

PACIFIC ADA CENTER  
HEALTHCARE AND THE ADA WEBINAR  
INCLUSION OF PERSONS WITH DISABILITIES  
3/25/21  
2:10-4:00 P.M. ET

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>> LEWIS KRAUS: Welcome to the Health Care and the ADA: Including People With Disabilities Webinar Series. I'm Lewis Kraus from the Pacific ADA Center, your moderator for this series. This series of webinars is brought to you by the Pacific ADA Center on behalf of the ADA National Network. The ADA National Network is made up of 10 regional centers that are federally funded to provide training, technical assistance and other information as needed on the Americans with Disabilities Act. You can reach your regional ADA Center by dialing 1-800-949-4232.

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I want to remind everybody this webinar is being recorded and can be accessed on the ADA ADAPresentations.org in the archive section next week. This Webinar Series is intended to share issues in promising practices in healthcare accessibility for people with disabilities. The series topics cover physical accessibility, effective communication, and reasonable modification of policy issues under the Americans with Disabilities Act of 1990, the ADA. Upcoming sessions are available at ADAPresentations.org under the schedule tab, and then follow to healthcare. These monthly webinars occur on the fourth Thursday of the month at 2:30 Eastern, 1:30 Central, 12:30 Mountain, and 11:30 a.m. Pacific time. By being here, you are on the list to receive notices for future webinars in this series. The notices go out two weeks before the next webinar and open that webinar to registration. You can follow along on the webinar platform with the slides. If you are not using the webinar platform, you can download a copy of today's PowerPoint presentation at the healthcare schedule web page at ADAPresentations.org. At the conclusion of today's presentation, there will be an opportunity for everyone to ask questions. You may submit your questions using the chat area within the webinar platform and the speakers and I will address them at the end of the session. So feel free to submit them as they come to your mind during the presentation. To submit those questions, you type in the chat area text box, or if you are using keystrokes, press alt-h and enter that text in the chat area. If you are listening by phone and not logged

into the webinar, you may ask your questions by emailing them to [adatech@adapacific.org](mailto:adatech@adapacific.org). If you experience any technical difficulties during the webinar, you can send a private chat message to the host by typing in the chat window. Type your comment in the text box and enter. And you can also email us at [adatech@adapacific.org](mailto:adatech@adapacific.org) or you can call us at 510-285-5600. Today's ADA presentation -- the ADA National Network Learning Session is titled "How Crisis Standards of Care Can Ensure Equity for People with Disabilities During Times of Crisis." As hospitals around the country are increasingly stretched to their limit by increasing numbers of patients presenting critically ill with COVID-19, many find themselves unable to provide the usual standard of care for their patients. In these situations healthcare institutions may be required to shift operating under so-called Crisis Standards of Care, or CSC. These guidelines can help equitable distribution of limited resources during times of crisis, however, without careful and specific emphasis on protecting marginalized and minoritized unities, they may also exacerbate systemic inequities in care. This session will discuss the ways CSCs can be written and implemented in a way that safeguards equity for people with disabilities as well as members of racial and ethnic minority communities.

Today's speakers are Emily Cleveland Manchanda, an assistant professional of emergency medicine at Boston University School of Medicine, and works clinically in the emergency department at Boston Medical Center. As the director for equity initiatives within the department, her research and advocacy work focuses on mitigating the effects of racism and other forms of discrimination in clinical care. She is passionate about health equity and developing strategies to support equitable care for patients of all races, ethnicities, genders and abilities. Colin Killick is the Executive Director of the Disability Policy Consortium, an independent research healthcare ombudsman and civil rights advocacy organization in Greater Boston run by and for people with disabilities. Colin serves on the Advisory Committee to the Massachusetts Health Policy Commission and the Massachusetts Department of Public Health's COVID-19 Health Equity Task Force. After co-leading the Massachusetts disability community's successful efforts to repeal the state's first and second versions of the COVID-19 Crisis Standards of Care, he served on the committee that drafted the third and final version of those standards. He has multiple disabilities himself and believes strongly in the necessity of intersectional advocacy against the morse forces of racism, homophobia, misogyny. I will now turn it over to you, Emily and Colin.

>> EMILY MANCHANDA: Wonderful. Thank you so much for that kind introduction. I think with that bit of background we can go ahead and jump right into our presentation. So as mentioned, we are going to be discussing how Crisis Standards of Care can ensure equity for people with disabilities. I'm going to start and then we'll turn it over to Colin after a bit of a closer look at what Crisis Standards of Care are. Next slide. So we have no financial relationships that we need to disclose that relate to this presentation. Next slide. And here is the outline for our presentation. We'll first consider what Crisis Standards of Care are and why we need them. We'll dig a little deeper into how CSCs actually work, and then think a little bit about how they can perpetuate inequities within the healthcare system. We'll then talk about best practices and next steps with the

consideration for what we can do not just during the COVID pandemic but beyond to ensure equity during other times of scarcity. And we'll leave time at the end, of course, for questions and discussion. Next slide.

So our objectives are that by the end of the session each of you would be able to explain why we need Crisis Standards of Care, and identify three ways in which the existing crisis standards that are in place in many states across the country may discriminate against marginalized populations. We also hope you will be able to identify three ways in which we can ensure greater equity in CSC-guided decisions by the time we finish the session today. Next slide.

So essentially Crisis Standards of Care create structure and rules to guide ethically challenging decisions about rationing scarce resources. As the H1N1 virus spread back in 2009, the HHS Assistant Secretary for Preparedness and Response asked that the Institute of medicine develop guidelines for resource allocation in times of scarcity. The resulting report led to a series of recommendations and original workshops for developing Crisis Standards of Care. That IOM report and the workshops identified a number of ethical principles on which crisis standards should be developed. Those include fairness, duty to care, duty to steward resources, proportionality, consistency and accountability. Those principles are meant to be considered when developing guidelines for how specific resources can be allocated during any type of scarcity. Crisis Standards of Care are meant to be flexible, so that they can be applied during any kind of crisis. So as we have discussed, obviously, in this context, during a viral respiratory pandemic, but also during a natural disaster or a mass casualty event, such as a terrorist attack. Essentially Crisis Standards of Care enable healthcare teams to shift from a lens of duty to care for the individual patient to caring for the broader population when we don't have our usual resources available.

Next slide. So to think about why we need them, I'll give you a couple examples. You can imagine a situation, or if you're a clinician like me, it's easy to imagine a situation in which you might have four patients who come into the hospital into the emergency department very, very ill, and need to be put on a ventilator. They need to have a breathing tube put in. However, you might learn as multiple things are happening across the emergency department at the same time that there are actually only two real ICU level ventilators left in the hospital. Alternatively you can click, you might imagine that there are three patients within the ICU who need dialysis. They all need dialysis relatively emergently, however, it may be the case during times of crisis that there's only one dialysis nurse who is available. You can click. And he may already have worked for a full shift already. So rationing of care in many parts of the United States is hidden from the view of the treating physician, so hidden from the emergency department physician who is deciding about a breathing tube or hidden from the physician in the ICU who is thinking about who gets dialysis first. Instead what we often face is access to care being limited by economic status, insurance or proximity to healthcare facilities. These upstream social determinants of health that really ration based on access and are the reason that we have undermined supported inequitably distributed health resources which lead to risks in disease. Even the more affluent hospital systems in

Manhattan, for example, can become severely limited during times of crisis, such that a different system is needed for prioritizing patients so that we can safely and equitably determine who should be prioritized over someone else. Without Crisis Standards of Care we remain in our usual state of first-come first-serve healthcare, or perhaps even worse, we may end up relying on treating clinicians to make determinations about who should receive priority. Decision making at this micro level limits opportunities to leverage resources across institutions or to compare patient needs across a facility or a region. So you might imagine -- click -- in this situation, there might be another institution down the street or just across the state line, for example, that has extra ventilators that they don't need in that particular moment or that particular day that they could lend to this institution to prevent two of those patients who are on transport ventilators from having adverse outcome. They may also have additional staff who they could send across town to work as a dialysis nurse in that ICU if they are not themselves in the same position of scarcity. So, the next slide...

Without Crisis Standards of Care or other guidelines, the clinicians who are caring for patients -- you can click there -- may be left to make the decisions on their own. And that will almost inevitably lead to moral injury on the part of that treating clinician. The decision about who should live or who should die is not one that we are trained to make, particularly in the moment. Bias about perceived quality of life and whose life is worth saving can also easily enter into those decision making processes, even if unconsciously. And at the same time -- you can click -- without published and publicly available guidance, resource allocation decisions made by hospitals or clinicians may create understandable perceptions of injustice among families of patients who are de-prioritized from receiving those resources. So Crisis Standards of Care should be developed and made public before a crisis in order to standardize decision making and should also reflect the ethical principles of the community in which they're going to be used. You can click to the next slide. Unfortunately, however, we know that not all states have Crisis Standards of Care that have been published, and, in fact, as of the summer only 39 states in the country had some version of a CSC document.

So map shows dark blue states which have Crisis Standards of Care guidelines that provide specific instructions for how to prioritize patients for resource allocation. Those lighter blue states have a more general guideline and those purple states were ones that were in development over summer and presumably now have been finalized. I apologize the map is not completely up to date.

As far as we know, only Arizona officially enacted Crisis Standards of Care at some point during the pandemic, although we know there were rationing decisions made in California and New York at various points of the past year. It's not clear the extent to which the guidelines in Arizona or anywhere else were used to guide the allocation of resources or which resources were allocated using their CSC frameworks. So we'll go to the next slide and turn to a consideration of how Crisis Standards of Care guidelines actually work. Firstly, it's important to recognize that the prioritization scoring or allocation decisions under Crisis Standards of Care are made by a triage officer who should not be treating physician or someone who has a direct doctor-patient relationship

with the individuals who are under their care. So that's just an important consideration of an external -- not necessarily external to the institution but an additional person who doesn't have that individual duty to care for the patient, but rather has more of a system-level lens and view of the overall needs of the population that they're caring for.

The structure for crisis standards involve four phases really. The first phase determines who gets in. So the exclusion criteria that are incorporated into many Crisis Standards of Care are one thing to consider. Next the crisis standards focus on the acuity of a patient's condition, how sick that person is in that given moment. Most also consider some version of long-term benefit or longer-term benefit before resources are then allocated. That's step three here. And then there is also a provision for the reconsideration of resource allocation over time, which we'll discuss in the coming slides. All right, so we can go to the next one. So for exclusion criteria, you can click, this is a question of who is considered eligible for resources in the first place. So many states have exclusion criteria that limit consideration for access to intensive care or other limited resources during times of scarcity under their crisis standard. There's wide variability here from broad statements, for example, in Washington, that any significant underlying disease process that predicts poor short-term survival is part of their exclusion criteria. Alternatively some states have very highly specific metrics, like in Kansas where they said severe burns on a patient in any of the two following conditions, age greater than 60, total 40% body surface area affected or inhalation injuries should be excluded from consideration. And those are generally things that are based on a very low likelihood of survival even if resources were available. Some states, like New York, have chosen to omit broad exclusion criteria with the exception of patients who would not typically be allocating resources even during normal times. So, for example, a patient who gets brought into the emergency department and has a very prolonged course of CPR and all of the other resuscitation efforts but has shown no signs of recovery. In those cases we typically terminate efforts because we feel that they're futile. So, once we move beyond exclusion criteria, we'll go to acuity. The first real step of prioritizing patients under standards is a consideration of who needs that scarce resource the most. And all the crisis standards in the U.S. incorporate the use of what is meant to be an objective scoring system. And this is called the sequential organ failure assessment or SOFA score or the modified SOFA which uses slightly different clinical data. The score is translated into a priority category, usually 1-4 based on the patient's prognosis for surviving that acute illness that they present with. SOFA incorporates data from patient's vital signs, heart rate, breathing, that type of thing, as well as lab results and exam, which is based on the Glasgow coma scale, GCS, which we'll talk about in a bit. So validated and predicting mortality at the population level among patients sick or critically ill with infectious process, patients who have sepsis, but it's not a triage tool and may not actually be as good at predicting likelihood of survival from a viral respiratory illness like COVID. But for the purposes of prioritization under Crisis Standards of Care a patient with a higher SOFA score receives lower priority because they have a poorer predicted survival. So the next step is consideration in most states of a likelihood of benefit. So most Crisis Standards of Care provide additional adjustment to a patient's priority score based on predictions of longer-term survival. Like considering the patient's other health conditions, the triage officer or team

is asked to predict the likely long-term benefit. That is usually done by decreasing the priority of patients who are seen to be less likely to survive more than another five years even if they were to make it through that acute illness. And by further de-prioritizing patients who have such serious medical conditions that they're likely to die within the next year. So each patient's priority score is then calculated. You can click. And that generates a priority category. And so resources are then allocated according to that priority 2. It may be that additional tie-breakers end up being needed in order to allocate resources even within a given priority. Again, there's lots of variability here across states and we'll get into specific examples, but some states say that with all other factors being equal, triage teams can make decisions based on age or pregnancy or an individual's role as an essential worker with increased assumption of personal risk. Others rely solely on a lottery system for allocating resources among patients among a single priority tier. And we'll talk a little more about those tiebreaker criteria later in the talk. Most Crisis Standards of Care also explicitly state that resource allocation should be reconsidered at specific time intervals. You can click. For example, this may be done daily to determine whether resources should be reallocated within the cohort of patients who need them. So this helps to get around some of the problems inherent in first-come first-serve system whereby you might have patients who would benefit more from a resource who arrive later in the process or in the pandemic. Reallocation would involve withdrawing care from lower priority patients in favor of allocating them to someone who is more likely to benefit at that given time. Next slide.

So I just want to pause for a moment, because you just had a lot of information thrown at you in the past 10 or 10 minutes. And for some people this may feel really abstract or theoretical, while for others who might have been put in the position of making some of these really difficult decisions or seeing decisions like this being made for their friends or family, it may be a little bit overwhelming to have thoughts of these really challenging issues brought up over a webinar. The decisions about Crisis Standards of Care are really some of the biggest ones that doctors and healthcare professionals face both in terms of our caregiving and just as humans. And so I want to pause to acknowledge that these are really challenging ethical and moral issues, and while we try to do the best we can, they're always very, very difficult conversations to have. So, from here I do want to turn to thinking about how equity can be incorporated into Crisis Standards of Care and insuring that everyone has access to equal resources even during times of crisis. So, we can go to the next slide.

So we think now about how Crisis Standards of Care may perpetuate inequity. We'll do this through asking three questions. And the first of these is: Where are Crisis Standards of Care most likely to be needed? So I would argue that in my experience, poorly resourced facilities may become more easily overwhelmed by a surge of patients during a pandemic. This is in part because of the differences in the ease with which facilities can control availability of inpatient beds and in anticipation of a large influx of patients. So big wealthy private medical centers profit from filling a high proportion of inpatient beds with patients who are there for elective surgeries. These can be cancelled if you know there is a big wave of patients coming either from a mass casualty event or from a COVID pandemic or something that is a little more foreseeable.

Hospitals where I work fill the majority of their inpatient beds with unplanned admissions, for example, through the emergency department. So our ability to flex our inpatient space in anticipation of a surge really is very different from that of private medical centers that rely more on elective procedures to fund their institution. There are also differences in the ways in which facilities are compensated and we saw that some of the relief aid that was delivered to institutions differed significantly between safety net hospitals which received less federal support and private centers which leveraged more connections and agreements to receive more support than even those place that is were hardest hit. We'll go to the next slide. So the second question of equity is between patients rather than between institutions. Who is likely to be sicker on arrival? We note that among patients who require COVID, people with chronic comorbid conditions like COPD, obesity, hypertension, diabetes or renal disease are more likely to require intensive care than people without those conditions. Because those same conditions are significantly more prevalent among black, Latinx, Native American, disabled and other marginalized populations in the U.S., on the whole these groups are more likely to become severely ill than white people who don't have disabilities. This may mean that at the population level people from marginalized groups are, again, on the whole more likely to have a higher SOFA score and thus end up being given lower priority for resource allocation under Crisis Standards of Care. Even the seemingly objective SOFA score may systematically discriminate against some groups unless we're careful. For example, people with significant motor or speech disabilities may have a lower GCS score, a lower Glasgow Coma Scale which is incorporated into the SOFA score if they're unable to follow motor commands or speak clearly even when they're not sick and at their functional baseline. As Colin will discuss more, there were several successful lawsuits filed in the past year by disabilities rights groups based on these concerns which led to CSC revisions in at least six states to ensure protections for people with disabilities. Next slide. And so the last question in terms of thinking about inequity and how Crisis Standard of Care may perpetuate them, it's important to think about with regard to who or may not survive the next five years. So, predictions of long-term benefit can be really problematic. Your typical 18-year-old will almost certainly have a greater life expectancy than an 88-year-old no matter how healthy they are. But as the age gap between people competing for a scarce resource narrows, they're underlying health conditions by increasing the important role in determining who will be more likely to benefit from that resource in the longer term. The same life limiting morbidity health conditions and social determinants of health that lead to black, Latinx, Native Americans becoming sicker than white Americans reduces individuals life expectancies. People with disabilities linked to ALS, cystic fibrosis, SMA and those who require assistance with activities of daily living may be perceived as having a lower likelihood of survival past five years whether or not that is actually true. The Crisis Standards of Care that ask the triage team to add penalty points for likely death within five years, for example, will deprioritize patients with chronic lung disease or home oxygen or chronic dialysis.

These Crisis Standards of Care, therefore, can introduce systematic stability and race-based bias into their seemingly objective frameworks. All right, so next slide. What do we do about it? I'm going to make some specific recommendations about the

actual Crisis Standards of Care guidelines, which you can look through your state to see if any apply for your particular situation. And then I'll turn it over to Colin to discuss the bigger picture in terms of advocacy and legislative opportunities. Next slide. So, we're going to talk about six ways in which Crisis Standards of Care can safeguard equity. One relates to planning. One relates to access to resources, three are related to scoring mechanisms and a little bit more of the technical details of Crisis Standards of Care, and one final recommendation about tiebreaker decisions. And also I just want to pause and take a moment to give credit to my colleagues within the Society of Academic Emergency Medicine and the Massachusetts Coalition for Health Equity with whom I collaborated for these recommendations and these are included in a statement by ISAM last summer and the reference is at the end of the presentation. Next slide. The first recommendation is for coordination. Pooling of resources between regional institutions has to be exhausted before Crisis Standards of Care are enacted at any single facility. We saw this fail in New York last year where providers at Elmhurst and Queens would have been unnecessary if patients were transferred to less affected hospitals in other boroughs. State departments should ensure that coordination agreements are created ahead of time to allow for procurement and sharing of resources as well as patient transfers between facilities. We saw this happen in Boston in the peak of the first surge back in April and lives were saved as a result of transfers of patients out of my hospital into other hospitals in the city who still had space despite the surge of patients.

Particular emphasis needs to be put on creating agreements between resource facilities and safety net facilities nearby. They may have a more limited ability to adapt in anticipation of surge of patients. Having a national healthcare system through which we pooled our resources remains a pipe dream of mine, but explicit coordination for future public health crises should be created to allow and reward facilities and states collaborating across their traditional borders. Next slide. So just a moment again thinking about exclusion criteria to just say that broad exclusion criteria that limits access to critical care resources even during times of scarcity should really be limited to avoid excluding wide segments of the population. For example, age cutoffs or use of subjective or vague exclusion criteria like dementia, which was listed as an exclusion criteria in an original document in one of the states, may lead to healthy individuals who have a reasonable chance of survival being categorically denied access to resources that have been scarce. This is true for heterogenous groups of patients, individuals with cancer or patients who require dialysis. Some may have an excellent quality of life and many years of life left to live. If required, exclusion criteria in Crisis Standards of Care should be limited to truly objective conditions for which a patient has an obvious and imminently dire prognosis. Again, things like unsurvivable traumatic injuries or ongoing CPR that has failed to resuscitate a patient. Next slide. So we'll turn now to three recommendation for the technical aspects of Crisis Standards of Care and how we allocate resources if we need to. So in the ideal world we would have disease specific triage tools that would predict mortality for each of the patients giving us a validated likelihood of survival based on individual presentation. Unfortunately we don't have that. As we discussed SOFA was not meant to be a triage tool. However, until we have improved tools and something that works better for COVID, SOFA may well be the most



objective means of quantifying a patient's acute sickness. As we'll discuss next, the tools have to be applied with consideration and even with adjustments because we understand that they are limited. Next slide.

So crisis centers of care scoring systems must explicitly protect the rights of people with disabilities to have equal opportunity to access resources even when they become scarce. So hospital policies and procedures need to afford reasonable accommodations both for support people during hospitalizations even when we have changes in policies and for evaluation of patients under crisis standards. So patients who, like my son, have cerebral palsy, may not be able to follow motor commands or communicate verbally even when they're at their baseline. Scoring systems like SOFA which incorporate GCS or other seemingly objective measure of function must not give lower scores to people like him who have disabilities.

The language and recommendations can be incorporated into local and other state crisis standards guidelines.

It's also important to think about how some of the other factors in our lives may influence presentation and what gets measured in crisis standards. So if some measures within seemingly objective scoring systems track very closely with adverse social determinants of health, then we should also reconsider them and make some adjustments. For example, the disproportionate burden of chronic kidney disease among black and brown people in the United States may lead to worse SOFA scores since one measure of kidney function is included in SOFA. To adjust for this, some states, again like Massachusetts, because of our advocacy, have capped the number of SOFA points you can add to a patient's score if they have chronic kidney disease at baseline. This still a colorblind policy. It's adjustment for all patients, but at the population level we expect this would provide a greater protection to people of color who, again, have greater burden of kidney disease on the whole.

Next slide. This is my last recommendation for the actual technical Crisis Standards of Care piece. Which is Crisis Standards of Care should only consider the likelihood of surviving the acute illness and not the number of life years or longer-term benefit. Consideration of longer-term mortality introduces a systemic racism and discrimination against people with disabilities into the resource allocation process by biasing resource allocation against populations that have both the higher prevalence of chronic disease and shorter life expectancies on the whole. If patients have a degree of illness, their degree of need for the resource that's become limited or scarce is equal, and neither long-term survival predicted life years left to live or age should be used to make allocation decisions. As we discussed, the underlying medical conditions that track disabilities or racial and ethnic health disparities will already have played a role in the patients presentation when they got there and how sick they are. And so those are already going to have contributed to the patient's relative priority under Crisis Standards of Care. All right. We'll go to the next slide, my last recommendation. When a tiebreaker is needed to determine which patients within a given category should get a scarce resource we really would want to use a lottery. There are several groups that

thought about how this might be done, and some have recommended something like a weighted lottery, which might give additional priority, a little bit of edge to historically disadvantaged groups, for example, patients living in poverty, or individuals who bear greater individual risk, healthcare workers, bus drivers, grocery clerks or other frontline essential workers required to keep our society functioning even during times of crisis. There's a system that was developed at Pittsburgh for allocating scarce medication, like the antiviral medication we can use to improve survival in COVID, and that provides an interesting example how we might think about a weighted lottery. Next slide. So these six recommendations are really meant to help us think about how to improve existing Crisis Standards of Care and now I'm going to turn it over to Colin to talk about what we can do moving forward.

>> COLIN KILLICK: Thank you so much, Emily. Can you hear me?

I'll take that as "yes" unless something pops in the chat. I'm Colin Killick, I'm the Executive Director of Disability Policy Consortium, a civil rights advocacy organization in Massachusetts run by and for people with disabilities, and we wound up leading the fight related to Crisis Standards of Care here in Massachusetts. Next slide, please. So what this came down to for us is in order to work on this issue you have to understand what the actual question at stake here is. It was tempting, I think particularly for policymakers to view this as something objective, as a utility maximization problem. It was a matter of finding the right formula, the right algorithm, the right points system. And because such measures were rationed, were objective because they involved numbers that they were therefore objective. That this was a problem that could be solved, that there could be a correct answer to. And in fact that's not true. And in fact the technical nature of these standards, the fact they involve these complicated scoring systems, I actually think it in some ways more likely for adverse outcomes to occur, because they obfuscated the actual question at stake. A profoundly moral question. A very simple question and one that impacts people with disabilities not just in this one area but very broadly throughout essentially every aspect of their lives. And it's this question: Whose lives do we value? And by "we," I mean we as a society and by "we," I mean specific people. Whose life do you value and do you believe that everyone's lives are equally valuable or not? Next slide. Because, in fact, people with disabilities, a lot of people with disabilities are systemically devalued in our society. In all kinds of areas, right? It shows up, for instance, in the fact that we still face massive discrimination in accessing housing, in accessing employment, in accessing education, right? Here in Massachusetts in 2021, it is still -- there is still no requirement that an employee only area of a business be accessible. There are academic studies like people like Lisa Scherr which show if you mention a disability in the cover letter for a job you're a third less likely to get it. It's just not discrimination. It's violence, right? A study by a foundation a number of years found that half the people killed by police have a disability. Half. People with disabilities making up 20% of the population. We're also highly over-represented in cases of domestic violence, both intimate partner violence and violence parents against children. In fact, there's longstanding and quite disturbing

pattern of parents or care takers who kill their disabled children being led off with very light sentences because of a perception that the life of that child was less worthwhile because of their disability or even that the parent was committing a so-called act of mercy by killing that child. Many states people with certain disabilities are blocked from receiving organ donations or disability status is a strike against someone in eligibility for organ donation. And that's not only disabilities that reduce someone's life expectancy but also many states people with intellectual disabilities are barred from receiving organ donations because it's perceived their lives are inherently lower quality, are less worth living. And then this lastly comes to a metric which is widely used in health policymaking, and there's been a national push used in the pricing of prescription drugs, which it is in many other countries. It's a metric I was taught. I went to public policy grad school at Harvard and we were taught to use this metric, a good example of utilitarian. It's a metric which is literally based on the presumption that the more disabled you are the less your life is worth. It will put a value on your life. For instance, it will say if you have -- when it defines severe epilepsy, you have a quality weight of 0.54. Which is to say your life according to this metric is worth 54% of the life of someone with no disability at all. And a treatment that extends your life by one year would only get credit for 0.54 years of life. And this is our entry into this. My organization has been fighting the use of that metric and others like it at both the statewide and national levels for a number of years. And we were told by policymakers again and again, you're imagining this. This metric is purely being used for price negotiations, for cost effective analysis. No one actually believes that the lives of individuals with disabilities are less valuable than the lives of people without disabilities. No one is actually suggesting people be denied care, denied lifesaving care on the basis of their disability. And then the pandemic happened. Next slide, please. It hasn't... there we are. So as mentioned states adopted the Crisis Standards of Care and in many states they adopted these categorical exclusion criteria saying that people with these specific disabilities would be denied ventilators, denied ICU admission, denied hospital treatment. Here is a more blatant example. In the state of Alabama, among many other exclusions said if you have an intellectual or developmental disability we will not provide you with a ventilator while Crisis Standards of Care are active. Because in their judgment the lives of people with intellectual and developmental disabilities are not high enough quality for the use of a ventilator on them to be valuable. In Utah and Tennessee, if you had ALS, multiple sclerosis, spinal atrophy, cystic fibrosis, if Crisis Standards of Care were in effect you would not be admitted to the ICU at all. If you required any level of ICU care, you would be left to die. In Florida anyone with a neurological disorder requiring, quote, lifelong assistance with most basic activities of daily living, and incredibly broad categorization that would capture many of my coworkers and close friends and I'm sure people on this call, if you fit that criteria and COVID-19 standards of care were active, you would not be admitted to the hospital at all. You would be turned away at the hospital door if you had that consider, because your life was chose to not be worth saving. And New York, while their policies were generally better than these, their crisis standards included a clause saying that if someone -- not only someone with a severe disability not be assigned a ventilator if they came to the hospital, but if they came in with their own personal ventilator, that they used for a chronic medical condition, that ventilator, if there was a shortage could be

taken from them and reallocated to someone else whose life was judged to be more worth saving. Fortunately in none of these states things did not get to the point where these standards were actually used in part because they were immediately and vociferously challenged by disability rights activists. For those sort of folks like me living in blue states, you know, who might be feeling smug at this moment, discrimination happened here too. It was just in subtle ways. Next slide. So more subtle forms of discrimination occurred in a couple of ways. So talking about short-term metrics, the SOFA score, this metric that was used to assess short-term survivability. And not necessarily ideal for that, uncertain if it was actually valid in the case of COVID-19 but the best metric available. The trouble is that the SOFA score -- and Emily can speak to this better than I could, but it's designed to assess acute injury, right? You have a kind of implicit baseline that before the person sustained the condition from which they are presently suffering, before they contracted COVID, that scores in these areas were quote/unquote normal. So when you have someone with an underlying disability, they on some of these metrics may give false impressions of low likelihood of survival that are, in fact, not accurate. The Glasgow coma scale is an example of this. This is one thing we quickly got overturned in Massachusetts. Because it measures among other things motor acuity. I have the fine motor skills of your average five-year-old, but that has nothing to do with my likelihood of survival. It's a developmental disorder. It has to do with the connection with my brain and hands. But if I were to be assessed using the Glasgow coma scale I would show up as having reduced life expectancy because that test is built on the presumption that before, say, the COVID infection in this case, the person's motor skills were normal. There's kidney function tests, where in this case it's less specifically that kidney function -- poor kidney function indicates reduced chances of short-term survival, although it probably does state that, but in particular the kidney disease and particularly elevated levels of creatinine, metric for kidney disease, are particularly high among people of color for reasons to do with environmental racism basically. And so in Massachusetts ultimately the final thing developed the amount of points someone could lose from short-term survival score based on kidney function tests to make it less racially.

But this question around long-term survival, long-term benefit, right? And this question of what are we trying to save, right? What is the thing we are trying to maximize, right? And is it lives or is it life years, or is it quality life years? Because you get different answers there depending on which of those you are doing. Next slide, please.

Because this was the core of our argument. Saving lives is equitable. Saving life-years is not. What I mean by this is here in Massachusetts, the first version of the standards that came out said without limitation our goal is to save life years, right? So you have two people in the hospital, they're probability of short-term survival with a ventilator is the same, but person B is predicted to live 20 years and person A is predicted to live 10 years. That means by person B, you save twice as many life years. In fact, saving one person who is expected to live 20 years provides just as much value as saving 20 people who are each expected to live one year.

And this on the surface sounds reasonable, right? It's the notion of save the most years of life. Except that inherently all kind of disabilities reduce people's long-term life expectancy, right? And this is a problem for a number of reasons. It's a problem because many of those conditions, diabetes, heart disease, cancer, asthma, kidney disease, etc., are predominant in people of color and low income people. Also the fact as we said earlier, people with disabilities are massively marginalized group of people or discriminated against people. Studies consistently show they get poor quality healthcare throughout their entire life, and now someone arriving in the hospital having lived a life experiencing discrimination and receiving poor quality healthcare is being told that in no small part thanks to the consequences of those things their life is worth less and they are being sent to the back of the line for receiving care. So that's one major problem. The second major problem, as it turns out, is that physicians are -- physicians do really good work under difficult circumstances, not actually very good at predicting long-term life expectancy. It's an incredibly difficult thing to do. You know, we all know in the disability community dozens of people who were told five, ten, fifteen years ago that they had two or fewer years to live. That happens all the time. In fact, actually, what often happens is that the presence of disability is used as shorthand for reduced life expectancy. So even if these measures were perfectly accurate, they would be discriminatory, but it is compounded by the fact that they are not accurate. Next slide.

So, there are two major problems. One is the metrics are wildly inaccurate, and also that short life expectancy is often the result of discrimination. People have shorter life expectancy because they are not breathing clean air, because they are not drinking clean water, because they are exposed to lead, because they are exposed to violence, because they live in a food desert, right? Or because they have a disability, which may in and of itself not do anything to shorten their life expectancy actually but because it subjects them to poverty and discrimination and marginalization they have a shorter life expectancy. So our understanding is that in Massachusetts if the first version of our Crisis Standards of Care were used, which said without limitation, prioritized on expected life years, thousands of people with disabilities would have been de-prioritized because of the disability itself or because of their age. Standards also said use age as tiebreaker. So whenever there was a tie, the older person would lose.

Next slide. So in response to this, the community fought back. We objected early, we objected often, we objected loudly. We got a lot of press coverage. We took every available opportunity to signal to the government and public that this community had been disenfranchised. We pointed out there were no disability representatives on the group that wrote the standards, that we were at no point consulted, that there was no effort made to understand our perspectives or to ensure that these metrics were not discriminating against our community. And importantly we brought disability justice advocates and racial justice advocates together to advocate for these issues. We threatened legal action, and we threatened complaints to the Office of Civil Rights at the federal Department of Health and Human Services. Ultimately in Massachusetts we didn't have to file suit because the Office of Civil Rights struck down other states' standard that used the same approach that we did. So they first repealed the first set of

standards. They replaced it with one that said -- that capped the criteria at five years. They said it will only kick in if you're predicted five years to live. Which is mild improvement but highly discriminatory. We continued pushing and again threatened to file a complaint. That was repealed. And on third try we got to the table. I and a couple other disability rights advocates were appointed to committee and we ultimately succeeded in writing standards that were significantly friendlier to the disability community. Next slide, please. So our goal we set, we set the goal of Crisis Standards of Care would be save the most lives. Count every life equally and save the most lives you can. And therefore the thing to prioritize based on is likelihood of survival to discharge, right? That's the fair approach in our view. Get the most people safely discharged from the hospital as you can, right? Now, this will still disadvantage people with disabilities. Because many disabilities, chronic conditions will make it less likely that someone will survive, right? But we think it is fair. It is a nondiscriminatory goal to save the most lives. We believe age should not be considered and comorbidity should not be considered except inasmuch as survival to discharge is effective. We got 85% there in Massachusetts I would say. We got the five-year rule struck down. They kept in a provision saying you could consider whether someone was expected to have less than one year to live. We would like to see it paired back to survival to discharge but five years to one year was significant improvement. Next slide.

But you think Crisis Standards of Care are far from the only problem. Because of that standards that are merely nondiscriminatory are actually not sufficient. Because the harms of Crisis Standards of Care were potentially massive, but thankfully largely theoretical because as Emily mentioned ultimately Arizona was the only state in which the standards were actually used in a formal way. But at the level of the individual facility or the individual doctor, there were real life-threatening instances of discrimination. There was a case in Texas, a particular infamy, case of black disabled college professor named Michael Hixson whose doctor was caught on tape saying that it was not worthwhile to provide him with life-saving COVID care because he was paraplegic, because he was a wheelchair user. And that doctor, over the objections of Mr. Hixson's life was allowed to terminate his care and he died. In Oregon, it was -- it was found that despite Crisis Standards of Care never activated there, there was systemic discrimination against people with disabilities, particularly pressuring people with disabilities, including those with intellectual disabilities, did not directly impact their life expectancy, efforts to pressure them into signing do not resuscitate orders that said -- it would mean they would not be provided with life-sustaining care like ventilators. That led to the state of Oregon passing legislation making it illegal for any doctor or medical facility to tell someone or their family or even suggest to them that they had to sign a do not resuscitate order or other advanced directive as a condition of receiving care. Finally, as we speak, we're engaged in a pretty substantial fight around vaccine prioritization, people with disabilities not being given sufficient access to vaccines, right? And this is a thing that varies wildly. For instance, in California or New Hampshire or New York or Georgia, all of them have made fairly broad allowances for people with disabilities that substantially increase their likelihood of dying if they contract COVID, cystic fibrosis, for example. Those folks in those states can get higher vaccine priority. But in a state like Massachusetts, none of that has been done. The only

medical conditions that get you any increased priority are the ones on that first very narrow list of conditions from the CDC, which are almost all conditions that are incredibly common. So someone with cystic fibrosis completely out of luck.

And secondly we know that ableism is quite rampant among physicians and discriminatory beliefs about people with disabilities. There was a study just a couple of months ago by Lisa Iazzoni, head of Institute for Health Policy at Mass General Hospital affiliated with Harvard that found 80% physicians believe that people with disabilities have worse quality of life than non-disabled people.

56.5% of them strongly agreed they welcomed patients with disabilities into their practices. Also a study in 1994 upheld in subsequent studies in more recent years by Gerhardt et al. that among emergency room physicians specifically only 18% of them believed that they would be glad to survive a spinal cord injury themselves and a significant minority of them believed that the less effort to be made to save someone's life if they would have a spinal cord injury. By comparison, 92% of people in the same study who actually had spinal cord injuries reported that their quality of life was good or better, right? So there's a huge disparity between the people who actually have the disabilities and the physicians in evaluating how high the quality of life of people with disabilities actually is. Next slide, please. So for all these reasons we believe the Crisis Standards of Care need to not merely be nondiscriminatory, they needed to be anti-discriminatory. We believe that as the Massachusetts standards now do the need to explicitly forbid the consideration of any quality of life standard, anything like quality, it needs to explicitly state that not just as a whole but individual hospitals or individual physicians cannot make decisions about who gets care based on a presumption about people having a higher or lower quality of life because of disability. We felt there needed to be institutionalized safeguards and appeal process where folks can go to if they feel their disability was improperly considered in determining whether they would receive lifesaving care or not. We felt it was vital and Massachusetts standards reflect that people with disabilities must maintain communication access, including having sign language interpreters for deaf people and family members or aides accompany people with disabilities, intellectual disabilities or other communication disorders to ensure their wishes be heard even if hospitals are otherwise not allowing visitors due to quarantine. And the last thing that is vital there be mandatory bias for them, for physicians during emergencies to explicitly counteract these potential sources of bias. Next slide.

So this is my last slide here and I think we already going to questions. But the question is then... what now? What do we as advocates do? What should society as a whole do? So one thing is legislate before the next pandemic, before the next crisis. Because while we all hope something like this won't come around again, it is likely that someday we may well be back in this same position. And even between those things discrimination at the individual provider level, facility level is rampant. In Massachusetts we introduced a bill called an act relative to preventing discrimination against persons with disabilities in the provision of healthcare, docket SD1911 in the Massachusetts Senate. I'm happy to send information about this. In Massachusetts this would forbid if kind of discrimination that occurred in the crisis, the first version of the Crisis Standards

of Care here as well as discrimination at the individual provider or facility. And that would also get to the second point, is forbid other forms of healthcare discrimination. We need to forbid use of qualities throughout the healthcare system as recommended by the National Council on Disability last year and do additional work broadly to investigate and deter healthcare discrimination against people with disabilities. And finally we think we need to start working now to address bias in the system. We need to work with physicians to shift the way they view disability and critically we need to get more people with disabilities into the healthcare system, get more people with disabilities becoming doctors to combat this systemic bias and ensure that when a person with a disability is ill, that it won't be going to the hospital because it ultimately takes their life. Thank you so much.

>> LEWIS KRAUS: All right, thank you so much, Emily and Colin. That was a tremendous presentation. And there are references there for a moment. And now we'll -- this is our chance. So do remember to submit your questions in the chat window and we'll get to those in a moment, and I just wanted to follow up on one thing that Colin just described or talked about, and that was the Lisa Iazzoni study. Lisa did present on that at this Webinar Series last month. So if you want to hear more detail about her study of physicians and bias, disability bias, you can look at the ADApresentations.org archives in the healthcare section and see that. All right. Let's turn to questions that came up and they'll be a little chronological, so we'll go back to the beginning. For coordinating doctors for sending patients between hospitals, how do you handle patients not having coverage at that other hospital or with that other doctor?

>> EMILY MANCHANDA: That's a fantastic question. Thank you for asking it. You know, part of the problem in equitable access to healthcare in our healthcare system overall is that our access is largely determined by our insurance policies in the country. And the cost of insurance is obviously differential and shaped by many factors, including employment, which is then in turn affected by people's race and many other things that are discriminatory. As it currently stands there is no framework for establishing coverage and for coordinating without consideration of coverage between hospitals. And so what we saw happen in Boston during the pandemic, during the first peak of the pandemic I should say is that based on the goodwill of hospital administrators, individuals were transferred with costs covered, for example. Or we picked patients who had an insurance system that was covered in both institutions, and those were the patients who were transferred over. What we need are coordination agreements that incentivize financially, because that's how they work and incentivize coordination between facilities. So Boston Medical Center where I work is the hospital for the region and provide free care if needed for any patient who comes in. Our motto is exceptional care without exception. We mean that without exception based on insurance or anything else. So, unfortunately, we don't have a system that exists yet to allow us to coordinate across facility lines without consideration of coverage. What we need is one that makes at a minimum makes exceptions for transferring in times of crisis. These are



things that could be federally funded to compensate hospitals for taking transfer of patients otherwise unable to pay or otherwise uncovered.

>> LEWIS KRAUS: Thank you. All right. Next question is also for you. I'm going to group two of them together. People are interested in some of the processes that you described. So they want to know if the SOFA scores on the quality matrix are available to the patient and the family.

>> EMILY MANCHANDA: So I can certainly speak to the former. I will probably defer to Colin in terms of quality, because it's just an area that I'm less familiar with at the policy level. But SOFA is a publicly available published in the medical literature score, scoring system for predicting mortality from sepsis. So if you were to Google sequential organ failure assessment, you would turn up some of the papers that have -- that developed and validated those scores. So those are certainly available publicly. Quality matrix I'm actually less certain where those are available.

>> COLIN KILLICK: I can speak to that. The data is out there if you go looking for it. And it's not terribly easy to find or presented in a format that intelligible. I should be clear that to this point qualities are not being used anywhere to make decisions about individual patients. That's a problem we're actively trying to get ahead of because we're worried it could go there. With regard to qualities it's more at the formulary level. Where states or private insurers are suggesting that they use quality to determine whether or not a treatment will be offered, will be available. So, for instance, there was a concerning case a number of years ago that disabled advocates fought back against, including us, where CVS Caremark was going to offer to the insurance companies that worked as pharmacy benefit manager, that they could deny coverage for certain medications based on their quality score. So the sicker -- the more disabled you are, the less likely it would be that your medication would be covered by your insurance company, right? So that's the kind of thing we're really worried about. But in principle there would be nothing to stop that metric also being used in an individual case.

>> EMILY MANCHANDA: And we know from the study that physicians inherently even if unconsciously incorporate considerations of quality of life in their decision making about patient care.

>> COLIN KILLICK: We also talk about quality logic in the pandemic, like quality wasn't being explicitly used, that same notion, people with disabilities had inherently lower quality of life and should be de-prioritized for receiving care was rampant. It was just informal.

>> LEWIS KRAUS: Great. Next question. So, actually, Colin, on your suits, or your actions, were they done under the ADA? Or were they referencing the ADA, or how are you --

>> COLIN KILLICK: Yes. I can say that the primary organization-I think it urge -- I urge people to check them out and donate if able. The primary organization actually file the

complaints was the Center for Public Representation. They're based in Massachusetts but they're a nationwide organization. So they would partner -- and they're a legal advocacy organization. They would partner with local disability rights organizations to file either lawsuits or what are called OCR complaints, basically requests that the federal government intervened to stop a state policy. And then those state level organizations would join with them. So here in Massachusetts had we ultimately had to file it would have been a joint effort between them and us. And, yes, the rationale for those was absolutely that those measures violated the ADA because the ADA requires that public services be -- services in general be provided on a nondiscriminatory basis, that a public or private entity cannot deny someone a service on basis of their disability. So argument is healthcare treatment is a service, right, these are people being denied that treatment or states proposing to deny people that treatment on basis of their disability, and therefore the ADA is being violated. And by and large federal regulators at the Office of Civil Rights fortunately agreed with that assessment and forced states to modify those policies.

>> LEWIS KRAUS: Okay. And somebody just asked if you could put the link to that organization in the chat.

>> COLIN KILLICK: I'm getting that now.

>> LEWIS KRAUS: Great. And just to sort of clarify there, so there's two elements, right? There's the creator of the CSC who might be the state government, is that correct?

>> COLIN KILLICK: It's always the state government, yes.

>> LEWIS KRAUS: So they have that responsibility, the individual hospitals would also have a responsibility under ADA or Section 504, is that right?

>> COLIN KILLICK: Absolutely. So, for instance, the Hexan case in Texas, that hospital almost certainly, that judge, for that matter, almost certainly violated the ADA. That was a clear-cut case on an audio recording of that doctor saying that this person should be denied -- that he should be taken off of ventilation and feeding because of his disability. Unfortunately, it's frequently the case that enforcement of federal law, enforcement at that level so rarely happens -- it so rarely happens in individual cases, right? Because the resources necessary for federal intervention are so limited and often people's only recourse when discrimination occurs under federal law is file a lawsuit. Which it's difficult and time-consuming and expensive. And that's why here we're really pushing hard for a state law because that can be enforced by stated agencies, by local prosecutors, etc., who are considerably more numerous and able to in practice legislate those things. I mentioned earlier here in Massachusetts that there's no state law requiring that employee only areas be accessible. The ADA requires that all areas of a commercial building -- newly constructed building be accessible. But we found here there's widespread instance of that happening anyway, because state building inspectors can only enforce state law. So it's a similar problem here.

>> LEWIS KRAUS: Another question... can you recommend a bias training curriculum?

>> COLIN KILLICK: That is an interesting one.

>> EMILY MANCHANDA: A very interesting one.

>> COLIN KILLICK: Actually there's very little out there. We are developing one ourselves, because of this. If you get in contact with me, we are hoping to get a grant from the Boston Foundation to roll this out. We have one we use for our own employees and taught to high school students and community organizers. National Council for Independent Living does have some resources if you look at their website . Disability Rights Education and Defense Fund, DREDF, has some good arguments on this. But systematic curriculum, there unfortunately isn't a lot out there. Watch this space and once we have something up and running, I'll loop back with the ADA Center to help get the word out.

>> EMILY MANCHANDA: Specific to within healthcare, again, there's very little that is evident-based, and there are a lot of people, myself included, who are working on teaching physicians about bias, and my focus is more on racial bias, although disability rights also come into my work as well. There is a resource library that contains some resources within the Society for Academic Emergency Medicine. I'll put the link in the chat. The academy for diversity inclusion and equity medicine consolidated resources from elsewhere and has those posted. I believe that's all publicly available, sort of an example.

>> COLIN KILLICK: I will say if anyone is from a hospital or health system and would want this kind of training, please do get in touch. It is something that we could develop and work with you on.

>> EMILY MANCHANDA: Absolutely.

>> LEWIS KRAUS: I will also put in a plug for the fact that all of your regional ADA Centers would be able to provide this kind of training in an ADA context because almost every training that we do has a disability awareness segment, which is basically a similar kind of a focus. So you can certainly contact your regional ADA Centers for help with that. Let's see what else we've got.

Do EMTs and other first responders also utilize these bias metrics when deciding on site of a disaster, who to take back to a hospital and who to leave? A CSC for them?

>> EMILY MANCHANDA: Another great question. So there are triage -- there are first responder triage tools that are designed to help categorize patients according to who is most likely to be saved. The ones I'm familiar with very focused on immediate survivability without consideration of longer-term survivability. And while there are different metrics for pediatric injuries or adult injuries, I have not seen -- it's not an area

that I thought deeply about, so I'm sure there are ways in which they are biased, but they are more focused on the imminent survival of people injured at a disaster scene.

>> LEWIS KRAUS: Okay. Next question... what are the chances of getting medical school and other provider training altered in the long-term to include training on disability implicit bias as part of a response to what we have seen with COVID-19's impact on people with disabilities? What would be needed to get that change?

>> EMILY MANCHANDA: That's a great question, Sylvia. Thank you so much for asking it. You know, so the answer is very likely that these are going to be changed, that medical education and other provider training for clinicians, it is changing right now. Many of the areas that we have been focused on specifically addressing relates to racial bias in medicine and the ways in which racism is perpetuated and really just entrenched in medicine and medical education. Everything from, you know, what color are the simulation mannequin's skins to how do we learn about dermatologic skin diseases and on whose skin do we see pictures of those in our texts and textbooks? And thoughts about biological race, like supposed inherent differences between how people's organs work or other traits that historically we have been taught track with race, which in fact do not. The curricula that are being developed to talk about bias absolutely do include, the conversation I have and the concessions I read on thinking about bias, unconscious and otherwise, incorporate information that is meant to address unconscious bias against people with disabilities. And ableism in general. So there certainly is work within this space, but it's something that has to change at the local level, at the institution level and at the level of each of our schools and our testing centers. Med schools teach to the test. So if there are questions that we are required to learn in order to pass the tests, I think that can be a powerful driver of change. Some of the organizations that create board certification exams and medical school entrance exams or medical school graduations, and USMLE licensing examinations are places we can pull levers to track change. There's certainly generationality to it, though. The folks coming through medical school now are talking about micro aggressions and unconscious bias. I'm not that old. I graduated medical school in 2013 and we didn't talk about it at all when I was going through training less than ten years ago. Things are changing rapidly in this space and it gives me hope for the future.

>> COLIN KILLICK: I think just to add to that, because I think you spoke to it very well, a big part of this is getting more people with disabilities into medical schools, right? I think that people with disabilities -- disability bias will be fought fairly effectively if folks have disabled peers who are themselves doctors. But there are substantial barriers to disabled folks in medicine, including entrance requirements, some of the requirements for tests or professional standards that accommodations aren't allowed. I point folks towards the work of Cheri Blauwet, one of the most prominent wheelchair using physicians in the country, a practicing physician and professor of medicine at Harvard Medical School, and this has been major cause for her helping to get more people with disabilities in the medical profession. This training clearly needed -- there's also I think more doctors need to spend time in some clinical rotations and that sort of thing doing work in rehabilitation as a medical specialty. One thing that showed up in the work of

Dr. Iazzoni is that rates of this are much lower rehabilitation physicians amongst emergency room physicians because they spend time with people with disabilities and know them and see ways in which people with disabilities having lower -- apparent lower quality of life actually has less to do with their biology than with lack of access to accommodations. So that's a critical piece of the puzzle.

>> EMILY MANCHANDA: I wholeheartedly agree with that, Colin. One of my residents, had a spinal cord injury while he was a resident and the process of having him come back to complete his residency training as a wheelchair user was incredibly educational for our institution and everybody who worked with him and was transformative in the institutional sort of capability for supporting people with disabilities. Not just people who have physical disabilities, but others as well. And so it really changed the perspective of program leadership, you know, we can't answer everything with representation and diversity and ability, but that is a huge component for sure. And if you aren't exposed to it, then it's very challenging to learn that I think in the same way that, you know, if you grew up in a racially segregated area, it's hard to unlearn the things you are taught if you have no exposure as a physician to caring for people with disabilities, it's understandably difficult to appreciate the ways in which their care should differ from the ways which we care for other patients. So there's absolutely an exposure piece that is critical to moving this forward.

>> LEWIS KRAUS: All right. And one last set of questions here before we close. Coming back to the Crisis Standards of Care. So how would you recommend for anybody who is listening, for them to monitor these or to -- and/or to object to them or raise concerns about them? Or how would you recommend people take steps here?

>> COLIN KILLICK: I think a couple of things. Talk to your legislators and get them involved in these kind of things. Encourage them to work with your local disability rights organization and ask if they're working on these issues. Press coverage is huge. Even politicians who don't care very much about the impact of an individual constituent will care very deeply about a bad -- a news story that makes them look bad. And journalists are interested in these stories often. And then one of the key things is whenever these things are being considered, there may be people with disabilities on the committees writing the regulations, right? So if you see this kind of thing going on, ask that question immediately and repeatedly and loudly until they actually agree to put somebody on the committee. Only when I and others got on committee did something change.

>> EMILY MANCHANDA: I completely agree. The power of public shaming through the press is unparalleled for moving political -- for moving policy. Again, we all have blind spots and group of largely white male able-bodied physicians who are in charge of healthcare systems across the country have big blind spots and it's not through any malice generally speaking. They're just simply not exposed to the issues, and no one at the table who wrote the initial Crisis Standards of Care for Massachusetts thought about the ways which a Glasgow coma score could be discriminatory. It never occurred to anybody. So it's critical we have representation there. If you're interested in pursuing this further at your state or your local level, each institution will likely have its own

guidance, whether that is public will depend from one place to another. The state level guidelines are widely available and there's a paper in here that I wrote this summer "Comparing Crisis Standards of Care Between States," the Appendix has a link. Web pages change frequently, but the state guidelines as of the summer were available in there, so you can review them. And then you can also look to some of the folks who have written about this issue, both from a disability rights perspective and more broadly about Crisis Standards of Care in the literature. There are people who have the ear of policymakers and may be able to point you to guidance for who to speak with.

>> LEWIS KRAUS: All right. We realize that many of you may still have questions for our speakers and apologize if you did not get a chance to ask your questions. If the question is an ADA related question you can contact your regional ADA Center at 1-800-949-4232. If you wanted to talk to Emily or Colin, their contact information is there on the screen for email or looks like maybe Twitter. Thank you very much for that. You will receive all -- all of you will receive an email with a link to an online session evaluation. Please complete that evaluation for today's program as we really value your input and want to demonstrate its value to our funder. We want to thank Emily and Colin today for sharing their time and knowledge with us. It was a very interesting presentation. A reminder that today's session was recorded, and it will be available for viewing next week at ADApresentations.org in the archive section of the healthcare section. So watch your email two weeks ahead of time for the announcement of the opening of our registration of our next webinar, and thank you all for attending today's session. And have a great rest of your afternoon! Thanks again, Emily and Colin!

>> EMILY MANCHANDA: Thank you so much.

>> COLIN KILLICK: Thank you!