



## **ADA Live!**

### **Episode 80: Rationing of Medical Care and Protecting the Rights of People with Disabilities**

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**Speaker:** Alison Barkoff and Katheryn Rucker from the Center for Public Representatio

**Host:** Barry Whaley, Project Director - Southeast ADA Center

**Alison Barkoff:** Hi, I'm Alison Barkoff.

**Katheryn Rucker:** And I'm Katheryn Rucker.

**Katheryn Rucker & Alison Barkoff:** And you're listening to ADA Live!

**4 Wheel City:** (rapping)

**Barry Whaley:** Good afternoon everybody. On behalf of the Southeast ADA Center, the Burton Blatt Institute at Syracuse University, and the ADA National Network, I want to welcome you to Episode 80: Rationing of Medical Care and Protecting the Rights of People with Disabilities. I want to remind you, this episode was recorded on April 16th. Hello, I'm Barry Whaley. I'm the director at the Southeast ADA Center And for starters, listeners, I want to remind you, you can submit your questions about this or any other ADA topic at any time at [adalive.org](http://adalive.org).

Alison and Katheryn, we're living in extraordinary times. There's no other way to say it. One of the many aspects of this public health crisis is the limited supply of equipment to treat patients in need. We see shortages of personal protective equipment, gloves, face

shields, gowns, sanitizer, and more importantly, a potential shortage of ventilators. Because the coronavirus, COVID-19, is a respiratory illness, some models are suggesting the demand for ventilators will exceed the supply. And should that happen, medical staff will have to prioritize who gets lifesaving treatment.

Many states provide no guidance for medical staff who may be faced with rationing care. Other states have issued directives for rationing of care that discriminate against people with disabilities. Because of widespread assumptions about quality of life and life expectancy of people with disabilities, there's genuine fear in our communities that people with disabilities will not have equal access to medical care. Ensuring equal access to medical care for all will require exceptional advocacy and focus during these unprecedented times.

Alison and Katheryn, I want to thank you for being on the show. There are several anti-discrimination laws that come into play during this time and let's start with the Americans with Disabilities Act and Section 504 of the Rehab Act. How did these anti-discrimination laws apply to medical care decisions?

**Alison Barkoff:** Thanks Barry for having us on the show today. Both the Americans with Disabilities Act and Section 504 of the Rehabilitation Act prohibit discrimination on the basis of disability. Title II of the ADA covers public entities. That would include states that promulgate policies and public hospitals and healthcare facilities. Title III of the ADA relates to public accommodations and that covers private hospitals and private healthcare facilities. And Section 504 covers healthcare establishments that receive federal funding, which almost all hospitals do, whether that's through Medicaid or Medicare. And it also covers actions of the federal government. Importantly, the ADA and Section 504 not only prohibit intentional discrimination based on disability, but it also requires covered entities to provide equal treatment and access to services and programs, and prohibits the use of criteria or methods of administration that have the effect of discriminating.

That translates to a couple core ADA and 504 principles. The first is any decisions about healthcare treatment have to be based on individualized assessments based on available current objective medical evidence, and means that decisions cannot be based on

generalized assumptions about having a disability, or stereotypes, or even based on the fact that someone has a particular diagnosis as well as quality of life judgments. The second core principle of the ADA and 504 is that reasonable modifications or changes to the policies that are generally applicable may have to be made to provide equal treatment and equal access. That could be anything from effective communication for people who are deaf or hard of hearing, blind, have cognitive disabilities, or speech disabilities to making accommodations for people with mobility impairments or people who use assistive devices or durable medical equipment. That's the big frame of the ADA and 504 in this context.

**Barry Whaley:**

I see. Thank you. Yeah. There are also two other anti-discrimination laws we should talk about, Section 1557 of the Affordable Care Act as well as the Age Discrimination Act. How do these laws apply in these medical care decisions?

**Alison Barkoff:** Section 1557 of the Affordable Care Act prohibits discrimination based on race, color, national origin, sex, age, and importantly disability. And it expanded it to a number of additional health programs and activities, including any healthcare establishment that receives funding from the US Department of Health and Human Services, or is administered by Health and Human Services, or the health insurance marketplaces and plans that are offered by issuers who participate in the marketplace. It really takes the ADA and 504 and expands it, both on disability and age and other protected classes, to these additional healthcare situations. The Age Discrimination Act prohibits discrimination on the basis of age in programs receiving federal funding. It's basically like Section 504, which is about disability discrimination in programs that get federal funding, but relates to age.

**Barry Whaley:**

What kinds of discrimination are people with disabilities concerned about in accessing care during the pandemic?

**Alison Barkoff:** I'll start off with some big picture and then my colleague Katheryn can talk about some of the really specific things that she's seeing as she's working with people with disabilities and other advocates in Massachusetts. As the world was starting to watch the COVID-19 pandemic unfold, first in China and then across Europe, we began seeing the rationing of life saving treatment happening in real time. And disabled activists often say we are the canaries in the coal mines, particularly some of the most vocal activists who use ventilators, people like Alice Wong of the Disability Visibility Project and Crip The Vote, people like Diane Coleman of Not Dead Yet, really began sounding the alarm in the United States. And these are people who started talking about the direct fear of what would happen if they got sick and went to the hospital. People started looking at whether their states or hospitals had plans in place for rationing care.

And I think for many people, no one had really looked into these crisis standards of care. Some states had created them as part of disaster planning. A number of states about a decade ago when the H1N1 outbreak started put together these types of plans, but it really hadn't been on the radar of most people in the disability community. As we started looking at these plans and dusting them off, we saw incredibly concerning discrimination in the plans. In addition to concerns about rationing care, as the virus started spreading and hospitals were putting in place limitations or actually no visitor policies, advocates started raising concerns about how that could translate to denying access and equal care for people with disabilities who needed support in the hospital setting to be able to communicate, to be able to make decisions.

And then finally, big picture. We're really seeing discrimination not just in rationing of lifesaving care, but other concerns about how the disability community is being left behind. We're seeing that so many people with disabilities are particularly vulnerable to getting the virus and having very poor outcomes, including higher rates of death. At the same time, we've been working so hard with Congress to try to get some of our needs met in these COVID-19 relief packages, but most of our priorities haven't been included. We're fighting for funding to help people with disabilities be able to stay at home. We know that people are at highest risk if they are in congregate settings and we know that if they're going into the hospital that's so far downstream. We need to be putting

preventative measures in place. People who are providing community services are not prioritized for access to personal protective equipment or PPE. And we've been fighting hard to get community providers designated as essential workers to protect both themselves and the people that they're serving. We're seeing discrimination and deprioritizing people with disabilities across the board.

**Barry Whaley:** And before we go on, Katheryn, this is a virus that the ground zero of this virus I want to say are people with disabilities. When you look at the people who are most likely to become very ill and their lives are in danger, are people who have a disability that's affecting a major life area, whether it's liver disease, those other diseases as well as older people, people over 60 who are likely to have acquired disability as well.

**Katheryn Rucker:** I think you're right and we've heard some of those very same concerns in our work in Massachusetts which was focused particularly on issues of rationing of care and how that would affect both people with disabilities but also people who are older adults, who are more likely to have underlying comorbidities, and members of our communities of color. And specifically some of the issues that they were concerned about, in addition to the ones that Alison mentioned had to do with really the potential vulnerability for the kinds of unconscious bias that has affected all of those communities.

Although we didn't have a policy that explicitly discriminated against individuals with a particular diagnosis, our policy happened to penalize people who had underlying conditions that might affect their longterm prognosis. People were quite worried that the individuals who would be making triage decisions wouldn't have the time or really the expertise to understand the complexities of their conditions and how that might affect their ability to benefit from treatment. And they were also concerned that they would be deprioritized for care because of stable underlying conditions that really didn't have any impact on their short-term survivability.

**Barry Whaley:** Yeah, that's an excellent point. Thank you. Generally, discrimination against people with disabilities is not unique to a pandemic. We have... as both of you have mentioned, there is a long history of this unconscious bias against people with

disabilities in regard to medical care. In what other areas, medical care, do people with disabilities face discrimination?

**Alison Barkoff:** As you mentioned, there's a long history of discrimination by the healthcare system against people with disabilities. I think if you talk to virtually any person with a disability, they have a personal story to share. Whether a doctor refused to talk to them and talked to someone else with them, where a doctor devalues them based on stereotypes or makes assumptions that, "Oh, you're a person with a disability so you're not capable of making your own healthcare decisions." We're starting off already through a lens of distrust and real conflict between people with disabilities and the healthcare system.

Discrimination against people with disabilities in healthcare goes so far back and all the way up to the US Supreme Court and relating to the long and sad history of forced sterilization of people with disabilities. Over the last decade we've been fighting against discrimination and access to other types of life saving treatments like organ transplants, and many states have had in place or hospitals have had in place policies that outright exclude people with certain types of disabilities, for example intellectual disabilities, for reasons that have nothing to do with whether they could benefit from the organ transplant and follow the protocols for recovering in the broader healthcare policy.

There are some types of assessments called quality-adjusted life years or QALYs that are a way for making treatment decisions that inherently begin these quality of life judgements and penalize people with disabilities. It's really a long history of discrimination in the most direct ways. And then there's the problems that people with disabilities face in being able to access healthcare, whether we're talking about someone who's in a wheelchair being unable to get on an examination table, or a woman who has a physical disability and is unable to get a mammogram, all the way to hospitals and doctors not communicating in clear and plain language with people with intellectual disabilities or other speech disabilities. We have a long history coming into this knowing we have a thumb on the scale when it comes to people with disabilities in the healthcare system.

**Barry Whaley:** Yes. Thank you so much. I want to turn to your organization, the Center for Public Representation. We know you've been involved in filing I believe seven complaints now with US Department of Health and Human Services, the Office of Civil Rights. Can you discuss these complaints with us?

**Alison Barkoff:** As the virus started spreading and coming to the United States and it became clear that this really was going to be an incredibly serious pandemic that there might be need for rationing, the entire disability community as well as members of Congress and federal agencies started focusing on there is a need for the Department of Health and Human Services, Office of Civil Rights, to get out guidance and remind all states and all hospitals that they have obligations to ensure they are not discriminating when they're developing these kinds of policies.

At the point that we started conversations about filing these complaints, there had already been letters from the National Council on Disability, from large coalitions of disability advocates including the Consortium for Citizens with Disabilities, and members of Congress urging the Office of Civil Rights to get guidance out urgently. We thought that we could add to that pressure by filing a number of complaints and being clear. This isn't just theoretical. There are actual plans out there that discriminate. And in a single week we were able to work with other national organizations and local organizations including primarily state protection and advocacy organizations and file four complaints in a single week, which led to a lot of pressure and guidance coming out of the Office of Civil Rights.

We started with a complaint in the state of Washington. Literally they had finalized a policy, it hit the papers on a Friday night and by late Friday night we were already on the phone talking with the Washington Protection and Advocacy Organization about how to put together a complaint to file it by Friday morning. The Washington complaint was a protocol that explicitly prioritized people who were healthier and younger over people who were sicker and older. They directly took disability into account, including explicitly considering physical and mental disabilities in prioritizing. And we used that complaint to really lay out the legal analysis of why plans like this violate the ADA, and 504, and

Section 1557, including because there was no individualized assessment, it was relying on disability diagnosis and presumptions about quality of life and life expectancy.

And they were denying treatment to people who were using the words of the civil rights statutes qualified that is people who could benefit from and survived the treatment. And in that case we had some individual name complainants. One, for example, was a 28 year old with cystic fibrosis who under this scheme would have absolutely been completely denied access to lifesaving treatment based on the fact that she had cystic fibrosis. But in her individual case, her cystic fibrosis had not really impacted her health. She had never had serious health issues, never been hospitalized. We also had an individual with an intellectual disability who would have been deprioritized, and similarly had no reason from a medical perspective in her individual case why she wouldn't benefit from the treatment, survived the treatment.

That complaint got filed on a Monday. Within a day, we filed a complaint about the protocol in Alabama that categorically excluded people with some intellectual disabilities and cognitive disabilities. Within another day we filed a complaint in Kansas that also excluded people with certain disabilities as well as had such a controversial policy about taking away ventilators from people who were using them in the community. If they came into the hospital, they were at risk of losing their vents.

We filed one that week in Tennessee that's pretty similar to Kansas in terms of excluding people with certain disabilities. And those were all within one week. Since then, we have filed three additional complaints or worked with P&As in filing complaints. One in Pennsylvania. And the biggest concerns there are about the reliance on longterm survivability and the use of comorbidities and disabilities in ways that heavily deprioritize people with disabilities and is not at all related to immediate term survivability. In Utah, it's a plan that categorically excludes people with certain disabilities. In New York, there is a policy of reallocating vents like in Kansas. We've been able in a very short period of time to put a lot of issues in front of the Office of Civil Rights.

**Barry Whaley:** It's just shocking to me, Alison, the people putting these documents together were clearly discriminatory at the time they were written, and they still made it to

the light of day. Alison and Katheryn, thank you. ADA Live! listeners, if you have questions about this topic or any other ADA Live! topic, you can submit your question at +1 404-541-9001, or through our website [adalive.org](http://adalive.org). Let's pause now for a word from our featured organization, the Center for Public Representation.

**Commercial:** The Center for Public Representation or CPR is dedicated to enforcing and expanding the rights of people with disabilities and others who are in segregated settings. The Center for Public Representation uses legal strategies, advocacy and policy to design and implement systemic reform initiatives to promote their integration and full community participation. Working on state, national, and international levels, the Center for Public Representation is committed to equality, diversity, and social justice in all its activities. The Center for Public Representation has been providing legal service to people with disabilities for over 40 years. For more information, visit [centerforpublicrep.org](http://centerforpublicrep.org).

**Barry Whaley:** Welcome back Katheryn and Alison. Before the break we were talking about OCR complaints. Has the Office of Civil Rights responded to any of these complaints?

**Alison Barkoff:** Just a week ago, the Office of Civil Rights did respond to the first complaint. And I have to say as someone who has spent a part of my career working inside of the federal government and civil rights enforcement agencies and worked closely with the Office of Civil Rights, usually OCR takes months and months and months, sometimes even years to resolve a complaint. And what's pretty amazing is OCR has been moving with incredible urgency to respond to these complaints. A complaint that we had filed maybe two weeks earlier in Alabama was resolved last week on April 8th. The Office of Civil Rights use a process, it's called early case resolution, where it goes in and instead of going through a huge investigation and negotiation in terms of resolution, they go in, they work with the state and say, "Can we quickly fix this issue and come up with a resolution that at least addresses the most significant issues."

Last week they announced that they had reached a early case resolution with the state of Alabama. The announcement made clear that the policy in Alabama was illegal because

it categorically excluded people because of the presence of an intellectual or cognitive disability. And even though it wasn't the topic of our complaint, which was focused on disability, the Office of Civil Rights also said that the policy discriminated based on age by categorically excluding people based on age if they missed a strict age cutoff. What was important is, even though it wasn't an official guidance document, it gave more information about what is and isn't illegal that can be used by advocates all across the country.

As part of this early case resolution, Alabama withdrew the policy. They gave notice to every hospital across the state that it could not use that policy, that those types of categorical exclusions are illegal and it instructed hospitals about their non-discrimination obligations. There is a lot of important things that came from it. The piece that didn't, and we are working closely with stakeholders in Alabama is, the state had in the interim put out some crisis standards in general and it had some really great non-discrimination language, it talked in general about when resources would be triaged and how to do it. But it didn't have a specific protocol for making decisions about ventilators or other lifesaving treatment. And we think having just a non-discrimination protocol and those words that are incredibly important but not having the specifics about how decisions are made is incredibly problematic. And we are working together with our partners in Alabama, with the government and state leadership, to try to get them to put in place a more specific protocol with input from the disability and aging and other impacted communities.

**Barry Whaley:** You know, it's interesting Alison. I live in Kentucky. In the Commonwealth, there's no guidance for medical staff regarding rationing of care. And our concern is that medical decisions will be made by following the policies of individual hospitals. The non-discrimination language in Alabama could have been there, but really no meat to that on no structure. We're seeing that in Kentucky. I'm wondering what can be done in this situation to protect the rights of people with disabilities?

**Alison Barkoff:** I agree with you absolutely that we know the inherent biases that individual doctors have, that healthcare systems have. And I think if you talk to most of

those people, they don't think that they're making bias decisions or discriminating against people with disabilities. They're just saying, "Well, this is someone who probably won't live as long and we need to maximize life years." And they don't see that as irrational or discriminatory at all. I completely agree that leaving it to individual hospitals and doctors leaves a lot of room for the inherent bias and discrimination that we're concerned about. We are trying to make the best arguments that we can, that there is an affirmative obligation for states as part of its emergency and disaster planning, as part of its affirmative obligations, to ensure that recipients of federal funding do not discriminate, that they need to develop these specific protocols.

The biggest place where you can make a difference is creating political pressure around this. The pressure for transparency, the pressure to make sure that people know that if I go to hospital A or hospital B, I'm going to be treated the same. And that's where the coalition work at the state level that we're doing, and Katheryn's going to talk about in terms of Massachusetts, is so important.

**Barry Whaley:** Thank you Alison. Turning back to the Department of Health and Human Services, on March 28th of this year they did issue guidance about how anti-discrimination laws must be applied when doctors and hospitals are forced to make decisions regarding rationing of care.

**Katheryn Rucker:** Well, the OCR's bulletin is important to people with disabilities for several reasons, some of which we've already covered. But importantly, the directive makes clear that civil rights laws like the ADA Section 504, the anti-discrimination provisions, ACA, remain in effect during the national crisis. And as Alison indicated, it also says that people with disabilities shouldn't be denied access to medical care based on stereotypes, or misguided assessments of their quality of life, or more utilitarian judgments about a person's relative social worth.

Instead, the decisions about how to allocate medical care should be based on individualized medical assessments. And the other thing that the bulletin does a good job of is underscoring, as Alison said, some of the affirmative obligations that states and private actors, hospital systems have to ensure that people with disabilities have access

to effective communication and reasonable accommodations. I think one of the limitations of the bulletin, which we've talked about already, is that it doesn't really suggest exactly how states or individual hospitals should put those important directives into practice, be it in crisis standards or specific triage protocols. That's why this wave of national and local advocacy has really become so important.

**Barry Whaley:** Thank you Katheryn. A few minutes ago we talked about these OCR complaints that had been filed. And other than filing complaints, what efforts have there been by state advocates around rationing of care? For instance, when there are more patients that need a ventilator than there are available ventilators. Have they been successful?

**Katheryn Rucker:** Alison can certainly talk about the national scene, but here in Massachusetts we have those very same concerns. We have a high level of positive cases here, transmission. We're expecting that wave to crest sometime next week. Still, we are very lucky that we have a robust and really engaged group of self advocates, legal services and policy organizations, our protection and advocacy agency, a lot of people who care about these issues who we were able to quickly mobilize to work on them. And we started by trying to marshal those resources and develop a strategy that really drew on our respective strengths with some people working out front in a very public way. Other people working behind the scenes.

We had a multi-pronged approach where we were trying to engage directly with our administration and people who were most central to our COVID-19 crisis response, but we were also reaching out to key state officials, to legislators, and to our hospital associations and medical professionals too because as you indicated, even though states are issuing guidance and standards around crisis protocols, many of these decisions are going to end up being made on an individual case by case basis based on a particular hospital or hospital system's triage assessment.

We wanted to make sure that we were reaching out to those hospital associations, or medical society, other contexts we had in the medical community and sharing with them criteria that we had developed that we thought would be useful to them in evaluating their

own triage plans, making sure that they were avoiding both explicit and unconscious bias, avoiding discriminatory outcomes in the operationalizing of some of these triage principles. And we were also trying to lift up to them examples of model language that could avoid penalizing people with disabilities either because of underlying comorbid conditions or assumptions about their longterm prognosis.

**Alison Barkoff:** And I'll just add that the work in Massachusetts has been incredible. The breadth of that coalition of disability, and healthcare, and aging, and racial justice groups is incredible. And we are seeing similar type of engagement all across the country. At this point, I think I've... probably the Center for Public Representation is one of the legal backups that works with the P&A network. And at this point we've probably worked with 20 or more P&As across the country that have been directly engaging with their administration at the state level, pulling together coalitions. And there's been several examples already where we've seen the coalition work make a huge difference. Just to give three recent examples, in Illinois similar to Massachusetts, there's a very broad coalition and as a result of their advocacy, just last week, the governor issued non-discrimination policies that apply to all treatments that focus on disability, on race, and also on economic disparities for people who may not have insurance.

It was really a great model and the advocates are continuing to work with the governor and other state leadership on operationalizing those principles into specific crisis standards of care. And I'm really hopeful that may be a national policy. In Colorado, the disability community got very engaged, had some specific concerns about the existing crisis standards of care, had some very specific demands about changes that need to be made. And last week the state issued new crisis standards of care that was actually adopted by the governor in an executive order. They are mandatory and applying to all hospitals across the state. And they did a great job in pushing for some really important changes like no categorical exclusions, no reallocation of ventilators, and a lot of commitments around accessibility and effective communication.

And the last example that literally just happened in the last 24 hours comes out of Wisconsin where recommendations for crisis standards of care had come out to the

public. They're being voted on as early as today. And a coalition of disability advocates talked about the significant concerns both with the substance of the plan and how it could discriminate against people with disabilities and also the lack of stakeholder engagement. And just last night the governor and Department of Health leadership put out a directive to the committee developing the plan that they have to appoint an expert from the disability community and providing treatment to people with disabilities on that committee that's developing the standards. They want to have the committee look at all of the OCR complaints that we have filed and other model plans that we've identified and also that they have to have stakeholder engagement. I think that's really some important examples of how separate and apart from the legal process that we are trying to use at the Office of Civil Rights coalition work and state level political advocacy can have a huge impact.

The last place that I'll also mention that there's been a lot of concerns and some really great work done because of state level advocacy is concerns about limits on PPE and concerns about people getting infected going into hospitals. There still is a need for exceptions to these no visitor policies. And just in the last week, the state of New York as well as the state of Oregon have put out statewide policies that require hospitals to make exceptions to those no visitor policies when they're needed to make sure people have the support they need to access care, to communicate decisions. Those are some really important places where state level advocacy has made a really huge difference.

**Barry Whaley:** And it seems to me, Alison, that even in this terrible situation that there are a lot of positives that perhaps as a result of these advocacy efforts now we will see more parity in regard to medical care and for people with disabilities. Thank you. I'm wondering how can advocates get involved in their own states? Do you have any resources that can help them?

**Alison Barkoff:** The Center for Public Representation together with other national advocacy organizations have put together a number of tools to help say to advocates, "We know that we can't work in 50 states all at once over the next two weeks. We're trying to create tools to support people." First, CPR has a webpage that we've put together all of these materials on medical rationing. All of the background materials that

we've talked about today, the Office of Civil Rights complaints, state advocates, letters, and that's available from our main webpage at [centerforpublicrep.org](http://centerforpublicrep.org).

We've also created two specific tools to help state advocates. Right after the HHS Office of Civil Rights bulletin came out, as Katheryn mentioned, it has really great principles, but it doesn't really describe how to operationalize those. We work together to put out a guidance to state and healthcare providers on how to avoid disability based discrimination in COVID-19 treatment and really took what HHS had and went a level deeper and really talked about what does this mean in practice. That document was endorsed by 90 national disability and health care organizations. And it's a really important tool and many people have been using that in their state-based advocacy.

In addition, just last week, we put together a tool to help state advocates evaluate the crisis standards of care in their own state. Specific questions that you can ask yourself looking at plans, identifying both the direct discrimination as well as provisions that could indirectly discriminate against people with disabilities and in that document we give examples from other state crisis standards of care that are both problematic as well as model policies. We're hoping that we are giving the tools to advocates to really make progress in their own states.

**Barry Whaley:** That's great. Thank you. Katheryn, what advice do you have for state advocates?

**Katheryn Rucker:** Well, based on our experience in Massachusetts, I would really encourage people to think broadly about who their potential partners might be in this effort. This experience has really, I think if there's one silver lining, it's that it's encouraged us to move out of our normal advocacy circles and silos and to work and collaborate with groups who are equally engaged in other important spheres like aging and racial justice communities. That goes from medical professionals as well. We really weren't very tied into those communities. Not as much as we should have been. But what we found was clear pretty quickly was that in order to be most effective and to best amplify our collective concerns was to really broaden our coalition to include all of those groups and that's produced both a more comprehensive set of recommendations and changes for our crisis

standard plan, but also allowed us to speak with one voice and to do so in a way that's gotten a lot of attention politically and in a variety of circles here in Massachusetts that we might not have been able to activate this politically otherwise.

**Barry Whaley:** I would agree with that, Katheryn. I've been working with a coalition group here in Kentucky and I'm amazed that people who really I have never spoken with before have all come together and are speaking with one voice. That's great advice. Thank you. Perhaps the biggest question we should discuss today, what if one of our listeners today is worried that they are, or maybe somebody that they care about could be denied equal access to care and discriminated against because of a disability? What should they do first? Who should they contact for help and what steps should they take?

**Katheryn Rucker:** Well, there's probably a few important suggestions we can offer to listeners today. As Alison mentioned, CPR and others have been engaging with the national network of protection and advocacy agencies which are present in every state. The P&A in your state should be well aware of these issues. They may already be engaging in state level advocacy about crisis standards and they are probably also looking for individuals who either are at risk or have been experiencing some of these issues, both to help them in their individual cases and to work with them to illustrate the kinds of problems that need to be addressed at the statewide level.

We'd also suggest, and I've actually heard many of these suggestions in our self advocate community here in Massachusetts, that this is a really important time for people to make sure it's clear who they've designated to make healthcare decisions for them if they can't, whether that's a healthcare proxy or another kind of document and to have copies of that document available if they need to go to the hospital.

We've also been talking with our communities here about making sure that if they need specific accommodations and communication, whether that's equipment, or tools, or a support person or family member who can assist them in communicating their treatment needs and preferences that that's written down somewhere in a plan or a document that they can bring with them to the hospital. And also that people ask about and are aware of

exceptions to visit the policies that would allow individuals with disabilities to request specific accommodations.

Just one more thing to add is that many of these triage assessment plans have an appeal process. And to the extent that exists in the hospital where your family member or you yourself are receiving care, it's important to both ask for a copy of the triage protocol and information about that appeal process. It's obviously an expedited appeal, but knowing about it ahead of time would make it easier to use that process if there was a dispute about how someone may or may not be prioritized for care.

**Alison Barkoff:** And just to add a couple of things to what Katheryn said, completely agree that protection and advocacy organizations are probably the place that can most quickly help you with an issue. But to the extent that you have state disability laws in place or your state has a crisis standard of care or other statewide policies, the state human rights commission may be another place where you can contact to get assistance and resolve issues.

I'll also mention that the Partnership for Inclusive Disaster Strategies, which is an organization that works with a network of organizations all across the country to help with disasters and is incredibly active during the COVID-19 crisis, has set up a national hotline and they are also a place that's taking this information. Oftentimes referring to P&As and other agencies and just so people have it, their hotline is +1 800-626-4959. And for people who are more connected in the Independent Living Movement and may be attached or have relationships with centers for independent living, those are also organizations that are very engaged around this issue and are interested in trying to resolve these issues. There's a lot of ways that people can take some proactive steps, or if they need help there are lot of organizations that can help them.

**Barry Whaley:** That's excellent advice. Thanks to both of you. That's really good. Alison and Katheryn, thanks for being our guests today and sharing information on this very important topic, rationing of life saving medical care and ensuring that the rights of people with disabilities are protected. Thanks listeners for joining us for this special edition of ADA Live! Our guests today have been Alison Barkoff and Katheryn Rucker.

You can submit your questions and comments on this podcast at any time online at [adalive.org](http://adalive.org). Every episode of ADA Live! is archived, with streamed audio, accessible transcripts, and a resource page. For more ways to tune into ADA Live! Listen to our SoundCloud channel at [SoundCloud ADA Live!](https://www.soundcloud.com/ada-live) Or you can download ADA Live! on your mobile device by searching for ADA Live!

As a reminder, the Southeast ADA Center has developed a coronavirus resource portal for accurate information that can be found at [adasoutheast.org/coronavirus](http://adasoutheast.org/coronavirus). Listening audience, we also want to remind you to celebrate, learn, and share the ADA. You can check out the ADA anniversary toolkit from the Southeast ADA Center and the ADA National Network. We have logos, social media posts, monthly themes, and other resources to keep the ADA celebration going. That can be found at [adaanniversary.org](http://adaanniversary.org).

Finally, if you have any questions about the Americans with Disabilities Act, you can submit your questions any time online at [adalive.org](http://adalive.org), or you can contact your regional ADA Center at +1 800-949-4232. And remember, those calls are free and they're confidential.

This is Episode 80: Rationing of Medical Care and Protecting the Rights of People with Disabilities. I want to remind you, this episode was recorded on April 16th. ADA Live! is a program of the Southeast ADA Center. Our producer is Celestia Ohrazda with Beth Harrison, Mary Morder, Emily Ruber, Marsha Schwanke, and me. I'm Barry Whaley. Our music is from 4 Wheel City: The Movement 4 Improvement. We'll see you next episode.

**4 Wheel City:** (rapping)

[End of Transcript]

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