Disability Discrimination in the Rationing of Life Saving Covid Treatment – Who Gets Left Behind?
APRIL 15, 2020

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Hi, everyone. Welcome to Disability, Discrimination, and the Rationing of Lifesaving Covid-19 Treatment -- Who Gets Left Behind. This webinar is sponsored by the ABA Commission on Disability Rights and Section of Civil Rights and Social Justice, and this panel is one of many in a series of rapid-response webinars on the Covid-19 pandemic.

During today’s program, we encourage you to ask questions. You should see a control panel with controls such as Audio Options, Chat, Raise Hand, and Q&A. For the purposes of this webinar, we ask that you submit your questions through the Q&A, not the Chat function. We will address questions at the end of the panel.

We will be sharing a recording of this program to everyone who has registered so that you can share it widely with your networks. Please feel free to leave us feedback or ask questions for follow up.

My name is Shira Wakschlag, and I’m the Director of Legal Advocacy for the ARC. Our other presenters today include Jennifer Mathis, Director of Policy and Legal Advocacy for the Bazelon Center for Mental Health Web; David Carlson, Director of Advocacy for Disability Rights, Washington; Ivanova Smith, Chair of Self Advocates and Leadership; Allison Barkoff, Director of Advocacy for the Center for Public Representation; and Samantha Crane, Director of Public Policy for the Activist Six Cell Advocacy Network.

Before we get into the weeds of the legal analysis and the various complaints that have been filed, it will be helpful to have some basic background on Covid-19 treatment rationing, as well as the broader concerns about disability discrimination in the medical context.

In mid-March, we started seeing media reports that Washington state officials were discussing the possibility of rationing care in the event of a shortage of medical equipment and personnel. In response, on March 20th, a coalition of disability rights groups, including many of those participating on this call, sent a letter to the US Department of Health and Human Services Office for Civil Rights, which we’ll refer to during this webinar as HHS-OCR, in case you hear that abbreviation. The letter was sent to ensure that, if the current pandemic results in government decisions to ration treatment, decisions about how medical treatments should be allocated are made without discriminating based on disability.

The following week, national and local groups, including those on this call, partnered to file four complaints concerning disability discrimination and treatment rationing plans with HSS-OCR in order to further highlight the specific concerns about these plans and the urgency for HSS-OCR to issue guidance to states on how federal disability rights laws apply here.

The first complaint was out of Washington, which had been one of the epicenters of the epidemic. This was followed by complaints out of Alabama, Tennessee, and Kansas, and more recently, Utah, Pennsylvania, and New York.
Every plan is different, but some of the problematic criteria within the plans, which will be discussed in more detail later in the presentation, include categorical exclusions from treatment on the basis of disability diagnosis, quality of life assessments in place of objective medical evidence, long-term survival speculation beyond the prognosis for Covid-19 treatment, failure to provide for reasonable modifications in receiving treatment, including allowing for longer time on a ventilator, reallocation of the ventilators of chronic ventilator users, and overall failure to provide for a thorough individualized review of each patient to avoid decisions based on diagnoses and stereotypes.

In addition to the specific concerns with the crisis standard of care plans, there’s a long history of disability discrimination against people with disabilities in the medical context that is necessary to understand as a backdrop here. As outlined in the Washington complaint, concerns about disability discrimination in receiving medical treatment are not new. Studies have repeatedly documented a persistent bias by medical providers and bioethicists against people with disabilities and a failure of medical providers to fully appreciate the value and quality of life with a disability.

These problems are reinforced by the dramatic under-representation of people with disabilities in the medical profession. With medical discrimination, the provider may not view their actions as discriminatory and claim or believe that they were trying to do what was in the patient’s best interest. But people with disabilities have been denied and continue to be denied treatment because of improper decisions based on implicit biases about the quality of life and inherent worth of people with disabilities.

Accordingly, research has shown that patients with disabilities experience healthcare disparities, including lower rates of screening and more difficulty accessing services compared to people without disabilities. Disability advocates have been fighting against this bias for decades to ensure they can receive equal access to life-sustaining treatment, and we are continuing this work in challenging Covid-19 treatment rationing plans nationwide.

Today, we’re going to get into more detail on everything I just mentioned. Our presentation will include a discussion of the legal framework that applies to treatment rationing plans, some of the state-level advocacy efforts that we’ve taken, the complaint submitted to HSS-OCR and the agency’s recent guidance, resources for advocates, and then a question and answer with the audience.

So first, we’re going to hear from Jennifer Mathis, who’s going to discuss the legal framework.

>> Hi. Thanks, Shira. So I’m just gonna give a little bit of background on the various federal laws that apply here and talk a little bit about how those laws apply to the particular situations that we’re seeing, and then others will talk in more detail about how they apply in the complaints filed and in the guidance documents that have been done for folks.
So, I think you all can guess that the ADA (the Americans with Disabilities Act) certainly is one of the core legal protections here. I just want to start by saying that the fact that we are in the midst of a pandemic does not mean that the federal disability rights laws don't apply. I think there were some suggestions from some quarters that maybe, you know, these civil rights laws in some way were diminished or didn’t really apply because of a pandemic, and in the guidance that was issued by the federal government, the chair referenced the HSS Office of Civil Rights makes clear that these laws continue to apply, pandemic or not.

And so, the ADA, it’s mainly Titles II and III of the ADA that apply. Title II applies to public entities, state and local government, and that would include states that are promulgating rationing policies for how to allocate scarce medical resources, public hospitals, public healthcare facilities. Title III of the ADA applies to privately run public accommodations. And so that would apply to healthcare facilities that are private, including private hospitals and ICUs that are implementing rationing protocols.

Section 504 of the Rehabilitation Act also applies to pretty much all of the same entities. Section 504 applies to healthcare establishments that receive federal financial assistance, states that receive federal financial assistance, and actions of the federal government itself.

Section 1557, which is the non-discrimination provision of the Affordable Care Act applies to healthcare establishments that receive federal funding from HSS or are administered by HSS, health insurance marketplaces, and plans offered by issuers who participate in the marketplaces. So these laws apply, essentially, to the states that are developing and designing and promulgating, issuing these rationing policies and the healthcare providers that would be implementing them if they do end up going into effect.

So, some of the core legal principles that apply here, the most core principle is individualized assessments. That’s, I think, the most core principle of disability rights law. An individualized assessment has to be done based on the best available current medical evidence and not based on generalized assumptions about a person’s disability. So when you are making decisions that affect people with disabilities, like decisions about who is qualified for treatment, we have to do an individualized determination and not simply make presumptions based on someone’s diagnosis or someone’s falling within a general category of condition or disability.

A covered entity can’t presume that somebody is not qualified to receive treatment based on a disability diagnosis without that kind of individualized determination. That includes presumptions based on judgments that someone’s disability might impact their quality of life in a negative way. That includes presumptions that somebody’s disability impacts their prospects for long-term survival. That includes presumptions that somebody’s disability impacts the intensity of resources that are required for that person to receive treatment. So you can’t be acting based on generalized assumptions about a person’s disability, and the protocols that are designed can’t be designed based on those kinds of presumptions. That if somebody has X condition, X diagnosis, that means that that person is not going to be a good candidate for Covid-19 treatment.
Denials of treatment, I think what we’ve seen is that denials of treatment in these protocols, the protocols sometimes enable those denials of treatment to be based on either outright exclusions based on someone’s disability, or that they simply negatively weight someone’s disability. They consider it a negative factor. It counts against the person. Both of those types of determinations, whether it’s an outright exclusion or whether it just counts against you, if it’s based simply on a diagnosis or the fact that you have a disability, that is not lawful. That is not an individualized determination that looks at your particular circumstances.

So who is qualified for treatment, I think, is one of the most important issue here as a matter of law. Whether a person’s qualified to receive treatment should be based on whether the person can benefit from the treatment. This is Covid-19 treatment we’re talking about. That’s the thing that’s being rationed, whether it’s ICU beds or ventilators or other supplies for Covid-19 treatment, if that is the benefit that’s being provided, then whether someone’s qualified should be based on whether they can benefit from that treatment. And that means whether they can survive that treatment, whether they can survive in the near term. If somebody is not gonna make it through the treatment, or if somebody is likely to die in the next week, then sure, that person might not be qualified to receive the treatment, but beyond that, somebody’s disability really should not come into play in terms of whether that person is qualified. The determination should be about the treatment itself.

Now, one might say, “Well, this is a pandemic, and so we get to set other kinds of qualification standards. So it’s fair to limit. Because we have to ration, we get to say that, in fact, we can further limit who’s qualified to receive treatment.” And that can be true that you can have other types of criteria to narrow who is qualified. People have done lottery systems. People have prioritized healthcare workers. People have done first come, first served policies. You know, there’s a variety of different way that you can allocate treatment that are disability neutral, that don’t base being qualified on having a disability.

But you can’t embed -- you can’t put disability or the absence of disability into being qualified. And that is based on Supreme Court law. So you can’t say that somebody’s only qualified to get Covid-19 treatment if they don’t have certain types of conditions or certain disabilities. That would be discriminatory.

So some of the types of discrimination that occur in the context that you will see in some of these protocols are protocols that do consider people’s prospects of long-term survival. So based on a pre-existing disability that the person has having nothing at all to do with whether this person can benefit from Covid-19 treatment, whether this person can survive that treatment and get out of the hospital -- these rationing protocols sometimes look at people’s ability to survive into three years, five years, ten years from now, and then look at people’s diagnoses and people’s conditions to make those determinations -- that is denying treatment based on a disability to someone who’s otherwise qualified to receive the treatment, can benefit from the treatment, can survive, and that, we believe, is not lawful under the ADA and the other disability discrimination laws.
Another thing that you will see in these protocols are determinations that are really about quality of life that negatively weight or outright exclude people with disabilities from receiving Covid treatment because of value judgments about these people’s lives. So for example, one of the complaints was about a policy in Alabama. This has now been resolved, but I think Allison will talk about this a little bit more, but in Alabama, the policy said if you have a significant intellectual disability that you would not get a ventilator. You were not a good candidate for a ventilator. And so that determination is not about somebody’s prospects for survival. That was not about whether somebody would be able to make it through the treatment. That was about -- really a judgment about the quality of people’s lives or the value of people’s lives. That is no longer in effect, thankfully, but that’s an example of kind of a quality of life determination.

In addition to that, there are, I think, reasonable modifications that should be made. That’s another principle of law. In these policies, you will often not see references to reasonable modifications that could be made, should be made, that the ADA and 504 and Section 1557 would require.

[CLEARS THROAT]

>> Excuse me.

Reasonable modifications to the usual policies and practices require to ensure equal treatment for people with disabilities. And so those might include, for example, interpreter services. If somebody needs interpreter services at the hospital, if somebody needs family member or a direct service professional to be present, even though ordinary rules might not allow it. I think here, there would have to be protective equipment, but that would be an example of a reasonable modification, is allowing a family member or service provider to be there with a person, even if that is a modification to the usual rules, the usual way of doing things.

In addition, modifications may include changing the way that the treatment protocols work. So for example, if somebody is typically allowed to be on ventilator for, say, two weeks before the docs start deciding that maybe now it is time to give up and to take the person off, because they’ve had sufficient time to recover. If someone has a disability, that might mean that they need a little bit more time on a ventilator to recover, then that might be a reasonable modification to the treatment protocols.

There’s all sorts of effective communication issues that come up. I mentioned interpreter services. There’s many other types of assistive devices, technology, auxillary aids, medical equipment that people may need as a reasonable modification to the usual policies.

And so those are some of the examples of how these legal principles apply in this context. And I’m going to turn it over to David to talk a little bit about the first complaint that was filed and how the law applied to -- the principles applied to what Washington State was doing.
Thank you, Jennifer. So, I’d like to talk specifically about the Washington complaint. And so, to start that, just explain who the folks were that pulled that together.

We had claimants and advocates come together over a weekend. The newspapers started reporting about the actual particulars of the plan on Friday. So by Monday morning, we had pulled together a legal complaint with the Office of Civil Rights at the Department of Health and Human Services.

The claimants were Disability Rights, Washington. I work for them. We’re a private non-profit organization. We are the protection and advocacy system for Washington State. So whatever jurisdiction you are in in the United States, there will be one of us. Northern Marianas has a protection advocacy system, all the way over to Maine. So everything in between.

And we advance the human and civil rights of people with all types of disabilities, whether that’s physical, or sensory, or mental health diagnoses, or intellectual, or developmental disabilities. We also had a claimant, an organizational claimant from South Advocates and Leadership, the statewide self-advocacy organization in Washington State that advances the rights of people with developmental disabilities. There’s a lot of public policy work, and we’re gonna hear from their Chair in a moment, Ivanova Smith.

And then, also, the National ARC, the ARC United States, the nation’s largest organization of and for people with developmental disabilities and intellectual disabilities. They promote the human and civil rights of people with intellectual and developmental disabilities, and all of our groups, really, focus on inclusion and fighting against discrimination.

And we had a number of great attorneys come together and think through these issues. Medical discrimination is not uncommon in the disability community. It’s actually quite common. So that -- we pulled from years of experience dealing with these types of issues, whether they come up in policies around who gets organs during organ transplants, or they come up with who gets involuntary sterilization orders issued against them. There are multiple ways that the medical profession and the disability community view disability differently, and the Washington plans are a really good example of that.

The Washington Department of Health and the group of hospitals got together and created a plan, as did the University of Washington’s Medical Center. The plans were developed by doctors and bioethicists, as most of these types of plans are. They were made public only after there’s local and national media coverage of this issue.

There’s initially some coverage of all plans in the works, and then the following day, the plan was actually handed to the media, and we could see what was going on there. The Washington State hospital officials and the Department of Health actually described the plan as “unthinkable”, and I think most people in our society think, you know, we’re in the US, we don’t have to deal with these types of issues, but I think all of the work that’s gone in over the years on emergency planning and preparedness has shown us that there is always a need to take very
credibly the threats that come around.

So while we’ve been able to deal with global pandemics in the past in a way that hasn’t affected us here, today, we’re seeing that it is.

So to jump into the plans, the Washington Department of Health guidance that was created with the Department of Health and the hospitals looks specifically at loss of reserves in energy, physical ability, cognition, and general health to decide who gets intensive care unit care and who gets referred to just go back home or receive palliative care.

The idea of loss of reserves and energy, physical ability, and cognition as being -- and general health -- as being the determining factors about whether or not you actually get the intensive care unit care that you need, that’s highly subjective. There’s a wide swath of how that could be applied. And we know that, as advocates for equity, that the more discretion you give people, the easier it is for implicit biases or structural biases to get into those decision makings.

So we wanted to address any unchecked bias that might allow quality of life issues to come up. I’ll talk in a moment about the distance between how often people in the medical profession view value of life of people with disabilities and how people with disabilities themselves value their own lives.

The University of Washington Medical Center’s guidance was more narrative in form. The first one I just described is more of a flow chart of when this happens, then this happens, and had very broad categories, as I just mentioned, that they had to fill in the gaps. The University of Washington Medical Center was more narrative, and it was a little clearer, but in its clarity, it was also troubling.

It specifically said that there’s a priority for treating younger and healthier individuals and allowing older and sicker, often associated with disabilities, to only receive palliative care, not receive the ICU care they would need to survive the Covid.

And additionally, they focused on overall survival. That’s healthy, long-term survival recognized by -- that this represents waiting, the survival of young and otherwise healthy patients over older, chronically debilitated patients. That’s their language. So, again, there is an explicit distinction made in very general terms of health, youth.

So the Washington complaint combined both our knowledge about the bias against people with disabilities found in medical settings with the anti-discrimination laws that Jennifer just mentioned to go through and point out where improvements need to be made.

So as Jennifer mentioned, with the reasonable modifications and the need to really focus on individualized determinations, one of the most important principles in disability advocacy and disability anti-discrimination laws is avoiding myths, stereotypes, assumptions, and instead, focusing on specific individualized approaches. So we wanted to make sure that we were
addressing the bias that sometimes comes in those assumptions.

We showed that there are studies that show bias in the medical field, that there are trainings that medical professionals get that perpetuate bias that already exist in our society, that doctors often may even offer people with disabilities options to die when they wouldn’t offer those same options to other individuals who don’t have pre-existing disabilities when they come in. And some bioethicists are openly hostile to people with disabilities and the concept that rights should apply across the board to everyone.

So within that landscape, we really wanted to push back on if that’s the framework in which people are coming in, and then they’re told in a very general sense, “Look at reserves of energy, physical ability, cognition and general health to decide who gets treatment, and look at long-term survival, and focus on younger, healthier patients,” and we know that there’s this generalized bias, what do we need to do?

So we really stressed you need to have individualized determinations. That’s not generalized assumptions. It’s not assumptions based on quality of life or whose life is worth living. It’s not about generalized survivability. It’s about survivability of this particular crisis. Can you get better from Covid? Can you be released from the hospital after you get better?

As Jennifer said, we’re not talking about, “Can you survive for ten minutes after we’ve cleared you,” but rather, “Are you better,” but not, “Are we looking at three or four years out?” And you must be -- all of these decisions must be based on the best available medical evidence, not on generalized assumptions.

So with that, I’d like to introduce Ivanova to talk about how this impacts, all of these issues impact Sale members and why you came on board with this complaint to push back against our plan that provided a lot of ability for medical folks to put their own biases into the system.

>> I’m Ivanova Smith, and I’m the Chair of Self Advocates of Leadership Sale. We are a coalition of leaders with intellectual and developmental disabilities, and we do like to say about advocacy policy won’t try to make sure that our civil rights are respected within the legislature.

And we had a lot of concerns about this “vaccinating”. Many of our members would be very greatly impacted by vaccinating. They have a lot weaker immune systems, and we know that our community will be hit harder by this virus because of, you know, it’s more at risk. So this is really important that we are not denied medical care. I really am fearful of getting this virus, because I don’t wanna be denied care, and I do not want my members to be denied care.

We also know there has been a long history of people with intellectual and developmental disabilities having their medical rights restricted, like a lot of people put under guardianships, where they don’t get to make their own medical decisions. There’s a lot of times where people have been denied treatment. They’ve been denied things like organ transplants and other life-saving care.
And so we wanna try to be proactive. And so that’s why I work with the Sale membership and our rapid response team with David Carlson to do this complaint, because we want society as a whole to see that we’re speaking up for ourselves, and we’re saying, “You can’t be denying us treatment. That’s against the ADA. That’s discrimination, and we won’t allow it. And you shouldn’t base my life’s worth on my intellectual disabilities. I don’t think that’s a fair way to assess if somebody deserves life-saving treatment.” And so we’re very passionate about stopping this discrimination from happening.

And another point I’d like to say is also, we also are working with the governor’s office. We’re telling them that they need to have self advocate’s representatives in these conversations. Nothing about us without us. We need to be at the table with these discussions on how we receive care, and we should not be excluded.

>> Okay. This is Allison Barkoff. Thanks so much, Ivanova, for sharing some of your perceptions. I’m gonna talk a little bit about some of the other complaints, the laws, the advocacy efforts that have been happening to get to guidance from the Office of Civil Rights, and then I’ll touch on the Office of Civil Rights guidance.

As Shira, and David, and Jennifer layed out kind of in the context, there’s this long history of discrimination against people with disabilities in accessing health care in general, but as we were watching what was happening in, you know, in the rest of the world and particularly in Europe in late February and early March, where we started seeing rationing of care happening, we actually saw the kind of discrimination that we all feared.

And by the time it was, you know, early March here, the disability community had very much activated around concerns about being denied life-saving treatment and feeling very strongly that there needed to be a clear statement from the federal government, particularly the Office of Civil Rights within Health and Human Services, to states, to hospitals and to other covered entities, really laying out what those obligations are.

We knew, as advocates and as lawyers, we could get out there and say that, but it’s understood in a very different way when it comes directly through guidance from the government.

By mid-March, there have been letters coming from the National Council on Disability, which is the independent federal agency that advises the federal government, the executive branch and Congress, on disability policy, imploring the Office of Civil Rights to put out guidance, and it was followed up a few days later by coalition letters from national groups, including the Consortium for Citizens with Disabilities.

By the time we started seeing state policies come out, there hadn’t yet been guidance, and we thought a really important way to kind of put pressure on the Office of Civil Rights and/or give them some vehicles to put guidance out about what is legal and illegal was by filing complaints. And I think David was incredibly humble. It was a really, really, really fast moving two or three
days. Most of the speakers, actually, every one of the speakers who are on the screen right now were part of kind of pulling this together. And it was a strategy both to make a big difference in Washington State, which was incredibly important, but really as a vehicle to get some national guidance out so we could have an impact across the entire country.

Within one week, building off of the incredible work that David helped lead and pulling together the legal analysis in Washington, we worked with stakeholders across the country. We really identified, you know, what are some clear examples of the different issues that Jennifer laid out, where there were examples of plans where people were categorically excluded based on their disability or heavily weighted, their disability was a negative factor that was weighted against them, or there weren’t reasonable modifications to how long you could be on a ventilator, or even some examples of policies that would take a ventilator away from someone and would use that in the community.

And within one week, this group working with state advocates and the P&A, as David mentioned, the Protection and Advocacy agency in each one of the states, and other coalition members have filed four complaints -- one in Washington, Alabama. Kansas, and Tennessee. And that was all the week of March 23rd.

So really in, like, ten days, the pressure was really mounting. We were very pleased on Saturday morning about things are moving so quickly and slowly, but it’s only been about two and a half weeks. The Department of Health and Human Services pulled together a press conference and released some guidance, and we think it’s incredibly important that this guidance went out. I’m gonna talk through some of the principles that were in the guidance. We’re still hoping that, either through additional complaints or follow up guidance, they’ll get more detailed. But the guidance was incredibly clear on a couple of the issues.

The first thing is that the guidance said that the goal is to ensure that covered entities that are covered by civil rights authority keep in mind their obligations to prohibit discrimination on the basis of race, color, national origin, disability, age, sex, and exercise of conscience in religion. So very clearly saying, you know, despite being in a pandemic, despite being even an emergency, these civil rights laws continue to apply. And when talking about the ones relevant to people with disabilities, the ones Jennifer spoke about, so Section 504, Section 1557 of the Affordable Care Act, and the ADA, that prohibit discrimination, they very clearly said, to quote, “These laws remain in effect.”

So to the extent that there was some conversation in the media or concerns that civil rights laws were kind of put aside in emergencies, this guidance made very clear that’s not the case.

So there were three pieces discussed in the guidance itself, and this has really been an effective tool for us in kind of follow-up advocacy. The first thing is exactly what Jennifer said, and it’s incredible when Jennifer says it or other advocates say it, but for HHS to be very clear about what constitutes a legal discrimination. And they specifically talked about when people are denied medical care on the basis of stereotypes, assessments of quality of life, or judgments
about a person’s worth based on the presence of disabilities.

The second thing that they said is, as Jennifer mentioned, a core principle of disability anti-discrimination law is that there must be individualized assessments. So being clear, the guidance said that decisions concerning whether a person is a candidate for treatment, or using the kind of legal words, whether they’re qualified, has to be based on an individualized assessment of the patient, that based on the best available objective evidence.

And then the third piece, as Jennifer talked about, are the legal obligations that covered entities have to make reasonable modifications to ensure equal access. And there are a lot of examples included in here about effective communication for people who may be deaf, or hard of hearing, or blind, interpreters for people with limited English proficiency, plain language in multiple formats, accommodating people with physical disabilities, mobility impairments, speech impairments, people who may be immuno-suppressed. So the important thing is this guidance really laid out the basis for all the things that we have been out there saying.

So just to touch on the couple complaints and some of the topics covered, as Jennifer mentioned, our complaint in Alabama focused on the categorical exclusion of people with intellectual and cognitive disabilities, as well as some exclusions based on age. In Kansas, there were also categorical exclusions, you know, based on disability diagnosis, and those included neuromuscular diseases and advanced immuno-compromised disorders, certain cancers. And then a policy that people who were living in the community and using ventilators, if they came in for Covid-19 treatment, that their ventilators could be taken away from them. So incredibly concerning.

In Tennessee, it was pretty similar to Kansas in terms of some of the categorical exclusions, but also referred to certain disabilities where people might need assistance with activities of daily living, which really gets to the core of kind of quality of life issues. The fact that you might need someone to help you bathe or cook has nothing to do with the fact of whether you can survive and benefit from the treatment.

In Pennsylvania, there has been a complaint filed where they were, like, very much on long-term survivability, and the scales that they used heavily weight the fact that you have a disability in ways that are related to immediate survivability. Utah had some categorical exclusions, and New York was similar to Kansas in terms of reallocating events.

So in addition to the guidance that came out from the Office of Civil Rights, we have a second announcement that came out just this week from the Office of Civil Rights that provides more guidance across the country. They resolved the complaint that we had filed with the Office of Civil Rights through a process that they call “early case resolution”.

And I’ll just say, as some of you who’s worked in the federal government in enforcement agencies, the fact that in, you know, a little more than two weeks, they were able to quickly resolve something and put something out, I think really explains the urgency that I think we
have convinced them of, certainly, and that they see in addressing these issues.

The OCR early case resolution laid out, I think, two principles that are legal principles that are applicable and that we’ve been using across the country. First of all, it said that the policy was illegal because it categorically excluded people because of their diagnosis, and in this case, it was intellectual or other cognitive disabilities. And it also had some really important principles in there around categorical exclusion based on age and saying that also is illegal when they set strict age cutoffs and completely exclude people.

So I think after the Alabama complaint, there’s actually even more out there around age discrimination. Through this complaint process, this resolution, Alabama agreed to withdraw the policy, gave notice across the state that the policy had been withdrawn, instructed hospitals across the state that they had these non-discrimination obligations. Stakeholders in Alabama are continuing to push for more detailed, non-discriminatory standards of care. Right now, there aren’t detailed standards of care, but it created an important legal precedent.

And I’m just gonna touch for one minute on, well, a lot has been done through kind of a more adversarial complaint process. I would say most of the advocacy that’s actually happening across the country is in kind of a disability coalition, sometimes broader than just disability groups, and sometimes with health care groups, and aging groups, and racial justice groups affirmatively working with governors and leadership in states to work to either revise existing policies that have discriminatory provisions in them or to affirmatively develop new policies.

And I’ll point to a few examples where advocacy has made a huge difference. A huge group of stakeholders, cross disability, racial justice, and aging groups in Illinois have been working very hard. The governor just, in the last few days, put out a pretty detailed order of non-discrimination based on disability, and race, and insurance status, and it’s working. And hopefully, in the next few days, we’ll be putting out some new standards of care.

In Colorado, there was a coalition, and the state working with that coalition really changed a lot of things that had been in that earlier policy, and they agreed to no categorical exclusions, no reallocation events, made a lot of commitments around accessibility, and that plan was actually adopted through an executive order. So it mandatorily applies across states.

And we’re also seeing just related to, I think, one of the biggest access issues, and David mentioned this, and what we’re hearing from people with disabilities and family members is the need for making reasonable modifications, the no visitor policies, and that is one place where advocacy has made a really big difference. Just in the last week, New York issued a state-wide policy that was very explicit about a number of circumstances where the no visitor policy, there would be exceptions, and that people with disabilities who need a support person, if it’s essential or if it’s medically necessary or otherwise essential for communication and other reasons, can have a support person.

There’s a great policy that came out of Chicago and one in Oregon that’s narrower, and I know
people are working to make it broader, but I would just kind of end by saying that this is -- even two weeks ago, where we were is a really different place than where we are now. I’d say, just guessing, we’re probably working with stakeholders in about 25 states, between OCR complaints and stake holders working with governors.

And I think Sam is now gonna talk about the tools we’ve created, because we think it’s really important for stakeholders to have tools to do the best they can to make changes through their advocacy.

>> Thanks. Thanks, Allison. So I’m Sam. I’m the legal director of the Autistic Self-Advocacy Network. And I will start by saying that as -- around the, you know, week of the 22nd or so when we were filing all of these complaints, there was so much going on. A lot of states were reaching out and talking to us about their policies. We really started realizing that we needed to engage state level advocates on this work.

The plans were coming out at the state level and even at the hospital level. They’re incredibly technical, and state level advocates, who were already on the ground trying to work on these and make them better, were reaching out and asking for guidance on how to read the plans and recognize when a policy was permissible or impermissible.

So for example, automatic diagnosis-based exclusions. We’ve heard from Allison, from Jennifer, and from David. Those are not allowed, even if they’re phrased as survivability or triage. Anything along the lines of quality of life determinations, anything that looks like this isn’t about whether or not someone’s living independently, and so we came out -- we started with guidance to states and healthcare providers on how to avoid disability-based discrimination and treatment rationing.

So we wanted -- the OCR guidance was really helpful, had some really good language, but it wasn’t incredibly detailed about exactly which kinds of provisions would and would be allowed. So we put together a quick guide, and that is available on the Center for Public Representation website. And I’m gonna put it in the Chat box.

But we started with sort of guiding principles, of lives of people with disabilities are worthy and worth saving. People need to have equal opportunities to receive life-saving treatment. The fact that a person might need support for independent living is not relevant. We shouldn’t use assumptions or stereotypes or bias, and the importance of individualized review, the importance of not reallocating ventilators that a person is already using in their daily life, and of course, reminding people of the federal disability rights laws still apply.

We went into, you know, specific examples of, you know, we would go -- we went line by line in the OCR guidance and fleshed them out with specific examples. So for example, the OCR mentioned that there needs to be a non-discriminatory policy, and we gave, as a specific example, that triage plans need to include a specific affirmation of non-discrimination. Make sure that all relevant personnel have training in non-discrimination, and the importance of
making these plans available to stakeholders and accountable to stakeholders.

We, you know, specifically went into, you know, guidance on you can’t have a diagnosis acting as an exclusion. You need to make reasonable accommodations, and here’s some examples of reasonable accommodations you need to make, and you are plan. If you, you know, for example, if you want -- you can’t use HIV status as a proxy for deciding who’s immuno-suppressed, ‘cause many people living with HIV are not actually immuno-suppressed because of effective management of HIV. The importance of making effective communication available to people who arrive at the hospital.

We later realized that we needed to go even further into detail for state advocates for evaluating plans, and we published a guide for evaluating plans, also on the website I linked. And it goes into examples of, for example, how to tell whether your plan is talking about ventilator reallocations. Sometimes, this is hidden by saying that people on ventilators are just going to be subjected to the same triage guidelines as everyone else, and that means -- that actually does mean that you might end up taking a ventilator away from someone who’s already using it.

Ventilator reallocation policies also happen where someone is on a ventilator at the hospital. They’re not improving, and you make the choice to take them off the ventilator so that you can offer that ventilator to someone else. And we talk about, in this guide, you know, the importance of making reasonable modifications to that policy. So someone with a disability might need just a little of extra time on the ventilator in order to benefit, and they shouldn’t be denied that.

And we even go into sort of technical advice on how to evaluate survivability guidelines. There’s something called a SOFA score that is supposed to measure the severity of someone’s illness, but it includes a question like, for example, does this person need mechanical ventilation? That could be a measurement of how severely ill someone is, but if a person was already using mechanical ventilation before they got sick because they’re a person with a disability and they used the ventilator long term, then it might not reflect the severity of the illness, and you shouldn’t be necessarily factoring that into the SOFA score. You need to be basing it on objective medical evidence.

I also think, you know, if you go to the website that I put in the Chat, you can also find a collection of law review articles, articles by medical ethicists, statements, a really useful statement by the American College of Physicians, and of course, copies of a lot of complaints and letters to the governors. If you are a local advocate, and you want to be part of participating in a complaint or evaluating your state or hospital plan, the website is a really good way to not only find resources like I discussed that will tell you how to evaluate the plans, but also give you some sort of ideas of what we’ve -- what complaints have, you know, like, some of the language that we’ve put into complaints, and some of the approaches that are available.
I also wanna talk about the importance of media advocacy to this movement. We’re really grateful that the media has been very responsive on this issue. I think it’s a compelling, you know, it’s a compelling narrative that, you know, one, we’re in crisis, who gets left behind, and who gets denied care. I think it seems to be really interesting to the general public, and we got a lot of high-profile media coverage from the very beginning of this process. And when we filed a Washington complaint, we got picked up not only by quite a few Washington newspapers, but also places like NPR, the Bloomberg, US News and World Report, the New York Times, and other pretty big media sources.

The importance of media coverage, it has a few different effects. One is it helps, obviously, raise awareness of the issue among the public. And it also helps frame the narrative and humanize the effects of the policies. It can also help put this on governors’ and hospitals’ priority list, because they have a lot to think about right now, and the more media coverage we get on this issue, the more the governors and hospitals realize, like, we have to actually pay attention to this and get this right, because the public is paying attention.

Vent reallocation is a really good example. So for example, in New York, the reallocation guideline that said that vent users who came to the hospital might be taken off their vents, it was sort of buried in an otherwise pretty good policy. And the justification, the way that they framed that guideline, was they said that if you don’t subject vent, long-term vent users, to these triage guidelines when they come into the ER, the result would be an unfair to everyone else, because a vent users would be getting special treatment, and they would be getting vents when other people in the same situation wouldn’t be eligible for them.

When we got really good media coverage of that policy, it helped contest the framing, and instead focused on the perspective of long-term vent users who were scared to go to the hospital for fear of losing the supports that kept them alive. And once you sort of reframe it in that way, it becomes much harder for hospitals to justify or states to justify that policy.

We also got really good coverage when HHS did put out its bulletin. We got covered again in NPR, Times. And again, that’s really helpful because it’s free outreach to people on the state level and local advocates so that they can know that this is happening. They know that there is a bulletin. They can then look it up and send it to anyone who needs to be made aware that, in fact, the law still applies in this crisis.

At the state level, media coverage can also help advocates identify exemplaries, so I know, for example, people have reached out to us who had read some of the media coverage about the complaints. So they reached out, and they, you know, expressed concern that either they or their family member would experience discrimination. And if you are looking for -- if you are, you know, a protection advocacy organization or you’re a local non-profit that’s participating in an effort to change these triage plans, then finding exemplars can be really helpful to moving things forward and pushing back on bad plans.

Thank you.
I don’t remember who goes next.

>> I think that’s all from all of our panelists, but we got a bunch of questions, so we’re gonna try to get through those as best we can. Feel free to keep putting them in the Q&A, and I’ll do my best to monitor. And thanks to all of our panelists, and thanks to everyone for participating and sending questions.

[END OF TRANSCRIPT]