

COVID-19 Medical Rationing Panel Discussion Transcript, April 3, 2020

Host: Ted Kennedy Jr.

Guests: Maria Town, Roger Severino, Kara Ayers,
Samuel Bagenstos, Jennifer Mathis, Silvia Yee

Introduction

MARIA TOWN: We will do our best to answer questions in the order they are received at the conclusion of this call. Again we ask you hold your questions until the end so we are sure to cover all of the material that the speakers have prepared for us today. If you would like to utilize closed captions, I have sent a link in the chat box. That will connect you to the StreamText for this event.

This event is also being recorded. And if you're unable to remain on the call, you should disconnect now.

The recording will be available on the AAPD website early next week.

And with that I'll turn it back to you Ted, thank you.

TED KENNEDY Jr.: Thank you, Maria, and I also just want to give a shout-out and note of gratitude to Susan Diegleman, who is on our AAPD Board and also works at AT&T and we thank Susan for facilitating this conference call today. So welcome to our teleconference on "Disability Rights and Medical Rationing". In the face of COVID-19 my name is Ted Kennedy Jr. I'm a healthcare lawyer at Epstein Becker Green but I'm speaking to you in my capacity as Board Chair of the American Association of People with Disabilities. So I'll be your host and moderator today.

We're really grateful for the participation of our very distinguished panel members who I'll be introducing in just a moment these are many of the leading experts in the area of health and disability law. But before I do, I just want to offer a brief introduction on why we're here. And what we hope to accomplish on today's teleconference.

So we see it every day, COVID-19. It's stretching the resources. And capabilities of our nation's healthcare delivery system. And this pandemic poses significant threats to -- and fear among people with disabilities. People with chronic illnesses and people with pre-existing healthcare conditions. So this call was quickly organized in response to recently issued treatment rationing

directives announced by several states and regional health authorities that would permit their local hospitals and provider networks to deprioritize ventilator access and other needed treatments for people with disabilities in favor of younger, healthier, non-disabled patients. And these alarming announcements were met by a series of responses and formal complaints written and spearheaded by many of the panelists on this call.

So we'll be covering several important topics today. No. 1, what are the rights of people with disabilities in the healthcare setting? Two, does -- how does disability bias and discrimination affect healthcare decision making? And three, are there model protocols? Do process protections, individualized assessments, that the disability rights community considers best practices? That hospitals should be adopting to protect themselves from disability discrimination and ensure compliance with the law.

So following this moderated Panel Discussion, we'll allow for Q&A from participants. AAPD also plans to organize a follow-up call in the next week or so with advocacy groups and others to develop future action steps. And explain what individuals can do

if they feel that they have been denied needed healthcare because of their disabilities.

And just a quick disclaimer, as always, on this call, you'll hear many different views and opinions expressed. This is what democracy and policy development is all about and the views and comments of the panelists and participants are not necessarily the views and opinions of AAPD.

So just you all have the list of panelists in front of you. We are joined today by Professor Kara Ayers from the University of Cincinnati, a national expert on protocols for treatments for people with disabilities. Professor Samuel Bagenstos, professor of law at the University of Michigan. And a leading legal scholar on disability law and policy. Jennifer Mathis, legal director of the Bazelon Center for Mental Health Law and fellow AAPD Board Member. And Silvia Yee, senior staff attorney with the Disability Rights Education and Defense Fund. So before we turn to the panelists, we do have a guest on the phone who we have invited to make a series of comments and respond to a handful of questions and that is Roger Severino, director for the Office of Civil Rights at the U.S. Department of Health and Human Services for the last three years. Mr. Roger Severino, welcome. We thank you for authoring

the recently OCR bulletin issued on March 28th reminding healthcare entities of their continued obligation to abide by U.S. civil rights laws during this pandemic, including the people with disabilities -- that people with disabilities cannot be denied medical care based on their disability. So we have asked Mr. Severino to say a few words and respond to a couple of questions before we start our panel today. Mr. Roger Severino, I turn the teleconference over to you.

ADMINISTRATION GUIDANCE & RESPONSE

ROGER SEVERINO: Thank you, Ted. This issue has personal relevance to me in two ways. One, my sister is on the front lines. She is an emergency room nurse. And we are talking about these questions of what if. What if she's faced with a terrible choice of what to do if they don't have enough resources? And my parents, as well, are approaching 80 and have underlying health conditions. So what if they are put in a situation where they have to go to a hospital and there's not enough resources.

Now, as of right now, the Administration has done everything it can do in its power to make sure that the resources are available to the states and a question of rationing can be avoided. However, we

have to prepare for those what if scenarios. States are now gearing up and issuing centers of care and helping to guide medical professionals. Now, it is true that states have tremendous flexibility on this question of resource allocation. However, with our bulletin issued Saturday, we're informing states and providers that there are guardrails that must be respected that in our response to this unprecedented crisis we don't lose sight of our fundamental humanity of what makes America special, that we don't leave anybody behind, that we don't discriminate on the basis of disability, age, race, sex or religion. That everybody has a place. That we don't fall back to some sort of ruthless utilitarianism where we separate the fit quote-unquote from the unfit that's not what America is about. And ultimately the question is not really ultimately what is medicine. It's ultimately a moral question within legal bounds. It will be a reflection of our character, how we respond to this crisis, making sure that people are not pushed aside for some sort of callous efficiency and that's a message we've been saying and we've had a really good response. California piggybacked on our announcement with their own announcement and the Mayor of Philadelphia, as well, and we hope that additional states will take note and the principles are simple, you cannot use

stereotypes about a person's disability in order to ration care.

You have to use individualized assessments. And you cannot use judgments about a person's relative worth or utility to society when using crisis standards of care.

It's those principles that we put forward in our bulletin encouraging the use of the best available objective medical evidence. And interaction with patients themselves. And their lived experiences. And making sure that everything is taken into account our bulletin was broader than disabilities we have touched on age, language access, accommodation but another question that's upfront on a lot of peoples' minds is the question of disabilities and there's fear out there and we have responded in response to a bipartisan outpouring of concern. Members of Congress, civil rights community, disability rights community, the pro-life community. Ordinary Americans want guidance. And we're working on additional guidance. I cannot promise a time. But at least the bulletin itself has put out the principles that we have put forward. In addition, we have opened up investigations against states with their crisis standards of care to ensure that they are complying with the law and so far we've had good

response and we expect a very cooperative environment as we work together with the states to make sure that they respect those guidelines. So I appreciate the opportunity to be able to address you now. This is an incredible -- an incredibly important moment in our nation's history and the way we respond and band together to make sure that everybody has a seat at the table and nobody is pushed behind will be a reflection of our national character. Thank you.

TED: Thank you for those comments. Before we let you go, Roger, I'm wondering if Sam or Jennifer, Silvia or Kara, do you have any questions that you would like to ask the director before he departs the call?

DR. KARA AYERS: Sure this is Kara Ayers. Dr. Roger Severino I appreciate the remarks that more guidelines seem to be in the future. Can you give us an idea of what those multiple communities you mentioned have asked your office for related to guidelines? I know you may not be able to specify what guidelines you're working on but what has been the need after this original memo was released that people have expressed to your office.

ROGER: Sure, the question of whether or not intellectual disabilities would be taken into account.

Questions as to reallocation of resources. There's incredible concern that if somebody with a disability that is already on a vent comes forward, would their vent be taken away. Of course we don't want people to come forward -- we don't want people not to come forward due to that. Questions about quality of life judgments being taken into account and also folks in need with assistance of activities of daily life. And how are those persons going to be accounted for and taken care of in issues where there may be scarcity of resources. And any guidance we may issue would be guidance. There is as I mentioned tremendous flexibility for the states. But we would be focused on the guardrails themselves. To make sure that at the very least, at the very least, these states are taking into account the rights of persons with disabilities, the age Discrimination Act, limited English proficiency, all of those questions on a front end so somebody like my sister who may be put in a very difficult situation will have those principles available so it's not just made up on the fly. If I can add one thing, for folks on the line if you hear of instances of discrimination on any of the protected bases please follow a complaint with the Office for Civil Rights and we'll act expeditiously, [HHS.gov/OCR](https://www.hhs.gov/ocr) and file a complaint on the complaint portal there and we're making sure anything COVID-19 related will get top

priority so thank you for keeping us involved of what's going on on the ground.

TED: Well, Director, thank you so much for taking the time out of your schedule to join us today. As you know this is a very important issue for the disability community. We appreciate your consideration of these really important issues. And look forward to continuing our communication with your office in the weeks and months to come, thank you so much.

ROGER: Thank you.

DISABILITY RIGHTS LAWS & HEALTH CARE

TED: So continuing on to the conference and closing the questions for our panelists, I think it's important to set the stage for just a moment. And I'll be asking some questions, directing them to one of the panelists but then after they respond, the other panelists, please feel free to add some additional thoughts, comments, of your own. So the first question is to you Professor Samuel Bagenstos. What is the critical issue here? How do Federal disability rights laws apply to the healthcare setting? And what were the specific state actions that prompted you to file your recent complaints?

SAMUEL BAGENSTOS: Great, yeah, so I really appreciate the chance to talk here. What the disability discrimination laws do is first of all they apply to virtually all medical healthcare decisions. They apply to decisions made by hospitals, by health systems. By state agencies that regulate health. And all of the laws, they are a little bit different in how each of them is written. But they all essentially require the same thing. Which is that there be no discrimination against qualified individuals with disabilities because of their disability and the reason why we have that and why it's so important in the context of healthcare is we have in the United States a history of bias towards people with disabilities. But it's specifically in the healthcare system. A very documented history of medical professionals underestimating both the quality of life of individuals with disabilities and the prognosis in terms of number of years survived by their patients who have disabilities. So it's very important that we have rules that as Director Roger Severino is saying will really ensure that when doctors and healthcare administrators and health systems are making these decisions, they are not relying on what might even be unconscious stereotypes about disability. But instead are

acting based on individualized consideration and the best available objective evidence.

What we saw that prompted the complaints that have been filed and a number of us on this call actually worked on these complaints, was states or healthcare systems adopting policies that explicitly used the existence of a pre-existing disability as a criterion for deprioritizing an individual for life-saving care.

And to be clear, this is a disability that did not make it more difficult to treat COVID-19. It was just a deprioritized factor because of some concern that living with that disability would lead to a lessened quality of life or perhaps a shorter life, even though the person would be able to survive after receiving the treatment for Coronavirus. And implicit in there and sometimes very explicit was a judgment that what healthcare intervention should be about is maximizing some total of Quality-Adjusted Life Years or something like that, which is really this sort of ruthless utilitarian calculus that Roger Severino was just talking about. What the disability discrimination laws require is for healthcare systems to make sure that they are not acting with bias they are not underestimating the quantity or quality of life just because they are dealing with individuals with disabilities and they

are making individualized decisions based on the best objective evidence and that's what these complaints were designed to enforce.

TED: Jennifer and Silvia, can you comment, make a couple of comments? And some of the examples of policies that trigger disability rights concerns? So could you provide a little bit more background on like some of the specific concerns that were raised by these state directives and some common scenarios that you encounter Jennifer and Silvia.

JENNIFER MATHIS: Sure, this is Jennifer and I can explain a few of the specific examples that we saw that were the subject of these complaints. So for example, in Washington state there were some protocols that specifically recommended that in the event of a shortage of resources that triage teams should consider transferring patients with quote-unquote a loss of reserves in energy, physical ability, cognition and general health to be transferred to outpatient or palliative care out of the hospital, in other words to stop receiving life-saving treatment.

There was another protocol that overall survival, which we are prioritizing, and our goal is to maximize overall survival, we are defining that as not just surviving the treatment, recovering from

the treatment for COVID-19, but healthy long-term survival. In other words, you know how good is your life going to be? How healthy is your life going to be? Regardless of whether or not you can make it through the treatment. And how long is your life going to be if you can make it through the treatment. and they acknowledge that this represents survival of young healthy patients more than that of older critically debilitated patients.

In Alabama, what we saw was a triage plan specifically for the use of ventilators in a shortage. And that specifically singled out people with intellectual disabilities, for purposes of rationing ventilators. What it said was hospitals should not off ventilator support in the event of a shortage for people with quote-unquote severe or profound mental retardation, moderate or severe dementia or severe traumatic brain injury. So again, those folks, regardless of their ability to recover from the treatment, to be able to benefit from the treatment for COVID-19 were being excluded and deprioritized for the treatment because of essentially what their lives were deemed to be like, either lower quality or shorter duration afterwards.

Kansas had a plan that actually was based on a plan from New York that would actually reallocate or take away ventilators from people with

disabilities who use those ventilators on a regular basis for a disability. So if you went into the hospital and used a ventilator on a chronic basis that you might actually lose that ventilator, it might be taken away, and given to somebody else who was deemed higher priority than you for a COVID-19 treatment. And obviously people who lose their ventilators tend to die. Because they can't breathe.

So again, without an individualized assessment of that person's prospects for recovery, it simply would reallocate the vent. And also actually excluded people, certain people, from treatment based on things like advanced untreated neuromuscular disease, people with certain forms of cancer and others.

And so again, disability-based exclusions regardless of an individualized assessment of how that person would fare in recovering from treatment.

In Tennessee, there were guidelines that excluded people with advanced neuromuscular disease who require assistance with activities of daily living or require chronic ventilatory support from getting critical care, including COVID-19 treatment. In the event of a shortage. And people with traumatic

brain injury and certain other folks also based on disability diagnoses would be excluded. So those were the kinds of things we were seeing. Those were four states. Those are the ones that we filed the complaints. There are similar policies in some other states. And I know a number of states are actually in the process of developing those protocols right now. But those are the kinds of concerns that Sam was talking about where the consideration is really not about whether somebody can recover and benefit from treatment but, you know, how we value their lives and what we think of either the quality of their life or how long we think they are going to live in the long term.

TED: Silvia, please. You know, I know that both you and Gretta have been among the leading public policies and legal offices -- DREDF you have been the leading ones can you comment on what you heard from Jennifer and Sam and add some of your thoughts.

SILVIA YEE: I totally agree. Jennifer went through a litany of the many, many conditions that are triggering discriminatory judgments I just wanted to add an update about what Sam was saying towards discrimination and bringing up issues very relevant to treatment right now.

Historically there have been a lack of accommodation, a lack of physical accessibility, a lack of effective communication in healthcare for people with disabilities and that certainly affects the situation right now. People with -- who are deaf, hard of hearing, people who have developmental disabilities that affect communication, going to a hospital, you may have a developmental disability that does not at all impact on your ability to benefit from treatment. But it may impact on the ability to understand the treatment, to consent to it, to appreciate what's going on. And if you are not given the time and the accommodations you need to be able to communicate that will definitely impact you and your benefits of the treatment because of the discrimination.

COVID testing sites that are not accessible and you don't find out if you have COVID until far later than you should. I mean, these are all things that are impacting the healthcare that people with disabilities are receiving. And I just wanted to raise that as an issue that needs to be addressed as well.

TED: So Silvia, why do you think that OCR issued their guidance document to address disability -- guidance and then turning to in addition to -- and I

would invite of course the other panelists to comment on that is what is the practical effect of that OCR guidance?

Was there a concern that these state directives were going to keep coming and would accelerate decisions not to treat patients with disabilities? Can you make a comment on that before Jennifer and Sam may weigh in, as well.

SILVIA: I do think that across the country individual hospitals and medical systems are making these decisions right now in addition to sort of state guidance. It was very important. The timing was very critical of getting the complaints out and of having this guidance come out. I think it really established a floor of discrimination. It really established clearly that the kinds of categorical exclusions that we saw in the four states that Jennifer detailed and the kinds of judgments that are being made by medical professionals that are clearly influenced by quality of life stereotypes, those are against -- they run against disability rights laws. They should not be used.

And I think that was an important thing to establish right off the bat.

JENNIFER: Yeah and this is Jennifer. And I would just add that I think there was a concern that this really had to be done right away. Because this is upon us. We are starting to see some of those decisions already being considered. In some places. And from everything that we understand about what is happening with hospitals being overwhelmed, not having enough beds, not having enough equipment. Not having enough Personal Protective Equipment that we are -- we are in the -- going to be in a place in a week or two weeks where this is an issue. And -- in a lot of different places. So it was really critical that OCR act quickly and we were really appreciative that they were able to get out that guidance as quickly as they did. Because we do think it's going to be really important for states and hospitals to pay attention to that as they are finalizing protocols or revising protocols when they need to to make sure that they are in compliance with Federal law.

SAMUEL: This is Sam.

TED: Yeah, do you have a comment about the practical effect that the OCR guidance document has or maybe areas in which it has fallen short that you would like to see it, you know, strengthened and improved? I would be interested in your comments.

SAMUEL: Yeah, I think it's a really strong first start. I think the most important thing to do right away was to make clear to everybody in the healthcare system as this crisis is upon us, as Jennifer said, that there are certain rules you have to apply. There are certain protections that apply in the healthcare system. You know, when we're in an emergency context, we don't want doctors and nurses and health and hospital administrators to have to make these choices. You know, based on their own instincts. Whether or not we trust their instincts because there's just too much information they have to process so we want to make sure they know ahead of time the rules of the road and I think it was super important for OCR to step in and use a really big megaphone to say the law prohibits some of these policies that you have in place for this eventuality you need to make these decisions quick because you want to make them legally and my sense is a lot of the folks who are working in hospitals really want something like this. They are welcoming doing the right thing. They want to do the right thing. They just want to know where it is. I think that's where the next step comes in. I think it's very important for OCR, HHS in general, and folks in the advocacy community like us in all of the states to be working with the hospitals and health systems and medical

professionals where we are to try to give them more concrete guidance about what it is that these general principles of law require. I mean, there is a document that about 90 leading disability rights organizations around the country signed off on that was just released actually less than an hour ago nation wise that I hope that folks who are on this call can get shared to them that does try to go into a little bit more detail to explain what OCR's statements mean. But that's a process that has to happen on a more intensive basis state by state. And I know that HHS OCR is working right now on providing assistance to states. And in responding to these complaints. Their goal is not to what can people for doing the wrong thing -- whack people for doing the wrong thing and certainly not to allow them to do something wrong and have a tragic result but instead what they want to do and we want to do is everybody knows how to do the right thing before the tragedy really happens.

JENNIFER: This is Jennifer, I just want to add very quickly that I was going to suggest that we give people a way to get that guidance that just came out today. And I think it will be on a number of our websites. And I think it will be on AAPD's website, as well. So hopefully we can ensure that people are able to get that document.

SAMUEL: Yes.

KARA: Ted I just wanted to let you know my audio had dropped but I'm back on now.

RECOMMENDATIONS & BEST PRACTICES

TED: Good Kara I was just about to ask you a question before and then we're going to turn to recommendations from the panel. The broad questions for the entire panel that I think will also be reflective of that -- the document Sam and Jennifer, that you just alluded to applying HHS guidance to states and healthcare providers on avoiding disability-related discrimination in treatment rationing.

And that document will be on the AAPD website shortly after this call.

But before we get to the area of recommendations, your specific best practices and model protocols, et cetera, I just wanted to ask Kara, because you know you have -- your career has been about how to think about these various ways to help medical decision making, rationing, including issues such as the quality of life concepts that disfavor people with disabilities. I'm just curious to know if you have a couple of recommendations that you think

that the disability rights community should be considering.

KARA: Yeah, sure. I think a big problem with quality of life is it's so ambiguous and when we hear this used as reasoning for making sometimes life or death decisions about healthcare, sometimes the general public assumes that there's a more objective way to measure quality of life than there actually is. You know, even for social scientists like myself I'm trained as a psychologist when we measure quality of life whether it be using paper and pencil measures or surveys we directly ask people with disabilities or their family members about their life and how they would rate their quality. Even that is problematic. Because those measures are based on norms that are based on a non-disabled population.

But you know that's not at all what we're talking about in these cases. We're talking about healthcare providers looking at a person with a disability and in this case in a very ill state with COVID-19 or even just looking at their chart and basing their beliefs about quality of life on a diagnosis.

So it's really a complete guess about quality of life. It's more about the least -- it's about disability

about a life with a disability than it is about the reality of a person's life and we're really probably measuring ableism than we are true quality of life and the research has been out repeated studies have showed that healthcare providers significantly underestimate quality of life for people with disabilities. But when we ask people with disabilities themselves in a large aerial view most report their quality of life to be fairly good.

So when we ask the doctors, though they view quality of life is quite bad so that gap in between is where these decisions will be made and that's what's frightening because the question really comes down to who are we going to believe are we going to ask the person themselves that we're asking about their own quality of life are we going to believe someone else who doesn't know that individual and have been taught by society that a life with a disability is not worth living and has less value.

TED: Thank you for sharing with us some of those insights and thoughts. So what we're going to do now is for the next while on the phone is speak to some recommendations. I know that Sam and Jennifer have just alluded to this document that is now -- I didn't know whether it was officially released. But I take it it has been officially

released. Some of -- I know -- the panelists on this phone had a hand in writing and thinking about this is applying HHS guidance to states and healthcare providers on avoiding disability-related discrimination in treatment rationing.

So what I would like to do is just before we open it up for questions in about ten minutes or so, look to -- you know, broad questions for the entire panel. And these are some of the questions that I have about are there best practices, such as model protocols, due process protections, individualized assessments that hospitals and other providers should adopt to prevent disability bias and ensure legal compliance? And are there good examples of what hospitals should be doing now? Are there some state laws or perhaps protocols that have been developed by professional medical society or ethics Think-tanks that we could look to for good ideas about what the disability community should be thinking about and the steps that it should be taking? So I know those were some broad questions but I would like each of the panelists to weigh in on, you know, these best practices. You know, what should all model protocols have? What are the elements of a good protocol, et cetera? So Sam, I'll just begin with you and we can go down the line.

SAMUEL: Sure. So I think this is something that really has to get implemented in every health system. And obviously the way it gets implemented might be a little different in different places but I think there are some basic principles that are important.

So one principle that's important is we need to have a requirement of objective evidence. We need to have guardrails against people acting, assuming they are free of bias because most people are not free of bias in general. And the kinds of biases that we have just heard about are pretty persistent. So that requires in particular a demand for individualized review of each patient. Just not keying off of a diagnosis and allowing the diagnosis to determine what we think that the prognosis is going to be, that requires a rule that when you're deciding whether to give someone treatment, that's life-saving treatment in a situation of scarcity, you allocate the treatment based on what's most likely to help that person survive as opposed to what's most likely -- which patient is most likely to lead the kind of life that you think is a good or a long life.

So obviously nobody thinks -- or very few people think that if it's clear that a patient is going to die tomorrow from a pre-existing condition that they

have to get a ventilator when someone else who is not going to die tomorrow, you know, could otherwise use it. If death is inevitable one way or another, if we're in a tragic triage situation, people understand that. If it's inevitable in the very short-term term. But once we start -- short term but once we start talking about the judgments of prognosis that extend over a longer period that's the moment when stereotypes start to come in and biases start to come in and certainly when we talk about quality of life as we have talked about. So I think it's important to look at benefit of the patient in terms of short-term survivability and there can be ways of implementing that and discussing what that means. As opposed to expectations about their lives in the long-term. And then I think it's also important that there be a process where people are given notice of what their rights are when they go into treatment and their family members are. And also have an opportunity to seek some sort of review of a decision not to treat them with life-saving treatment. And obviously this all has to happen quickly. Nobody is talking about this as like a court proceedings. But there has to be some way that it's not just a summary decision that leads some people to death and some people not to death.

And then the final thing I would say is right now we're in a crisis. So we're talking about what to do in a crisis. And that's really important. And obviously we should be talking about that.

But there's a time that we need to really start talking about all of this stuff when we're not in the crisis. When we're making decisions about how to invest in or whether to invest in things like stockpiles of the machinery and other equipment we're going to need during a crisis. And we have to understand that those decisions matter not just on a mass level but they matter to particular groups of people maybe more than others particularly they matter to groups of people with disabilities.

So when we made the decision as a society or government to underinvest in pandemic response, to underinvest in our stockpiles, that was a decision that had a predictable effect on people with disabilities.

And we can't use that decision that was made in the past without fully considering the interest of people with disabilities as a justification right now for saying, well, sorry. Too bad. We don't have enough stuff to go around so the people with disabilities ought to be the ones to die. And I think

it's important to have that principle in your mind as you're thinking through these issues.

But I know Jennifer and Silvia will have other more specific things to say, as well.

JENNIFER: So this is Jennifer and I would just add a couple of things. I think Sam did a lot of the essential principles that apply here really well. I would add with respect to individualized assessments, I think it's important to understand that just because disability is considered a factor, it's not sort of the sole basis of an outright exclusion from treatment. That doesn't mean you're doing an individualized assessment. So if, for example, having an intellectual disability or having spinal muscular atrophy or having certain types of brain injury are a factor rather than an outright exclusion, they count against you. That doesn't mean, well, you know -- well, we only consider them as a factor and therefore we did an individualized assessment. An individualized assessment actually considers your specific circumstances. Not your diagnosis. But how does it impact your ability to recover. So for example, one of the complainants in the Washington state complaint or actually one of the people who was talked about in that complaint had cystic fibrosis and she said you know miosis particular fibrosis

might be seen by some docs if they don't do an individualized assessment as an indication that I am not likely to recover. That I'm not likely to survive the treatment.

But in fact, if you look at my records, if you look at my individual circumstances, I actually have quite good lung capacity that's actually better than the average person's. So you need to look at that person's specific circumstances, whether it's a factor or whether it's an outright exclusion, it doesn't matter. It can't be based on diagnosis.

And then also there is the idea of reasonable accommodations or modifications. That's a standard part of disability rights law, of non-discrimination. And reasonable accommodations can be -- can come into play in a lot of different ways in this context. Sometimes that might mean somebody needs an interpreter or you know effective communication to kind of be able to understand what's going on and to communicate with the doctors or other medical professionals. It might mean having a disability service professional come with somebody or a peer support person. It might mean actually thinking differently about the treatment. So for example, if the standard protocol is having somebody be on a ventilator for X number of days to see if they begin to get better

and if they don't, then at some point people talk about removing the ventilator. If somebody has a type of disability where it might actually mean that they need to be on the ventilator a little bit longer, then that might be a reasonable modification to the usual policy. So those are some additional types of principles that come into play here. And I think Silvia can talk about some additional ones.

SILVIA: Thanks Jennifer. I mean, I have three specific ideas relative to medical rationing and then a bigger idea about diversion. But some of the procedural things about medical rationing is it's really important that hospitals and medical systems, states, that they really make their medical rationing policies prevalent. That it be transparent enough. So people can see it you can't react with input if you don't know what it is. We have been researching all of the 50 states and territories to see the different policies out there and it's not always able to get at it all. So there should be a requirement when hospitals have a COVID policy or pandemic policy, it be out there. Also, the second thing, to the degree that this is at all possible, it's one thing to have principles for hospitals and doctors to see. It may be much harder for them to actually understand how see how it works. So to the extent there can be any kind of disability training of the triage teams that

are making these decisions, this is of course very -
- an urgent request. But there are researchers
and projects out there, funded projects that are
looking specifically at how to train doctors that can
be made available. We've been hearing about
some of them ourselves. So this is something that
could be started right away. That kind of training
and awareness.

And also the requirement -- and this may seem
like just a geeky thing but I think it's critical, as
well. That data on what happens with the triage
and the rationing and who is getting ventilators.
That has to be collected. My fear is that -- I mean,
eventually we really do want ways to assess the
capacity to benefit from ventilators or from critical
care. We need ways that actually adjust and
understand how disability figures into that. And
when we look about a at this time I don't want it to
be that people with certain conditions or
disabilities, they will be listed as, oh, died. And
there's no distinctions between someone who died
because they didn't get ICU treatment or a
ventilator was denied. Or someone who died even
after that treatment was administered. That's all
going to go into information that will affect the
lives of people with disabilities and their ability to
get treatment even after this crisis.

The idea about diversion is -- it's a big one. I mean, if we can avoid people with disabilities being subjected to the triage in hospitals in the first place, that's really, really important. I mean, the country has put in social distancing guidelines for most of the country. But for a lot of people with disabilities who have personal care assistants and other health needs, they cannot avoid having contact with individuals. They have to have contact with their personal care assistant. They have to have contact with people who help perform their daily lives this is a workforce that needs some protective equipment to be able to perform their work safely. If there can be a workforce -- teams of personal care assistants, nurses, doctors, telehealth, I mean, those regulatory possibilities have been put in place through things like Appendix K and things that CMS has done to relieve regulatory burdens. 1,135 waivers that the states can apply for. There are ways for states to put together teams that will help people with disabilities to stay safe at home. And older persons, as well, to stay safe at home. And this is something that is not just for people with disabilities or older people. It helps keep all of society safer. And it helps relieve the burdens on hospitals. It's a win-win that we need to be looking at. And -- but it can only be done with dedication, with a lot of thoughtfulness and with

cooperation from the state from hospitals from doctors from people with disabilities and advocates.

TED: Thank you for that. Kara, before we open it up for questions from the call participants, do you have any thoughts or final comments or suggestions?

KARA: Yes, I would definitely echo what the other panelists have shared. And I think just kind of adding a bookend is clearly we're in the urgent work of a crisis right now. But I'm trying to take note of how many lessons that we're learning quickly. And we do have opportunity to do some rapid awareness building. But I also think we really need to make a commitment to long-term changes in our education and training and healthcare providers. Just really emphasizing that medical discrimination is a root cause of a lot of healthcare treating people with disabilities and ableism shouldn't dictate our care in a crisis or beyond so I really want to see those lessons put to work after this, as well.

PHONE CALLS

TED: Thank you. So we-- so we have 15 more minutes for this call. Kevin, are you there? I want

to ask you to moderate this. Because I don't know who is queued up for this call. And just ask the people posing the question to direct that question to one of the panelists and in 15 minutes I'll just make a couple of concluding remarks. And that will be the end of the call.

So Kevin, can you please proceed?

OPERATOR: Absolutely. Please press 1 then 0 on your touch tone phone at this time if you wish to ask a question. 1 then 0. Please stand by the first question is from the line of Marina. Please go ahead. One moment, please. Okay. Your line is -
- your line is open now. Please go ahead.

CALLER: Good afternoon, thank you so much for this call. My name is Marina. I was on a bioethics call I have a two-part question I don't know who is best to answer this.

I was on a bioethics call yesterday with about 200 bioethicists and there were recommendations being put forth and that's where it became very clear that disability voices are very urgently needed on the triage teams and committees because that's where really the guidelines are being set.

I was wanting to know more how we can go about doing that. I was also told that hospitals are taking precautions against lawsuits for clinicians and doctors partly in response to the OCR guidance because also clinics don't want their clinicians to feel burdened and feel attacked for their clinical decisions. So that's one point of concern. And the second I have I'm in New York City and I have a friend with cystic fibrosis and his medical team told him that if he -- he's not on a -- he's not on a ventilator but he was told if he needs to be hospitalized during the COVID period for his cystic fibrosis and will need a ventilator that he won't be eligible for one. And I want to understand if this is allowable. Thank you.

KARA: I can speak to the first part of your question. This is Kara Ayers I also think the issue of underrepresentation is a decision-making circle, it's a significant one. I'm a person with a disability. I sit on our hospital's Ethics Committee and an issue that I'm exploring right now doing some research is what disability representation is like across Ethics Committees in hospitals. And I know that oftentimes or committees are once removed from the triage teams that you mentioned but it's one place that I know of could use more direct representation from people with disabilities. I think you're exactly right that those

experiences and voices are missing and we need to figure out how to get more of them to a place where they can be heard and make a difference. I know as advocates, we're here. We just need places to make our voices heard and listened to but I'm hoping other panelists can speak to either that question or in addition, the other one.

SAMUEL: Yeah, this is Sam. Let me just say a couple of things in response. One is, you know, as someone who is both an academic and an advocate in this area, one of the things I think is really striking is there's a world of bioethicists. And there's a world of disability rights activists. And people with disabilities. And you know, there's just not that much intersection between the two worlds. And so that often leads the bioethicists to have a lot of internal conversations and kind of assume that they have worked out all of the relevant issues and assessed all of the relevant interests. And that leaves often disabled people on the outside kind of knocking on the door and saying, hey, you have forgotten about under the circumstances. And I think we're seeing some of that now. I think there is an openness among a lot of folks in the bioethics world both academically and at the level of hospital ethics committees to listen now. But you know it's coming from a place

that historically hasn't had a lot of disability representation. So I think that's important.

I think it's also important, you know, the idea that, well, of course everybody wants to make sure that the people who are making tough decisions, the people who are exposing themselves to illness, who are working really hard to save peoples' lives, you know, nobody wants them to be unfairly subject to liability. And that's why what we want to do is we want to make sure that the rules and guidelines are clear ahead of time. So it's not people making discretionary decisions in difficult circumstances. But we actually have a set of principles that people can follow that are then incorporated into protocols by hospitals and health systems.

And I think that's the best way to ensure that people are protected.

You know, I think that -- and I totally get all of that.

So I think those are important considerations. And obviously if you're running a health system, you know, you're thinking about all of those considerations. But it's important to have the disability voice there when you're creating the

policy. Because otherwise you see the kinds of policies that we're seeing in many places around the country.

JENNIFER: Yeah, this is Jennifer, I would just add to that. I mean, certainly I think this is the quintessential context where you can say nobody is interested in going after clinicians and suing them for money or something like that. The interest is not about making people lively but the interest is in saving peoples' lives and frankly if you are bringing a lawsuit because somebody did something wrong in this context it's usually going to have been too late so really I think the best way to shield people is just, you know, as Sam said, really this is an educational issue. And also this is a good lesson learned that, you know, folks have pointed out that we really do need to going forward find ways to get disability voices more centered in these bioethics discussions. And it may be too late. In some cases where we are right now. But hopefully even to the extent that that can happen now and that is, you know, very much what we're trying to do, hopefully it can have an impact even know as well as going forward.

And I do think that what was told to your person with cystic fibrosis that simply because of cystic

fibrosis he wouldn't be able to get life-saving treatment if he were to be hospitalized I think would violate the ADA. I mean that is exactly the sort of diagnosed based non-individualized determination is what the ADA and Section 504 and the Affordable Care Act, non-discrimination provision all prohibit.

SILVIA: Right this is Silvia.

TED: I think I would -- I know we're getting to the end of the call here. I would like to have another question if possible. Not to cut this short. But Kevin, is there another question on the line?

OPERATOR: Yes, one moment, please. The next line is going to be from Christopher. Please state your last name.

CALLER 2: Hi, it's Christopher Noff from Disability Rights Legal Center in Los Angeles Jennifer and I recently had the joy or pain of dealing with the anticipated defense I'm going to talk about which is and particularly with personal care attendants, I think that we need to have guidelines that address the fundamental alteration defense. And the response that we're going to get when people with PCAs seek treatment. So I just wanted folks' thoughts on that.

SILVIA: This is Silvia I'm just fundamental alteration to bring a personal care assistant with you, is that what your --

CALLER 2: Yes or whatever accommodation or whatever -- I'm anticipating hearing that response from a healthcare center. In terms of a request to serve a person with a disability if there's any advocate on their behalf or any argument made on their behalf.

SILVIA: Right. So I mean this is Silvia. Yeah, we've been thinking through some of those things, as well, fundamental alteration. But in terms of, I mean, the fundamental issue -- the fundamental goal is to provide life-saving healthcare. That's the goal of it. I think that hospitals and other treatment centers should be working to have guidelines and disease control guidelines in place that a person care attendant or other family member that's needed would have to comply with. That's sort of a given. And that's probably a concern sometimes with some CPAPs other ventilator units well-being brought into a hospital. But it's not an impossible thing. It needs to be addressed beforehand. And needs to be worked out. Just as having you here, simply your presence is a fundamental alteration. It just --

does not -- that seems like an over-- too much -- it's an argument that I don't think can stand because there are actually articles out there, as well, that talk about the kinds of things that can be done so that it's -- the accommodation is reasonable and possible.

TED: Thank you. Kevin, I think we'll take another question, if there is one.

OPERATOR: Yes. That's from the line of Anna Fern, please go ahead.

CALLER 3: Hi, I'm in touch with here in Philadelphia. I'm an advocate and thank you for recognizing our Mayor for his anti-discrimination statement. I'm hearing concerns from people who run long-term care facilities that they are unclear about how to get the additional funding or supplies that came through through the CARES Act. The state association leading HPA along with related unions have written to the Governor to ask for assistance. To date one facility got a limited amount of supplies. And to Silvia Yee's point part of this is preventing those folks who are on vents who are -- who have complex needs from even getting to the hospital.

And so what advice would you have or have you seen any good strategies for coordinating and making sure some of that Federal relief gets to our facilities?

TED: Silvia, did you want to speak to that question?

SILVIA: Yeah, sure. This is something we're all actively working on I think sort of the tracing through, where is that equipment then? Where is it going? How is it being divided? That -- I think that one strategy that is going to be needed is working across sectors so that Unions and advocates both for older individuals and for people with disabilities there's really going to have to be a coming together to get the pressure on this. And that's hard. Because that kind of coming together takes time. And this all feels so very urgent. But I think that there is a lot of individual and -- individual organizational sector kind of advocacy happening. And that's -- that in some ways is harder to push off -- I mean it's easier to push off by a Government or department than a sort of unified voices. I mean it probably seems like kind of generic advice. But I think this is a really hard one at this time.

CALLER 3: Thank you.

JENNIFER: Yeah this is Jennifer -- go ahead.

KARA: I was going to say we developed a call script so that advocates and providers can contact their local agency like municipality that's contributing to make them aware but then we also circulated at least for Pennsylvania the PIMA form to formally request. But I think if we could have a national strategy, it might help us get the word out with all of the other counties.

JENNIFER: That's a great idea. And there are obviously also some websites that collect you know some of the guidance that's out there that provides some flexibilities for states so that they can do some of the things like telehealth that they couldn't have necessarily billed for before. And that's all helpful but on the issue you raise of supplies, some of the problems I have seen are that people are willing to pay, even if they have the funds, they can't get the supplies. I was on a call a couple of days ago with a state where we represent about 4,000 people. In long-term care facilities who have a right to get out. And they said, they don't have masks. And they said, we'll pay. You know. It's not that we don't have funding to pay for it. But we can't find them.

That's a pretty -- that's a pretty bad situation we're in. And I don't have a good answer.

TED: So this is Ted speaking. We just have to move on in the interest of time I think we have time for one more question. So Kevin, please proceed.

OPERATOR: And that question -- one moment please -- comes from the line of Greg. Please go ahead.

CALLER 4: I'm with the ARC of California. A question, thank you, first of all, for all your work particularly at the policy level which is so important. My question is more at the ground level. For people today who are concerned that they or their family members or the people they advocate for are going to be in the hospital tomorrow or in two weeks, what can they do now, if you can? Somebody mentioned a call script, can you give us access to those to call -- who should we call? The hospitals I suppose. And then the second question is when that time comes -- when that time comes when my nephew Will who has autism the EMTs are on the way to pick him up because he's having trouble breathing what can I do to -- or anybody in that position do to influence

the physicians and personnel who are going to be treating him?

TED: Jennifer or Sam or Silvia, do you have any practical advice for what individuals should do if they feel they could potentially be denied needed care because of their disability?

JENNIFER: Go ahead, Silvia.

SILVIA: I was just -- on this ground level, the people I know with disabilities, the things they would do is they fill out like some of the know my rights sheets or -- they will write on their bodies. I want life-saving treatment. They will have as much possible in this time when it's hard to bring anyone with you, they will have friends and advocates phoning in, being present, insisting that communication devices are present. I mean, it comes down to whatever you can -- whatever you can do. Which sounds cliché. But these are the sort of when you're in that situation and the ambulance is coming, you know someone is going to be in the hospital, it's being as absolutely clear as possible that you know your rights. And that people are watching out for you. And yeah, communicating that.

CONCLUDING REMARKS

TED: Just to your point, this is Ted speaking, as I mentioned at the beginning part of this call, AAPD plans to organize a follow-up call on -- to address just the types of questions that you asked. So please, I invite you to check on the AAPD website for that. We plan on assembling other advocacy groups on what the specific action steps we all need to be taking. And what individuals should be doing, if they feel like they have been denied needed healthcare because of their disability.

I also want to invite everybody here to take a look at hot off the press recently released disability community response. Including whose authors are here with us today on the phone, applying HHS guidance to states and healthcare providers on avoiding disability-related discrimination and treatment rationing. I think provides a lot of really practical steps, protocols, ideas, elements that every hospital and healthcare provider should have in place, including the transparency measures that Silvia discussed.

So at this point before we conclude, and I just ask the panelists if they would like to make a couple of concluding remarks I want to thank Susan Diegleman, again -- and AT&T. AT&T is one of our leading corporate partners at AAPD. I would like

to thank Susan for facilitating this conversation today. As well as Maria Town, our President and CEO and thank you, Maria, for all that you did to organize this call and all that you'll continue to do to ensure the rights and opportunities for people with disabilities.

I just invite our panelists in the short moment we have ahead to just make a few concluding remarks and that will conclude our call today.

SAMUEL: Yeah, so this is Sam. I think this has been a terrific discussion. Obviously these issues are going to continue to ramify over the next several weeks and months. And I think it's just important that people be in touch with the disability advocacy organizations in their communities. Whether it's their local ARC chapter or their local protection and advocacy service. Because you know these issues I know raise lots of questions. And even when people want to do the right thing, they often don't know what it is. And often you need some technical assistance at a very specific level. So please do keep in touch between the advocacy community and the healthcare community.

JENNIFER: This is Jennifer I would add -- go ahead.

KARA: This is Kara. I would echo what Sam said in terms of connecting with our community, if you're not already connected. One of our greatest strengths is within our disability community. And now is the time to grab onto that and not leave anyone behind. And just reiterating the importance of not only the inclusion of disabled voices in these decisions from everything from before this in terms of making decisions about what supplies and care resources to have all the way to after this in terms of what lessons we're going to learn. We not only need to include disabled voices but we need to prioritize them in terms of making sure they are not dismissed and they are being listened to throughout.

JENNIFER: This is Jennifer and I would just follow up and say for all of the advocates, those who have not yet made approaches to your state to sort of find out, to identify what protocols they are using, if they have any, what schemes they are following, it's urgent that you do so. As Sam said earlier, there is actually a lot of willingness on the part of many folks who are involved with developing these protocols to engage with folks and to try to do the right thing. That has not happened because they have been very siloed from our voices. But certainly people should be

asking and should be right now trying to influence those processes as much as possible.

SILVIA: This is Silvia and I appreciate everyone's thoughts on this conversation and putting this together. I know -- I mean we've had this discussion. We have talked about how heartbreaking it is for providers to make these decisions and I also find it equally heartbreaking to hear the fears of parents of children with disabilities and children with disabilities about going to the hospital and going for care. I think I would just really plead that every think even as we're in the midst of a crisis about what we want - - what we want our world to be after it. Because it will pass. And we still have to think ahead. About the values we have. And the values we want to survive after.

TED: So thank you, everyone, I think I speak for everyone on the call. I'm sorry we couldn't get to more questions on the call. But on behalf of the American Association of People with Disabilities and the entire disability rights community, I think we all owe a debt of gratitude to Professor Ayers, to Samuel Bagenstos to Jennifer Mathis and to Silvia Yee, thank you for your leadership and thank you for continuing to fight the fight and for all of the work that you're doing in your comments and

recommendations and suggestions, we look forward to working with you in the weeks and months ahead. Thank you very much, everybody. That concludes the AAPD call this afternoon. "Disability Rights and Medical Rationing" in the face of COVID-19. Thank you all for joining us.

OPERATOR: Thank you, ladies and gentlemen, that does conclude your conference. We do thank you for joining. You may now disconnect, have a good day.