

WEBVTT

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00:00:20.070 --> 00:00:27.540

Rochelle Walensky: There we go we're still two minutes early so we didn't want to be late, but I just want to make sure we're not missing anyone before we get started.

2

00:00:31.170 --> 00:00:39.270

Bethany Lilly, The Arc (she/hers): guys are they're missing on our side, I think I see most I know a few people are off camera but we'll be back on in a minute.

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00:00:42.090 --> 00:00:46.230

Bethany Lilly, The Arc (she/hers): Oh Mia says from link isn't working so let me try and reach out to her.

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00:01:00.300 --> 00:01:01.950

Karen Remley, CDC (she, her): Jamila it's good to see you again.

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00:01:05.310 --> 00:01:08.760

Jamila Headley: good to see you too thanks for meeting with us.

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00:01:11.130 --> 00:01:11.550

Jamila Headley: Like.

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00:01:19.590 --> 00:01:22.620

Jamila Headley: I'm CDC folks do you know if.

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00:01:24.570 --> 00:01:39.150

Jamila Headley: MIA it, saying that the ID isn't validated, I want to make sure that she was added directly to the invite from by you all, if that's to make sure that that's not getting in the way of her joining, but hopefully we can get it sorted out for her to join.

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00:01:42.570 --> 00:01:43.380

Dori Salcido, CDC: can check on that.

10

00:01:44.250 --> 00:01:44.550

Okay.

11

00:02:03.240 --> 00:02:03.780

Bethany Lilly, The Arc (she/hers): There we go.

12

00:02:10.710 --> 00:02:13.290

Karen Remley, CDC (she, her): Bethany do you want us to get started.

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00:02:13.800 --> 00:02:15.090

Bethany Lilly, The Arc (she/hers): I think that'd be great okay.

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00:02:15.150 --> 00:02:16.290

Karen Remley, CDC (she, her): Great well.

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00:02:16.530 --> 00:02:33.120

Karen Remley, CDC (she, her): Good afternoon, everyone I'm Karen Remley the Director of the National Center on Birth Defects and Developmental Disabilities at CDC and it is my pleasure to introduce Dr Rochelle Walensky, who is the director of the centers for Disease Control I'll turn it over to you, Dr. Walensky.

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00:02:33.570 --> 00:02:44.100

Rochelle Walensky: Thank you so much, Dr. Remley good afternoon I'm really grateful to have this time with you and really to be able to talk with you directly and mostly to hear from you.

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00:02:44.520 --> 00:02:50.670

Rochelle Walensky: And I hope that today's conversation can be an opportunity for me to listen, there are many things I could say.

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00:02:51.030 --> 00:02:58.710

Rochelle Walensky: But, really, what I want to do today is listen and to learn from you on how we can do better how CDC can do better, and how I can do better.

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00:02:59.400 --> 00:03:11.730

Rochelle Walensky: I acknowledge that my words last week, though unintentional were hurtful and I'm sorry for that and for how they reflect on me this agency and our federal COVID response.

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00:03:12.180 --> 00:03:25.500

Rochelle Walensky: Those words don't represent, who I am or how I live my life. I spent my academic career focused on breaking down barriers, increasing access, partnering with communities, and advocating for policy change.

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00:03:26.430 --> 00:03:37.290

Rochelle Walensky: As a doctor, in my own clinical practice, I saw each patient as a person, as a mother, a father, a child, an individual and not as their disease or their disability.

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00:03:38.280 --> 00:03:52.950

Rochelle Walensky: One of the reasons I'm in this role as the Director is that I saw the devastating disparities and inequities that existed even before COVID-19 and which were made worse by this pandemic and I fought at every opportunity to address them.

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00:03:54.090 --> 00:04:04.680

Rochelle Walensky: You just met Dr. Karen Remley, many of you know her already. She's here with us today, because we take this work so very seriously with the disability community.

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00:04:05.430 --> 00:04:22.590

Rochelle Walensky: I appreciate having this time with you and how we can do more and learn more so that we can all do better, so thank you for taking the time, thank you for joining, and thank you for convening us and I'm here to listen I'll turn things over to Bethany Thank you.

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00:04:23.910 --> 00:04:27.750

Bethany Lilly, The Arc (she/hers): Thank you so much, I am also really glad that we could find the time to chat.

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00:04:28.260 --> 00:04:35.610

Bethany Lilly, The Arc (she/hers): It would be really helpful for us if folks from the CDC like Karen who I've actually never met before could introduce themselves in the chat I.

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00:04:35.910 --> 00:04:41.340

Bethany Lilly, The Arc (she/hers): don't want to spend time on that, since we don't have a lot of time, but just to give us a sense of who else is participating.

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00:04:41.820 --> 00:04:53.040

Bethany Lilly, The Arc (she/hers): and we, as I said, are very grateful, this time for this time because we wanted to discuss specifically why this was hurtful and what our community has been experiencing over the past two years.

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00:04:53.430 --> 00:05:02.610

Bethany Lilly, The Arc (she/hers): And it sounds like you have some experience from that but it's very different from a provider perspective than it is from being a person with lived experience and being a person with a disability.

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00:05:03.390 --> 00:05:07.230

Bethany Lilly, The Arc (she/hers): we're not here really to soothe our own feelings, but we feel that the CDC.

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00:05:07.560 --> 00:05:16.590

Bethany Lilly, The Arc (she/hers): really needs to take steps to return the trust of the disability community not based exclusively on your comments but based on policy actions over the past two years.

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00:05:16.920 --> 00:05:24.090

Bethany Lilly, The Arc (she/hers): And we want to establish a couple things the beginning, and we appreciate you expressing that you will apologize for this being hurtful.

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00:05:24.690 --> 00:05:34.650

Bethany Lilly, The Arc (she/hers): For us it's very friendly folks that did feel hurt um we understand you were referring to a study we understand that your remarks were cut by the network and that others have taken them out of context, and we know that must have been.

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00:05:35.010 --> 00:05:40.560

Bethany Lilly, The Arc (she/hers): challenging in many ways, but the study you were referring to we represent the folks in that study, who died.

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00:05:41.040 --> 00:05:47.730

Bethany Lilly, The Arc (she/hers): And those people with for or more comorbidities those lives remain at less risk at this point because of them are calling and.

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00:05:48.090 --> 00:05:50.940

Bethany Lilly, The Arc (she/hers): Throughout the pandemic, we have in the folks who have died so.

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00:05:51.330 --> 00:05:59.760

Bethany Lilly, The Arc (she/hers): I really want to turn it over to Matt and to Julia and to Elena and Natalie to talk a little bit more about the experiences we've seen over the past two years.

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00:06:00.090 --> 00:06:06.390

Bethany Lilly, The Arc (she/hers): And then I'll go ahead and we can turn it over to some of the more concrete policy asks we have but I'll start by kicking it over to Matt.

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00:06:12.300 --> 00:06:13.350

Jamila Headley: Matt we can't hear you.

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00:06:15.510 --> 00:06:26.310

Matthew Cortland: Thank you, can you hear me now? fantastic, my name is Matthew Cortland. Thank you all for being here today, I am a senior fellow at Data for Progress where I focus on chronic illness and disability.

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00:06:26.820 --> 00:06:40.950

Matthew Cortland: At the outset I want to apologize if I'm not at my best, right now, my partner has COVID 19 and is isolating in the other end of our home and, as I am up at night listening to her cough.

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00:06:42.510 --> 00:06:48.900

Matthew Cortland: As someone you know she has three or more chronic health conditions co-morbidities four or more actually co-morbidities.

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00:06:50.340 --> 00:06:57.360

Matthew Cortland: I worry about her because her life matters a great deal to me, and I know that she's up at night worrying about me getting sick because.

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00:06:58.740 --> 00:07:04.440

Matthew Cortland: I am also one of the 10s of I am also one of the 10s of millions of Americans with four or more comorbidities.

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00:07:05.130 --> 00:07:09.960

Matthew Cortland: And I'm immunocompromised. I don't I don't want to debate specific prevalence studies, but about 3%.

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00:07:10.500 --> 00:07:15.390

Matthew Cortland: of Americans, including children and adults are you know immunocompromised, we are literally millions of people.

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00:07:15.960 --> 00:07:22.140

Matthew Cortland: I appreciate your apology understand that to some extent, your remarks were taken out of context, but it is not at all, encouraging.

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00:07:22.590 --> 00:07:38.070

Matthew Cortland: To us or our loved ones that COVID-19 mortality amongst the vaccinated is falling disproportionately on those who are medically complex, who are immunocompromised, who are disabled, who are chronically ill with that I'll turn this over to Julia. Thank you again for being here.

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00:07:41.520 --> 00:07:51.270

Julia Bascom: Thanks Matt and thank you, Director I'm also a person with four high-risk conditions for COVID and many other co-occurring condition, I represent the Autistic Self-advocacy Network.

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00:07:51.780 --> 00:07:59.670

Julia Bascom: Which means I represent a community where people are already at high risk and it's common to additionally have multiple other disabilities and risk factors.

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00:08:00.300 --> 00:08:12.030

Julia Bascom: What people with disabilities have heard consistently over the course of the pandemic is that our deaths are expected inevitable and less tragic than the deaths of other people.

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00:08:12.750 --> 00:08:20.280

Julia Bascom: And we heard this message prior to the pandemic as well, we know it's actually the default implicit belief that most people have about people with disabilities.

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00:08:20.820 --> 00:08:28.410

Julia Bascom: And sometimes this belief is expressed directly through word, but often is expressed through action like policy choices, or through an absence of action.

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00:08:29.100 --> 00:08:35.970

Julia Bascom: And over the past few years, what I've seen from my community is that many disabled people have looked at the policies put forth by the CDC.

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00:08:36.540 --> 00:08:40.500

Julia Bascom: and have been forced to conclude the position of the CDC is that it matters less when we die.

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00:08:41.310 --> 00:08:52.650

Julia Bascom: When you were talking about the death of people like me and you dismissed us as being unwell, to begin with, you were saying what we've heard loud and clear, for two years, I also really appreciate the apology, and I think the disability community will too.

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00:08:54.150 --> 00:09:03.030

Julia Bascom: What we're going to need to see that apology really translated into those policy actions and I'm hoping we could spend the majority of our time talking about that. Thank you I'm going to pass it to Natalie.

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00:09:05.760 --> 00:09:25.590

Natalie Kean (she/her) Justice in Aging: Good afternoon. I'm Natalie Kean and I'm here today on behalf of Justice In Aging and the older adults in our communities that have heard this message too that their deaths are inevitable and their lives are not valued and this is especially true for older adults with disabilities.

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00:09:26.640 --> 00:09:43.260

Natalie Kean (she/her) Justice in Aging: And for communities of color who are losing their elders because policy choices are not valuing their lives. So many of the people with multiple chronic conditions in the study you were referring to, and in our country.

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00:09:44.400 --> 00:10:02.790

Natalie Kean (she/her) Justice in Aging: are older adults themselves and people with disabilities age, and we need to keep that in mind, this is not a monolith and we need to take specific, targeted actions with our policies and that's what we're here to ask for today.

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00:10:03.480 --> 00:10:04.080

Elena.

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00:10:05.340 --> 00:10:06.600

Elena Hung, Little Lobbyists (she/her): Thank you, thank you Natalie.

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00:10:08.250 --> 00:10:22.440

Elena Hung, Little Lobbyists (she/her): Thank you, I am Elene Hung I am here on behalf of Little Lobbyists, a family lead group advocating for children with complex medical needs and disabilities and, in addition to what the others have already said, I want to know..

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00:10:23.610 --> 00:10:36.480

Elena Hung, Little Lobbyists (she/her): Dr. Walensky that both your comments and your policy choices as Director are also extremely damaging to chronically ill and disabled children who, I assure you are watching and listening.

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00:10:37.110 --> 00:10:45.240

Elena Hung, Little Lobbyists (she/her): I'm a mom to an amazing seven-year-old disabled daughter Xiomara was born with a number of serious medical conditions.

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00:10:46.170 --> 00:11:00.000

Elena Hung, Little Lobbyists (she/her): Including lung disease and chronic kidney disease. And Xiomara is the reason that I do this work she and I have worked together for several years now, to help make policies more inclusive and accessible for kids like her.

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00:11:00.720 --> 00:11:07.350

Elena Hung, Little Lobbyists (she/her): and your comments and your policy choices conducted in your leadership role as part of this administration

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00:11:08.400 --> 00:11:20.040

Elena Hung, Little Lobbyists (she/her): undermined the work that we are doing to raise our children our disabled children to see that their lives are worthy it undermines the work that I'm doing as a parent.

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00:11:20.430 --> 00:11:30.420



Elena Hung, Little Lobbyists (she/her): the work that my organization is doing across the country and the work the disability community as a whole is doing to ensure that kids like mine, get a chance to grow up.

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00:11:31.200 --> 00:11:48.540

Elena Hung, Little Lobbyists (she/her): When chronically ill and disabled people are dying at disproportionate rates and the CDC is telling chronically ill and disabled children, that that is their fate, and that is the part of the harm that is being done here that I want it to raise for your awareness, Bethany.

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00:11:50.880 --> 00:11:51.690

Bethany Lilly, The Arc (she/hers): Thank you, Elena.

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00:11:52.710 --> 00:11:57.300

Bethany Lilly, The Arc (she/hers): And thank you all, I mean, I know that it can always be hard to share personal experiences and I just want to.

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00:11:58.200 --> 00:12:07.560

Bethany Lilly, The Arc (she/hers): Thank you, and I am sure everyone else on the call would also want to extend that thanks. Yesterday, we sent you a letter in conjunction with a number of other disability groups.

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00:12:07.950 --> 00:12:15.450

Bethany Lilly, The Arc (she/hers): detailing specific policy actions that we would recommend that the CDC take to better serve the disability community and to start rebuilding that trust.

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00:12:16.260 --> 00:12:27.030

Bethany Lilly, The Arc (she/hers): I want you to be fully aware that we have also requested a meeting with Secretary Becerra to discuss things that HHS can do. We understand that the CDC is only one actor among many governmental actors.

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00:12:28.170 --> 00:12:41.430

Bethany Lilly, The Arc (she/hers): And we are also we've spoken some of us have spoken to the White House, and we expect those conversations to continue but we'd really like to get into a substantive discussion of some of the specific requests and recommendations we have, and so this can be.

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00:12:43.110 --> 00:12:45.060

Bethany Lilly, The Arc (she/hers): Trying to keep us on time there we go.

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00:12:46.530 --> 00:12:55.710

Bethany Lilly, The Arc (she/hers): So I will then turn it over to I'm going to turn it back over to Elena for a minute just to talk a little bit about some of the communication that we think would be helpful and then to Julia.

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00:12:56.250 --> 00:13:04.050

Elena Hung, Little Lobbyists (she/her): Oh, thank you, oh I'll try to be brief, so let's be clear that the trust between the CDC and the disability community.

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00:13:04.440 --> 00:13:09.900

Elena Hung, Little Lobbyists (she/her): has been broken, we acknowledge the apology, you made at the start of this conversation.

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00:13:10.740 --> 00:13:16.110

Elena Hung, Little Lobbyists (she/her): And that is the first step, the first step to repairing our relationship, the first step to repair that broken trust is

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00:13:16.560 --> 00:13:25.380

Elena Hung, Little Lobbyists (she/her): a public apology, not just an apology to the organizations here, but a public apology from you Director to the larger disability community.

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00:13:25.890 --> 00:13:31.680

Elena Hung, Little Lobbyists (she/her): And the reason we opened this meeting today discussing why this has been so hurtful is because we don't feel.

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00:13:32.160 --> 00:13:43.920

Elena Hung, Little Lobbyists (she/her): that the CDC understands the impact of your words as Director and the actions have on our lives. We don't feel heard and we don't feel represented by our government.

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00:13:44.550 --> 00:14:03.060

Elena Hung, Little Lobbyists (she/her): Many of us here have served on the disability policy team that helped inform an inclusive platform for then candidate Joe Biden and based on these policies we worked really

hard to help elect and put in office this administration. My organization little lobbyists.

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00:14:04.080 --> 00:14:19.920

Elena Hung, Little Lobbyists (she/her): endorsed Joe Biden, specifically because of his explicit commitment to the disability community he promised me that he would protect my disabled child's health care, like it was his own and he made that same promise to the disability community.

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00:14:20.970 --> 00:14:27.360

Elena Hung, Little Lobbyists (she/her): Our community has shown up time and again to protect public health, we let the efforts to save the ACA when it was under attack.

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00:14:27.690 --> 00:14:35.940

Elena Hung, Little Lobbyists (she/her): We were the first to go into and stay in lockdown when the pandemic hit and yet time and again, our community has been forgotten.

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00:14:36.630 --> 00:14:41.550

Elena Hung, Little Lobbyists (she/her): So when we tell you that we feel betrayed by this administration.

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00:14:42.210 --> 00:14:50.580

Elena Hung, Little Lobbyists (she/her): Please, please, please understand that we have been told in countless meetings and listening sessions by this administration, by you

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00:14:50.940 --> 00:15:08.730

Elena Hung, Little Lobbyists (she/her): that people with disabilities, would not be left behind, and then we have spent the past year being left behind. And when we watch our disabled friends and family members die in congregate settings and die at disproportionate rates because of failed policies, it is a betrayal.

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00:15:09.750 --> 00:15:22.800

Elena Hung, Little Lobbyists (she/her): When we are the ones who are most at risk in this pandemic, but have been left behind, without reliable and adequate access to life saving vaccines masks and testing, it is a betrayal.

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00:15:23.370 --> 00:15:32.130

Elena Hung, Little Lobbyists (she/her): And when we hear you publicly say that it is quote encouraging news that we are the ones dying, it is a betrayal.

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00:15:32.850 --> 00:15:41.400

Elena Hung, Little Lobbyists (she/her): And that betrayal warrants a public apology. Your commitment to rebuild trust and work with the disability community in good faith.

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00:15:41.850 --> 00:15:53.310

Elena Hung, Little Lobbyists (she/her): begins with a public apology, based on an understanding of the harm done specifically how the CDC's policies are directly related to the frustration we're feeling today.

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00:15:53.970 --> 00:16:07.080

Elena Hung, Little Lobbyists (she/her): And most importantly, we need you to follow through on that apology through changed policies and we are ready to discuss those policy asks with you. I'm going to turn this over to Julia. Thank you, thank you for listening.

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00:16:08.910 --> 00:16:09.690

Julia Bascom: Thank you Elena.

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00:16:11.040 --> 00:16:17.850

Julia Bascom: So we're about to launch into those policy recommendations and I'm hoping we'll have enough time to get through them and have a real conversation about them.

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00:16:18.420 --> 00:16:27.180

Julia Bascom: Underlying those recommendations so as a key programmatic element that I want to highlight. The CDC urgently needs to develop infrastructure throughout the agency.

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00:16:27.660 --> 00:16:32.100

Julia Bascom: to support effective communication and inclusive policymaking with the disability community.

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00:16:32.580 --> 00:16:40.260

Julia Bascom: I know we have a lot of disability representatives at the CDC on this call, right now, and I really appreciate the work they're all doing, but I want to be really clear.

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00:16:40.680 --> 00:16:45.600

Julia Bascom: That when we say this we're saying what exists right now is wildly insufficient to the need.

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00:16:46.470 --> 00:16:53.820

Julia Bascom: Many organizations have repeatedly raised the need for an investment in this infrastructure over the last two years, due to the absence

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00:16:54.450 --> 00:17:02.880

Julia Bascom: of adequate support for this kind of real partnership and regular communication with the disability community, we saw widespread confusion.

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00:17:03.390 --> 00:17:08.580

Julia Bascom: at the state and local and individual level about which disabilities qualify as high-risk conditions.

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00:17:08.910 --> 00:17:17.370

Julia Bascom: about who should be prioritized for vaccinations, what counted as congregate settings or long-term care settings among many, many, many other examples.

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00:17:18.300 --> 00:17:27.330

Julia Bascom: So we believe that regular meetings with disability organizations, at both the staff and the leadership level within and across all centers of the CDC

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00:17:27.810 --> 00:17:32.160

Julia Bascom: will help to ensure that the CDC is conducting the necessary internal education.

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00:17:33.030 --> 00:17:38.850

Julia Bascom: That you're, including the needs of disabled Americans in policy development from the beginning, no matter what that policy may be.

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00:17:39.480 --> 00:17:48.780

Julia Bascom: And that we're improving the accessibility and the inclusivity of your public health messaging and implementing best practices going forward to prevent a lot of the problems we've seen over the last few years.

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00:17:49.170 --> 00:17:55.500

Julia Bascom: This is a really crucial element of the work that the CDC must do to re earn the disability community's trust in the interest of public health.

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00:17:56.580 --> 00:18:01.920

Julia Bascom: We could talk a lot more about that, but I'm going to turn it over to Matt. Matt kick us off with some of the bigger policy recommendation.

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00:18:02.640 --> 00:18:09.960

Matthew Cortland: Thank you, and I just I, I want to be very clear that I'm going to talk about specifics, but Julie's point

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00:18:10.500 --> 00:18:18.450

Matthew Cortland: about including disability chronic illness and immunocompromised perspectives in policymaking is the overriding goal.

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00:18:18.900 --> 00:18:25.650

Matthew Cortland: I'm going to talk about specific examples, they are not exhaustive, by any means, I want to be very clear they're just meant to highlight.

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00:18:26.190 --> 00:18:33.360

Matthew Cortland: I'll be completely honest with you Director my graduate training is in public health from Boston University's Graduate School of Public Health my juris doctorate is from

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00:18:33.600 --> 00:18:42.780

Matthew Cortland: The George Mason University School of Law, I do this for a living, I do not understand how to operationalize CDC's technical guidance and again I want to be very clear.

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00:18:43.200 --> 00:18:48.990

Matthew Cortland: I don't wish to be unfair, I understand CDC's role is primarily in technical guidance in this circumstance.

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00:18:49.590 --> 00:19:00.180

Matthew Cortland: I don't understand how to operationalize, for example, the technical guidance about isolation and quarantine that has been promulgated to both non healthcare workers.

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00:19:00.750 --> 00:19:19.260

Matthew Cortland: and healthcare workers, I know this has been it is complex and it is difficult to communicate about, but when CDC's guidance says that immunocompromised people are meant to be avoided by the general public, I don't know how to identify like.

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00:19:20.430 --> 00:19:28.440

Matthew Cortland: my my immunocompromised state my chronic illnesses are not apparent to the general public, we need to have a real conversation about how we operationalize this guidance.

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00:19:28.950 --> 00:19:34.140

Matthew Cortland: At the same time, CDC has guidance to healthcare professionals and I again.

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00:19:34.680 --> 00:19:46.230

Matthew Cortland: I understand that it is necessary, as someone whose life literally depends on the health care service and delivery system remaining intact, I understand it is necessary that the service and delivery system continue.

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00:19:46.770 --> 00:20:00.360

Matthew Cortland: However, guidance that tells physicians and nurses and and MPs and PAs is, and I could go on and on every single person in the hospital is important to make that hospital RN is, as you well know, when that guidance.

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00:20:01.980 --> 00:20:06.900

Matthew Cortland: tells folks, for example, to leave to go back to work, while mildly.

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00:20:07.320 --> 00:20:16.680

Matthew Cortland: mildly symptomatic I don't know what mildly symptomatic means my health care, my treating health care professionals, the nurses who take care of me and my physicians office at.

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00:20:17.430 --> 00:20:27.060

Matthew Cortland: At the health care system that you use to practice that they don't know what that means, and my point here is that when guidance.

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00:20:28.290 --> 00:20:37.560

Matthew Cortland: For quarantine and isolation is designed in such a way that people like me and the millions of people I represent are protected, that guidance protects everyone.

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00:20:37.950 --> 00:20:47.190

Matthew Cortland: If you are protecting us, you are protecting everyone and right now we are not being protected by this guidance, and so I understand there are technical challenges here.

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00:20:48.870 --> 00:21:00.750

Matthew Cortland: I still do not understand personally why the use of rapid antigen tests, I've heard your briefings with healthcare professionals, I understand.

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00:21:01.200 --> 00:21:12.300

Matthew Cortland: What CDC has said so far, it does not speak to my concerns as a chronically ill immunocompromised and disabled person who has to go to healthcare settings in order to continue to live literally and so.

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00:21:13.380 --> 00:21:26.340

Matthew Cortland: Reserving some number of rapid antigen tests for a population, we know is positive for SARS-CoV-2 it's literally one of the highest risk. It's almost a tautology to say that people who have COVID-19

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00:21:26.850 --> 00:21:37.890

Matthew Cortland: are carrying SARS-CoV-2 but that's true, and so, how do we target interventions to protect immunocompromised disabled chronically ill people who need to go to healthcare settings.

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00:21:38.310 --> 00:21:47.730

Matthew Cortland: How do we target CDC guidance, so that when I am out in public people people are protecting me people are protecting Elena's child.

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00:21:49.020 --> 00:21:57.660

Matthew Cortland: These are again just top lines, I don't expect you to have nitty gritty details here, I want to be clear I'm just saying if guidance.

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00:21:58.050 --> 00:22:09.540

Matthew Cortland: is operationalizable in a way that protects me and people like me, it will protect others. The other thing I wanted to mention very briefly is, I know the administration has recently.

137

00:22:11.100 --> 00:22:12.600

Matthew Cortland: announced a mask initiative.

138

00:22:13.860 --> 00:22:24.750

Matthew Cortland: Data for Progress I looked at this 39 to 40% of people are still wearing cloth masks you know Director, because you wrote about this in 2020, you wrote and invited commentary in JAMA.

139

00:22:25.140 --> 00:22:31.680

Matthew Cortland: Internal Medicine, about how great N95s are protecting healthcare providers, if nothing else, if nothing else.

140

00:22:33.120 --> 00:22:41.760

Matthew Cortland: When I go to a hospital, I shouldn't have to worry about adequate source control that the nurse has a surgical mask because.

141

00:22:42.150 --> 00:22:59.670

Matthew Cortland: There is no guidance forcing essentially for-profit healthcare operators like health hospital systems nonprofit health across the board, this is not a siloed problem we are seeing doctors and nurses, not being given sufficiently protective PPE, to protect patients and

142

00:23:00.750 --> 00:23:12.960

Matthew Cortland: your own words from 2020 I just I do not understand the failure to issue guidance saying a surgical mask or and N95 is more protective because people look to CDC for this even though

143

00:23:13.440 --> 00:23:23.190

Matthew Cortland: even though 40% of people 39 to 40% of people are still using cloth masks people understand that N95 or more protective we asked, I checked I didn't want to come here today and talk to you unprepared.

144

00:23:23.700 --> 00:23:32.790

Matthew Cortland: And so, this is the sort of guidance where if everyone is using a mask that provides better source control, and by that just for the non-public health folks we mean prevents them from

145

00:23:33.480 --> 00:23:40.740

Matthew Cortland: essentially spewing SARS-CoV-2 viral particles into the air that's what source control provides if we're not

14

00:23:41.490 --> 00:23:47.400

Matthew Cortland: if there are steps available to protect everyone to provide better source control that will protect everyone that will protect me.

147

00:23:47.700 --> 00:23:54.840

Matthew Cortland: will protect other people on this call it would protect the people who can't be with us here today and that's the sort of guidance, just top line.

148

00:23:55.620 --> 00:24:03.840

Matthew Cortland: I don't want to go through a laundry list, I just wanted to give a couple of examples of the kind of policymaking that if it were inclusive

149

00:24:04.380 --> 00:24:16.950

Matthew Cortland: and worked with chronically ill and you know immunocompromised and disabled people would actually protect everyone. With that I want to turn it over to my colleague Mia Ives-Rublee from the Disability Justice Initiative at the Center for American Progress.

150

00:24:18.300 --> 00:24:29.790

Mia Ives-Rublee (She/Her): Yes, thank you for taking this meeting with us on as Matt said, my name is Mia I've truly I'm the Director for the Disability Justice Initiative at the Center for American progress.

151

00:24:30.750 --> 00:24:48.900

Mia Ives-Rublee (She/Her): I am here to talk as, as you can see, I am a disabled person who is also Asian American so I'm a person of color. I represent a lot of individuals who have been significantly impacted by this community by this

152

00:24:49.350 --> 00:25:05.640

Mia Ives-Rublee (She/Her): pandemic and want to ensure that the CDC understands that the disability community is as diverse as the United States is. Accessibility is not just providing information and ASL and Braille

153

00:25:06.540 --> 00:25:28.860

Mia Ives-Rublee (She/Her): accessibility means that we must include reviewing a number of variables, including physical access, virtual access language and community access. For example, much of the CDC guidelines and guidance, is our only easily available in English, Spanish and ASL.

154

00:25:30.030 --> 00:25:44.340

Mia Ives-Rublee (She/Her): That leaves many Asian Americans and Pacific Islanders to have to call hotlines to get information in their language I've looked through your website to try and figure out how to gain access to

155

00:25:45.000 --> 00:25:50.280

Mia Ives-Rublee (She/Her): really important information on COVID and could not find it and was referred

156

00:25:50.640 --> 00:26:06.150

Mia Ives-Rublee (She/Her): to hotline to do that. We know that the largest variance in obtaining at least one vaccine is within the Asian American Community comparing disabled and non-disabled people, so that means that we are critically

157

00:26:06.630 --> 00:26:20.100

Mia Ives-Rublee (She/Her): missing a step and ensuring that disabled people of color are able to receive the vaccines that are so important, and that the CDC and this administration have pushed.

158

00:26:21.330 --> 00:26:27.780

Mia Ives-Rublee (She/Her): I also wanted to talk a little bit about the President's promise to make high quality masks and testing free.

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00:26:28.530 --> 00:26:34.740

Mia Ives-Rublee (She/Her): We don't know exactly what he means by high quality masks so that would be great to know but

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00:26:35.250 --> 00:26:43.650

Mia Ives-Rublee (She/Her): one of the things that I think about is you know, I understand that the CDC does not have control over distribution

161

00:26:44.010 --> 00:27:06.450

Mia Ives-Rublee (She/Her): and sort of those policies, but I do know that you all provide technical guidance to ensure distribution takes into account marginalized communities and the effects it will take to be able to ensure that people utilize the resources and health suggestions that that are **man-made**.

162

00:27:07.650 --> 00:27:17.580

Mia Ives-Rublee (She/Her): So requiring people to go online to find their closest testing systems or testing center impedes communities from obtaining them.

163

00:27:17.880 --> 00:27:35.640

Mia Ives-Rublee (She/Her): We know that almost 40% of disabled people don't have direct access to a computer and 30% of disabled people don't have access to a smartphone and that's just disabled communities. We're not even talking about internet disparities and transportation disparities.

164

00:27:36.930 --> 00:27:42.480

Mia Ives-Rublee (She/Her): A recent article also I want to talk about another thing which was a recent article published by the

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00:27:43.020 --> 00:27:51.990

Mia Ives-Rublee (She/Her): New York Times noted a difficulty for blind individuals to access testing. The CDC does not provide guidance or assistance in helping

166

00:27:52.350 --> 00:27:58.170

Mia Ives-Rublee (She/Her): blind and low in vision individuals understand how to navigate these issues.

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00:27:58.500 --> 00:28:07.170

Mia Ives-Rublee (She/Her): Which has forced many individuals who are blind or low vision to have to rely on others, even if they need to self-isolate.

168

00:28:07.470 --> 00:28:19.200

Mia Ives-Rublee (She/Her): So we have a lot of individuals who are stuck at home because they aren't sure if they have COVID and they want to protect the people in their communities, but aren't able to access tests.

169

00:28:19.500 --> 00:28:41.370

Mia Ives-Rublee (She/Her): And there's a lot of different suggestions on how, and it would be great for the CDC to push for the administration and for manufacturers to develop ways to ensure that disabled people have access to these resources. Thank you so much, and I'm going to send it over to Natalie.

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00:28:43.440 --> 00:28:50.910

Natalie Kean (she/her) Justice in Aging: Thanks Mia this is Natalie again. I want to talk a little bit about vaccine access specifically.

171

00:28:52.110 --> 00:29:07.620

Natalie Kean (she/her) Justice in Aging: You know, and despite repeated statements throughout this pandemic that people with disabilities and older adults are at highest risk, it feels as though we have been thought about last or set aside as being too complicated in a lot of these decisions.

172

00:29:09.120 --> 00:29:24.960

Natalie Kean (she/her) Justice in Aging: Since before the vaccines were approved, we've been asking for specific consideration for all the unique needs and situations of people with disabilities, of all ages and in all living situations and some improvements have been made.

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00:29:26.100 --> 00:29:33.780

Natalie Kean (she/her) Justice in Aging: But many of these issues, continue to resurface every time decisions are being made about another dose or booster.

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00:29:34.170 --> 00:29:54.210

Natalie Kean (she/her) Justice in Aging: And we are deeply concerned by the lack of targeted strategies to get vaccines to people with disabilities and we want to see this changed. For example, booster uptake in congregate settings is still lagging, especially in facilities, where more residents are people of color.

175

00:29:55.500 --> 00:30:11.790

Natalie Kean (she/her) Justice in Aging: Inclusion of unpaid home and family caregivers in they have not been included in priority groups, the same as paid caregivers in the community, this must happen to protect the high-risk people that they care for.

176

00:30:13.110 --> 00:30:32.340

Natalie Kean (she/her) Justice in Aging: And to ensure protection of kids with complex medical needs and disabilities and enable their inclusion in school and our communities, we need a far more robust pediatric vaccination response. I know currently it's around 20% of eligible kids that are vaccinated.

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00:30:33.600 --> 00:30:43.470

Natalie Kean (she/her) Justice in Aging: And there remain many open questions with respect to vaccine doses and boosters specifically for

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00:30:44.100 --> 00:31:00.030

Natalie Kean (she/her) Justice in Aging: people with Disabilities. Members of the Consortium for Citizens with Disabilities Health Task Force wrote to you in October, about the lack of clear guidance on boosters for people with pre-existing conditions that cause them to be at higher risk,

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00:31:01.110 --> 00:31:07.590

Natalie Kean (she/her) Justice in Aging: best practices for high-risk individuals and mixing and matching mRNA and viral vector vaccines.

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00:31:07.980 --> 00:31:15.870

Natalie Kean (she/her) Justice in Aging: The relationship between someone who has high risk versus someone who is immunocompromised and who should be eligible for a third dose.

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00:31:16.440 --> 00:31:36.390

Natalie Kean (she/her) Justice in Aging: And also for immunocompromised people many may remain unaware of their eligibility for a third dose and a booster or which comes first and how to get those. It's the messaging has been very confusing. I'm going to hand it over to Maria Town to talk more about that.

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00:31:38.280 --> 00:31:45.810

Maria Town (She/Her) AAPD: Thank you Natalie and thank you, Director once you for your time as someone with disabilities that make me high risk for COVID-19.

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00:31:46.200 --> 00:31:55.800

Maria Town (She/Her) AAPD: I quite literally worked as hard as I could to get vaccinated as soon as possible, ultimately, I received the Johnson and Johnson vaccine.

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00:31:56.280 --> 00:32:07.920

Maria Town (She/Her) AAPD: and have said had to navigate significant uncertainty regarding whether or not I needed additional vaccinations which kind of explanations, I could receive and when I can receive them.

185

00:32:08.490 --> 00:32:25.680

Maria Town (She/Her) AAPD: This uncertainty and lack of clarity and guidance specifically targeted at people like me has resulted in me engaging in further isolation missing vital and necessary health care management opportunities and just to put a really tangible point on this

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00:32:26.700 --> 00:32:31.050

Maria Town (She/Her) AAPD: my mobility and my health has declined, not as a direct result of COVID-19.

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00:32:32.550 --> 00:32:38.040

Maria Town (She/Her) AAPD: But, as a result of enforced isolation, so that I can be confident in my ability to survive.

188

00:32:39.240 --> 00:32:52.710

Maria Town (She/Her) AAPD: But I am less confident in my ability in my ability to reenter society as we go into a post pandemic era, because of how my health has declined, as a result of isolation and unclear guidance around vaccination.

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00:32:53.550 --> 00:33:02.670

Maria Town (She/Her) AAPD: My experience is not that uncommon something I am keenly aware of, as the President and CEO of the American Association of People with Disabilities.

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00:33:03.360 --> 00:33:10.290

Maria Town (She/Her) AAPD: Particularly for people with disabilities who are unstably housed or who have limited access to transportation.

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00:33:10.740 --> 00:33:18.030

Maria Town (She/Her) AAPD: The Johnson and Johnson vaccine to call it was one shot was by far the most practical option, so there are millions of people like me

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00:33:18.450 --> 00:33:28.560

Maria Town (She/Her) AAPD: waiting in this uncertainty just hoping that we can hang on to our health long enough to reenter our communities and broader society, once the pandemic it's over.

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00:33:29.370 --> 00:33:35.880

Maria Town (She/Her) AAPD: In addition to the necessary guidance Natalie described, I am going to re-emphasize a point that many of my colleagues have made.

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00:33:36.300 --> 00:33:52.590

Maria Town (She/Her) AAPD: The CDC should provide additional resources directly to immunocompromised or high-risk people, work with professional organizations, medical colleges and others to ensure that this guidance, is reaching practitioners reaching the medical community.

195

00:33:54.390 --> 00:34:07.170

Maria Town (She/Her) AAPD: But, that alone will not be enough, while this outreach the medical community is important, there is significant distrust of healthcare, public health and medicine in the disability community.

196

00:34:07.740 --> 00:34:16.440

Maria Town (She/Her) AAPD: Some of this distrust was fostered by the actions of the CDC but your agency is not the sole perpetrator.

197

00:34:17.070 --> 00:34:28.140

Maria Town (She/Her) AAPD: People with disabilities are living with decades and decades of medical violence. This is a whole branch of science, that says, we are, we are defective and I know

198

00:34:29.070 --> 00:34:40.020

Maria Town (She/Her) AAPD: Karen is on the line I heard her say a few days ago that she doesn't like the name of her agency, because from the moment a child with a disability is born it marks them as defective.

199

00:34:41.520 --> 00:34:48.660

Maria Town (She/Her) AAPD: When you think about the role of medicine in people's lives, particularly people with disabilities, you have to consider those kinds of factors.

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00:34:48.960 --> 00:34:57.570



Maria Town (She/Her) AAPD: And so it is vital that the agencies, specifically work with organizations serving multiply marginalized high risk, and immunocompromised and disabled people

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00:34:57.930 --> 00:35:06.060

Maria Town (She/Her) AAPD: so that this guidance can be disseminated and translated by trusted actors. I know some of this work is already happening in both the CDC and across

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00:35:06.300 --> 00:35:13.320

Maria Town (She/Her) AAPD: Health and Human Services, but as an example of how the COVID-19 vaccination outreach has excluded the disability community

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00:35:13.920 --> 00:35:26.340

Maria Town (She/Her) AAPD: in the hundreds of organizations that are partners in the COVID-19 community core there is not a single organization specifically focused on the disability community. Not one.

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00:35:27.660 --> 00:35:33.090

Maria Town (She/Her) AAPD: We welcome further conversation on this, and with that I will turn it over to my colleague Jess Davidson.

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00:35:36.990 --> 00:35:43.800

Jess Davidson (she), AAPD: Thank you, Maria my name is Jess Davidson and I'm the communications director, the American Association of People with Disabilities.

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00:35:44.190 --> 00:35:48.630

Jess Davidson (she), AAPD: And the final point that we want to make today, before I hand things back over to my colleague Bethany.

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00:35:49.020 --> 00:35:54.300

Jess Davidson (she), AAPD: is that not only has the pandemic posed an extreme risk to people who are already disabled

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00:35:54.600 --> 00:36:03.990

Jess Davidson (she), AAPD: it has also been a mass disabling event, and that is something that we don't feel that we're hearing represented in the top line message from the CDC or from other government actors.

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00:36:04.290 --> 00:36:11.100

Jess Davidson (she), AAPD: The truth is we don't know, and we probably won't know for a long time how many COVID cases, especially in this current spike may cause long COVID.

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00:36:11.400 --> 00:36:21.240

Jess Davidson (she), AAPD: And we've seen some study results that have estimated ranges as high as one third to more than one half of COVID survivors may develop temporary or permanent long COVID disabilities.

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00:36:21.750 --> 00:36:27.360

Jess Davidson (she), AAPD: As someone who has attempted to navigate accessing adequate care in this pandemic, as opposed to viral illness patients.

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00:36:27.630 --> 00:36:36.630

Jess Davidson (she), AAPD: I have to say it is gravely distressing to me, every time I hear it suggested that our society should simply accept that most people will get this virus.

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00:36:36.870 --> 00:36:41.220

Jess Davidson (she), AAPD: knowing how many millions of Americans might be grappling newly with long COVID at this moment.

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00:36:41.730 --> 00:36:51.930

Jess Davidson (she), AAPD: Until last January, I was in perfect health until I caught a run of the mill mild not COVID winter virus just a virus, we thought it would go away in a couple of weeks, and it triggered

215

00:36:52.230 --> 00:37:01.470

Jess Davidson (she), AAPD: post viral illness very similar to long COVID, including intractable chronic pain, dysautonomia, postural orthostatic tachycardia syndrome and severe chronic fatigue.

216

00:37:01.890 --> 00:37:07.200

Jess Davidson (she), AAPD: What scared me most was actually not the fact that I was a 26-year-old, who one day could get out of bed, and the next day I couldn't.

217

00:37:07.440 --> 00:37:13.380

Jess Davidson (she), AAPD: What scared me most was how equipped more than 12 different doctors in six months, seemed to be to help me.

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00:37:13.620 --> 00:37:20.730

Jess Davidson (she), AAPD: They did not know what to do. My mother, who has spent the pandemic is the charge nurse in my hometown hospital's COVID unit in Fort Collins Colorado

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00:37:21.060 --> 00:37:31.500

Jess Davidson (she), AAPD: collectively, she and I could not determine how best to navigate the exact healthcare system and hospital and what she has worked for 13 years and from which I received competent care for the first 21 years of my life.

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00:37:31.830 --> 00:37:41.310

Jess Davidson (she), AAPD: I think just about any post viral illness patient would tell you that the structure of our current medical system is not designed to catch, diagnose or long-term or short-term treat

221

00:37:41.490 --> 00:37:50.910

Jess Davidson (she), AAPD: post viral illnesses and I felt like I was falling through the cracks. Becoming newly disabled or chronically ill during a global pandemic it's an experience that I would not wish on anyone.

222

00:37:51.240 --> 00:37:55.980

Jess Davidson (she), AAPD: As soon as I realized the increase risk that I faced by developing a chronic condition during this time,

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00:37:56.190 --> 00:38:02.190

Jess Davidson (she), AAPD: after hearing my mom's stories from the hospital and after witnessing the way that disabled and chronically ill people had been treated during this pandemic.

224

00:38:02.490 --> 00:38:12.510

Jess Davidson (she), AAPD: There are no words for how scared and vulnerable, I felt. Every time I went to the grocery store and saw somebody who wasn't wearing a mask. The message I received was I'm done with this and I don't care if that kills you.

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00:38:12.870 --> 00:38:17.520

Jess Davidson (she), AAPD: It was one thing to receive that from people in society, but to be honest, since Omicron hit

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00:38:17.820 --> 00:38:28.350

Jess Davidson (she), AAPD: it feels like the entire health care system medical system and government have kind of conceded that point as well. And it has been the most painful moment for me personally, since when I realized how at risk, I was when I got sick.

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00:38:28.980 --> 00:38:36.810

Jess Davidson (she), AAPD: I moved more than 1000 miles at enormous fiscal expense to get access to the doctors that I needed back in DC something most patients cannot afford to do.

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00:38:37.200 --> 00:38:41.970

Jess Davidson (she), AAPD: And then I became part of the 25% of dysautonomia patients who get a diagnosis, in the first year.

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00:38:42.300 --> 00:38:50.100

Jess Davidson (she), AAPD: Once I had that diagnosis, which I thought was supposed to be the hard part it was still unclear how to proceed with treatment. Patients are suffering.

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00:38:50.520 --> 00:38:59.760

Jess Davidson (she), AAPD: Autonomic dysfunction has emerged as a common symptom of long COVID, we know that dysautonomia is a common feature of other post viral illnesses. In 2013

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00:39:00.360 --> 00:39:10.740

Jess Davidson (she), AAPD: Dysautonomia International say that five times fast conducted a survey of 700 patients that found that the average diagnostic delay for those patients was five years and 11 months.

232

00:39:10.950 --> 00:39:21.660

Jess Davidson (she), AAPD: 50% of patients traveled more than 100 miles from home to receive POTS related medical care and prior to being diagnosed with POTS, 59% of those patients were told by their doctors that their symptoms were likely

233

00:39:21.990 --> 00:39:29.760

Jess Davidson (she), AAPD: all in their head or a result of mental health issues. 27% of patients visited more than 10 doctors for their symptoms before being diagnosed with POTS.

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00:39:30.060 --> 00:39:37.860

Jess Davidson (she), AAPD: Please hear me when I say that, if only 5% or 1%, let alone, one third or half of COVID patients are becoming disabled by long COVID

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00:39:38.160 --> 00:39:47.190

Jess Davidson (she), AAPD: far too many hundreds of thousands of Americans are currently suffering greatly while simultaneously being told that they're suffering is not real or will resolve on its own, in a few weeks.

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00:39:47.490 --> 00:39:53.190

Jess Davidson (she), AAPD: This is a great injustice. We appreciate the significant research that has been invested in addressing long COVID

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00:39:53.460 --> 00:40:03.870

Jess Davidson (she), AAPD: but we believe that the CDC and the federal government as a whole must do more, not just on long COVID but on post viral illnesses in general, about which the medical community seems to know very little at this time.

238

00:40:04.380 --> 00:40:13.200

Jess Davidson (she), AAPD: People developing long COVID are suffering and are struggling to access care because of lack of research dollars previously that we're not decided to go towards conditions like myalgic encephalomyelitis,

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00:40:13.590 --> 00:40:25.290

Jess Davidson (she), AAPD: chronic fatigue syndrome, postural orthostatic tachycardia syndrome, dysautonomia and fibromyalgia. Research initiatives on long COVID must include these similarly presenting conditions.

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00:40:25.680 --> 00:40:33.600

Jess Davidson (she), AAPD: And if the CDC cannot prevent these patients from getting COVID than the very least, these patients are owed by their government, is for the government to be extremely committed

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00:40:33.840 --> 00:40:38.460

Jess Davidson (she), AAPD: to responding to the ways in which their health and lives have now been changed by getting this virus.

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00:40:38.760 --> 00:40:50.310

Jess Davidson (she), AAPD: Becoming disabled is not a tragic thing it is a normal part of life and of the human experience but becoming disabled and feeling failed by the medical system, your doctors, society and your government

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00:40:50.520 --> 00:40:57.780

Jess Davidson (she), AAPD: is tragic and it is wrong and the CDC should be prepared to use all of the tools at its disposal to embrace being responsive and responsible.

244

00:40:57.960 --> 00:41:06.330

Jess Davidson (she), AAPD: to the patients who did get this virus and who were lucky enough to survive it and now are looking at the rest of their lives. I'm going to turn it back to my colleague Bethany Thank you.

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00:41:08.100 --> 00:41:18.450

Bethany Lilly, The Arc (she/hers): Thank you Jess and thank you to all of our speakers um I want to acknowledge that we just read an extremely long laundry list of policy concerns and issues to you.

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00:41:18.810 --> 00:41:24.600

Bethany Lilly, The Arc (she/hers): But we did want to reserve time for the CDC to respond or for any thoughts or follow up questions that you might have.

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00:41:25.140 --> 00:41:37.170

Bethany Lilly, The Arc (she/hers): As Julia made very clear, we would expect this to be the first of many conversations will be having with different centers and with the leadership of the agency, but we really want we wanted to be respectful and we do appreciate you giving us this time.

248

00:41:40.410 --> 00:41:53.580

Rochelle Walensky: yeah maybe first I just there's one piece, I want to understand and that goes back to your comment Matt on masks because I just want to make sure I understand where you are with that were you speaking specifically to healthcare settings or to population?

249

00:41:58.950 --> 00:42:14.490

Matthew Cortland: The very least, the very least that I would expect is guidance for healthcare settings that insists essentially on N95s because as you've written in JAMA Internal Medicine they provide better respiratory protection and source control.

250

00:42:16.890 --> 00:42:28.230

Matthew Cortland: It's a really the ask is one of the very least that we would expect, I think, is for healthcare settings as for the general public, the current guidance

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00:42:30.090 --> 00:42:36.540

Matthew Cortland: I'll be honest with you, I don't quite understand CDC's position at this time, you issued a couple of tweets that said

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00:42:36.900 --> 00:42:43.260

Matthew Cortland: the guidance will always be to wear a well-fitting mask I couldn't agree more a mask will only filter air

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00:42:43.710 --> 00:42:47.070

Matthew Cortland: of it fits well but cloth masks don't fit well

254

00:42:47.460 --> 00:42:55.980

Matthew Cortland: that's sort of and they don't provide very good source control they don't they don't stop people from spewing out SARS CoV-2 they don't provide very good respiratory protection to the wearers

255

00:42:56.250 --> 00:43:03.780

Matthew Cortland: meaning they don't really protect you that well against Omicron again I want to be very clear, I understand the science has changed we're dealing with a new variant.

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00:43:04.410 --> 00:43:12.570

Matthew Cortland: CDC needs, you know I fully understand that you need time to gather data that you're an evidence-based organization, but we are now

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00:43:13.200 --> 00:43:21.900

Matthew Cortland: in a world in which Omicron, is the dominant variant it is, it is much more transmissible according to CDC's own publications than previous variants

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00:43:22.380 --> 00:43:29.160

Matthew Cortland: And I would expect masking guidance to develop into to really what for me

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00:43:29.970 --> 00:43:37.380

Matthew Cortland: as a chronically ill and immunocompromised disabled person, I'm looking at is there is a thing that actually CDC guidance could do.

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00:43:37.800 --> 00:43:44.220

Matthew Cortland: That would protect me a lot more than where we are now, which is 39% of people using cloth masks instead of

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00:43:44.760 --> 00:43:58.410

Matthew Cortland: either disposable surgical masks or N95s which provide better source control and better respiratory protection and I'm really when I'm when I'm thinking about well I need to go to the pharmacy they're wearing cloth masks I know that's not stopping SARS-CoV-2.

262

00:43:59.550 --> 00:44:02.220

Matthew Cortland: So it's really the healthcare setting

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00:44:02.730 --> 00:44:12.930

Matthew Cortland: just because we are like by virtue of our existence forced to go to those places like I had to go to a Mass Eye and Ear last month I didn't have a choice, if I wanted to continue to be alive, I had to go in and

264

00:44:13.590 --> 00:44:21.240

Matthew Cortland: N95 but people are still walking in with cloth masks and not all of the providers wearing N95 so guidance

265

00:44:21.480 --> 00:44:32.130

Matthew Cortland: that addresses healthcare settings would be the sort of the bare minimum, and then a broader population guidance that recognizes, we are almost two years into this thing now we are two years into this thing.

266

00:44:33.480 --> 00:44:38.880

Matthew Cortland: It's time to move beyond cloth masks we are no longer in the crunch, in which you are trying to figure out

267

00:44:39.360 --> 00:44:50.640



Matthew Cortland: how do we extend N95 supply, so that they exist in the OR. We're not in that crisis place anymore 3M is doing new stories that they have plenty of capacity for their

268

00:44:50.880 --> 00:45:06.450

Matthew Cortland: 3Ms, I've got I am literally distributing these to folks who rely on SSI because SSI is \$794 a month and you don't have the money to buy an N95 mask when you're living in enforced poverty so really that sort of guidance.

269

00:45:07.530 --> 00:45:16.110

Matthew Cortland: it's a broad thing, and I know there's a lot of data and I don't want to monopolize the discussion, I look forward to further conversations about this.

270

00:45:16.440 --> 00:45:23.910

Matthew Cortland: But it's a healthcare setting and then a general population setting and if you protect me, Dr. Walensky you've protected almost everyone.

271

00:45:25.740 --> 00:45:41.070

Rochelle Walensky: Yeah um so thank you for that I will. I do want to acknowledge that we're working actively on updating our masking guidance, I think, our masking website and information. I still believe that any mask is better than no mask.

272

00:45:42.210 --> 00:45:57.090

Rochelle Walensky: And that you know wearing the best protection, you can is you know, should be the optimal right. I do want to first say thank you for sharing your experiences your lived experiences.

273

00:45:58.470 --> 00:45:59.430

Rochelle Walensky: I can't.

274

00:46:00.570 --> 00:46:13.170

Rochelle Walensky: pretend to understand all of your lived experiences, but hearing them is really I'm learning a lot, I fully continue to need to learn more there's no question about that and I'm committed to doing so.

275

00:46:13.710 --> 00:46:25.620

Rochelle Walensky: I think I want to acknowledge that I too have family members who are disabled, I have taken care of patients, I have community members who are disabled, and so

276

00:46:26.460 --> 00:46:39.270

Rochelle Walensky: I do bring with this a dose of understanding, some of the disability communities, I can't I don't know all of them, but some of them and I'm committed to learning more.

277

00:46:39.810 --> 00:46:59.370

Rochelle Walensky: We've done a lot since we started, we have more work to do. We started and we didn't have a disability metric on our website, which was intolerable as far as I'm concerned. We now have a means of collecting data our health equity

278

00:47:01.680 --> 00:47:17.640

Rochelle Walensky: initiative that started this year is not just racial and ethnic minorities, this is disability communities and many other areas where we are committed to looking at the data and I said to my agency

279

00:47:18.720 --> 00:47:26.730

Rochelle Walensky: we can't do anything about data that we don't know about and oh, by the way, seeing the data is not enough.

280

00:47:27.120 --> 00:47:33.840

Rochelle Walensky: because we need to take action and I've actually said I no longer want to report on inequities I want to do something about them.

281

00:47:34.410 --> 00:47:44.400

Rochelle Walensky: And I've said that loud and clear to my agency, and we need to see the data first so that we know where to take those actions um I know from my

282

00:47:44.820 --> 00:47:55.350

Rochelle Walensky: life from before coming here that the best way to do this work is in partnership, the best way to make a difference is to have the active voices at the table.

283

00:47:55.770 --> 00:48:09.900

Rochelle Walensky: I'm committed to doing that Dr. Remley has been a key part of that, and what I will say is again I'm sorry for how hurtful my comments were, they were not intended that way.

284

00:48:10.380 --> 00:48:26.280

Rochelle Walensky: But what I do hope after this conversation is to double down on a commitment, because that moment that was hurtful for all of us, I think, mostly for you is the motivation to lean in and do better.

285

00:48:28.020 --> 00:48:34.320

Jamila Headley: Dr Walensky. Jamila Headley here, I just have one more ask for you, I know that we are at time.

286

00:48:35.100 --> 00:48:41.910

Jamila Headley: But I really want to ask if you can make an explicit commitment to commit to ongoing meetings with you

287

00:48:42.420 --> 00:48:53.790

Jamila Headley: and with others on your team with this group of people, I know, we made it as an ask, but I wonder if you can make it a really explicit commitment to that and an explicit commitment to who will follow up with us to make sure that that happens.

288

00:48:54.510 --> 00:49:07.110

Rochelle Walensky: Yeah what I'd like to do, I will commit that CDC leadership will be engaged senior leadership will be engaged. Dr. Remley will most definitely be among those I will commit to being engaged myself.

289

00:49:07.500 --> 00:49:18.540

Rochelle Walensky: I have learned over the last year that I can't commit to anything in the next 24 hours, and so what I really do want to do is say yes, I will be engaged.

290

00:49:18.990 --> 00:49:34.650

Rochelle Walensky: Will I'd be at every meeting, I'm really true to my word and I don't want to commit something I can't I really can't do, but what I can say is we, as an agency, we are committed to this, our senior leadership is committed to this, and if I can't be there, I will absolutely hear the read out.

291

00:49:37.920 --> 00:49:38.400  
Jamila Headley: Thank you.

292

00:49:44.280 --> 00:49:51.600  
Bethany Lilly, The Arc (she/hers): And thank you to all the advocates and for all the CDC folks who attended and thank you very much again for meeting with us and listening to our concerns.

293

00:49:52.620 --> 00:50:06.300  
Rochelle Walensky: And I'm just Matt you explicitly noted that you have a loved one who is unwell, so please I wish speedy recovery, I hope that is not the case for others, but I wish you all a speedy recovery.

294

00:50:07.470 --> 00:50:07.860  
Thank you.

295

00:50:11.700 --> 00:50:16.170  
Dori Salcido, CDC: Thank you everyone, we look forward to future conversations appreciate your time today.

296

00:50:16.830 --> 00:50:17.820  
Rochelle Walensky: Thank you very much.

297

00:50:18.240 --> 00:50:21.900  
Jamila Headley: And thank you Bethany for facilitating us so expertly yeah.

298

00:50:22.590 --> 00:50:24.150  
Bethany Lilly, The Arc (she/hers): always happy to keep us on time.

299

00:50:25.020 --> 00:50:25.770  
Karen Remley, CDC (she, her): Thank you Bethany.

300

00:50:27.480 --> 00:50:27.870  
Rochelle Walensky: Thank you.

301

00:50:30.060 --> 00:50:30.750  
Bethany Lilly, The Arc (she/hers): Bye everyone.

302

00:50:36.390 --> 00:50:37.770

Jamila Headley: I'm going to stop the recording.