, that they acknowledge that most people with developmental disabilities can’t actually safely do, such as wear a mask and maintain a six foot distance. It isn’t surprising that service providers and disability agencies are confused because there’s so much doublespeak in the official documents. These are very confusing ways to say that people with developmental disabilities are at high risk. And the what the Department of Developmental Services and regional centers are proposing are to try to define some people with developmental disabilities as low risk but it’s important to realize that that’s not consistent with the data that’s not consistent with the CDC guidelines and that all regional center clients are high risk regardless of their age or their medical conditions. So how do you assess the risk of any service that’s being offered? To you, when considering the risk of any proposed activity or setting here things you should consider. Remember that even if you’re willing to take risk for yourself, the people who you expose won’t just be strangers. There’ll be people, the people closest to you, the people who you love and the people who depend on the most. So the question the relevant questions are, how many close contacts will it add to my life? The people who are considered close contacts are people who you would be within six feet of for more than 15 minutes. Are those close contacts following everyday prevention measures strictly and limiting their contacts? Will I know who the people I’m in close contact with are if they get exposed or if I get exposed so that we can be informed and quarantine or isolate? Can I do everyday prevention measures and follow them strictly? Is the ventilation in the place? I’ll be good. How long will my close contacts be the more time the more risk? So 15 minutes is safer than an hour, for example, and one hour is safer than six hours? Who will like suppose if infected and what will the consequences be? And do I have a safe and reliable plan for when I’m exposed? So what does this mean for day programs or other site based programs? Bottom line, programs that primarily serve people with developmental disabilities cannot safely run indoor programs with group activities. Bottom line, doing so is against medical advice. According to the Centers for Disease Control. The situation unfortunately is unlikely to improve in the next few years. If we proceed with opening day programs, it’s going to be a disaster for our community. Day Program, participants and staff will get exposed and will in turn exposed family roommates, residential service
providers and regional centers will be overwhelmed with needs that they don't have the capacity to meet. Hospitals and skilled nursing homes are not safe backup plans.

So what are safer alternatives? I wish we had time to talk more about the exciting possibilities for the future and the creative ways that people are adapting. And I think we should have another town hall to focus on what we can do moving forward. But some brief ideas are we can hire household members to provide service we can have a single consistent aid or a small team of AIDS provides service in our homes with precautions we can have a condition And aid take take you out into the community in private transportation, not public transportation. We can meet one on one outside and uncrowded places with precautions. We can take drives, we can do window and drive by visits. We can take virtual field trips, and we can participate in the exciting and growing online social, spiritual, educational and vocational work worlds, which offer a lot of opportunities for inclusion and doing things we've never done before. It's never been more available.

So some of you may say yes, I know there are risks but I but I, I really want to go to my program and I want to take the risk anyhow. If you want to risk going to a day program, you will likely get exposed to COVID-19 and you need a solid plan for what you will do when that happens. Don't Count on the regional center day program or healthcare system to find a solution for you, it's unlikely they'll be able to do so in a timely manner. If you don't have a plan, it's likely you will expose others to the infection. And you may not have the care in place when you when you're ill. So ask how, how many additional close contacts you'll have and how to minimize them. A close contact again is anyone who is within six feet of you for 15 minutes or more as what procedures are in place to trace the contacts of every person in the program so that people in the program can quarantine, develop a plan to have a service provider or family member on call at all times, who will be able and willing to pick you up from the program if there's someone sick or an exposure that person will need to do to be willing to take care of somebody who may have been exposed to COVID-19 or who may have symptoms, they need to be able to pick you up within an hour of getting a call secure protective equipment. This is medical
medical masks, gloves, gowns and eye protection, private transportation, the safe place to go where you won't expose others. That that's available to you with without notice and make up a back, make a backup plan in case your service provider or a family member is unable to help because if you're sick or exposed, it's possible that the people in your household or the people that you rely on may have been exposed as well and may not be available to you. Here's my contact information. And I look forward to talking to you.

Judy Mark  25:51
Thank you so much, Clarissa. Those were really was I was personally amazed by the incredible amount of information you were able to provide in such a short period of time and such important guidance, I think, from a healthcare professional that we should be getting as opposed to sometimes our political leaders who don’t necessarily have the right lens to think about these things. Our next presenter is Lisa Locky, who is also first and foremost a parent to also an amazing young woman. And, but, but we asked her here as well, that she also has the hat of running a really wonderful community based a program that has particular interest in serving those individuals who have some really high needs. And I know that you’ve been struggling with how to help the families you serve and also to make sure you’re protecting your staff, so as to make sure you’re protecting your own child to participate in some of those activities. So Lisa, thank you so much for joining us.

27:04
Thank you, Judy. And thank you, Dr. krupke. That was really as a parent and as a program director, that information was so important and so meaningful and timely because we are in the stage now of looking at what potential reentry or reengagement practices would be safe. But I am first and foremost, as Judy said, I have a 30 year old young lady, my daughter, Emily, who has a genetic disorder tuberous sclerosis, and a seizure disorder, developmental disability, as well as underlying health issues. She has a heart condition and takes medication that compromises her immune system. So we as a as a parent, as a family feel that we cannot be careful enough with Emily's care and her exposure to others. people in the community, she has essentially been, you know, mainly at home with us, she goes out for walks in the community, incredibly enough for us, she will wear a mask, she’ll wear a cloth mask, which is amazing because she doesn't even like to wear a hat to protect her from the sun. And so that is a blessing for us that she is able to tolerate that. But we have been very carefully limiting her exposure to caregivers and really trying to make sure that she stays healthy. She's not able to follow a lot of the other safety protocols independently. She needs a lot of assistance to do that. So I understand as a parent of somebody who is at high, high, high risk, the fear that that people have around re engaging into the community. As a program director that is one of the biggest
challenges we moved from. We've always been a community based program and we've tried to provide individualized supports person centered planning and Person Centered ways of doing what we do in the community. But we don't have a center where we provide support, we are out, you know, the adults of the program, take public transportation under normal circumstances, they're out and about in the community, the whole time going to different public places. From the time that we got the safer at home directive, we switched to being able to provide in home supports for the adults in our program that requested that and many of them did. I know for me as a working parent, would not be able to do my job if I did not have somebody coming into the home to support Emily. And many, many, many of the adults in our program, they also they requested and they needed the support. We were fortunate enough to be able to provide enough staff to to give that support The individuals, and we've tried to be careful as we can about it. We have a way that staff does online, they do self checks every morning, before they go into the home of the adult that they're supporting. We keep track of that information. If somebody has symptoms, we have to take a pause on being able to provide support, we take into consideration the desires of the family, whether they want only one person and they're okay if they don't have a substitute staff person. So we've tried to and we've provided our staff with some of our families as well. We have provided them with PPE, so that everybody can be protected. And we've developed you know, guidelines soon, quickly, that we gave out to all of our clients and families and staff about what to do if they've been exposed to COVID-19 what to do if they feel symptoms. So we have done, you know, as much as we can, but it's still a very tricky situation. Anytime you have a staff person going to someone's home, you are also risking, you know who they are in contact with. So we have tried to manage that we've been super lucky that we have not had anybody in our program, who actually came down with COVID. We've had a few people that have been around others. And so we've been lucky with that. And we've been doing so we've been providing the In Home supports where there have been needed and as the you know, as everybody realized that this isn't going away anytime soon, we've had additional clients and families request in home support. So we've been able to bring staff in and and and provide that support. We've also done a lot of zoom meetings and zoom activities. We've done everything from music classes, art classes, virtual plays, Tour's trips to different places, we've been games online, everything that we can think of that would engage the participants in our program. And you know, some of them participate in every single event, some of them pick and choose which ones that they enjoy more on. And it has been successful to the extent that we have been able to stay connected as a community. And that's been really important for the mental well being of a lot of the adults that we're supporting, that they're able to see their friends, they're able to see staff, they can talk to one another, they feel that connection, because that is something that we also are looking at and take into consideration is what has been the impact on the adults that we support of being socially isolated to a greater degree than any of us could have
imagined. So it’s been really important to us that we make sure we are trying to keep that sense of community and and provide whatever supports we can to help with that. Interestingly enough, we have had some of the adults in our program with the lessening of some of the demands and the transitions and being out in the community, some of our clients have actually experienced a decrease in some of the anxieties that they might typically experience. Others have actually had an increase in those anxieties and frustrations, because they’re not able to get into the community. We have had a few of the clients who were able to express it independently say, you know, COVID is over, we’re done. We’re going back to, you know, see our friends. So we’re really at a point now we’ve done surveys with our clients and families and surveys with our staff to try to get an idea so We can plan going forward, who is comfortable resuming some kind of community activities? Do we have a small small group of no more than four to six clients and coaches that might want to meet at a park and stay six feet apart? But they’re in an open environment? Do we we know for sure that nobody nobody in our program, we asked a question about public transportation. And really, nobody is comfortable with it. And I can completely understand that because I would not allow my daughter to get on a train or a bus, or even an access or a Lyft or Uber. And that puts an additional burden on our program, in terms of once we do start to make reentry plans, how will we transport adults into the community even if it’s just to get out to go to the beach or to go to a park? A lot of the clients have been going for walks as my daughter has around their neighborhoods, but Now we’re looking at, you know, are we able to safely get people to other locations that are a little further away. So we really are trying to take all that into consideration and we’re trying to do it in a person centered way. We’re listening to families, we’re also listening to staff who have concerns as Dr. cryptokey was saying, they don’t want to bring anything home to their kids or some of them live with elderly family members. So we want to be sensitive to everybody’s health. That’s the primary goal for us is to keep everybody safe to manage the the different challenges that come with the isolation and to try to figure out how as a program, when and how it’s going to be safe to reengage to provide small groupings, not in an enclosed space, but just to allow for some type of reengagement with one another and how we’re going to safely do that and what our program is going to look like. And we’re, you know, trying to make plans that will be both short term and long term.

Judy Mark 36:16

Much Lisa, that was really, really helpful. And you know, just really respect the fact that you’re trying to do is provide service in so many different ways both individually as well in
in the home and as well as I remotely for those that doesn't work for everybody. We know that right. Thank you, our last presenter and then we're going to open it up to all of you who are who are watching. It's Eden wrap. Eden is a self advocate and she's on our board of directors, but that's just one of the many, many things that she's involved in, including she has a job and she has, which is she has a job and an essential place and she also So he is involved in many advocacy activities as well as her church and social activities. And so I had asked Eaton to tell us as a self advocate, who has been posting like amazing things on Facebook about things that you can do during the Coronavirus, stay at home order. How you know what she thinks of going back to work what she thinks of going back into group settings or church and you know any kind of worries that you may have about this so thank you for joining us Eden.

37:31

Hi, my name is equipment do you say hi my name is Emma Matt, and I just turned 25 I am involved in my community, his friends and family. You are my thoughts because of my love for my parents to have health conditions and I now at that age when they are more vulnerable to COVID-19 I am hesitant in two places. For example, for right now, I am not taking public transportation to work for a while until Corona virus cases go down a lot. And depending on the vaccine, at at Mar pizza, we are a family and so we like to take care of each other. So they usually keep me behind the cannon maybe as much as possible. And we all wear masks to effort to intake temperatures before we clock in, and we wash our hands a lot. So I feel safe mostly, especially since my shift during pandemic under two ads at a time now that Diamond has started. They are scheduled like down in the lobby every 15 minutes during busy times and every 30 minutes. Because to me, like last month three to 5pm shift before me for COVID-19 the shift captains and coworkers will often tell me to go in the lobby, sanitizing tables, taking this to the back and wiping down the list where the trash is. I will often do that a lot. But because a coma night teen is kind of risky and concerning. So they don't have a new that much anymore because they want to protect me but say it They forget and they sent me to do that. I wouldn't want to have to wear a face shield over my mask. Not only to protect myself but also protect other people. Especially my parents who are at the age. So I would kind of look like a bandit I am not out in the lab. Me usually except for taking my 10 minute break and go to the back seeing a good avoid diamonds. So I don't have joined all How concerned are they you still have backups and sanitizing What? No, but now they decided to go to something stronger than Navin good bottle. This this task is important. But it is not but it is not my job not like President Clinton don’t fall in boxes or making sometimes bits as well unknown orders to many people acted a little older like my parents. So I'm not sure I would want to go back quite yet for service. I miss meaning with the young and now
move in person. But museum is they have an outdoor hang out with a six week nuisance in and when man I might think about it, but not is it eating or drinking with other people talking without Matt. So as much as important to me I want to be there for people I know I'm building on the eating is people and we will probably keep naming for Sunday worship and Bible study as an American Sign Language I would like to to meet again and it might be comfortable again pretty much ever Oh young and not like me to get it

because when we moving on nine aching frustrating not me able to see into that into other sign makers about who I met small. I had a bad experience before until from now. So for now, I love American Sign Language make it a frustration and different perspectives of COVID-19 But so my man could have COVID-19. Without symptoms, then maybe I will pass. But if we could mean app I will shield and sit far apart Well, maybe two minute. Few minutes was developed as a musical exercise for seniors to help with the cognitive processing and motor planning 92 of her family by musical Connect, come through inclusion, have a vision and we're trying to bring it from Japan to also help people in the disability community. Me for COVID-19 we were meeting at the Japanese got to institute to teach seniors and I was getting trained I can help the disability community in the future, but the other students in the class See me is so the train is completely I kind of nervous returning because most of the students are a little older than my pant so I do not feel comfortable going back to training until in that scene shot and play. So my musical goal is on hold for now. Mainly I have no intention because I'm on one especially all the students and I don't want them to die. But my book club and community hang out. I have trouble with it because I was young and not laughing to get really sick come covenant team. But there is one member who is healthy, but men but manically sensitive, and so I am not sure I want him to come and participate So too as a member, I also happen to also have an age neck my parents, so I am not sure if they want their son or daughter to come. I don't mind the dining output to me is fine. Ever since matter pizza we open. I feel better about going out. I'm a little concerned about my mom coming with us because I don't want anything to happen to her. So if you hear me without eating out, if I were to attend to all my five minute musical training, I would have to wear both my mask and I face Georgia Tech them and myself is people out work for And asked me to do a lobby, then I would wear my face shield pass my mask. So not only will my parents be safe, and the people will be saved, face so this is important and outside this battery inside, but because I love my parents and don't want to hang out with a group of more than 10 people before the vaccine, thank
Thank you even that was amazing. All three presentations were incredible. And I hope gave those of you in the audience who are self advocates and family members, some things to think about as as you are trying to figure out what the risks are for moving forward in this in this community and they’re in our country right now. So now we’re really getting opportunities to self advocates and family members who are in our audience to weigh in. And you can do this in one of five ways. We actually have five ways. The first one is you could write something in the chat. And we’ve been monitoring that so far. That’s honestly not my preferred way that you’re doing it because the chat is constantly moving. The best thing to do in the chat are things like comments to our speakers, like everybody’s praising you even for what a great job you did. If you have a very specific question for any of our presenters, you could put it in the q&a, which you’ll find at the bottom of your screen. And that way, I can really monitor that. You can also raise your hand and what we’re going to do is allow you to be a presenter to present your comment or your question you didn’t if you have an opinion, we want to hear it. And when we see your hand raised, we’ll call on you, and then our program assistant. And we’ll be pulling you over to be a presenter. And once you make your comment, we’re going to put you back in as an attendee, the last way that you can ask a question or make a comment is through Facebook. We’re live on Facebook, and we have somebody monitoring the questions there. And we will go ahead and ask your questions or provide your comments from Facebook. The reason why we’re going to verbally do this as much as possible is because there are some people who aren’t who don’t have access to what’s being written. And so we want to be able to say it out loud. Not to mention that the recording of all of this is going to be going on our Coronavirus Resources website and they will not have access to any of the chats or comments. Speaking of that, if you would like more information on or see all of our previous webinars, this is I believe our 13th webinar we have been started on March 19 and turned around very quickly. Probably Did a resource website and you can find that it’s been in the chat but it’s Disability Voices united.org backslash CV CV for Coronavirus. So what we’re going to do is I’m going to start on Oh, let me I didn’t tell you the fifth way. The fifth way is for our Spanish speakers who are listening in on a separate conference call line. At a certain point, I’m going to ask Lorna, our interpreter to unmute those phone lines and ask if there are any comments or questions from that line, and she will present them on our call and interpret them into English. Okay, so, so I think we’re going to get started there with a number of questions. A lot of them are directed at you, Dr. krupke. But I will ask a couple of those and then we’ll go to comments from the audience. I want to let everybody know that our priority is to get comments from self advocates and family members. If we get through all of those, and if you’re a professional in our field, if you’re a service provider, or work for a regional center or an agency, you know, we do want to hear from you. But our first priority is to hear from self advocates and family members. Okay, so to get started, um, let’s start with one of our initial questions.
Oh, I see that that Clarissa you may have been answering them. I'm going to go back because not everybody can see the QA and a lot of people are on the phone. So I'm going to go ahead and answer. I'm going to go ahead and read some of these questions, Clarissa so that you can answer them verbally. So one of our questions was asking about n 95 masks and would they be available for high risk individuals and staff? Could you please answer that?

Yes, access to protective gear is, is still a problem even in hospital settings, the regional centers and State Council have secured a supplies so if you are taking care of someone sick or have a special need, you can go to your regional center or the State Council to ask for help securing some supplies. But we probably will not. I'm quite certain we won't have enough to do that for everybody for routine care and most of that equipment will have to be reserved for people who are sick even though others would certainly benefit from it.

And is it correct that with an N 95 mask, it needs to be specially fitted for you to make it actually work well.

It'll certainly work better. Yes, they are sized and you have to wear them correctly and consistently. You have to take them on and off. safely so yes, you do need medical training in order to safely put on the equipment and take it off without contaminating yourself and and to use it wisely. But even hospitals are still reusing 95 masks and doing other things to preserve their supply because there isn't enough. Thank you.

Another question is How is the risk level presented by staff itself staff who may be working with multiple individuals, or multiple agencies, including skilled nursing facilities or who live in a large household has very level of occurrence to precautions?

That is a really good question. If you're going to a site based day program, you may not have access to that information so you have a lot more control over who you hire, and
asking questions about their behavior. Their And the risk factors if you hire people yourselves or if you work with the small agency. Also, some service providers may have policies. I know in many of the residential homes that I provide, they’re not allowing staff to moonlight in hospitals, for example, and are paying attention to that, that type of risk in their in their staffing and are not offering hours to people who are taking, taking more risks, but you have very little control if you’re going to a large program.

Judy Mark 53:35
Okay, and I’m going to take one more question and then I’m going to go to a comment from the audience. What if we were in a county with a low number of cases?

53:47
The problem is that certainly lower numbers makes everybody say first so the more we all stay at home and protect our community, the safer is for everybody and especially people who are vulnerable. But the problem is that it takes a while for people to get symptoms get tested, have those numbers reported. And it usually people have the virus for several weeks before they’re sick enough to need hospitalization. So there could be a very big outbreak that you don’t know about. And the data that we have represents what was going on in the community two or three or four weeks ago, for example, what happened on Memorial Day and what happened at the protests is just being reflected in the numbers now.

Judy Mark 54:46
Thank you. Karissa. All right. So we’re going to take a first comment or question from an audience member, Yunus. So Ed, can you please bring us in from The attendees into the into a panelists. This will just take a moment and she will be joining us. Eunice Hi, you can unmute yourself units and you can even put on your video. Hi, Eunice. I have a comment or a question.

55:20
Yes, I am. I’m so thankful for all of this information that you guys are giving us. Especially you know, in my case I am alone. I take care of my granddaughter. So I’m brilliant risk. And this is why from the beginning when all of this started on the on the 16 I just did not send Jasmine to the center my den director center. And they keep telling me that they’re going to open by AI, especially now after listening to Dr. cripple about that, you know, caregivers
and I am address and just me surgery. Word condition. I don't think that I will be happy sending her at all this year. I don't think so. Because it is not safe. And you know she had difficulties with the, with the math even though she keep it but she is very sensory oriented girl. And you know, I don't know the other ones at the center how far they're going to be. And it's very hard because they said that the place where she is, is in the second floor and is full of people and people are worse and Jasmine. I don't know why they keep her there because they say the behaviors but she does not have that many in the past two years there. So that was at the beginning when she was adjusting. So I think that I hope that I the regional center will support me with with this, that I don't think that we are ready For Jasmin to go back is going to start all over the adjustment for her when she gets back. So she's going to probably have behaviors people are going to be grabbing her, or her grandma is, you know, to hold her down because what she does she she's so injured herself when she's upset. And you know, she's going to bring bring it here and Amal and I'm the only one that they care of her. So I'm really, really now more frightened to send her there after listening to Dr. cripple, because of all the problems they don't have, like, Who's going to take care? I told them about the physical distance, who's going to keep them away from Jasmine? She needs to if she goes there, she needs to have an aid. Yeah, but um, but they say oh, no, we cannot have to put them in the house. Have an aide somebody that will be able to keep the other people away from her to be able to make sure that she keep the mask on, to be able to contact to go wash your hands and all of that Jenny's a very smart girl and you just need to prompt her and she just do it. But if there are other people around how you're going to avoid it if there is only three days and it's about 25 people so

58:27
it’s very stressful. It’s very, very stressful.

58:33
And all of that but you know I prefer not to send her I prepare for a

Judy Mark 58:41
unit we feel the stress you’re under the pressure under and and it's what we hear a Disability Voices United have been hearing from many people you’re not alone in this. You know, we believe that that your your granddaughter should be getting some some level of supports. services but just not in a group setting. And, you know, if we can be of any help to ensure that you are getting the support you need for your granddaughter, please reach
out to us because we want to try to be helpful. I, I know I met you just yesterday and I
hope that I hope that we can be helpful to you, but especially as your granddaughter
starts to enter the self determination program, which will open up a lot of opportunities for
her to have more individualized.

59:27

Yes. And talking about that real quick on how can I keep the people she had one person
working for her for the past like 12 years, 12 or 13 years now. And she worked for an agency
that is paid by the regional center, then orange triangle regional center, how can I keep
those three girls that no Jasmine? Because it's been so hard because it's super hard to
train other people because yelling is unbearable. So that's this big problems. So now they
know her very well. How can I keep them if I go in? So determination? Can I still keep
them?

Judy Mark 1:00:07

Yes, you can. And what I'd like to do is maybe to talk to you after this offline and help
guide you. And we can also do that through some of our SDP Connect calls. Okay, get you
connected. So let's say that I'm going to have to move on to our next caller. But thank you,
Judy, so much. Thank you so much that your your comments are heard loud and clear.
They really, thank you. Thank you. I'm going to go now to another question from online
that we've received on in our QA. What health monitoring tools should be used at home to
assess the status of individuals with the inability to directly report symptoms.

1:00:54

That one's for me.

1:00:56

So okay, so

1:00:58

So certainly People who can't report symptoms should be we should be monitoring their
their contacts and their risks and exposures. We should also be monitoring their
temperature. We should be monitoring any symptom like sneezes or coughs that they
might have. But the reality is that things that they only they can report like I can't, I've lost my sense of smell, or other symptoms. We can assume that people who have difficulty communicating their symptoms are we're going to recognize COVID late and then they will probably when they don't have symptoms or when they have symptoms that they can't report expose other people to the virus and that's part of why people with developmental disabilities and their caregivers are at higher risk because we are going to recognize COVID late in them where we may not recognize it at all and there's not there aren't perfect solutions for that.

Judy Mark  1:02:02
Thank you. One more question is trying to ask you examples of things and whether there'll be safe or not Dr. krupke. So Georgia is asking about her son who's living with her, and they’ve not been out but they do invite one or two people at a time to enter through the back gate and socially distance on the patio. Her son sits in a wheelchair with a seatbelt does not move around. And another option is, is it safe to go to somebody else's backyard pool and swim? She said she would swim with her son, I have another supports person to sit on deck and social distance throughout. I mean, are these kinds of small, you know, one household to another, where you're seeing socially distant and seeing outside the entire time? Would you consider that a safe activity?

1:02:53
We need to think about in terms of risk reduction, that what you described is certainly dramatically safer than going to a site based day program or vocational program because it's outside because there's limited number of people because the people are in the so called social circle. There's no risk from the pool itself. This virus is it's transmitted through through the air and coughs and sneezes, it's not transmitted through water so you're not going to get it from swimming in the same pool. You if you got within six feet of somebody, when you're swimming and coughed or sneezed or smoke or then potentially you could get it that way. But if somebody is on the deck and you're in the water, then there's very little and it's outdoors where there's good ventilation that is, on the scale of activities. You can do a very safe one and and doing something in someone's yard really depends on how, how well people do the social distancing and whether they can wear masks or not. And it's certainly a lot safer to meet someone in outside in your yard than it is to meet them in your home. Fewer people is better than more people, people in your household is safer than adding adding new household contacts. So I think what you described sounds like the type of thing that we should be moving towards. Because people do need opportunities to build and maintain their circle of support, to get to exercise to have sunshine to to see the people they love and isolation and isolation and
for not having healthy lifestyle has its own health risks as well. So that that sounds like the kind of compromise that makes sense.

Judy Mark 1:04:57

Thank you. I'm wondering if I can turn to Lisa for a moment. Because I know that your your day program is providing some of those opportunities as well. Do you want to give an example of how you're doing it?

1:05:08

Sure. So we are, again with the consent of the individuals their informed consent, because we know many of the people that we support are also struggle with communication. We are starting to look at small groupings. For example, a group of four to six would meet at a park, staying six feet apart in the outdoors or go on a hike together but staying six feet apart. We do support many individuals who require hands on physical support for a lot of their needs. So that I think that that had come up as a as a question. So for example, My daughter is one of them. She requires a maximum physical support for a lot of her daily living needs and her hygiene needs. So as long as she's wearing a mask and the caregivers are wearing a mask, gloves and people are washing hands. We feel that, you know, we have to take into account the needs of the the support needs of the individual. And then and then as Dr. Creepy was saying, trying to minimize the risk, so we are not allowing and won't for some time allow larger gatherings. We won't be gathering indoors we are fortunately we're moving into summer so the weather should work in our favor. Except if it gets super hot, but that's as a program. That's what we're trying to do. Can we have Is it safe to have a group of four to six and I mean, four to six people, not four to six clients with all their staff, but four to six people meet in an outdoor location where they are able to safely social distance. And then the other consideration is, are those individuals people who will be able to wear a mask one of the in our survey we’ve asked questions not just who the adults that we're supporting the self advocates, if they'll wear a mask But are they comfortable with their staff person wearing a mask because for some of the adults in our program, they are not always comfortable being near somebody who is wearing a mask. So all of those as we plan and as we try to work on on the reengagement and the re entry plans, all of that are, those are all the things that we're trying to take into consideration, keeping everybody safe trying to recognize and deal with the psychological and emotional, you know, issues that come with being so isolated and not being able to get back to any semblance of a typical schedule. We actually do it came up earlier about a job. I think even you were talking about that. We actually do have one young man who has been able to continue, he works at a he works at mud pizza, but he is
able to wear a mask and gloves and his staff that support him. So he's been able to keep his job during this whole time, which he's been very happy about. But they're not doing in a mud pizza has just been for takeout and delivery. So he's able to go in where his mask where his gloves, practices, safe hygiene practices. But most of the adults that we support that have jobs in the community that most of those jobs have they've been furloughed from those.

1:08:27

Thank you.

Judy Mark 1:08:29

Okay, I'm going to ask Linda green to come in and make her comment. So Linda, when Ed brings you in? Just take a moment to bring her in. And remember everyone that you can continue to make your comments on Facebook or through the q&a or through the chat. Hi, Linda. Welcome to commoner question. Yes, I do. So what I run is I'm in the Bay Area, and I run A nonprofit for sports and recreation. Now we have been closed doing zoom, we do dance and we do sports programs and everything for the kids. I also teach programs for the downside your connection, and they were at my dance school. So I want to know are there safety protocols out there for the sports and recreation programs because here that we are running, you know, classes in a dance school. Even though it's a family dance school, we've shut down now they're telling us countywide that gyms can open July 1, but beyond that a large portion of our clientele pretty much half of them are have a special needs population. How do we go about doing something like that? And I of course am looking at the special needs population, their safety. So is there any safety protocols in place on how to, you know, safely reintroduce programs For these individuals, thank you. Yeah, these cats, you know, we're doing zoom. I've retained a lot of students, but some of them because I also take students who need an all levels of support with minimal to full on hand support, and we take the challenges and everything. So some of these kids are getting tired of zoom after this many months, they aren't money to do it, you know. So it's like, and I'm also in special education. So the same thing, these kids are getting bored of doing their lessons on zoom. So I just want to know if anybody knew of any protocols or what, you know,
Judy Mark 1:10:39
that Thank you. I don't know if either Clarissa or Lisa want to try to

1:10:45
take that

1:10:48
person, but that that zoom might not be stimulating and people are sick of zoom.

1:10:53
No.

Judy Mark 1:10:55
Living try to rephrase that. So it's not so much the can she go back to an interview First
class, and what kind of protocols would that be? I'm assuming Linda you mean an in
person class, right? indoors indoors and

1:11:08
multiple, multiple people?

1:11:11
It It doesn't matter what you're doing, whether you're doing an art project or class or
social skills, but what matters is how many close contacts are you introducing How good
is the ventilation? How long is the contact? And those are really and can people do those
protective measures? So if you can do a class where people can socially distance and
where there's good ventilation, what what activity and you don't share objects and you
know, if you can do something meaningful like that, then then that may be okay but you
the essence of most of these programs is to Be able to get those hugs and to share
objects and to get close to people that that's the whole point of these programs. And
when you take that out, then you have to think, Okay, well, I have to wear a mask, I'm
exposing myself to all this additional risk. And by by doing the protective measures, it's
just not that much fun. And I could have more fun at home with my, with my group or doing something one on one that I could in this environment with all these restrictions, so you have to compare not just what it used to be like, but what it would have to be like now and see if you either if you're doing everything that you need to do, can you have a program that you actually want to attend or not? Or is it is it gonna lose? It's what what you liked about it.

Judy Mark  1:12:53
Thank you, Clarissa.

1:12:54
I just wanted to say Linda I the zoom fatigue is absolutely real. There's also a, you know, a lot of the adults that we support need assistance to access, zoom or other types of online activities. So if they don't have somebody in the home that's able to support them. If a parent is working, you know that that can be challenging, too. So I just wanted to add that.

Judy Mark  1:13:20
Thank you, Lisa. Once again, I want to tell everyone that you can ask your questions on Facebook, through the q&a in the chat or by raising your hand by going clicking on participant at the bottom and clicking on raise hand. But primarily, we are looking for comments and questions from self advocates and family members. While we love having service providers, regional center staff and others on our call, initially, we really do want to try to get these comments so that we can bring your concerns and questions to the Department of Developmental Services. Right now. I'd like I'm going to talk about something but I'd like to ask Lorna to Go to the Spanish speaking parents who are on the phone and ask if any of them have any questions. While she's doing that,

1:14:11
um, I

Judy Mark  1:14:13
just wanted to tell everybody that there are alternative ways for you to receive services through participant directed services. We did a webinar on this and on self determination,
I encourage you to look at our Coronavirus resource website. Sometimes having these individualized one to one supports, particularly by a person who’s close to you, either in your household, or maybe a neighbor or a close friend or cousin, Aunt uncle, to provide these to provide these services so that you’re really minimal, minimal minimum, what did I want to say minimizing the ability to have like x, you know, extend your extended contacts with the regular world. So I really encourage you To look that, look for participant directed services, ask your service coordinator if your service coordinator has never heard of participant directed services, there is very clear guidance on the DDS website and you can ask to speak to their supervisor and if their supervisor hasn’t heard of participant directed services. I think at that point, you can probably call the executive director of your regional center who definitely knows what they are. Um, so Lorna. Judy,

Lorna Silva  1:15:28
I have three questions from a Spanish speaking parents. So I have first question from Lulu and she wrote it on the chat and there is a follow up question to that. So the first question is if a mother can choose a hospital where the child could go, assuming that there is a risk, Loma Prieta, Clara preguntas Korean chat, asking for clarification on the question

1:16:03
Thank you. Okay, so go ahead.

Lorna Silva  1:16:06
Or if a person with special needs, if they need to go to the hospital if somebody with special needs, if they need to go to the hospital, or is there any type of restriction? Yeah, and

Judy Mark  1:16:20
I think I think that she’s specifically asking Dr. querque about the ability of the parent to be with their dragon in the hospital. So you talk about the directive.

1:16:31
Okay.
So,

Lorna Silva 1:16:34
so Okay, going, actually, there is a little something, it's like the question is also specifically if the parent if our relative somebody is allowed to be with the, with the person with a disability being exposed, okay.

1:16:47
Yes, many hospitals have policies that limit visitors but exceptions can And should be made for people with disabilities who have difficulty communicating or who need other kinds of supports. And there has been some I didn't I'm pausing for translation if you

Judy Mark 1:17:16
want. Oh, she’s she's simultaneously translate Oh, oh,

1:17:20
okay, sorry. And, and there has been some legal work done on this by communication first, to ensure that people who need disability accommodations in the hospital from a familiar supporter can get them so there are new policies by Department of Health and Human Services saying that hospitals should make those adjustments. But realize if you’re going into a hospital as a supporter, you you are someone who could potentially be exposed to COVID could expose others to COVID and and Well, that support is critically important. It's also critically important that you follow all directions and that you learn how to keep yourself and the person you're supporting safe and that you don’t infect others or spread virus throughout the hospital.

Judy Mark 1:18:17
Thank you so much. Yeah, that was a huge victory. I'm really pleased with that. I wanted to somebody had asked in the chat about the information on participant directed services, I put it in the chat. It's the plain language version that DDS has produced, which is really helpful. And you and there's more information. You should know that DDS has a
whole section on Coronavirus on their website, offering all kinds of directions that they have provided to regional centers and the flexibility that they’re giving to us as as individuals and families to be able to get the kind of services that we need during this time when when group programs are closed down. And so I think it’s important for families to to look into the website and see what opportunities exist. And I’m going to go back to the q&a because there’s just so many questions on there. Uh, if it’s okay, here we go. When my son’s day program has been meeting over zoom and doing breakout in smaller groups, I would not be comfortable for any other participation for my son until there is a vaccine. Do you know how long regional centers will be funding supporting this limited daycare funding? So I’ll try to answer that because we don’t know. What we do know is that real regional centers of the state of California has enabled regional centers to pay for the absences of people due to COVID-19 who participate in these group programs. And so therefore D programs at work programs and other congregate programs had been able to continue to Bill, even if they’re not providing in person services or even providing full day program services. This has become problematic for a lot of people you should know it’s become problematic because a number and I’m not including Lisa’s program in this at all. But there are some programs that have not been providing services and yet continue to build. We know, we did a survey and spoke and got an over 450 respondents, half of them who who use congregate programs reported that they were receiving no services at this time, not even remotely. So, you know, that’s obviously a problem. The state cannot continue to fund programs that are not providing the services. And so they now are saying how are we going to allow have these services provided so that so that programs can stay funded and but at the same time, people are getting served? So that’s really what this reentry plan is trying to address. And obviously, you know, there’s a lot of people including myself, who have very big concerns about going back to the way we were before in any kind of even in a modified way to have 510 15 people with staff in an enclosed setting with recirculated air. I personally don’t see how that is feasible without taking an enormous risk and just accepting the fact that some that some if not all, people will get sick from doing that kind of activity. Okay, does anybody else want to so to answer try to answer the question. We’re not sure when things are gonna get back to normal here. I think it’s impossible to predict. I

1:21:50

fall I don’t think it’s

1:21:53

I don’t think it’s that difficult to predict. I think what what we know now that we We didn't
know before is that it's not going to go back to normal. The plan right now is that this virus is going to be with us for a long period of time. I can't tell you whether it's going to be many months or many years, but it's going to be with us for a long time. There may be a treatment or vaccine that comes along that makes it safer. But there's nothing that on the horizon that is likely to happen in the next 18 months, or, you know, 18 months, I would say would be the soonest it could possibly happen and the barriers for happening that soon are great, so I wouldn't count on that happening. And so what we really need to do is think about adjusting to living with this virus and figuring out how do we make good lives happen? Knowing that we have these constraints rather than hoping that in a number of weeks or months, we're going to be able to go back to our own lives because frankly, that's not realistic. Mm hmm. Thank you.

Judy Mark 1:23:06

There's a wonderful question from a sibling and boy, we love siblings so much. We do a lot of work in our organization with siblings. She is reporting that her brother is 60 years old and it is in between a rock and a hard place receives 24 hour supported living services through regional center vendor before COVID he was taken out to activities five days a week. Now he has no stimulation. And he is really suffering unable to use a computer. They do call him every day, but they she hasn't seen him in a long time because she's also in a vulnerable demographic. What kind of activities outside his home would be the least dangerous for him. There is a daily drive by for lunch by the senior center and I know you started to respond, but I just want to say as a caregiver, to my son, and that is, to me, it's really outrageous that he's not being taken out every single day. He could go out seven days a week, there is community activities that you can do in a very safe way. My son has a one to one aide and he goes out all day, every day, seven days a week. And he's taking walks, he's going to parks, he's going to drive throughs and taking his drive through lunch and eating it in a park. He is the LA County libraries have reopened and you can order they haven't opened for indoor but you can order your books and DVDs and CDs online and you drive in and they bring out a bag with your books that you ordered. And then he gets to take those to a library or listen to those in the car. There's a lot of activities that exist that you can really have have a full for, you know, community experience without getting close to people and to do it safely, and the supported living provider the day program providers, this is the time for them to be stepping up and doing what, where is being done for my son? I don't know if Clarissa really sorry. He didn't want to, you know, respond to that.

1:25:21

Yeah, for the purposes of time we cut a couple slides where I went, when I went over
some of the things we can do and I think we should have a whole town hall talking about this. Nobody should be stuck at home with a single parent and no other supports doing nothing that is unacceptable. That is unacceptable. Everybody needs social interaction inclusion with both disabled and non disabled people. They need sunlight they need exercise. They need to continue to learn they need opportunities. To to make a difference. Just to give you an idea, I serve people who have very high support needs and very high medical needs. And some of the just to give you there's so many ideas of what we can be doing that we really need to be focused on that right now. But just let me give you a few ideas a group of homes, put together a progressive dinner so that each home made one course of the meal they delivered. So one person made the appetizer one person made the vegetable one person when one homemade the the main course one person made the dessert and they delivered the different courses to each other and then they got on zoom and they all ate the same meal but in their own homes online. We we've had people in different homes making parts of a quilt We've had people doing cooking projects so that they so they, they made dog biscuits and then this was done by putting the ingredients into a Ziploc bag and then hand over hand helping them to manipulate the the ingredients and then helping them to roll it out and and and press cookie cutters into it. And then they took the the items to the local shelter to feed dogs so they were able to do a service project that there's no reason why people need to be stuck at home bored with nothing to do if you don't have access to the internet and could could benefit from that and don't have access to the technology. That's a problem that we should be working on solving today for you call an IPP and say look, I am I can't. I can't tell the health with my doctor. I can't participate in The group in the the social programs that I want to participate in with this computer This is equipment I need adaptive equipment I need that's essential and and solve that problem today. We should not have people who don't have computers and internet access in our community at this point. It's in the central it's an it's an essential piece of equipment for accessing health care for accessing everything right now. So, I mean, those are just like a couple activities. Everybody's different and what they're interested in, but there's no reason why people need to be socially isolated. There's no reason why we can't find ways to maintain their family relationships and have FaceTime visits, zoom visits, backyard visits with family members. I had a patient of mine, my mother had cancer and was nearing death and and we did a number of things too. We decorated the car and made, made a nice card and drove it by so so he could see her and and she passed away and, and now and we were able to, to go to her, you know, make a safe way for for him to go to his funeral people, people don't need to be people. It's important that people are not stuck at home that that creates its own health risks. And it's important that people are not unobserved and that they maintain their circle of support. And if they don't have a circle of support that we build it so if you're a solo caregiver and you don't have anybody to help if you got sick, that's not a safe situation and you should be having an IPP right right now, right now, to solve that
problem so that you have an agency or a hired staff or another relative who’s paid to provide you with some backup because that’s not a safe situation for you. That’s not a safe situation for the people in your life. And that doesn’t

1:30:01

And I just wanted to add that you know, one of the challenges as a program running a community based program is trying to provide that so my daughter as well the the staff that work with her are able to take her out for drives, they go and they get, you know, food to go, they take her to the park or the beach to go for walks. And we have that happening with many of the adults that we’re supporting. But it’s an additional transportation cost because either you know, somehow the people who the staff that are driving the individuals they need to have their transport you know, their gas and mileage covered we as a program don’t have enough vehicles to provide for everybody that would want to get out and about if you know we have many staff people that actually don’t have their own cars so they’ll take a bus to get where they’re going. Which is another question that we have on our surveys are you comfortable with the staff will work with the with your son or daughter or you as a client as a self advocate comfort? Trouble with you know, somebody who has to take public transportation to get to you. Also, you know, even if we were to go in groups, we would not be putting a lot of people back into those vehicles, where we used to, you know, drop people off in different areas, we could get seven or eight people in a vehicle, we will not be doing that any longer, we will have to be cleaning the vehicles, we have a protocol that we’ve developed for that. So those those are some challenges that we face as a day program, even when we’re providing the in person in home support for the adults in the program. How do we get everybody out in the community, you know, recognizing that there is an additional cost to doing it with, you know, staff driving their vehicles or being able to provide program vehicles in instances where those are needed. So all of those are things that we’re trying to figure out how we’re going to work around that or get additional help for that.

Judy Mark 1:31:59

Thank you. So much um, I’m gonna now

1:32:03

um, Oh, go ahead even you know that I have down to demand that I’m 24 and even now I am home all day every day. I’m not isolated. Even though my parents at that age with a mobile mobile I, every day I would take I have a routine in the morning when I go out. I will
have a morning walk and I have an evening walk in and it made me scary. It made me scary and not acceptable to be isolated in my life when I first found out about COVID-19 I was so angry. Maybe I thought I was so angry because I thought I was losing my family. I thought I was losing my friends. I thought that my life wouldn't mean the same anymore. But as the stay at home order and continued home, I'm out my mind my mind set things up. And I'm like, No, like, what can I do at home? That would not make me isolated. So every week, my mind fitness trainer would come to my backyard to have

1:33:43

fitness lessons. And then

1:33:47

we have piano lessons in Miami that

1:33:51

is that it all has to do with the mindset and how you think of it in another payment A lot of parents may are scared and they have this one mindset and so in may get to see the future. And so what is important is to think about, okay, how can I get my son and daughter and increases life with being at home, so not theirs when they said, but also, I know that I am getting back to work on Fridays my family would go out to have fun by themselves, and they wouldn't leave me. So it’s important to have number one is to have a bite mindset. Number teams in mood and inclusion and loudness, everything is patience and time begins patience and time will allow people to get bought in my covenant.

Judy Mark 1:35:12

I think everybody need I want to just Paul said, edits just what you said it and everybody needs to watch that. So hopefully everybody did. You're getting a lot of thank yous online in the chat. Definitely you're the most popular in the chat. Sorry. Sorry, Clarissa and Lisa. I want to know ask Anna or Ana, I'm not sure how you say your name to be brought over ahead. Because she she put a question in the q&a, but also wants to ask, ask it through our chat. So go ahead, Anna. Hello. I'm Anna.

1:35:50
Yes, I'm a parent. I'm here with my son Brian. He's 34. He's got severe autism, cerebral palsy. He's not verbal he has a host of things that he is but because of the autism piece very much into routine, and he was very happy in his day program because they he had a one on one there because he has some self injurious behaviors to here and there and buttons now since all this problem with a covert he's been here with me all the time. And I have absolutely because I'm an immigrant. He was born here in the US but I'm from somewhere else so my family's not here. I don't have any family my parents already passed away. I'm already on close to my 60 and, and I myself you know become more vulnerable to so he will not wear a mask and he would not want to, you know, interact much with me and we have computers we have a tablet, I have a phone I have all kinds of things to make and look at this. Look at that, but he's not really To that he's you know, cognitively he's like a one two year old. And he’s just more like, concrete things. So, so far he hasn't seen anyone from the program and they've they've dropped things for him to do here, but nobody has really come in to see him. Exactly or anything I'm amazed to hear all the stories of some of you can have that for your daughters. I'm glad someone does you know, but other than that, you know, I'm he's it just says provider. So that is he's my job. I also had a part time job in the school district, but I'm here and he's lucky that because there are no school I can be here with him all the time. So I'm very dependent on that because you know, on the only one that makes the income and it's very hard, you know, if I miss some of that income, so I’m also so worried that when I do go back to work in if that he's not back in the programs, what am I going to do in that meantime? Because like I said, I'm the HSS worker, I can no longer you know, ask for from that end, you know, I cannot ask anyone to cover for him. But right now my biggest concern is that he's been here for over, like almost going on for months. And I can't take him out because he’s, he goes, drops in the floor, he doesn't walk, walk because he has cerebral palsy. I mean, I could wheel him out, but because of the autism, he gets very upset and starts, you know, biting himself when I take him out, and he definitely won't want to do a mask. And so I’m just kind of stuck because I wish I wish he could with safety precautions, the program that like I said this for high behaviors, so they do he does have a one on one. And if they could arrange You know, for just taking him like you were mentioning, Judy, about your son being able to go out, you know, to, with somebody, you know, go off or to a park or something doesn't have to be big gatherings or anything. Something for him because I'm really, you know, a strength of seeing him like that, you know, and it's like,

Judy Mark  1:39:27
I'm the only one for him. No, I feel for you, I really do and you're not alone. You there's a lot of families like, like you who this we're now in four months of having to do everything. We are the caregiver, the therapist, the nurse, the doctor, that everything for our child, And to me, that's not acceptable, that is not acceptable, that you are not getting the support
that you need. So the first thing that I want you to do, the minute that this webinar is over is to call your service As coordinator at your regional center and tell that individual that you are not doing well that your child is not doing well. And that in particular, you want something called participant directed services, which is available to all people where you can hire people that you know and trust a cousin, an aunt, an uncle of sibling, a neighbor, fortunately, he doesn't have no buddy we have

1:40:27
nobody not having

1:40:31
no friends, no. Well, maybe I have coworkers but they’re like, parent educators like myself, that work in the school district and you know,

Judy Mark  1:40:42
we want to make some extra money. So,

1:40:46
or many and the person who used to who used to support him one on one needs a job. There's really no reason why you can't hire them.

1:40:56
You're all still getting paid from his program that he goes But probably leaving they've been including those that can follow up on su meetings and things. But mine doesn't. So there is no, you know, I have the biggest screen there. If I mean, but I can make him sit, but he just takes a look. And then he runs away. And so I yeah, and the regional center has given us a maximum of 40 hours in home.

1:41:28
You know, care, but the thing is there
Judy Mark 1:41:33
or is that per week? 40 hours,

1:41:35
40 hours every no for de for a quarter? I think

Judy Mark 1:41:39
yeah, that's not there's no maximum. You're not getting anywhere close to the services that you could get on what I what I'd like to do,

1:41:49
Hannah is I'm

Judy Mark 1:41:50
going to give you my personal email address privately in the chat. And you know, I'd like you to send me an email and I'll try to help you okay, because you You're not getting the kind of support that you really need. And there's a lot of community based organizations that also can

1:42:05
I just ask you which regional center you're in the East Bay region

Judy Mark 1:42:10
and we know people in the East Bay too that will try to get you help.

1:42:14
Yeah, because I mean, somebody can come over but then is nothing for him. He's still laying in the floor, you know, on interested in everything is somebody just to watch like protective supervision kind of thing, but they won't interact with him like he needs to, you know, like, like he needs he will be so good if somebody could come like you're saying take him out to a park just for a little while he wants to do it but I can't always be doing that.
I'm also scared if I get sick then that's it, because it's just me and him.

1:42:47
Absolutely.

1:42:48
You might consider also a lot of autistic people are thought to have significant intellectual disabilities because they don't speak but and and because they don't have good control of Their movement but actually but actually are understanding everything and doing anything I don't know. I don't know your your child but it may it may be because the level of the things that he's being exposed to are too basic for him not and and that trying to provide a higher level of of information and programming and whatnot instead of doing preschool stuff might make a big difference and he may have sensory issues which are making it difficult to go outside like bright sun may be difficult and so you might want to experiment with some different things like going out later in the day when the sun’s not so bright or other other. We try to figure out why he doesn't want to go out what what is what's going on there and it may be sensory.

Judy Mark 1:43:55
I'm going to now go to log back to Lorna, we have Another question from a Spanish speaking parent or a comment. And once again, you can ask your questions through the q&a. I'm going to ask your questions on Facebook.

Lorna Silva 1:44:14
Okay, so I have a question from Judy and her question if you have an adult with a disability, and if that person is not able to follow, you know, the safety protocols is that person could be considered for liable, you know, if they become infected, or they infect somebody, is there any liability for that person?

Judy Mark 1:44:33
So, first of all, no one really has a liability issue when it comes to COVID. I mean, there's actually even a question right now about how you could make companies who don't protect their workers liable. And there's some efforts by some Republicans in Congress to make them not liable if they do that, if it’s, you know, neglect, but I really wouldn't worry
about About a person individually being liable. That being said, if you are a person with a disability and cannot socially distance, meaning you have to have a one to one person supporting you, and you cannot wear a mask, you still have the right to be out in the community. The requirement that Governor Newsome made last week for people to wear masks had a very specific exemption for people with developmental disabilities who cannot wear a mask. So there, you know, if you want to be completely safe, let's say you’re bringing this individual into a space where there might be some concerns. First of all, you shouldn’t be bringing them indoors if they’re not, if they’re unable to wear a mask unless you know it is completely safe, which is hard to do. But if they’re one of the things you might want to do, but I’ll try to find it and put it in the chat is To print out the governor’s the governor’s requirement and and highlight that exemption for people with developmental disabilities, and just carry that with you, in case anyone says, I’m sorry, you’re walking in this park, you should know your child should be wearing a mask, and you say they have a developmental disability. And here it is on paper. I’m hoping that you don’t have to get to that point to do that, considering I walk around Manhattan Beach and I see all these like 20 somethings and teenagers who clearly do not have a disability who are running around in bikinis not wearing a mask, and nobody’s asking them to produce any excuse for it. But, you know, certainly you can do that. And I’ll try to get that information and put it out. It’s already in there. Thank you. Ed has put the guidance in the chats for you to see and you know, see what page it’s on. Um, Lorna Was there any other comments or question? From the Spanish line

Lorna Silva 1:47:08
give me a moment I just asked them just a second.

Judy Mark 1:47:12
I’m also going to say I see people’s hands raised. And I know some of them and I love some of them. But I’m really trying right now to get people who are family members and self advocates. And once there are none of those left, then I will offer time for providers to speak.

Lorna Silva 1:47:30
No more questions from the Spanish line. Thank you, Lorna. Appreciate

Judy Mark 1:47:33
that. Um, okay, so going. I’m gonna I have a couple from the chat of people. Um, I, we
Okay, so we have so many from the chat. Let me see if I can get a few um some of which we’ve already answered. So here’s one that we just got in how do you? How do you just feel comfortable finding staff and using staff that is going to work with your child one to one. And so I can just I’ll try to answer that first as a, as an individual who has been has has two staff working with our son who are not there simultaneously, so that they don’t interact with each other. One of the things you heard Clarissa say is you want to have your circle as limited as possible. So there’s somebody said to you, you have COVID today, how many people have you been in contact with that circle is as small as possible, right. So so we have a one of our staff tested positive for COVID. Very, very early in March very early in this pandemic, before anybody had access to mass or gloves or all those things that are now available. That you’re hearing people passing out, we had none of that we had nothing. And it was quite a crisis for our family. And this is an individual that we totally trust and had a very small circle herself. But she had a roommate, and her roommate, um, brought in COVID into her she had one roommate, and that’s it. That was her circle. And that roommate had a tiny cold. That was considered a tiny cold early on. Remember, this is March so people had colds back in March. And it Aggie never got tested and gave it to her. And I can tell you that she brought it into her home, she was with us 10 hours before her first symptom, which means she was definitely contagious and none of us were infected, because we were practicing, you know, hand washing, social distancing as much as possible, wiping down surfaces and this is what we have to practice. So even when we have a trusted person coming into our home, there still has to be constant hair. Washing and helping that person with a disability wash their hands with with soap and making sure they’re doing it. But I may be closer Lisa Eden, how do you trust people who are coming into your home?

1:50:14

Well, anybody who comes into your home is introducing any any person that you get closer than six feet from for more than 15 minutes is introducing some risk to you to you and your family and to your household. I think that most of us are going to need to take some risk, there’s not that and a need to balance the risk of having contact with somebody against the risk of not having contact with not having any contact. So if you know none of us will be healthy. If we stay home all the time. never see anybody. Never talk to anybody or health issues will be missed, we'll get out of shape, we'll, we'll we'll be lonely. We, you know, we're that that’s a risk in and of itself. So so we probably all will need to take some risks, but there’s a big risk, like going to an indoor place with to do group activities with a lot of other people who have difficulty doing precautions, that that’s one type of risk or going to a concert in an enclosed arena with thousands of other people that that’s a big risk. A little risk would be finding somebody that you trust that you that you are very honest with that you asked to be very honest with you, and that you try
to take care of each other as best you can. We’re going to have to take some of those little risks, because this isn’t going you know, it’s one thing to have a very limited circle that only include your household for a week or a month or a few months, but we none of us can do that safely for the long term and we need to plan for the long term. So we’re going to have to take some little risks and and you know, you know what you’re going for, and then you’re just gonna have to use your, your social skills and your and your judgment

1:52:27

and to decide to decide how to

1:52:31

how to take, you know how to take some, some level of risk. That’s limited.

1:52:38

And I just wanted to say as you know, all of that those were considerations that we took into account. When making the decision as a day program, are we going to provide those in home support for the self advocates, the adults that needed it, because we knew we were going to be introducing some additional risks into those homes and to those clients, but we felt that if we were honest with the families and the clients and that we were honest with staff, we’ve asked questions of people that we don’t normally ask our staff, which is Who are you coming in contact with? How many people do you live with who those people come in contact with. But we understood and I understand as a parent, first and foremost, but also as a program director, that there are some limited risks that I need to take if I want to have the support that my daughter needs that I need as a parent to help out with my daughter. And we, you know, went back and forth a little bit as a program to try to decide Are we willing to take the risk and and just, you know, inform our participants and form the the families and the staff and to be able to provide those supports so that people don’t end up in the situation where the adult is at home with one caregiver or a parent and has No other support. So I think you have to know the risks you have to try to minimize them. You have to you know, go with the protocols, the hand washing, hand sanitizing, we asked all of the families, if you’re going to have a staff person, come into your home, set up a, you know, hand washing station, make sure that you’re following protocols, we’re asking our staff to follow, make sure as you know, families that you’re being as careful as you can. But we just know that people there are a lot of people out there that needed that support. So we had to take that into account and and, you know, try to minimize the risk, but no, it is a little bit of a risk.
Thank you.

Um, okay, we’re gonna go now to Mary Suarez. If you can bring her over, we only have a few more minutes. We might run a little bit late. Just because I’m going to add I’m going to bring in Mary and Celeste for their final comments. Go ahead, Mary. You have to unmute yourself, Mary. We cannot hear you. You’re still muted Mary. Mary, are you there?

Okay.

Mary doesn’t seem to be at her computer or phone right. The second. So let’s let’s pull in Celeste then and

please. Thanks, ed.

So let’s did write a question in the in the q&a as well and I wanted her to be able to ask it in person.

Hi, Celeste, go ahead and then

unmute yourself.
1:55:38
Oh, I’m on zoom. Will it still come through?

1:55:40
Yes. I we are hearing

Judy Mark 1:55:41
you loud and clear.

1:55:43
Okay, great. Well, I’m kind of concerned about a couple of things. Mostly, I thought a lot of today’s talk would be about the status of reopening. And I’m not hearing a lot about that. My son is in a day program and this is day one. 101 and it’s just as my husband is retired, I like Ana am a parent educator at the school. So I’m not currently working. But it feels like there’s no talk about reopening. I was the one that put in the one section about, we have a small program 4000 square feet only 20, you know, under 25 clients, he needs to get back to some some socialization. And the regional center doesn’t seem to have been talking to our program about this participate participant services that I’m hearing about. I’m concerned about in some cases, we’ve already spoke about isolation when we talked to Ana and I saw another question on there about that. I’m concerned and that unfortunately isn’t the case in this situation. But with all of this going on the the care, giver, burnout and the abuse. There’s a lot of things Anything needs to be addressed because not only are we talking about the risk of bringing our loved ones out into the community where the only person you can trust is yourself for protection, but we just we got to find a way to get this back in there and you do have to leave a little bit in his hands when you take the risk of your child returning. We’ve got a great program, I want to see a case by case basis. When it comes to reopening I would have sent my child back a month ago because like I said, 4000 square feet and only, you know, under 25 clients

1:57:38
but they

Judy Mark 1:57:39
were talking about reopening. So Celeste, thank you for that. Those are excellent questions. And once again, we are hearing this from a lot of families so you’re not alone. Um, so where is the process reopening I so that I have no idea no, I’m going to answer it for you.

Okay, I was I was asking,

Hey, okay, so we’re the process can we call?

Um, is that

is that the Department of Developmental Services, which is the state agency that funds regional centers,

is
is developed is doing outreach to service providers, to family members to self advocates, to regional center staff, to many different people to get our feedback and this is part of that we’re getting feedback from all of you and we’ll bring it to the department as they are developing their what they’re calling re entry plan. I think they renamed it and I can’t remember what they are calling it. But they are changing. The name used to be reopening and re entry and now it’s something else. I put that information in the chat you’ll you’ll have to scroll back See in the chat, but there is I was
having trouble getting into the chat. That's okay. I'll poke around don't here's

Judy Mark 1:59:06
what people should do is to go to the website eds.ca.gov and do a search for the the Disability Services Task Force or DS Task Force. So they have a task force made up of all these people around the state who are very active in different organizations, service providers, regional center staff, and others who sit on a big committee basically, and provide advice to DDS about a range of issues and this is one of them. And so they are right now reacting to a set of measures that DDS is proposing. These measures have not been decided upon. There's a lot of concerns still out there about some of these measures. But here's what I want to say to you Celeste.

1:59:58
It is unclear

Judy Mark 2:00:00
exactly when de programs are going to be allowed to be reopened in a very modified way, there is not a single day program or any kind of congregate setting that meets in person in groups that will be able to reopen in the same way they were meeting before coding, that is just not going to happen and nobody should get their hopes up, then that is going to happen. DDS will not approve of that. The governor would not approve of that. It would be against lots of county measures as well. So if that is the case, then what is it that we can do that is different. And one of the things that you can do that is different is that the day programs these other kinds of in person programs can start to provide services in a different way in a person centered individualized way that is primarily outdoors that is safe, where you are only export each individual is only exposed to one staff and that it's limiting those risks. Another way, which I think is potentially a better and safer way to do it is to start utilizing selects you should when we get off the phone, call your service coordinator, and once again, ask for participant directed services. So I'm going to spend just one minute explaining that participant directed services have always existed. They're not new for COVID. They've always been there. It's just none of us have ever been told about that. What this does, it allows families or individuals to hire people of their own choice to provide support to them in the areas of respite, personal assistance, supported employment, and independent living services. There might be a sixth one is they Well, I can't remember. And so there are they're set. Um, there are the set services that people
can provide and you get to hire whoever You want whomever you want, as long as they you know, they have to pass some basic criminal background check, not fingerprinting, but you can hire whomever you may. And so it could be a sibling, a neighbor, a close friend, a paraprofessional, from the school, an aide from the day program who's out of work, there are so many people that you can hire to do these services. The problem is, and by the way, I should mention that is different than self determination. self determination is a program that you had to have been selected for for that because we’re in our first three year phase in period. And that is, it gives you even more flexibility because you can pay people what you want, you can negotiate fees, you can hire lots of different kinds of cool people that are outside of the regular shirt traditional system. But that is different and you have to have been accepted into the self determination program, but for everyone else in the traditional system, because that's only for 2500 people. So for everybody else, you can use these participant directed services and people are not using them because they don't know about them. And there's there I put in the chat. There's some great plain language materials about it. We have it on our Coronavirus website, that you can find the information about this as well as on your service coordinator should know about it. And if your service coordinator said participant directed what, then ask for their supervisor and no supervisor should know about it. And if they don't know about it, go straight to your executive director. Because everybody should be trained on this and you have the you have access to it. And that person they don't make a lot. That’s one of the problems that they’re not going to make a huge amount of money. They do make above minimum wage, depending on which service it is. So you might be able to pay someone to help you. You know, maybe you are going to work and you need support or you have an internship or you just want somebody to go in the community and help you. It gives you so much flexibility and again Families a break, which is what they need right now. So absolutely. So I want to thank you, Celeste. And I want to just, we're going to have to wrap up because we're going over and I know that there's so many questions and comments that we didn't get to. But I, Clarissa, Lisa Eden, do any of you want to have a closing thought?

2:04:23

Well, I just, you know, Group hug. This is this is really difficult to come to terms with what we have to deal with. And so this was the bad news day, but I'm hoping that the next town hall will be the good news day where we address some of these things. You know, what, what what we're doing now isn't working. And what we had before isn't coming back. So what can we do? And how can we do this? Well, how do we how do we reorganize His plans and service plans and use all those professionals who we need to, to enrich our lives. And I think there's a lot of potential there. And what we create when we're really creative, and we really think about what individuals need and what they want and what their ambitions are, what we create can definitely be better than what we’re leaving behind. It’s
just going to take, it's going to take a community and a lot of creativity and a lot of thought and and a lot of effort. And, but, but we're up for that. So let's do it.

2:05:42
Yeah, I just wanted to add on to that. That's exactly it as a day program, a community based a program. We are spending a lot of time trying to reimagine and rework and reconfigure how we provide those services. It's going to be if anything even more more self advocacy and more person centered planning and more, helping the individuals advocate for what they need. But how does that work in terms of being able to get back into the community safely? So we're spending a lot of time talking about how we're going to do that.

2:06:18
Thank you, Lisa.

Judy Mark
2:06:20
So I want to thank everybody. Once again, we record all of our webinars and they will be available on our Coronavirus Resources website. And, you know, please, please stay safe out there don't be taking risks, particularly with our community, we should not be taking risks. I just heard that there's another record setting day in the state of California for new cases and our hospitalizations are going up. And so your now is not the time to let the guard down. But that doesn't mean that we can't go out and we we as long as we go out safely where your mouth I forgot to mention that for those people with disabilities who can't wear a mask, that there are face shields that some people may be able to tolerate more. And that does help. It's not perfect, but it does help a lot. Those facials are available for free from the State Council on Developmental Disabilities. And some organizations such as Lisa's are also hand at handing out some of that equipment as well. So please come and your regional centers as well. So please get that equipment and get out there, take hikes, go for bike rides, go go into your local park, walk around your neighborhoods, walk around other people's neighborhoods, as long as you're staying safe and staying away from people that you don't know and that you don't trust. So I thank you all once again, and I hope you have a really good week. We'll be back next week. We will not be back next week with another webinar. It is July 4 week. So we are taking a one week break from our webinars but we will We'll be back the following week. And we are going to be talking about the re entry into education and employment for people who are who and how that looks for people with developmental disabilities, which has all kinds of
red flags all over it. So thank you to our panelists, Marissa and Lisa and Eden, you were amazing. This is one of my favorite webinars we’ve ever had. And thank you everybody and good evening.