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ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
CRISIS STANDARDS OF CARE DURING THE COVID-19 PANDEMIC
IS IT EVER OK TO DISCRIMINATE?
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>> I'm going to give us just a couple of seconds because everyone gets added gradually to Zoom here.

Welcome.

Welcome to our webinar, crisis standers of care during the COVID-19 pandemic, is it ever okay to discriminate.

Today for the next hour we will hopefully invite you to join us in this conversation to explore these complicated issues.

A little bit about our format today is that we would like to welcome you where we are each going to go through and introduce ourselves and offer introductory remarks and we will have some questions for each of us to think through followed by some Q&A from you the audience.

You will notice here in Zoom we are in the webinar format which is a little different than meeting format if you attended.

Down at the bottom you still have the Q&A -- you have the chat box as well as the Q&A box.

Both of those are available to you if you would like to enter questions. You might want to engage with the chat box and if you really want to make sure that we are able to see your questions -- able to see your questions, I would recommend dropping those in the Q&A.

We will try to look for them in both.

We would encourage you to add your questions as they come.

We will answer them at the end.

As you think of them, feel free to enter those into the chat box.

We will get started.

I will introduce myself.

I am Kara Ayers.

I'm the associate director of the Cincinnati -- as well as for dignity for health care for people with disabilities and partnered with multiple -- and the self-advocate network and family voices and A -- we are a collaborate effort working on addressing health care and inequities faced by people with disabilities and COVID has unfortunately magnified those inequities along the way.

On a personal perspective as well, I have a disability as well as more than one member of my family that makes us more at risk should we acquire COVID of bad outcomes.

So I have personally been invested in trying to better understand the crisis standards of care and also just public health response and where the disability voice has been heard and not throughout this.

As I kind of traversed through this, I know I'm probably not alone in hearing words like unprecedented and never before and that uncertainty can leave us unsure about where to look for guidance. It has helped me to look back at some of the writing of disability scholar Paul Long More discussing in his piece class of cultures of he talks about when issues of public health differences like this arise, how it's based in the differences of perceptions and values of -- perceptions of disabled and non-disabled people and that led me to think more about when these questions of when demand exceeds supply, how do we answer them.

For COVID-19, the demand has shifted a little bit so at first in the early months we were worried about ventilator supply. Then we realized that capacity of beds and staff was going to be just as much if not more of a concern.

And in March we started to see these crises standards of care all out from states and dis-- of care all out from states and we would be put in the back of the line and deprioritized for care meaning our care would be deemed as not worthy of the investment of time or resources.

Unfortunately, at my last count 11 states did deprioritize

disability with just categorical exclusions for care or rationing care away from different groups in our community.

I think what's important to note is that stigma and bias not science led those decisions.

So there is not significant evidence that shows that our survivability in many cases would be different but based on judgments about survivability but also about the quality of life with the disability and what a valuable life means.

And I think that led me to connect to previous research that I've read around how unfortunately health care providers often estimate the quality of life of people with disabilities much lower than those without.

So one study that I have been reviewing recently found that emergency room providers responded that only 18% of them would find life worth living if they were to sustain a spinal cord injury.

Whereas when you actually ask people with spinal cord injuries upwards of 95 to 98% deem their lives worth living and of quality.

So I think that this scary part is that the people that would be making those decisions and not to vilify them, but the% speculative of those who make those decisions comes with it and inherent ableist view that devalues life with a disability.

So as I have been trying to make sense of all of this and kind of look ahead at what solutions could I offer, the solutions that I have been looking more into have been a shift in the way that we understand these through an ethical paradigm.

So most of our ethics thinking has focused more on what is called a utilitarian view which I had to kind of self-teach ethics.

I'm a psychologist by training.

But I understood this concept of saving the most people.

And as people with disabilities we know that we often take more time or more capacity to do many things including with our health care at times.

So we are already at a disadvantage when that idea is to save more people is always preferred.

I have found it interesting that the United States is unique in some cases in the way that we prioritize the individual and this competitive fight for resources.

And I hope that the lessons that we learn from this is to take a step back and have more of an approach around solidarity and more of a care ethics approach where we would really look at kind -- really look at holding the line of looking for ways we wouldn't be in this situation in the first place but if we are, we wouldn't be excluding people on the basis of who they are and making assumptions about the value of their lives.

Kind of just concluding my opening remarks, I hope that our solutions are focused in not allowing to come to this place again but a focus on cooperation and really helping to rise the tide that lifts all boats.

Have been touched by the commentary that's talked about how yes, we are all in the same storm but in different boats.

And I feel that deeply as a person with a disability and just looking at ways we can rise that tide to help all of us be lifted through this.

We have a lot to talk about today and I'm really excited to hear from our panelists so I will pass it to you, Silivia, to introduce yourself and give opening remarks.

>> Thank you, Kara, I appreciate your remarks and your frankness about how this is affecting you personally.

I'm a senior staff attorney with disability rights education and defense fund national organization but we are also based in Berkeley, most of us are here and in California which has been a place where there has been surging -- the surging pandemic in a very present and clear interest and concern about crisis standards of care.

As well as concerns about another shortage which is vaccination.

Thinking about the title of this webinar, you know, is there a place to discriminate?

As a lawyer I think I inevitably start thinking about laws down to discrimination law -- down to discrimination laws and civil rights laws and the history of those --yo

>> That people with disabilities would face a focus on what can't be done rather than what can be done.

And a lot of common assumptions about what people with disabilities need and what they are capable of.

And that tended to look at the need for individual accommodations or modifications as almost a kind of cheating.

People with disabilities fought all of these assumptions and wanted to move away to have their lives dictated by a diagnosis.

As a result, the civil rights definition of disability is broad based.

And I'm going to read a little bit and educate what it is in the ADA which is what it is for Section 504 of the Rehabilitation Act of 1973.

So under the Americans with Disabilities Act the definition of a person with disabilities typically defined as someone who, one, has a physical or mental impairment that substantially limits one or more major life activities.

Two, has a record or has a record of such an impairment, or three, is regarded as having such an impairment.

And this was a really important step for the disability civil rights movement to make because the definition legally recognizes how people with disability can be disabled by the built environment as well as the social and cultural norms and mores that surround them.

The ways which things are done.

The assumptions that people make.

And I'm going into this because when the pandemic hit, there is a lot of increased public and medical attention in the concept of crisis standards of care, we saw crisis standards of care guidelines that explicitly indicated that.

For example, people had trouble breathing on their own or people with severe intellectual disabilities or people who had progressive medical conditions that would lead to death.

These were the kinds of things we saw in crisis standards of care that would allow medical professionals to triage these individuals out of care or delay their care.

In other words, it was a kind of pass that would allow a hospital or a medical system that wasn't a crisis standard of care stage to forego a true individualized assessment of the patient's capacity to survive and benefit from treatment.

It was a kind of short-cut, in a way. And it was one that many people in the disability movement recognized as being discriminatory.

And even those crisis standards of care that didn't necessarily point out specific disabilities as being subject to medical triaging, there was -- there were many crisis standards of care that afforded hospital decision makers with a great degree of discretion over determining who had the best prospects of survival and therefore get treatment and that raised tremendous red flags for many people with disabilities.

As Kara indicated, there are studies that showed how medical providers tend to think of quality of life as living without disabilities. And so having a disability means living a life that is inherently lesser in quality in some way and therefore potentially less valuable.

Or at the very least a life that will inevitably be shorter and that's also not always true.

And as Kara also has indicated, we are not going into this to vilify the medical professionals.

It's to really point out that there is a tremendous amount of implicit bias in the medical system, in medical education, and it is really hard to try to get around that when people with disabilities encounter

it and they have encountered well before the pandemic. They encountered it going to the hospital and trying to get accommodations that they need for effective treatment.

I think people with disabilities have encountered long held discrimination when they go and try to work with providers or try to argue that I actually know my disability pretty well and I know my body pretty well and this is what I need.

I think that kind of long held conflict is not unfortunately uncommon for people with disabilities to encounter.

And once again it's not pointing the finger or trying to be individually accusatory of any medical provider, but saying that the health care system as a whole has not always paid attention to people with disabilities and has often shortened, given less value to their lives because they are living with a disability.

So I'm going to end my minutes there and let us go on to the next speaker which I think is Jeffrey -- or Jeff.

And I will try to remember that.

And I know we will all come back to all of this in questions later.

>> Thank you so much.

Silivia, I was joking with Silivia before.

The only time someone calls me Jeffrey is when I'm in trouble.

We will see if Silivia resorts to that we will know I've done something wrong.

my name is Jeffrey Brosco and I'm a pediatrician and the associate director of the -- and my disciplinary back ground is history and health policy and ethics.

I have been taking care of children with developmental disabilities.

I have been teaching this to medical students and doctors and writing about policy and ethics.

And I was deeply involved in the efforts in Florida had come up with a crisis standards of care policy.

The state of Florida decided not to do anything but the Florida bioethics network put together a policy for our critical care folks and people with disabilities were involved in the very beginning and crafting the policy.

And when we brought it to the statewide and talked to the Florida DD council and disability rights Florida and our other partners it was interesting debate about what exactly is a disability.

And we will come back to that but I want to make three points that are uncontroversial.

The first is we absolutely need a policy for crisis standards of care. That's because all of the reasons we heard already.

If COVID pandemic is nothing else has displayed the implicit and explicit discrimination against people with disabilities and blacks and Hispanics and other groups in the United States. It's been horrible.

And we know that if a doctor or a nurse or health care professional is in the emergency room or in the critical care unit it has to make a split second decision about what to do and their implicit and explicit bias are bad for people with disabilities.

Having a policy removes them from that need to make a decision and in fact in most of the policy the done by a triage team separate from the clinician to bedside.

That allows the clinician to continue to advocate for his or her patients at the bedside.

But makes decisions about allocation of whether it's ventilators or other stuff based on a system that has been developed -- or has been thought to be fair and transparent.

So I think we all probably agree need to have a policy because absent that that it's rampant discrimination and horrible for clinicians to make decisions.

The second question and Kara mentioned before is what do you base that policy on?

And there are different ethical systems that is first come first serve which is health care now.

First one to the door gets treated.

The most fair thing is a lot of -- a lottery system where everyone picks a number and depending on your number you get the ventilator or don't.

I use the ventilator as shorthand for all resources.

Others have said that probably the best thing to do is if you have two ventilators and five people who need it you are probably want to try to use that ventilator on a two that are most likely to survive. And this is a little bit as Kara pointing out the greatest good for the greatest number utilitarian approach. We don't want to use the autonomy and respect for the individual and balancing that has been really difficult.

A number of policies across the country have tried to do just that using objective scores for who is most likely to survive getting out of the ICU and probably a lot of you learned about those scores and it -- at your heart rate, blood pressure and a whole series of objective measures that can be abstracted from a medical record without having to see the person.

The reason why that's so important is because as soon as you get to the bedside all of those implicit and explicit biases can fall too place.

Policy that focuses on who is most likely to benefit from a ventilator or other resources is the way you would say okay, we are using our scarce resources in the most effective way possible.

The other part of this is not just that you want your policy to reflect a certain set of values but you want there to be evidence behind it.

You want to know whatever you put in place works so you need to monitor it and check to see that your approach has been appropriate.

And if we get time I can tell you about research we have done in the University of Miami looking at these questions looking to say does our policy discriminate or turned out to be fairly evenhanded.

The hardest part in this debate has been about what exactly constitutes a disability.

And we in our policy and in our Florida bioethics network and been adopted by a number of hospitals across the state as well as the Florida hospital association says first and foremost you will not under any circumstances discriminate a person because of race, color, creed, disability, veteran status or a whole range of things that are consistent with federal law and just the right thing to do. That's pretty straightforward.

What's harder is when you start looking at, well, if someone has end stage cancer, or severe heart disease, or a medical condition, not a disability, a medical condition that makes it less likely for them to survive a serious infection, should that count in deciding who gets a ventilator.

And I would say that what was very interesting is we worked through this in Florida is that most people who have and I'm not sure what the right word is but I'm going to use the phrase traditional disability for a person who has Down Syndrome, autism, cerebral palsy, a sensory impairment.

By and large saying that does not count against you or for you for getting a ventilator but things like cancer, heart disease, diabetes actually might be important.

If they were -- we were very careful how we worded this.

If those medical conditions were likely to lead to death within one year or five years, and that should count as part of the tie breakers.

Much more controversial thing is whether age should be included at all.

And that's a lot harder.

And so the way I sort of think about is concrete.

Let's say you had two people.

One person is 32 years old and has autism.

Second person is 32 years old and has autism and end stage pancreatic cancer.

Would we say, well, no, we shouldn't make any distinct between the two people they should have an equal chance and we should flip a county. Or say the person with autism that doesn't have end stage cancer is more likely to survive long term and person with end stage pancreatic cancer will unlikely live more than a year.

But it makes more sense to privilege the person who doesn't have cancer.

That's the way we thought about it.

And when you try to research this and that is you do what's called participatory democracy, what do you think is the right thing to do most people would say, yeah, that makes sense.

So I'm going to conclude by saying a lot of these things will come back and I think that's where the lawyers disagreed with us meaning the doctors and health care professionals and a lot of the DD council and other folks in trying to figure out is it appropriate to use medical conditions as a way of deciding who should get a ventilator under those very difficult circumstances.

>> Kara, do you want me to go?

>> Yeah, sure.
Thanks, Jeff.
Andy, go for it.

>> Thank you.
I want to thank Jeff for suggesting that we do this.
We were going to do it as part of the conference and then we thought doing it after the conference in a more interactive form will be more conducive to having a good discussion and it's hard to do that in a one hour format.
We have a lot to say.
So I will try to be brief.

You know, Jeff, you and I talked about this just in the context of naming this talk and describing the talk.
I am personally, I wear the hat of a disability rights lawyer like Silivia, although obviously have strong ties to the AUCD network.
I do think there is a culture clash between disability rights perspectives on this topic and medical ethics perspectives on this topic.
Jeff, I feel like as is true of a lot of topics, you have a foot in a lot of different frameworks.

You understand policy, you understand clinical reality on the ground.
You understand ethics.
Don't assume those of us in the disability rights movement understand all of those things.
What I have found in California is that our public health leaders came out with draft crisis standards of care that were clearly discriminatory on the basis of age and disability.

And when the disability and older adult advocates interacted with them and including our secretary of Health and Human Services, they were convinced that they made a mistake and they changed their guidelines and there were physicians that got involved including physicians that you connected me to, Jeff, who were very helpful to us.

And I think if we didn't have those physician voices on our side, I don't know if we would have been persuaded -- I don't know if we would have been as persuasive to the mostly medical doctors we were talking to.

So I just want to point to that culture clash because I don't think physicians get exposed to disability rights frameworks as part of their professional training.

For those of us that are steeped in disability rights, trying to draw a line around which disabilities count and which don't count is very unnerving and it can lead to discrimination.

I'm personally not comfortable with some of the lines that you drew in your description Jeff, and it doesn't make me more comfortable to know that most people think that those lines are reasonable because most people aren't carrying a disability rights frame.

They are carrying an ableist frame or a utilitarian frame where they are trying to save the youngest healthiest people because they will live longer.

That's a -- live longer.

That's a common sense thing for people who haven't thought how that can lead to discrimination.

Jeff, I know you have thought about how it can lead to discrimination and you are trying to parse it in a way that makes sense to you.

I want to say the basic concept of disability rights is that if you have any underlying condition or you are perceived or have a history of having an underlying condition, and it leads -- and it leads to or can lead to discrimination then you are protected.

Clearly somebody with cancer that may have a three year prognosis is likely to experience discrimination when they are rationing health care or they are likely to experience negative attitudes about cancer and the value of their life whatever is left of their life when they are trying to access the scarce health care resource and I think they should be protected against discrimination and I believe -- and Jeff

you are the clinician and you can disagree if you don't agree, but my sense is our ability to predict how long somebody is going to live is not very good.

And our ability to predict the quality of life that they will have during those last years of their life is not very good.

I think the best standard for crisis standards of care is if somebody can benefit from the -- let's use ventilators as an example.

If somebody can benefit from the ventilator and be kept alive, they should have access to that ventilator like everyone else.

I do want to say why do we have a shortage?

Why do we have a shortage of ventilators?

Why do we have a shortage of emergency room beds?

ICU beds, vaccines.

All of those shortages are failures of government to have policy that can account for the reality that we are living through.

Failure of government at every level.

So I don't want to give government a pass.

We also need to do work with government to not have scarcity in health care like we have right now.

I will stop there.

>> Good points.

Thank you, everyone.

And we will circle back to expand on some of these as well.

This first question I will pose to the group, I know we touched on the civil rights and legal requirements in the development of the crisis care standards, I wonder if we can expand about that to also address the water adoption and implementation of these guidelines -- the wider adoption and implementations of the guidelines.

Especially around the implementation, many of us on the advocacy side are asking when will we get to the rationing -- we were worried are we rationing now and what about now?

I think the conclusion that I have come to is in many cases rationing was happening and maybe it didn't look like we pictured it in the scary scenes that were playing out with one ventilator and two people and pointing.

In making these quit implicit -- these quick decisions that are steeped in implicit bias, we know unfortunately it's already happening in some cases.

I wonder if you can expand on this piece with the crisis care standards and the adoption and implementation.

Do we want to go in the same word?

Silivia, do you want to get us started

>> Sure, I'm happy to start it I don't know if we always go in an order. Yeah.

A friend of mine or a colleague, my legal director has said that the crisis standards of care are not only -- the disability civil rights applies and civil rights laws in general apply in crisis standards standards of care but even more than that.

There are especially needed during crisis standards of care and during emergencies because that's exactly when the instincts and the assumptions and the ways they've always been doing things take over.

Implementation has been hard as here in California we have seen ICU come very, very close to full capacity.

And I think that even when you are not declaring a crisis standard of care, we have been seeing that this kind of decisions being made if you know you have two ICU spots left or one ICU spot and you don't have the staff, you will start as a provider start thinking about what are the other options here?

There is a great reluctance for hospitals to actually call it.

To actually say, okay, we are at crisis standards of care.

I have been thinking that, well, if you are effectively there and you are doing all of the same actions there is no benefit to not calling it and in fact you just don't trigger the due process requirements then.

How you could during a crisis standards of care there is often going a triage team as Jeff has said rather than an individual provider.

If you have a sense in a hospital that everyone is thinking, we don't have room, we don't have room.
This is my next patient.

Is this person going to take up that last room?

How will we squeeze them in.

What are we going to do.

Then every individual is in their own practice thinking about that and I think that's just just a reality.

It's hard to be in a hospital that is so close, so close to not having any room at all where all of the providers aren't aware of that.

It just has to be in the back of your mind.

There are also appeal processes that are triggered when you call a crisis standard of care and those don't necessarily come into play until then either.

I think I have seen one crisis standard of care that made a distinction that said in the contingency period before a crisis standard of care is called, they won't be taking individuals who are already in ICU and getting ventilation off of it.

So that was interesting.

Other than that, I have not seen that many distinctions being made in a guideline between the contingency period and the crisis standard of care period.

I thought that was actually a good thing, a good measure to keep.

An implementation is hard because for those who are in the -- for those people with disabilities in the field where they might -- the hospital might wrongfully be saying you can't have a support person.

You just have to be -- and other accommodations are not being afforded. For an individual that is alone in the hospital in the emergency room and thinking, I may not get my treatment.

It's 2:00 in the morning.

Have no idea where to turn.

I don't know what to do about this.

That's implementation and that's where the rubber really meets the road.

And if you -- if there is -- you can have the law out there.

You can try to grow awareness of the law, but at that point in that hospital it's really hard to have enough resources to provide concrete help.

Tangible help.

A reminder to hospital administrators and staff, that civil rights applies.

I'm not sure if that is what you were getting at

>> Definitely.

Thank you.

Those are great points.

Jeff or Andy.

>> Just to add on, I think Silivia is right and hospitals are loathed to have to declare the crisis standards of care necessary and as Andy was pointing out before is a government issue in that local governments have to say what our resources and are we appropriately distributing all of our resources best we can and we reached a point where that is no longer able then it should be a regional sort of decision to go to crisis standards of care.

It's hard for any one individual hospital to do that because it's always the possibility of transferring care and those kinds of things.

I want to get back to something that Andy and I were talking about before.

I don't want anyone to have wrong impression about people's perceptions in the example I gave.

Good news, too.

We did an ethics case at the beginning of the pandemic for our second year med students and five different individuals and were described briefly and asked the student who would you prioritize and set things up.

One of the examples was a young woman in Down Syndrome and one was a older man who had I forget if it was C3 paraplegia and sepsis and there was another person who was the mayor of the town who was ICU doctor and 92-year-old lawyer with heart disease.

Basically how would you rank them and why.

When the students did that, it was remarkable.

The A lack of disability discrimination.

And B, positive statements about disability.

So saying the person with Down Syndrome there is no reason not to give her the ventilator.

Person who has paraplegia, the issue he has sepsis as well and has nothing to do with his disability and there were dozens of Pro disability statements.

So much so that we put it together as a manuscript and it's under review right now and actually will be coming out we think fairly soon.

So sort of a piece of good news that one medical student -- 200 students from across the country here at the University of Miami displayed virtually no paper and pencil discrimination.

That's really I think good news.

The other thing is that when I talk about trying to figure out what our values are as a society, I was mentioning before the example of two with autism and one with cancer and what that difference is specifically what I was talking about are folks in the disability community, it was really only the disability rights lawyers who said, no, there is no difference.

But people with disabilities say, no, I think that's an appropriate distinction.

And the way to sort of dig into this deeper and to include a disability rights framework is there are things called participatory democracy where you get a random group of people that more or less represent a location of a region, a state, whatever.

And you spend a day or two talking about the issues.

Saying here are the different things.

You might have Silivia and Andy, Kara and I talking about the issues going through this iterative process saying what do we think is the right thing to do?

If someone is 92 years old and someone 22 years old and no difference, should we say that 92-year-old he has lived a pretty good life.

We should give the 22 year old a chance.

And some people say that's age discrimination and others would say that makes sense to me.

When you have a pandemic and limited resources like your policy to reflect as best you can a well informed set of values from the population.

So that would be my argument to try to say that's what the foundation

for this should be.

And part of the -- as I said before, any CSE policy that people with disabilities have a critical role in building the policy, making sure it's implemented appropriately and monitored afterwards.

>> This is Andy.

I guess what I would just add on the implementation question, Kara, here in California we had our guidelines from the state issued in June.

And Silivia and her colleagues had and my colleagues at disability rights of California and coalition partners have been working since June to try to figure out who in this state of California has the job of making sure that people with disabilities and older adults are not discriminated against.

And we thought that the Office of Civil Rights at the California Department of Public health which issued the guidelines would make sense as an enforcement entity.

But their enforcement was extraordinarily weak and extraordinarily not proactive.

We reached out to the California Department of Fair employment and housing which most states have they call them fair employment practice agencies but it's like a state civil rights enforcement agency.

And their director made clear to us he thought that they did have jurisdiction even though their name implies they do employment and housing.

He thought they did have jurisdiction over making sure that hospitals don't discriminate against people with disabilities.

It's been very hard to get them to do anything in terms of releasing guidance to hospitals on how to avoid discrimination and they certainly my sense is they don't want to release guidance to hospitals that the California Department of Public health doesn't agree with.

And I don't know that the California Department of Public health has clarity about what non-discrimination means in this context.

So long way of saying we have not had good implementation.

This is not the kind of thing that lends itself to a lawsuit.

It's very hard to build a case in realtime and get in front of a judge when crisis standards of care are being implemented.

I think we have work to do when we are not in a crisis to figure out what is the right policy, who are the right enforcement agencies, and

do those enforcement agencies have the expertise and capacity to enforce the law?

The Office of Civil Rights at the federal level showed some good leadership on crisis standards of care.

It's a tiny office.

And they don't have the capacity to implement non-discrimination protocols in every hospital in the country.

Not even close.

So I just think we have work to do in term of building that enforcement infrastructure assuming we can agree on what the law should be.

>> And can I add something to that?

I defer to Andy and Silivia on the enforcement questions.

There is one idea that might be worth thinking about, Annie and Silivia, and that is building into the policy that there has to be a review that should keep the data about who gets a ventilator or who doesn't.

Whatever the question may be and keep track of the characteristics.

And again I'm going to give you good news at least from the University of Miami.

We looked at 5,000 patient days over 1,000 patients.

We didn't have to use our crisis standards of care but at the height of it we were close.

And we looked back to see what happened for those 5,000 patient days and I think it was 1,230 patients or so.

And we were only able to look at race, ethnicity.

That is self-described Hispanic, status or self-described black because getting disability out of the medical record was hard to do.

Really good news.

What we showed was that there was no discrimination against black or Hispanic status self-reported.

And they were just as likely to get a ventilator as anyone else.

And even when you looked at comorbidities such as hypertension, diabetes and those things which are -- so the last slide of the tie breaker for these things to be concerned about, again, did not discriminate against blacks or Hispanics.

We need to look at that kind of data and say, well, did we discriminate on the base of age, disability status and other things to see how that works.

And I think if hospitals are required to report that, it would be easier to do enforcement

>> That point is well taken.

I will just say as Rylin said in the -- Rylin said in the chat, we don't get identification of disability status routinely and this is part of the challenge we are having with vaccines.

We keep saying to the California Department of Public Health you need to prioritize high risk people.

They say show us your data.

We know how many old people are dying.

Show us your data about people under 65 and we don't have good data.

I agree with you, Jeff, we need an after action report and I also agree with I think what you were calling for which is required better data collection.

>> Definitely.

I would agree, too.

I think that can bring us to our last question to wrap up before we take questions and I'm moving us to our last question because I see some interest in our Q&A box about this.

What is the relationship if any between these crisis care standards and vaccination policies and priorities.

And I know Andy, you got us started on that but I don't know if you want to complete.

I will add that there is a sense of frustration in these discussions around crisis and care standards, or crisis care standards by some and assumption our survivability were so vulnerability that it's not worth the investment of time and resources and supplies in saving our lives so it's frustrating to hear that when a vaccination is available we are told to get at the end of the line for that.

It seems as though that messaging isn't reflected in both places as been my interpretation of it and some frustrating moments.

Andy, do you want to continue since you linked the California approach to that?

>> Yeah, in the vaccine context, it's hard to know kind of who is making the decisions and why.

Clearly, ultimate decision maker is the governor in our state.

But he keeps changing the framework and the overarching goal right now seems to be we need a very simple way to get vaccines to as many people as possible and the simplest way they have been able to come up with is 65 and over and then essential workers prioritizing farm workers and teachers.

All of those sim Mrs. Ty Mex ins are -- though systemic mechanisms and vaccine prioritization, what I would just say is AUCD has a -- AUCD as a network has one foot in the disability movement and one foot in the clinical world and the medical research world.

And to the extent that AUCD can advance the thinking of the CDC and the departments and public health around the country around what we have learned from this vaccine.

The vaccine thing is a disaster everywhere in the country. Nobody has done the vaccines well.

Jeff, I think Florida got a lot more vaccines in arms initially than California did, but I'm guessing you wouldn't brag about how well the vaccine deployment is going in Florida.

So I just again I like Jeff's idea an after action report but applying the deeper relationships that the AUCD has with the disability community and thinking about if we had more time and we learned the lessons that we learned from this vaccine deployment, with a do we need the Federal Government to do better including the CDC but not limited to the CDC?

What do we need state governments to do better and what do we need local governments to do better.

In California, our 58 counties are making decisions every day that are not consistent with what the state is saying and it's like the wild west right now.

I don't know there is a simple solution, but what is happening right now is a complete and utter mess and it feels like it's an indication that we as disabled people in California have no political power.

Because we keep getting pushed down in prioritization.

I don't think it's driven by science.

>> Silivia?

>> The relationship between us and the -- the key relationships is one that you alluded to, Kara, if you were to put it bluntly people with disabilities are too sick to get COVID-19 treatment but not sick enough to get vaccinated.

So it's a seeming contradiction there.

And I think that in itself is one of the big links and that it's been very hard to get across to vaccination decision makers that there are specific groups of individuals, those people with disabilities who have significant visible disabilities who have already disabilities that affect the respiration and how they breathe, higher weight individuals.

That who are often sort of the ones that are most likely to be triaged out of care if there are multiple factors such as race, et cetera, that also are in there, that affects.

And that's a group that is distinct from the CDC list of comorbidities.

Which is often I think seen medically as, well, that's it.

That's the group of people with disability.

People on the CDC list of comorbidities and it's millions of people. How could we possibly have that group prioritized?

It's also because we are not looking more carefully at who is at risk?

Who is at risk within the disability community and those who potentially with means to shelter safely at home are not necessarily those who are at risk.

And I think we need to look at this far more carefully and try to be data driven and look at those under 65.

But if we are looking at healthy person who can shelter and is over 65 is getting the vaccine now while someone who has significant disabilities living in a group home is under 65 could be -- could have foregone medical treatment for months because of the fear and potential what would happen if they get COVID.

That person cannot be vaccinated.

That makes no sense from a medical or science or legal point of view to me.

And I do think that most people would agree given that kind of scenario and that understanding.

>> So I want to start with something that Silivia said at the beginning about being sick enough for not being sick enough for the vaccine but too sick for the ventilator and I want to be careful how we use these words because I would separate out -- I really think this is important, disability status from illness and I would say that autism, cerebral palsy are not a illness and should not be seen as being sick and not treated that way by the medical profession and we should separate that out from infections, cancer, diabetes and so on.

And I know that's a hard thing for the civil rights lawyers to agree with.

But from a medical point I spent the last 30 years to convince my colleagues that just because someone has Down Syndrome or autism or cerebral palsy doesn't mean they need to be fixed.

If they have an infection, yes, we need an antibiotics or whatever. I want to be clear on that.

Coming back to the vaccine thing, I share the frustration that I'm sure everyone in the country does that we are not getting to people fast enough.

And people with intellectual disability have three times the death rate from COVID.

There is no doubt people with cerebral palsy similar.

No doubt they are a high risk group.

You can debate if the best way to do things is to get the vaccine to the elderly and people with disabilities first because they are highest risk or first get it to the people who interact with them because they are the ones circulating the population and likely to bring it.

So that's a hard -- I don't know the right answer to that.

I do know coming back to the history of something that Andy said at the beginning, we as a country have not invested in public health.

We don't know who has a disability in this country.

We don't know who has it.

We don't know where anyone lives.

And we have from the beginning as a country said it's about the individual.

How he or she does.

Supported by family and local community.

And we have never wanted to have a strong central government that tried to figure out how to do things.

This is one of those times where it's not in our favor.

And it would be interesting to see if nations that are more centralized in their health care system and have a stronger public health apparatus, if in the long run they do better with vaccine distribution.

So far what we had is an unmitigated disaster.

We are trying and you can tell every state has tried to do this but no one seems to have gotten right yet and it is frustrating.

>> Jeff, just real quick, a nuance from California, our state like lots of states have prioritize the direct support work force which is good and are indeed -- our D D-director at the state level included family care givers in that which is good.

The challenge is that a lot of the direct support workers like a lot of the front line health care workers are refusing the vaccine.

So if we assume that is a protection for the people they are caring for and then they don't take the vaccine the not a safe assumption. We don't really have the science down yet about whether you can be a carrier even after you had the vaccine.

So I get that argument but I don't -- I really do think we have to get to the actual people with disabilities if we want to be safe.

>> And I agree with you, Andy.

I can see the different arguments for how best to do this.

I agree with you we should vaccinate people who need it the most soon enough.

I can also think about my parents who are able to shelter where they are.

So they are incredibly high risk of COVID but they can shelter for

another couple months.

I hope they can shelter for a couple of months and will likely be okay. A lot of people who cannot shelter and they are at high risk.

So I can see the arguments on both sides of this.

>> It's also been an interesting interplay between those who have sheltered in place as an accommodation for their work because of their high risk status and in some cases we are hearing of that kind of being used on the flip side that well, you are working from home so you don't have exposure so therefore you wouldn't be prioritized with the vaccine.

It gets intermingled with employment accommodations I think as well which we can touch on a whole other realm.

I want to take a specific question from the chat box.

There are some great comments as well.

Aways back we had discussion about reallocation of personal ventilators in some states.

And I thought I remembered that was included in the memo back in March. But I didn't know -- so anybody want to comment on that?

>> I would just make a medical point that a personal home ventilator is not the kind of thing that will work in a hospital for someone infected with COVID-19.

It's an absurd thing that a doctor might consider that in the first place.

But I think we all agree you are not going to take the ventilator away from someone for whom that's part of their being.

That would be nonsense.

No one should want to do that.

>> I think I would just use it as a little bit of an aside to indicate, yes, exactly what Jeff said.

To take it a personalized ventilator and try to give it to someone else makes no sense.

I think there is also a bigger sense of the accommodations that people can get once they are -- they do go to a hospital and that is amongst those.

One of the big issues as can you bring in a support person with you during this time when visitors are not supposed to be allowed and we

would argue strongly that civil rights still apply.

That people can bring what they need to get effective health care and that could include a support person and that includes ventilators, that people are already using and that can present a particular challenge in hospitals where they are worried about the aspiration from the ventilators.

But nonetheless, you can't expect -- no one is going to do well in a hospital if they are not getting the c Pap they regularly use. Saying you can't bring it in is saying you can't have hospital care.

>> Comes down to another one of those implementation issues I know as well with having a support person as well.

We have several months it felt like we got over that hurdle that it should be allowed but we are still hearing from so many hospital the not trickling down to the ground and again as mentioned, it's one thing to know your rights and have evidence of them in front of the hospital administrators, but to actually get that problem solved in a moment in the hospital can be really difficult.

>> Yeah, I'm seeing some in the chat box as well re-iterating the importance of kind of trying to do our work to make sure we don't get in the same situations again.

So being more proactive.

I don't know if we want to offer some closing remarks.

I know we could all talk so much longer on this.

I'm hope to be contacted and I will put my contact information in the chat box but I'm sure maybe, maybe if you are all as well.

Any closing remarks you want to add?

>> Silivia, you want to go first this time?

>> Me?

I was putting my name in the chat.

Contact in the chat.

It's working on this, the past year I think has felt for many of us like wave after wave after wave of urgent situation.

And it's -- it was pandemic itself, it was the infections, it was hospitalizations, and coming -- and having close to capacity or being over capacity.

And now right now the latest one seems to be vaccination and they are all connected.

They all sort of stick around, too.

It's not like we are now in vaccines and we don't have to worry about crisis standards of care, unfortunately that's not the case.

Now we have to worry about mutating viruses.

So it's -- it's hard to get to any sense where you feel like you can have a long view of this or see a way out of it where we can manage to be fair, where we can achieve equity which is become -- we all are sharply aware of this year.

And still try to -- still try to move forward on getting against -- fighting against the vaccine.

So I guess that seems like -- it's not that is my conclusion. This is where we are.

I do think that it's vitally important for us to stay -- to stay connected and to try to see the bigger picture as hard as it is.

And when we talk about the need for data and the need for planning, we are looking at something of the longer view.

Eventually we will get out of this.

And eventually we can use this to make some critical changes about how we recognize people with disabilities.

How we record and get data on disability.

How we include people with disabilities and emergency planning.

That's great.

That's part of a long view.

I think another long view its really being very careful about being inclusive in our view of equity.

And in the heart of this urgent situation, I mean, I work as a disability rights attorney.

I advocate in the disability community.

Those are the concerns that are most pressing on me, but I really want to recognize that there are so much intersection with race, ethnicity, with age and there is this -- we really do need to try to recognize everyone who is at high risk and why that is and take a long view at addressing the structural problems.

Even though I know we are all tired and all in the midst of a crisis.

>> Jeff, do you want to go?

>> We only have a minute left so I will just say that this has been wonderful being part of this panel and Silivia is right. It's been an awful year and we have a moment here, right?

Where we can learn important lessons.

We had a chance to see things more clearly because of the pandemic and among those are the persistent inequities in our society and as Andy pointed out there is a role for government and together with all of us we can make a big difference.

And the last thing I want to say is we are incredibly lucky the vaccine is as effective as it is.

For anyone wavering whether to get it or not, the results so far all of the data show this is a remarkably effective vaccine with remarkably few side effects.

And we are need to get everyone on board because that's going to be really important.

Along with the fact that we have to continue to wash our hands, wear our masks and socially distance for the next six to nine months even if we get the vaccine as fast as we want.

Thank you.

>> And all I will add is thank you to Kara, the panelists. I want to acknowledge Rylin and John and the AUCD staff for their leadership on this issue going back to March and throughout the pandemic.

And also Allison who is now one of the Feds that is overseeing the AUCD network at the administration four community living she is a strong voice protecting civil rights on this issue.

I'm grateful she is in a leadership role for the Biden administration

and I look forward to good leadership coming from them and look forward to that happening quickly.

>> Thank you all.

Thank you to the panelists and I would echo Andy, thank you so much for AUCD for allowing us to have this discussion.

I know I have been looking forward to it and I think my co-panelists have as well.

So let's keep this discussion and this advocacy going and thank you all for joining us as attendees as well.

Thank you, have a great evening or day time.

>> Bye-bye.