I
>> I texted. I think we should start. Thank you for making the call happen in all of the ways. I'm going to mute everyone so we don't have background noise.
>> We need to be sure our captions are set. Let me see. Yes! Thank you so much to our captioner. First, a note on Zoom. If you want the captioning, on video, bottom of the screen, if you go to "more," you can choose subtitle. You can choose settings if you want to make it bigger.
>> If you need anything more, put it in the chat. Welcome, everyone. I'm Jessica Lehman. I co-facilitate the organizer forum with JoAnne from "not dead yet." This is the leadership alliance, a cross disability coalition. This helps bring diverse communities together to explore the intersections between disability and other identities to build power to make sure we have a voice to get all of the needs met, to have dignity and respect. We do a different topic every month. It’s the third Tuesday of the month at this time, so please mark your calendar if this is new. There is a form to let us know you are here today so we have an idea of who is joining. If you haven't done that, there should be a link in the e-mail you got, I believe on Facebook as well, so you can RSVP and let us know you're here. Let me see if I'm missing anything. Yes, a couple more housekeeping items. The format of today is, we have five amazing speakers. I'm going to keep my part short so we have time for all of them. We have questions and answer and dialogue after that. If you have questions, you can save them for the end. You can type them. That would be ideal, to type them into the chat.
window and read them when we get to that point. If you are on the phone, we have time to share that. Ask folks to stay muted until the end of the call or until you are speaking. I'll let you know if there is time to un-mute and speak. We also try to have ongoing discussion on the topics. An hour is never enough, so there is a lister which is organizer's forum at yahoo.com. There is an organizer forum. The website for the disability alliance is disabilityleadership.org. We have had challenges getting the forum and transcripts updated, so last month's is on the senior and disability action website. I can send folks links to that. The transcript will be available there as well. We covered the housekeeping items. Let me introduce today's topic. This is a hard time for all of us. It brings up all sorts of emotions and fears. It's also amazing to see how people are stepping up and supporting each other. Today, we want to talk specifically about care rationing for people who have the Coronavirus, Covid-19. We are seeing states and hospitals with policies that say if there are not enough hospital beds and not enough ventilator, we'll decide who gets those based on any set of criteria. Of course, those criteria often de-prioritize seniors and people with disabilities saying we don't have enough years left to live or we are less likely to have successful treatment or our quality of life isn't as good. There are all kinds of things said clearly that are kind of the sub text of what's happening here. There have been a number of excellent conversations and webinars about this. So many people are doing incredible work. I want to express gratitude and admiration for everyone working so hard on this really difficult topic. Today, what we want to focus on is what kind of community organizing is happening around the issue, and how can we expand that? How can we organize our communities to fight back and win. We are going to hear from speakers about what they do to get individuals in their communities involved in fighting this to talk about what they have done that you can take on in your city and your organization. Also, thinking about, as horrible as this topic is, how can we use the campaign against care rationing for disability communities. Long after the Coronavirus, once things are "back to normal" whatever that is, we are stronger. People know that disabled people are out here and we are heard on all of the other issues that we need.
We have five speakers today. I'm going to introduce all of them. Then we'll have them speak. Our first speaker is angel Myles, PhD. Angel is from access living in Chicago. She received her doctorate at university of Maryland college park. She completed her postdoctoral in applied sciences, and joined accessliving. She is responsible for healthcare and community based services and system advocates through an intersection Allens. We are going to hear from Ivan nova Smith. Ivanova was involved that rationing for Covid-19. We have Herman, a disability rights advocate. He is a first responder and co-executive direct or for the partnership of inconclusive strategies, with philly adapt and leader in disability right and full inclusion, before, during and after disasters. Then, we are lucky to have Max Airborne. He is an organizer rooted in fat liberation and disability justice. They cofounded fatrose.org. Then, we round out this incredible panel with Kathy. Kathy is the director for public representation. She became the executive director 2011. She has worked in the mental disability law field since 1977 and has extensive experience in providing representation to institutionalized persons throughout the country, litigating ADA and homestead cases. She is the former director of the Massachusetts project and the former chair of national disability rights network legal committee. She is co-Counsel in Oregon and Ohio seeking to promote the rights of those with psychiatric and developmental disabilities. Huge thank you to all of speakers. There was a small group of people that helped come up with the right group of folks to reach out to them. I'm not going to call you by name. You know who you are. Huge thank you to all of you. Let's turn it over to Angel. Take five or six minutes to share your thoughts.

>> Angel: Hello, everybody. Thank you so much for having me. Thank you, Jessica, for the introduction. This is a really hard topic, but some good things have come from having these conversations. Accessliving, we actively organize our community to hold the state accountable for challenging the possibility of healthcare professionals and institutions using rationing practices. One way that we did that -- the first thing we did is organized an organization -- the adequacy department along with the civil rights department, administrative leadership team, CEO, met and did some research to look at what guidance -- what statements have
been done in other states regarding healthcare rationing and challenging healthcare rationing. We looked at best practices, and others that weren't so good. We consulted advocates and experts like Joe, who advised us on key points we should make in our letter.

[Audio is breaking up]

We constructed a letter asking them to create a guidance followed by protocol for what healthcare institutions should do to prevent healthcare rationing. In the letter, we reminded the state that any use of care rationing in regard to disability would be discriminatory in terms of legislative rules in the ADA and ACA act and exception in section 504. We are not just asking to do something nice. This is a legal issue they need to take concern about, attention to. We developed the letter and decided it wouldn't be strong enough for us to be from access living. We reached out to our networks and were able to create a sign on. We have 140 organizations to sign on. A diverse group, some on aging and housing and homelessness. We got unions, SCIU to sign. We got strange bedfellows like nursing home institutions we normally fight with all the time, to sign on. That was really great. The letter was sent March 30th. The governor's office was done at a particular time. They communicated with a small group of us taking the lead on the governor and governor's office. Within a short time, the state agency was able to develop a letter, a guidance on April 10th, which was an antidiscrimination guidance in emergencies in response to the letter that we developed and are still happy about that. The letter was not just focused on people with disabilities. It was against discrimination in general. It did address specifically how this affects people with disabilities. We were glad because disability is the inequalities that people are experiencing in the healthcare system related to race and gender and all of that. We were fine with being included in that in a general antidiscrimination guidance, but it was more dupe cative. It didn't talk about how the issues affect each other. It was a great step in the right direction and victory, but in order to make it a protocol to take it a step further, we developed a survey for the community to experience discrimination, any healthcare rationing. We are accessing the survey to see if there is data happening, not just a fear. Right now, it would be ideal to have a protocol, but right now, there is not a lot
of pressure for the state to have a protocol because we are not in a situation where there is enough resources, so we have, right now, plenty of ICU beds, plenty of ventilators, and so because it doesn't appear to be -- at least from the state's perspective, an issue that's likely to happen, then they don't feel pressure to create a protocol. They feel like sending misguidance and saying it's illegal is enough. We would like to see more than that. Why didn't we take an intersectional approach? Our letter primarily focused on disability. We didn't necessarily highlight that people of color have higher rates of disability and all that stuff. We focused on how this affected people with disabilities in general because that topic is big and heavy and thick, and so we focused on that. The letter that the state came out with themselves, they decided rather than focus on the guidance just about disability, they created guidance in general that was broader. That addressed all of the multiple protected classes. They did not take the intersectional approach when they addressed the letter. They addressed it in a broader way. I hope that helps clarify. Okay, so right now, we are collecting data from the disability community to try to put more pressure on the state to create a protocol because our argument would be that -- just because there isn't a dire situation where we are running out of resources doesn't mean that rationing practices can't still occur. Ableism still exists. We prefer to have a protocol. It's an ongoing issue right now, so to be continued. To sum up what we have done is that we created a sign on letter. We created our letter based on research about what has been done, and also consulting experts about rationing and what's a problem and what best practices are for challenging that type of practices. We also provided -- we suggested in our letter, guidance in the framework from the disability community perspective. We are like, how to address the needs of the disabled community even in a situation with less resources.
[Audio is breaking up ]
Healthcare needs and not quality of life assessment on a case-by-case basis. Then, we are also creating a stakeholder survey to find out from the community exactly what's going on, so not just making assumptions about rationing is a bad idea, but what is happening on the ground, and we are
hoping to get more information about that. Anyway, that is pretty much what we did. I hope that was helpful. I'm happy to answer any questions. Thank you.

>> Jessica: Thank you so much, Angel. That was incredibly helpful and exciting work you are doing in Chicago, Illinois. I wanted to point out on the sign-on letter, I have heard about a number of letters going out in different states asking for organizations to sign on. One thing folks can do is provide such a letter as a sample from individuals to write their own to send in as a way to get more folks involved. The stakeholder survey, what a great idea. If you can share that, I would love to put that out to folks so they can create their own survey. Thank you, Angel and Amber.

>> Angel: Amber put information in the captioning comment area if people want to look for the survey. We can forward more information to you, Jessica, at the listserv.

>> Jessica: Sounds good. Thank you. Next we move to Ivanova Smith. Can you un-mute yourself?

>> Yes. I live in Washington state. We have been doing a lot of work here. I self-advocate leadership sale. We have been working with the governor's office to try to make better language for the guidelines. We have asked about being involved with training for the people in the triage teams that they get training on the value of equity and diversity and value people with disabilities. Also, making it so people with disabilities and lived experience are involved with the trainings, and there is a way for self-advocates to be part of the oversight of discussions. Nothing about us without us is respected. We are going things for the community numbers. We are trying to connect virtually. Anthony, past chair of sales, he created a group called "self-advocates speaking freely." It's Zoom calls we do everyday checking in with each other. Any self-advocate can join the Zoom calls. That's one thing we do with our membership. We sign on to letters. We signed on recently, one around making sure that dependents -- and we partnered with SAU775 with the letter. It was a joint letter about making sure dependents can get access to the stimulus money because that would help pay medical bills in the expenses that a dependent would need. We also signed on another bill that would make it so that people who can't drive can access drive throughs and still get the food through the drive through if they use a wheelchair thing or
any other type of -- you can walkthrough the drive through to get your food.

>> Jessica: I'm sorry to interrupt, but I wanted to ask you, can you also talk more about the complaints you were part of?

>> Ivanova: Oh, yes. The biggest thing we are doing is we are on a complaint with disability rights Washington. Other organizations against the northwest hospital network in Washington saying that the guidelines that would allow discrimination against people with functioning and using words like permission and how you are able to attend resources as a method of -- if you can get a ventilator or not, if you get medical treatment. That is a big concern. There is a long history of people with developmental disabilities having their medical care restricted and not getting put in the ICU, or not getting a ventilator when they need a ventilator or other medical treatment. Lastly, right now, dealing with a number of people first because we feel they were not getting treatment for the other conditions that they were having, so that is another issuer worried about. We are part of a complaint working with HHS and the governor's office trying to change these guidelines to be more inclusive and not discriminant based on any type of graphic or support needs either. We have concerns about the idea about how can you determine who survives and who wouldn't survive? That's really tricky, so we are trying to figure out language around that, that makes that more clear, and we are working with -- we are trying to work with the government's office. I have been working with David and others to make it so that they be -- they have to have explicit buyer strings. We have a stakeholder group with other organizations that represent marginalized groups that are part of these discussions that we are working together on making it so that everyone is included in it, and nobody is left out because all means all. Also, we are rooted in rights which is under DRW. They are working -- they are making videos of different people with disabilities talking about why it's important that they get a ventilator. We have been getting a lot of media attention. I have been on two MPL interviews about this topic. We emphasize that nobody should be experiencing medical discrimination, but we have experienced medical discrimination already. We are trying
to get the word out that this is something that's happening, and it's getting worse. We need it to stop. It violates the ADA, but it happens in ways indirectly. There are people not able to access medical care because all of the clinics are closed. If you have a routine procedure that you need once a year, you won't be able to get that now because all of the clinics are closed because of Covid-19. That could be something that is sustaining your life and you need to sustain your life. Those are other things that indirectly cause discrimination, cause trouble for our community. Also --

>> Jessica: Thank you so much for the things you are doing in the community, sharing all of these ideas.

>> Also, we have made plain language documents explaining to self-advocates. That's the last thing I wanted to add.

>> Jessica: Thank you. I'm glad you did. Maybe we can talk more about that in the dialogue. With the policy out there, they are not necessarily in language that everyone can tolerate.

>> I have several documents to help explain a bit of it.

>> Jessica: Wonderful. Thank you so much. Really glad to have your expertise here. The next speaker is Herman from disaster strategies.

>> Herman: Good afternoon, everyone. This is Herman. The partnership is the only U.S. national disability led organization focused on a mission on equal rights, disability rights and full inclusion with people with disabilities, and people with functional needs before, during and after disaster emergencies. We were founded by core light strategies around since the late '90s, focused on inclusion disabilities in disaster response. We have been directly working with the organization since less than 16 passing hurricane Maria. We were deployed -- I was considered the first quadriplegic, first responder. Most recently, we deployed to the Bahamas after the passage of hurricane Dorian. Now that Covid-19 is on top of us, most recent numbers are over 9,000 deaths in nursing homes. That's only what's being recorded. Seeing this massive rationing of services, the partnership began having daily calls on February 28th where initially, the first piece of adequacy tool that came out was a national disability right call to action put out on the third of March. Within a couple of weeks, we had 200 supporting
organizations, principally calling out for the continuity of services asking for the rations to come. On the ninth of March, we sent it to the White House Covid-19 task force and it's been used by Pennsylvania, California, Colorado, Washington and Ohio and many more on specifically addressing continuing services through personal services information, distribution and the ration of medical care amongst other things. In a moment, at the end, I'll post the links on the chat so you can see it and use it. Additionally, we have been collecting and putting together a resource list including all of the actions and many more from all of our community members as mentioned. The callout to rationing in Pennsylvania and Alabama. You will find March 30th, we put out legislative recommendations for public health emergencies and disasters which specifically points out we really need to put together and start thinking on when concurrent disasters are on coming. Soon hurricanes and fires will come, and if we don't have proper Medicaid state transition we can carry Medicaid across states, if we don't have proper funding for our entities like independent living and many more things that pieces of legislation are ready for disasters and disaster relief Medicare act will resolve in the coming months. I want to add that we have a hotline operating specifically for disaster and disability issues. The phone number is (800)626-4959. I will post that in the chat momentarily. We can be reached at info disaster strategies.org. We are mainly connecting people to local full, inclusive mutual aids preparing for the months to come. This is only going to get more difficult. The government is failing us across many levels. It is upon us, the community, to make sure that we survive this on the other side. People helping with disabilities in congregant settings are -- right now, our most prized possession, and we need to collectively call out congregant settings and the government at every level needs to implement money following the person transitioning to the community and the debts that are going to be called out. To quickly close up, I want to thank you all for joining. It's most important that we reach out our communities with the information being put out and that we include all members of the disability community in the times to come. This is going to get much more difficult. We want you to know that the partnership this year to help in anyway we can.
Jessica: Thank you so much, Herman. Thank you to you and Shaylin for all of your hard work. I'm going to move along to Max Airborne from fat rose.

Hi, everyone. My name is Max Airborne. I work with fat rose, an organization I co-founded with my partner Don, also on the call. Right now, one of the things we like to do in fat rose is cross movement organizing. We like to think about the connections between different movements and where they could support us all toward collective liberation. Right now during Covid-19, we had friends from the fat legal adequacy research education called flair, called us up and asked if we wanted to work together around the care rationing and triage stuff. We were like, yes. We formed a coalition. We call it nobody is disposable, a hashtag we started using to bring fat and disabled people together for -- in solidarity with closing the camps last summer. It's an effective way to link our issues. There are a lot of commutes considered disposable in the community. We need to join together and think about how they intersect and how -- who is really at risk with care rationing? It's not obvious to everyone. It's important for us to spell it out. Disabled people are at risk. Fat people are at risk. You can see this in the triage guidelines. You might have to dig to see that's happening. If you look further, you can see people of color are more likely to be disabled or sick or a shorter life span. We know why that is. It needs to be spelled out a lot more. We need to join communities to fight this stuff. When we think about people who are in nursing homes and congregate settings, we need to make alliances with people in prison. They are in a congregate setting too. We need to think about who is at risk. It's much broader than just us. A few of the things we are going. One is, we are thinking about medical providers. You know they have no PPE -- or not enough. They are putting their lives at risk too. Though we might think of a medical provider as our enemy, because often they are, it's really important for us to make an alliance with them right now. One of the things our coalition did is create an open letter to medical providers trying to create an alliance with medical providers. I'm going to post a link in the chat. Don just did. Have a look at it. It's really trying to make an alliance. It's saying we are all being considered disposable, including you medical providers. It's taking a different
approach around forming this alliance with them. We saw the California care ration -- I can't remember what it's called, the California Department of Public Health came out with guidelines about how hospitals should be rationing care when it comes to that. They pit medical providers against patients in this way, creating triaged panels from the hospital making the decisions and the doctors and nurses are just pawns in the system where they are soldiers following orders. It's really clear that we could be making an alliance with medical providers. Really, check out our open letter and sign it if you can, and you will be able to stay in touch with us that way. Another thing we are doing that Jessica wanted me to talk about is solidarity selfies. People can get engaged from home to express their views about what's happening right now. We invited people to post selfies using the hash tag "nobody is disposable" and talk about why they are opposing care rationing. We are going to do another iterative of the campaign. If you want to stay in touch with us, sign the open letter and we'll have your e-mail address. Even if you don't do that, we'll send out an e-mail with Jessica to let you know what's happening. Check it out. Nobody is disposable.org. That's where you can find out more information. I'm being told I have no time left. Check. >> Jessica: I'm sorry, Max. I feel like each of the speakers deserves three hours to tell us about the amazing work you are doing. I appreciate what you were saying about intersectionality and all of the groups that we need to keep in mind are affected, and not just separate groups, but the overlap within the communities. Max and I were plotting about the solidarity selfies, wondering if we can get everyone on the call to commit doing a solidarity selfie next week posting it on social media, getting friends from organizations doing it. If you haven't seen it on the Facebook invitation, if you have seen that and we can share that again, I think I posted the one of Max holding a sign saying "nobody is -- Can you commit to doing it next week and putting it on Facebook or Twitter? Wonderful. We'll follow up on that next week. Thank you, Max and Don. Our final speaker is Kathy from the center for public reputation. Because we only have a couple of minutes for questions, write your questions in the chat, or e-mail me. We'll pick a couple of
questions and follow up with the speakers as well. Go ahead, Kathy. You're still on mute.
>> Cathy: thanks very much for having me. I love organizing. I did it -- a lot of community organizing starting when I was in college. I think in some ways, thinking about how to respond to rationenning, drew on that experience. We decided that we really, in order to be effective and have the biggest impact, we wanted to build a broad coalition. We looked at the different disability groups we wanted to involve and include. There were disability led organizations we identified. We had the protection in adequacy program, the brain injury association in Massachusetts, the arc in Massachusetts, prisoner legal services, the alliance for the mentally ill. We had a very broad group of disability organizations that we started with, and a number of advocates, legal advocates as well. Then, we decided that we needed to go beyond that as everyone has been commenting, the issues are not just the issues of rationing and how historically bad healthcare and low expectations have affected people with disabilities. They have also affected people from other communities. We really focused on doing outreach to the communities. We included people from racial justice communities, and then, that included, we have in Massachusetts a big brain trust at Harvard called the Charles Hamilton Houston center for race, the architect for brown v. education. They are a think tank on racial justice issues. We expanded to the ACLU to join on to the complaint we were going to file. We did a lot of outreach to the medical community. Going back to what Max was saying and others, we saw them as allies here. We educated them quite a bit because there were overlapping issues with a group of young, committed people of color who were medical professionals, you know, doctors, nurse practitioners, working in the medical field and Boston in particular. What we mutually agreed, after learning from one another and listening to one another, we need to work together. There is an enormous amount of that going on. I'm going to blast through a couple of other ideas we worked with. We had a complaint to file. Instead we sent it to the secretary without the complaint to address the office of civil rights in Washington, and legal analysis for our secretary for health and human services. She sent people
back to the drawing board. At the same time, we had the black and Latino legislature up in arms about how this would affect people of color and they interjected people with disabilities into their language and what they were asking. The doctors we talked about had 500 physicians writing to the secretary. That got her attention to say the least. We had congressman Kennedy and a state representative writing and doing a lot publicly. They got a lot of press on that. We have been able to work with all of that. We brought in aging. Justice and aging joined our complaint that we have been able to -- there is a new protocol issued. It's not perfect, but it's way better. We are working in tandem as a group. I'll stop there.

>> Jessica: That is an maizing description of the work you are doing. We have four minutes for questions. Amazingly, strangely, I don't know that I see questions in the chat. Does anyone have questions? Max says, can Cathy talk about the victory in Massachusetts?

>> Cathy: Well, Max, we were talking recently as this morning whether it was a victory. I think there is a lot about what came out that's good. We can definitely have that on our Covid-19 web page which I think Alison shared with people and can pop into the chat if that's helpful. They have changed -- they have backed off on a lot of things. They have taken co-morbidities out. There was unqualified consideration of age. It's now a one to five year period based on what the office of civil rights did in Pennsylvania. We don't like that. We are putting a lot of thought into challenging that. We have doctors working with us on that. The aging -- the age discrimination is distinctively in there. We need to address that. For now, we feel we have a lot of important things clarified and added to the standards of care.

>> Jessica: Thank you. I want to make a comment. One thing increasingly in the news lately is the spread of Covid-19 in nursing homes and other congregate facilities. I have heard -- you know, a lot of concern in the disability community about making sure that, that -- that facilities for people with disabilities don't get forgotten. People there are getting sick as well. There is huge concern that when we talk about care rationing, we see it in a different form in all of the facilities because of ageism and ableism, people are basically forgotten. It's unclear when people are sick, are they going
to the hospital? Are they staying there? Are they kept isolated from others? I'm glad to see more energy put into protecting people in all of these settings. In California, I can say there is a group called the California association for alliance -- for nursing home reform. They have put out a number of recommendations around testing every staff person and resident in any facility that has cases. We are trying to expand that to any residential facility for people with disabilities or seniors to make sure people are getting tested, are isolated, separated, people who are sick and people who are not and a number of other things that can happen sending letters to policymakers, raising public awareness. Looking forward to working with you about that. The final question from Sheila. Go ahead, Sheila.

>> I had to figure out where the mute button was. I have noticed that when -- thank you. Medicare persons have a separate room but medical is not. At least one in clear lake I know about. I'm concerned that folks using Medicaid or having Medicaid aren't getting what they need. Another thing I asked at the seminar the other day, it's all well and good to prepare ahead of time, but I want to change print being the only means of communication. I would like thoughts on that.

>> Let me check in with the captioner.