

# The Treatment of Disability under Crisis Standards of Care: An Empirical and Normative Analysis of Change over Time during COVID-19

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## Abstract

**Context:** COVID-19 has prompted debates between bioethicists and disability activists about Crisis Standards of Care plans (CSCs), triage protocols determining the allocation of scarce life-saving care.

**Methods:** We examine CSCs in 35 states and code how they approach disability, comparing states that have revised their plans over time to those that have not. We offer ethical and legal analyses evaluating to what extent changes to state policy aligned with disability rights law and ethics during the early pandemic and subsequently as stakeholder engagement grew.

**Findings:** While disability rights views were not well represented in CSCs that were not updated or updated early in the pandemic, states that revised their plans later in the pandemic were more aligned with advocate priorities. However, many CSCs continue to include concerning provisions, especially the reliance on long-term survival, which implicates considerations of both disability rights and racial justice.

**Conclusions:** The disability rights movement's successes in influencing state triage policy should inform future CSCs and set the stage for further work on how stakeholders influence bioethics policy debates. We offer thoughts for examining bioethics policy making reflecting the processes by which activists seek policy change and the tension policy makers face between expert delegation and mediating values conflicts.

**Keywords** COVID-19, bioethics, Crisis Standards of Care, disability rights, health law

As COVID-19 forces providers to decide how to triage scarce resources, disability activists and bioethicists have engaged in a robust debate on how to allocate treatment should demand exceed availability.

At the beginning of the pandemic, prominent bioethicists made the case for rationing care on the basis of disability, prompting criticism regarding the potential for discrimination and bias (Brown and Goodwin 2020; Emanuel et al. 2020). These rationing proposals built on a research literature developed during the last two decades regarding Crisis Standards of Care (CSC)—defined by the Institute of Medicine (IOM 2009) as “substantial change in the usual health care operations and the level of care it is possible to deliver, which is made necessary by a pervasive or catastrophic disaster.” CSC plans (CSCs) articulate how to allocate scarce resources in the context of scarcity, giving providers instructions as to both the conservation of scarce resources and who shall receive them when there is not enough to go around. Many states had already adopted CSCs prior to the pandemic and others rapidly joined them as it became clear that COVID-19 would bring shortages of ventilators and other key medical resources.

While public health experts have long warned of the risk of widespread shortages of ventilators and other scarce resources in a public health emergency, prior to the emergence of COVID-19 state CSCs did not receive the same level of attention from civil rights advocates as other more imminent concerns. Consequently, policies developed prior to the pandemic were crafted primarily by bioethicists and clinicians with relatively little public scrutiny or engagement from stakeholder groups representing marginalized communities. These plans came under increased scrutiny only after COVID-19 prompted widespread shortages.

Disability groups have been on the forefront of such efforts because of the central role disability plays in CSC allocation criteria. Racial justice and aging groups have also engaged, often in collaboration with disability organizations (Network for Public Health Law 2020; Pressley 2020). Activists critiqued early calls from bioethicists to send disabled people to the “back of the line” through both explicit deprioritization and the application of ostensibly neutral criteria that disproportionately screened out disabled patients (Ne’eman 2020; Whyte 2020). These critiques reflect larger tensions between civil rights and clinical/bioethics frames for policy making regarding scarce resource allocation.

Such debates should both inform policy makers and contribute to a more robust understanding of how activists influence bioethics debates. This article advances ethical and legal arguments regarding how CSCs should approach disability, then provides an empirical analysis of how state CSC policies have evolved over the course of the pandemic. We also offer some initial thoughts to precipitate debate regarding processes of change in bioethics policy and the tension between expert delegation and stakeholder engagement in bioethics policy making.

## How Does the Disability Rights Movement Approach Crisis Standards of Care Plans?

We begin by articulating the disability rights critique on CSC policy, informed both by our own analysis and the communications produced by activists over the course of the pandemic (CPR 2021; CPR and Bagenstos 2020). We articulate both ethical and legal issues for consideration in evaluating state CSCs. Two key principles guide our analysis: first, that when Congress passed Section 504 of the Rehabilitation Act and the Americans with Disabilities Act (ADA), it articulated a broad set of circumstances in which expending additional resources on people with disabilities, even when inefficient, is legally required (Ne'eman 2020; Pendo 2020); and second, that the purpose of emergency life-sustaining medical care is to save lives during acute care episodes, not to maximize life-years or make broader societal judgments regarding who is worthy of care.

Our analysis in the first part of this article is split into seven sections, informed by the empirical work reported in the second part. That work makes use of a dataset we developed of 58 state CSC policies from 35 states. State CSCs were reviewed to identify key points of policy variation relevant to people with disabilities. We found five domains in which we observed significant variation with respect to disability: (1) use of categorical exclusions, (2) use of long-term survival, (3) use of resource intensity, (4) protections against reallocation of personal ventilators, and (5) modifications to prognostic scoring instruments. In this section, we discuss two domains held in common across CSCs as well as the five domains in which we documented variation.

### Quality of Life Judgments

One of the disability rights movement's earliest priorities during the pandemic was the rejection of quality of life judgments as an allocation criteria within CSC plans. In this, the movement has been successful—CSCs have avoided or prohibited quality of life judgments. This is a very straightforward application of disability rights law. Nonetheless, prohibiting quality of life judgments in CSCs represents an important victory, as they remain common in other areas of medical decision making, such as qualitative futility determinations and quality adjusted life year (QALY) calculations (NCD 2019). Though clinicians frequently rate disabled patients' quality of life as worse than that of nondisabled patients, this often conflicts with the perspectives of people with disabilities themselves

(Iezzoni et al. 2021; Stramondo 2021). Some CSCs have explicitly prohibited the use of the QALY and similar tools (Bateman et al. 2020). The clear rejection of quality of life as an appropriate CSC triage factor also helps open the door to long-overdue conversations on their appropriateness in non-pandemic decision making.

### Short-Term Survival

Most CSCs make use of some assessment of short-term mortality risk to allocate resources. While standards of quantitative futility have long permitted clinicians to deny care deemed exceedingly unlikely to be effective, CSCs also allow prioritization by relative short-term mortality risk. Major disability groups agree that using relative short-term mortality risk is not illegal within a CSC context (CPR and Bagenstos 2020). We also agree, since survival to discharge from an acute care episode is part of the purpose of lifesaving medical care. Thus, while optimizing for life-years represents an unacceptable departure from the purpose of emergency care, optimizing for lives saved is consistent with it. However, we contend that short-term mortality risk should be interpreted narrowly to avoid unnecessarily screening out of individuals with disabilities and to reduce the risk of bias from more subjective longer-term judgments. Our preferred standard would be survival to hospital discharge. Alternatively, a December 2020 joint statement from the National Academy of Medicine (NAM), the American Medical Association (AMA), and other major national medical associations has endorsed a similarly narrow standard, arguing that resource allocation decisions should be made based only on “likelihood of death prior to or imminently after hospital discharge” (NAM 2020). This joint statement (hereafter referred to as the NAM statement) was an effort by major medical groups to communicate lessons learned on CSC policy over the course of the pandemic to the field, including information on compliance with civil rights law and best practices for avoiding bias and discrimination. It represented an important acknowledgment and validation of disability rights claims with respect to CSC policy making.

### Categorical Exclusions

Exclusion criteria render whole categories of individuals with disabilities outside the scope of critical care, typically through restrictions on the basis of diagnosis and functional impairment. We argue that they are ethically

wrong and legally impermissible. Many pre-pandemic CSCs incorporated categorical exclusions on the basis of particular diagnoses, sometimes in association with specific levels of functional impairment. Under such exclusions, individuals with these conditions are automatically excluded from accessing critical care resources.

Some CSC plans have justified exclusions by presuming that patients with specific conditions meet criteria that render them ineligible. For example, many CSCs with exclusion criteria appear to have copied them from the 2004 Ontario Health Plan for an Influenza Pandemic (OHPIP) (Christian et al. 2006). The OHPIP articulates three rationales for exclusion criteria: (1) low likelihood of short-term survival, (2) an anticipated high use of resources, and (3) a low likelihood of long-term survival. We contend that the use of categorical exclusions is inappropriate regardless of rationale (and, as articulated below, we argue that the latter two of these rationales are ethically and legally impermissible).

Disability rights law requires an individualized assessment prior to deeming a person unqualified for a program or service on the basis of disability, in part because evaluating whether someone is qualified must be done while accounting for reasonable modifications. This is as true for medical services as it is for any other service that people with disabilities wish to use.<sup>1</sup>

Some might argue that categorical exclusions may be appropriate in circumstances in which treatment is exceedingly unlikely to be effective for every individual in a given category. While such circumstances do occur, treatment that is exceedingly unlikely to be effective can be denied under existing standards of quantitative futility. Since CSCs exist to articulate circumstances in which care that would typically be provided would not be, categorical exclusions should not be made use of in a CSC context. Avoiding the use of categorical exclusion criteria is also entirely consistent with CSC conditions. The recent NAM (2020) statement instructs providers to “make resource allocation decisions based on individualized assessments of each patient . . . such assessments should NOT use categorical exclusion criteria on the basis of disability or age.”

Ironically, those opposing claims for systemic reasonable modifications for groups of people with disabilities often rely on the idea of individualized assessment, arguing that because each diagnosis comprises people with different needs, group-based claims for modifications are

1. *Bragdon v. Abbott*, 524 U.S. 624 (1998); *Sch. Bd. of Nassau Cty., Fla. v. Arline*, 480 U.S. 273 (1987); *United States v. Asare*, 2018 WL 2465378 (S.D.N.Y. 2018).

inappropriate and must be sought on an individualized basis rather than emerging solely from the fact of a diagnosis (Stein and Waterstone 2006). It would be perverse to insist that individualized assessment is required for a modification to assist people with disabilities while allowing disability-related penalties to be imposed based on group-based judgments without individualization.

### Long-Term Survival

Many CSCs utilize prospects of long-term survival as a qualification for receipt of lifesaving medical treatment. In doing so, plans argue that this maximizes the number of “life-years” saved, whereas allocating on the basis of short-term mortality merely maximizes the number of lives saved.

In response, multiple ethical arguments have been advanced against the use of long-term survival as an allocation criterion. Others have pointed out that some life-limiting conditions are often the result of structural inequality, especially regarding race and class (Schmidt, Roberts, and Eneanya 2021). We concur and believe that disability should figure into that analysis as well, given that people with disabilities experience significant health disparities and bias from medical professionals (Iezzoni 2021; Krahn, Walker, and Correa-De-Araujo 2015). Although this does not address the permissibility of deprioritizing patients on the basis of life-limiting conditions that are not the result of structural inequality, we advance additional arguments for avoiding the use of long-term survival altogether.

First, within the same diagnosis, it is infeasible for physicians to determine whether a patient acquired the condition because of “structural” reasons as opposed to poor choices or random chance. Accepting such inquiries would also permit the allocation of medical care based on other judgments of personal behavior and moral worth (like denying care to patients whose conditions are the result of past smoking, obesity, or risk-taking behavior). Such an approach would corrode the equitable practice of medicine.

Some propose to avoid this assessment through the use of equity weights, prioritizing care to those from disadvantaged backgrounds by assigning numeric weights to forms of disadvantage (Schmidt, Roberts, and Eneanya 2021). Setting aside the legality of such an approach, doing so would necessitate quantifying the unquantifiable: policy makers would need to determine, with mathematical precision, the relative weight of each form of marginalized identity. A further alternative approach, assessing social disadvantage based on zip code, is worthwhile but insufficient in that it ignores forms of disadvantage that are not geographically congregated.

Second, even when dealing with diagnoses that were not acquired because of structural inequality, likelihood of survival is influenced by societal priorities. For example, life expectancy for people with cystic fibrosis and HIV/AIDS has increased dramatically as a result of research investments emerging from activism. Such instances demonstrate that the survival expectancy is not the result of random chance but is instead the result of societal choices about which conditions deserve investment.

Third, it is important to acknowledge that judgments of long-term survival are inherently uncertain and may be made using outdated information. This uncertainty is present even with condition-specific expert judgment and is compounded when such expertise is not available. Under such circumstances, clinicians may make decisions based on outdated information.

For example, many early CSCs included an exclusion criterion for cystic fibrosis with post-bronchodilator FEV1 < 30%, taken from the 2004 OHPIP exclusion criteria for conditions with “a baseline death rate higher than 50% within the next 1 to 2 years” (Christian et al. 2006). Tracing the citations that OHPIP relied on to ascertain that this exclusion met their stated rationale, we discovered its origins lie in a study by Eiten Kerem and colleagues (1992), which relied on cohort data from 1977 and 1989 (ASTP 1998). Unsurprisingly, life expectancy for people with cystic fibrosis has improved during the last 40 years. Even when the OHPIP criteria were developed, people with cystic fibrosis and post-bronchodilator FEV1 < 30% had a life expectancy above OHPIP’s stated rationale (Milla and Warwick 1998).

This has far-reaching implications. That outdated life-expectancy judgments were propagated in many CSCs without further scrutiny calls into question whether such judgments will be made based on the best available objective medical evidence. Even where particular diagnoses are not singled out, many clinicians lack the expertise to assess prognosis for patients with uncommon disabilities on a truly individualized basis. This concern has been acknowledged in several CSCs that require at least two providers to assess individuals with certain diagnoses prior to a denial of care, preferably including one with condition-specific expertise (Bateman et al. 2020). Such a safeguard is advisable for mitigating risk of bias in short-term mortality assessments but is insufficient to justify use of long-term survival.

Finally, we argue that permitting the use of long-term life expectancy may violate federal disability rights laws. In evaluating the permissibility of denying modifications to requirements that disadvantage people with disabilities, disability laws inquire first whether the modification is necessary and reasonable as opposed to nonessential or significantly changing

the nature of the program or service in question. If the requested modification would constitute a “fundamental alteration,” it need not be provided. The ADA’s prohibition of public entities using “eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities” is balanced against a showing that “such criteria can be shown to be necessary for the provision of the service, program, or activity being offered.”<sup>2</sup>

In the context of life-sustaining treatment, the essential purpose of care is to maximize lives saved, not to maximize life-years. This holds true even under CSC conditions, as the NAM (2020) statement affirms in indicating that providers should not make use of “judgments as to long-term life expectancy.” Accordingly, clinical determinations at the time of treatment should be based on saving or sustaining the lives of recipients, whether with or without preexisting disabilities, and should not be predicated on the unrelated issue of how long such individuals might survive after the provision of health care. To prevent discrimination under federal laws, medical providers must remain faithful to the purpose of life-sustaining care: simply to save lives.

### Resource Intensity

While not as common as long-term survival, some CSCs allocate by resource intensity (sometimes referred to as duration of need). Those who argue for using resource intensity contend that failing to do so will result in fewer lives saved than using a strictly efficient allocation of care that deprioritizes those who require greater resources. This is true, but it fails to account for distributional implications.

As Joseph A. Stramondo (2020) points out, prohibiting the use of resource intensity “may be inefficient, but is surely not wasteful.” Accepting some degree of inefficiency is embedded in disability rights law, which can require expending additional resources on reasonable accommodations and modifications in the name of equality of opportunity. We believe that the global adoption of this broad conception of nondiscrimination reflects an ethical norm in favor of accepting certain inefficiencies in the name of disability equality, not just a legal one.

It should also be noted that this is not a “blank check”; many people with disabilities will require modifications rising to a level of an undue burden or fundamental alteration of the program in question and thus be unqualified

2. 28 CFR § 35.130.



for those accommodations (Ne'eman 2020). But law and ethics both require some degree of modification, precluding a strict optimization approach that seeks only maximal efficiency.

This is true despite cases rejecting variation based on disability in certain contexts. The most prominent of these cases, *Alexander v. Choate*,<sup>3</sup> was handed down by the Supreme Court in 1985. The State of Tennessee reduced the annual number of paid hospital days for Medicaid patients from 20 to 14, without exception. The action was alleged to violate Section 504 because it would have a disproportionate impact on persons with disabilities who required a greater number of annual hospital days. The court rejected this challenge, ruling that as long as those with disabilities were not prevented “meaningful access” to the benefit, being affected differently by the same benefit did not constitute prohibited discrimination. This reasoning has been termed the access/content distinction (Bagenstos 2009).

The access/content distinction has been challenged on a number of grounds, most persuasively by Leslie Francis and Anita Silvers (2017). They argue that, according to *Choate*, the access/content distinction is constrained when the criteria for meaningful access is itself discriminatory for persons with disabilities. Hence, if doctors will not operate on an individual because she requires more than 14 days of hospital recovery, that action violates the patient’s meaningful access. For patients with disabilities seeking treatment under conditions governed by a CSC, meaningful access is barred when care is predicated on discriminatory criteria. Thus disability rights laws are violated in instances in which clinicians will not provide the same care because a disabled patient will require greater post-care resources. In such cases, federal laws would compel the provision of reasonable modifications (including utilization of some additional resources) as part of those patients’ equal access to health care.

It is unlikely that clinicians can evaluate future resource needs with enough precision to judge whether a particular patient’s more intensive anticipated resource utilization is likely to be reasonable or whether a future patient is likely to have sufficiently less intense needs to justify reallocation. Evaluating if a reasonable modification might constitute a fundamental alteration or undue burden cannot be done without considering the resources available to the entity engaged in resource allocation (Stein 2003).<sup>4</sup> Notably, in the ever-shifting chaos of a pandemic, hospitals are not able to predict what the state of available resources will be days or

3. 469 U.S. 287 (1985).

4. 28 CFR 35.164; 28 CFR 36.104.

weeks in the future. As a result, CSCs should not prioritize by resource intensity. The NAM (2020) statement concurs, indicating that providers “should NOT deprioritize persons on the basis of disability or age because they may consume more treatment resources or require auxiliary aids or supports.”

Criticizing disability activists, Govind Persad (2020) argues against concerns about relative allocation criteria, as policies deprioritizing patients with unfavored disabilities “would be expected to save more people with disabilities” overall. Responding to the argument that advocates should not abandon those subject to disability discrimination because other disabled people may benefit from discriminatory policies, David Wasserman, Persad, and Joseph Millum (2020) claim that such an approach constitutes “requiring solidarity with a specific group.” We emphatically disagree.

Persad’s approach would twist civil rights law beyond recognition, suggesting that individual members of protected classes cannot be discriminated against by a policy so long as more numerous members of the same class benefit in the aggregate (Bagenstos 2020). While protecting against group-based discrimination, civil rights laws create individual protections that all members of the group benefit from, even when they are not personally subject to discrimination. And where laws provide protection against discrimination that impacts only a minority of people with disabilities, advocates have every reason to maintain the right of each individual to make sound claims. Persad’s purely aggregate approach to assessing nondiscrimination would relegate civil rights law to a transactional enterprise between groups, rather than a system of rights protecting individuals.

### Reasonable Modifications

Most CSCs made use of the Sequential Organ Failure Assessment (SOFA) as their primary clinical instrument to assess short-term mortality risk for adults. The SOFA is a composite of different instruments, each of which contributes “points” to a patient’s overall SOFA score, with higher scores indicative of greater risk of short-term mortality risk—and thus a lower relative priority for care. Such prognostic scoring systems have not been found to be reliable in the context of COVID-19 but nonetheless remain in common usage (NAM 2020).

In response to critiques from disability groups, a growing number of state CSC plans have articulated reasonable modifications to clinical instruments used to assess short-term mortality risk, most notably the SOFA. Disability rights law requires covered entities, including health

care providers, to modify policies, practices, and procedures when necessary to afford access to individuals with disabilities, unless doing so would constitute a fundamental alteration of the service, program, or activity.

Modifications may be necessary when applying the SOFA and similar instruments designed to assess short-term mortality risk in acute conditions (Ne'eman 2020). Characteristics associated with stable underlying disabilities that are not predictive of short-term mortality may nonetheless result in an elevated score and thus inaccurately imply a greater risk of short-term mortality. The most frequently cited example of this concern is the Glasgow Coma Scale (GCS), one of several component instruments of the SOFA, which intends to measure acute brain injury severity. The GCS results in a more severe score for patients without intelligible speech or with impaired motor movement, giving such patients lower relative priority for resources. For patients with cerebral palsy, intellectual disability, or other underlying disabilities that interfere with speech and motor movement without greater mortality risk, unmodified use of the GCS deprioritizes inappropriately. Advocates have argued that CSCs should instruct providers to make modifications to clinical instruments to account for the needs of these patients. It would be difficult to argue that such modifications constitute a fundamental alteration when they ensure that clinical instruments are valid for the purpose they are designed to serve—assessing short-term mortality risk. Furthermore, the NAM (2020) statement notes the need to modify prognostic scoring systems “when necessary for accurate use with patients with underlying disabilities.”

Some plans have articulated modifications beyond prognostic scoring systems. For example, Rhode Island's November 2020 update to its CSC discusses modifications in the context of therapeutic trials designed to assess ventilator effectiveness, noting that trial duration may need to be longer “for individuals with disabilities who may need additional time to demonstrate effective progress” (RIDOH 2020). We endorse this approach.

The concept of modifying the SOFA to address systemic inequalities has recently been expanded to encompass racial injustice. Harald Schmidt, Dorothy E. Roberts, and Nwamaka D. Eneanya (2021) note that the SOFA also disadvantages Black patients, in part because “creatinine is higher in Black communities because of higher rates of chronic kidney disease . . . the consequences of health inequities and structural racism.” Massachusetts's most recent CSC revision sought to address this problem by indicating that patients with chronic kidney disease could be assigned only up to two points (instead of four) for elevated creatinine (Bateman et al. 2020). This represents a precedent-setting extension of the disability rights framework of reasonable modifications to other systemic inequities.

## Chronic Ventilator Reallocation

Early in the pandemic, chronic ventilator users were concerned that CSCs permitting the reallocation of ventilators might result in the loss of technology they consider part of their own bodies (CPR and Bagenstos 2020). Disability groups advocated that CSCs should explicitly exempt personal ventilators belonging to chronic ventilator users from reallocation, as opposed to ventilators provided by the hospital. Many plans adopted or revised later in the pandemic reflect such protections, and the NAM (2020) statement indicates that “providers should not consider for reallocation a ventilator or other piece of life-sustaining equipment that is brought to the hospital by a patient whose life is dependent on that equipment.” Individuals with disabilities have a right to bring their personal ventilators into the hospital with them as a modification to hospital policies that mandate the use of equipment only provided by hospitals—just as they have the right to bring their personal wheelchairs or hearing aids. It would be bizarre and medically counterproductive to prohibit or remove an individual’s assistive technology.

## How Do Crisis Standards of Care Plans Approach Disability?

### Methods

As noted above, we created a dataset of 58 state CSC policies from 35 states, seeking to identify each instance of a CSC that incorporated triage of scarce treatment resources. To do so, we coded each CSC along the domains of policy variation identified above. To be included in our analysis, a policy had to be endorsed by a state agency and contain criteria for the allocation of scarce resources. State CSC policies were identified through reviews of state websites in March, August, October, and January, supplemented by existing cross-sectional reviews of state CSC policies at different points during the pandemic (Caraccio, White, and Jotwani 2020; Cleveland Manchanda, Sanky, and Appel 2020; Piscitello et al. 2020; Whyte 2020). We included only the most recent pre-pandemic CSCs in our primary analyses in tables 1–3 and figure 1 to reflect the present distribution of CSC policies as of this writing but incorporated all identified versions of a CSC issued in table 4 and figure 2 to reflect change over time.

After we identified points of variation, each author reviewed and coded relevant sections of the plans identified in our search according to an agreed-on rubric. Subsequently, the lead author conducted a secondary review and reconciled any disagreements with the initial reviewer prior to proceeding

**Table 1** Summary of State CSC Plans as of January 2021 (N = 35)

	Total	
Categorical exclusions		
Incorporates	11 (31%)	
Does not incorporate	24 (69%)	
Long-term survival		
Incorporates	19 (54%)	
Does not incorporate	11 (31%)	
Does not incorporate & prohibits	5 (14%)	
Resource intensity		
Incorporates	9 (26%)	
Does not incorporate	17 (49%)	
Does not incorporate & prohibits	9 (26%)	
Reasonable modifications		
No	19 (54%)	
Yes	16 (46%)	
Chronic ventilator protections		
No	20 (57%)	
Yes	15 (43%)	
Summary Statistics for Plans by If Updated and Timing	Total	Mean disability rights index score
Never updated plans	n = 18 (51%)	1.67
<i>Issued pre-pandemic</i>	9 (50%)	0.78
<i>Issued early pandemic (Feb–May 2020)</i>	5 (28%)	1.6
<i>Issued late pandemic (June 2020–     January 2021)</i>	4 (22%)	3.75
Updated plans	n = 17 (49%)	3.12
<i>Last updated early pandemic     (Feb–May 2020)</i>	5 (29%)	1.67
<i>Last updated late pandemic     (June 2020–January 2021)</i>	12 (71%)	3.43

with further analysis. Our data is available in an online-only appendix. Most coding decisions were straightforward, but the varying definitions of long-versus short-term survival required some deliberation. We ultimately chose to code a plan as incorporating long-term survival if it included allocation criteria considering survival beyond the NAM standard of “likelihood of death prior to or imminently after hospital discharge.” We interpret *imminently* in this context to refer to days or weeks, not months, after hospital discharge.

For purposes of our initial analysis, we split plans into two categories reflecting whether they had been updated since their initial issuance. We

constructed a Disability Rights Index Score reflecting alignment with disability rights policy preferences within a plan. The absence of exclusion criteria, the prohibition of long-term survival, the prohibition of resource intensity, the inclusion of reasonable modifications to clinical instruments, and the inclusion of chronic ventilator protections each constitute one point of five. Where CSCs do not incorporate long-term survival or resource intensity, but do not prohibit them, they receive a half point in the relevant domain. In addition, to reflect different processes of change as both advocates and policy makers developed greater expertise over the course of the pandemic, we noted the timing of plan issuance and revision and reflected two time-based categories for the purposes of subgroup analysis: early pandemic (February–May 2020) and late pandemic (June 2020–January 2021).

## Results

As reflected in table 1, 18 states had not updated their plans during our review period. Of these, nine dated from prior to the pandemic, five were issued in the early pandemic, and four in the late pandemic. Seventeen states had updated their plans over the course of the pandemic, with five having most recently updated in the early period and 12 in the late period. Index scores reflect that both updated and never updated plans had higher scores in the late period.

Table 2 reflects the split between plans that were updated and those that were not along each of the five domains. Chi-squared tests are used to assess whether the presence of a revision is associated with a significant difference in the CSC domain. We find that states that revised their CSC plans are significantly more likely to lack categorical exclusions ( $\chi^2(1)=5.93$ ,  $p=0.015$ ) and have specified reasonable modifications ( $\chi^2(1)=4.8043$ ,  $p=0.028$ ). Chronic ventilator protections approach significance ( $\chi^2(1)=3.44$ ,  $p=0.064$ ).

Table 3 provides a subgroup analysis looking at the timing of plan revisions, using Chi-squared tests to evaluate if plans revised later in the pandemic made significantly different choices than plans revised early in the pandemic. We also reflect two-tailed t-tests comparing each domain within the early and late categories to the never updated category. We find that plans that updated late in the pandemic are less likely to have categorical exclusions ( $\chi^2(1)=5.44$ ,  $p=0.02$ ), more likely to prohibit or not incorporate resource intensity ( $\chi^2(2)=10.12$ ,  $p=0.006$ ), and more likely to specify reasonable modifications ( $\chi^2(1)=6.20$ ,  $p=0.013$ ) than plans updated early in the pandemic. Our t-tests also indicate that plans revised early in the pandemic were similar to those never updated, while plans

**Table 2** Summary of Plans by If Updated (N = 35)

	Never updated plans n = 18	Updated plans n = 17	Total n = 35	$\chi^2$ test
Categorical exclusions				
Incorporate	9 (50%)	2 (12%)	11 (31%)	
Does not incorporate	9 (50%)	15 (88%)	24 (69%)	(1)=5.93, p=0.015*
Long-term survival				
Incorporate	11 (61%)	8 (47%)	19 (54%)	
Does not incorporate	6 (33%)	5 (29%)	11 (31%)	
Does not incorporate & prohibits	1 (6%)	4 (24%)	5 (14%)	(2)=2.34, p=0.311
Resource intensity				
Incorporate	6 (33%)	3 (18%)	9 (26%)	
Does not incorporate	10 (56%)	7 (41%)	17 (49%)	
Does not incorporate & prohibits	2 (11%)	7 (41%)	9 (26%)	(2)=4.28, p=0.118
Reasonable modifications				
No	13 (72%)	6 (35%)	19 (54%)	
Yes	5 (28%)	11 (65%)	16 (46%)	(1)=4.8043, p=0.028*
Chronic ventilator protections				
No	13 (72%)	7 (41%)	20 (57%)	
Yes	5 (28%)	10 (59%)	15 (43%)	(1)=3.44, p=0.064

*Note:* Column percentages for each category are reported in parentheses. Percentages may not total 100 due to rounding. \* p<0.05, \*\* p<0.01, \*\*\* p<0.001.

**Table 3** Timing of CSC Plan Changes

	Last update early in pandemic (February–May 2020) n = 5	Last update later in the pandemic (June 2020–January 2021) n = 12	Total	$\chi^2$ test comparing early and late
Categorical exclusions				
Incorporates	2 (40%) [p = 0.717]	0 (0%)* [p < 0.000]	2 (12%)	
Does not incorporate	3 (60%) [p = 0.717]	12 (100%)* [p < 0.000]	15 (88%)	(1) = 5.44, p = 0.02*
Long-term survival				
Incorporates	3 (60%) [p = 0.968]	5 (42%) [p = 0.313]	8 (47%)	
Does not incorporate	2 (40%) [p = 0.807]	3 (25%) [p = 0.634]	5 (29%)	
Does not incorporate & prohibits	0 (0%) [p = 0.324]	4 (33%) [p = 0.078]	4 (24%)	(2) = 2.19, p = 0.335
Resource intensity				
Incorporates	3 (60%) [p = 0.331]	0 (0%)* [p = 0.006]	3 (18%)	
Does not incorporate	2 (40%) [p = 0.573]	5 (42%) [p = 0.473]	7 (41%)	
Does not incorporate & prohibits	0 (0%) [p = 0.154]	7 (58%)* [p = 0.008]	7 (58%)	(2) = 10.12, p = 0.006**

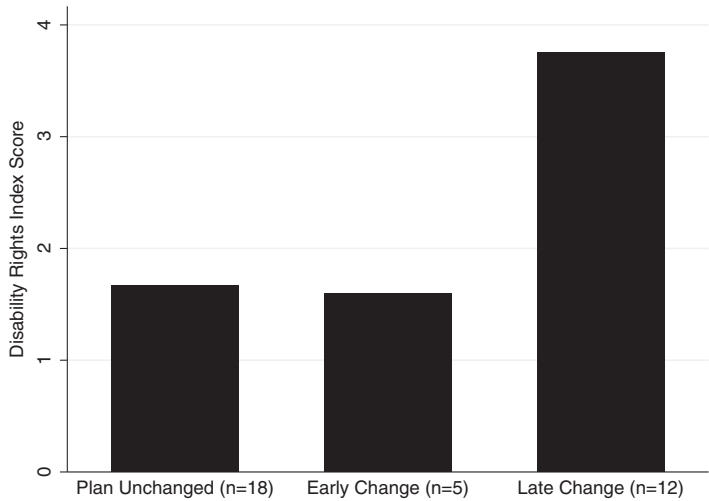
(continued)



**Table 3** Timing of CSC Plan Changes (*continued*)

	Last update early in pandemic (February–May 2020) n = 5	Last update later in the pandemic (June 2020–January 2021) n = 12	Total	$\chi^2$ test comparing early and late
Reasonable modifications				
No	4 (80%) [p = 0.735]	2 (17%)* [p = 0.001]	6 (35%)	
Yes	1 (20%) [p = 0.735]	10 (83%)* [p = 0.001]	11 (65%)	(1) = 6.20, p = 0.013*
Chronic ventilator protections				
No	3 (60%) [p = 0.651]	4 (33%)* [p = 0.037]	7 (41%)	
Yes	2 (40%) [p = 0.651]	8 (67%)* [p = 0.037]	10 (59%)	(1) = 1.04, p = 0.309

*Note:* p-values reflect t-tests for difference from the unchanged plan category. Chi-squared tests reflect differences between early and late pandemic. \* p < 0.05, \*\*\* p < 0.01, \*\*\*\* p < 0.001.



**Figure 1** Mean disability rights index score by if updated and update timing.

updated late in the pandemic were different from those never updated on every domain except long-term survival. Figure 1 reflects this graphically using our constructed Disability Rights Index Score.

We also reviewed within-state variation by reviewing 23 state plan revisions within 17 states (table 4). With the exception of New Mexico, Arizona, and Alabama adding long-term survival, and Vermont’s addition of categorical exclusions, all other revisions were toward greater alignment with disability rights priorities. We also reflect index scores for each new state plan and revision in order of release in figure 2, which reflects a shift toward greater alignment with disability rights priorities over the course of the pandemic.

Limitations

While our analysis compares states that never updated their CSCs to those that did, some states in the former group issued CSCs relatively late in the pandemic and were thus exposed to models and activist pressure that early states were not. The inclusion of early and late never-updated states in the same category may mean that we understate the extent of CSC policy evolution by using both early and late never-updated plans as a point of comparison with updated plans. To address this, we provide analyses showing change over time across all plans in the online-only appendix. These reflect

**Table 4** Changes within States during the Pandemic as of January 2021

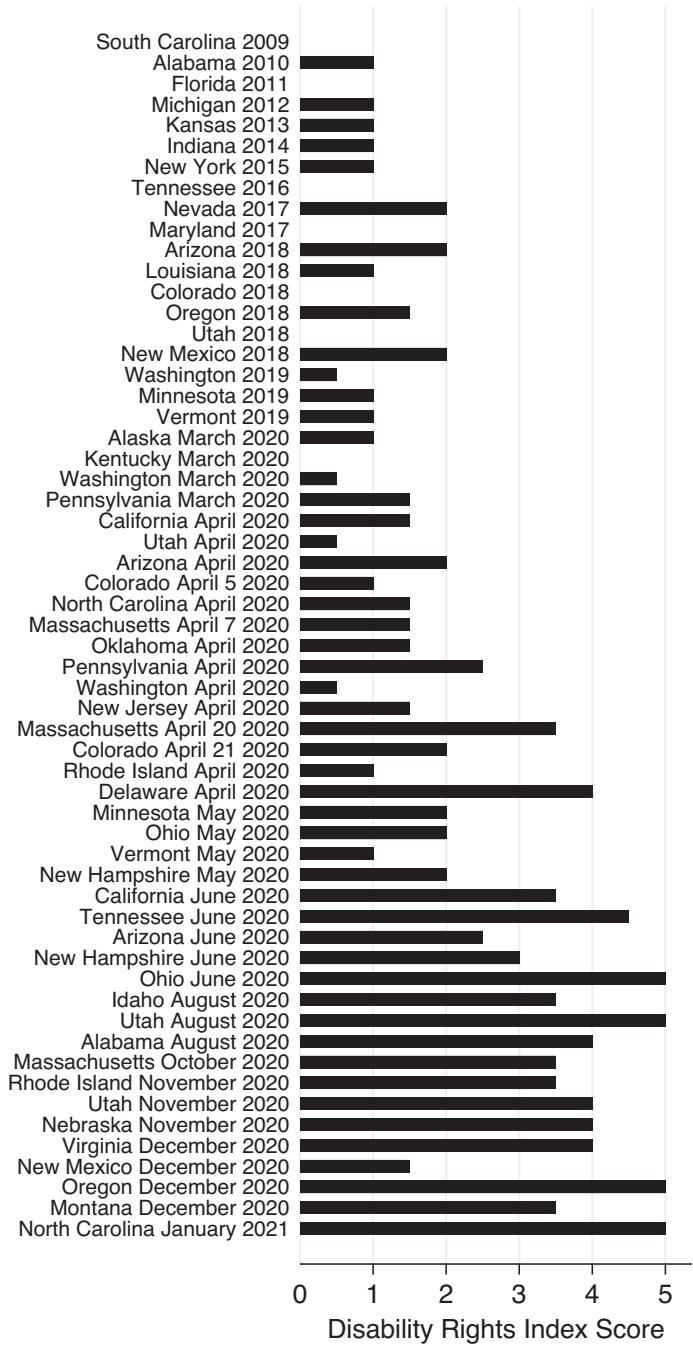
Greater Alignment with Disability Rights Positions			
	Exclusions added	Exclusions removed	
Categorical exclusions (8 modifications)	1	7	
	Provision added	Provision removed	Prohibited
Long-term survival (12 modifications)	3	5	4
Resource intensity (11 modifications)	0	4	7
	Protection removed	Protection added	
Reasonable modifications (11 modifications)	0	11	
Chronic ventilator protections (11 modifications)	0	11	

*Note:* Where plans were withdrawn without immediate replacement and included one of the provisions in question, we reflect this as removal.

similar results showing greater alignment with disability rights priorities over time, beginning from a worse pre-pandemic baseline.

While coding was relatively straightforward across most of our domains, determining how to code long-term survival in state CSC plans presented some difficult choices. States have defined short- and long-term survival differently. We chose a conservative approach, interpreting the NAM’s standard of “likelihood of death prior to or imminently after hospital discharge” as referring to a window of days or at most weeks after discharge, not months. We did so because we believe it is the appropriate standard. However, by sweeping both 10-year and 6-month survival windows into the same category, significant policy change within this domain likely went undetected.

We also note that some points of policy variation emerged too late to be included in our analysis. A growing number of states have adopted CSC provisions requested by disability groups designed to ensure that patients are not “steered” or pressured into consenting to the denial or withdrawal of life-sustaining care, including through advanced care planning decisions.



**Figure 2** Disability rights index scores over time.

This is an important area of both CSC and general end-of-life policy variation that we intend to explore in future work.

Some states have declined to issue CSCs, deferring to hospital systems and other providers to develop their own plans, a level of variation that our analysis does not capture. Finally, while we identified CSCs issued through January 2021, CSC policy is still evolving and we anticipate that further CSCs are likely to be issued that we do not capture.

### **Venue Shopping, Competing Frames, and Bioethics Policy Change**

Disability advocates have made significant progress in advancing their policy positions over the course of the pandemic, with the notable exception of long-term survival, which continues to be a source of concern for disability and racial justice activists. Our findings show that CSC plans revised later in the pandemic were more likely to align with disability rights priorities than those revised early in the pandemic or never revised. This pattern is consistent with growth over time in both the familiarity of state policy makers with disability rights concerns and the capacity of disability activists to influence public policy on a topic that has quickly moved from obscurity to prominence.

Disability advocates pursued a variety of avenues for advancing CSC policy changes. The website of the Center for Public Representation (CPR 2021), a disability group at the center of CSC advocacy nationally, references letters from advocates in 38 states and more than a dozen legal complaints. While some state plans describe collaborative processes through which policy makers and activists mediated disputes, negotiations took place against a backdrop of unprecedented advocacy mobilization and media interest in medical rationing, empowering activists to win victories that would not have been possible prior to the pandemic.

This raises important questions about the process of change in bioethics policy making. While much has been written about the merits of different CSC approaches (Bagenstos 2020; Emanuel et al. 2020; Ne'eman 2020; Persad 2020), little research has examined the processes by which they evolve over time. This is somewhat surprising. Though many CSC plans were influential at the start of the emergency, the extent to which nearly two decades of clinician-led CSC policy development proved of limited relevance as COVID-19 continued is genuinely shocking. Ideas that were considered central to CSC policy making prior to the pandemic, such as the use of exclusion criteria and resource-intensity judgments, have been removed and in some instances prohibited from use based on civil rights

concerns. While many CSCs adopted early or pre-pandemic do not yet reflect this progress, the December NAM statement reflected a major shift, endorsing disability-rights CSC priorities across the board. Though it may take some time for this progress to be consolidated across the country, the direction of policy making has changed dramatically. Exploring why may yield important insights on the nature of bioethics policy change more generally. Though we do not document the explicit process that led to CSC policy evolution in this article, the direction of these changes and the context within which they took place allow us to offer some suggestive hypotheses to help inform future work.

One potential explanation may simply be greater visibility. Pre-COVID-19 CSC policy debates did not attract the same level of mobilization. Even when activists were aware of CSC policy making and chose to devote scarce resources to a hypothetical threat, they were unlikely to have the same influence before COVID-19 placed CSCs in the media spotlight. Given the exigencies of COVID-19, clinicians are likely displaying more flexibility than they would have previously, as the need for regulatory certainty in a crisis may be more important than a preferred policy arrangement.

Whatever the reason, CSC policy making has witnessed a rapid evolution from an expert-led process rooted in the norms of clinical and academic bioethics to an arena in which clinicians and consumer stakeholders must mediate their disputes on a somewhat more equal playing field. While clinicians still have a central role in CSC policy making, they are now as likely to sit across from civil rights lawyers as they are moral philosophers. The venue of debate has changed, possibly permanently.

The political science literature has much to say about such transitions. Building on Robert A. Dahl's conception of a pluralist government made up of multiple overlapping but distinct domains of policy-making authority, Frank Baumgartner and Bryan Jones (1991) explored the process of "venue shopping" used by both industry and activist stakeholders to achieve a more favorable reception for their policy views. Such venue shopping seeks to "alter the roster of participants who are involved in the issue" by framing it as within the province of policy makers friendly to each side's priorities.

Baumgartner and Jones note that under pluralist arrangements industries may "insulate themselves from the influence of large-scale democratic forces through the creation of relatively independent depoliticized sub-governments" (1045). As an issue becomes more controversial, politicization ensues and the possibility of a change in venue becomes more plausible. They elaborate:

Technically complex issues . . . can be discussed either in terms of their scientific . . . details, or in terms of their social impacts. When they are portrayed as technical problems rather than as social questions, experts can dominate the decision-making process. When the ethical, social or political implications of such policies assume center stage, a much broader range of participants can suddenly become involved. Where a positive image dominates, specialists have strong arguments for demanding that political leaders grant them . . . autonomy. (1047)

However, when that positive image changes—perhaps as a result of increased public scrutiny in a crisis—an opportunity to shift venues and broaden the range of participants emerges.

Bioethics debates are uniquely well situated for venue shopping, as they cross multiple disciplines. It is rarely clear what policy makers have final responsibility for or which experts are most qualified to opine in bioethics disputes, not least because their typical combination of obscurity and controversy may not lend themselves to enthusiastic claims of ownership. Activists and providers who disagree on the substance of bioethics debates may play out such disagreements in part through disputes about which government agency or professional discipline has authority over them. Tensions between the civil rights and clinical frames to CSC policy may be best understood through this lens.

While it is certainly possible that the end of the public health emergency will mean a return to the status quo, it seems unlikely. Activists have built capacity that will persist. In the near term, it will likely be deployed to other COVID-19 priorities, such as vaccine allocation. In the long term, it may be used to address bioethics controversies unrelated to the pandemic, such as disputes about qualitative futility judgments or QALY-based rationing. Anthony Downs (1972) noted that issues that capture the public imagination are usually permanently changed, even after the public's attention moves elsewhere.

It is worth considering the rationale behind this venue shift and its implications for policy makers. With some exceptions (such as abortion), policy on controversial bioethics issues has usually been shaped by expert judgment, with legislators providing broad deference to clinicians and bioethicists to police their own behavior. Nominally, this is because of superior expertise to answer complex questions. But complexity is not the only factor that drives delegation.

Others have noted the risk that expert delegation may limit democratic accountability in the context of legislative delegation to executive branch

bureaucracies (Fox and Jordan 2011). Bioethics policy decisions involve a similar form of delegation, from traditional policy makers to experts in academia and medicine. As with congressional delegation, this can offer a mechanism to avoid controversial policy decisions. While complexity means some delegation is necessary, excess delegation is concerning.

Elected officials, appointees, and even civil servants are more likely to be responsive to stakeholder activism emphasizing the distributive consequences of bioethics policy. Delegation to experts deprives marginalized groups of an effective means of influencing policy that impacts their lives. Some maintain that this reduced democratic accountability is a positive feature, not a flaw, as it allows for more impartial, technocratic decision making by the bioethics profession. According to this thinking, resolving bioethics disputes via the political process fails to adequately represent the interests of those who are unaware they are at risk “while protecting the interests of a small group that is better positioned to organize” (Persad 2020: 48).

This argument might carry more weight if policy makers could delegate to truly impartial arbiters able to weigh the consequences of every policy choice without bias or self-interest. But in the real world, we must remember that clinical bioethics is not simply a field of intellectual inquiry. It is also a professional discipline with a distinct worldview and biases inherited from the medical profession and the broader society, which shape bioethicist views on disability (Iezzoni et al. 2021; Stramondo 2021). As Gregor Wolbring (2003) notes, mainstream bioethics often finds itself unsympathetic to disability rights claims in part because the field’s grounding in a medical framework primes its members to see disability only in medical terms, rather than the disability rights movement’s preferred civil rights frame (a distinction that reaffirms the importance of venue shopping in bioethics policy disputes). It should be noted that the field of bioethics is not a monolith. In part because of the aforementioned shortcomings, recent years have seen the emergence of a “disability bioethics,” informed by the disability rights movement’s values framework and the lived experiences of disabled people, intended to serve as a counter to more traditional “mainstream bioethics” (Stramondo 2021; Wolbring 2003). Analogous to similar feminist bioethics critiques, disability bioethics is deployed by its proponents to challenge the perceived excesses and errors of mainstream bioethics practice and to promote a civil rights frame in relevant discussions of bioethics disputes regarding disability.

In addition, because mainstream clinical bioethicists make decisions that can expose them and the providers that often employ them to legal risk,



they are incentivized to shape public policy to minimize liability. Policy positions advanced from this sector thus cannot be viewed as intellectual abstractions but must also be considered within the context of a profession that seeks to shape its own regulatory constraints. To be clear, bioethicists from many different backgrounds have much to contribute to policy debates through their specialized expertise—but the close relationship and overlap between mainstream clinical bioethicists and the broader medical profession means that policy makers should understand their advice as that of an interested stakeholder, akin to a labor union or industry group. Respect for professional expertise of those a policy maker is regulating is important—but absolute deference is inappropriate.

From this perspective, mainstream bioethicists should be seen as one stakeholder among many at policy tables convened to mediate bioethics disputes, rather than as the chair or convener. Policy makers should see themselves as mediators between a profession that offers substantive expertise but desires to minimize liability and consumer stakeholders that seek greater regulatory oversight to protect against discrimination. This is a not unfamiliar dynamic, similar to many other instances in which policy makers must mediate between industry and consumer stakeholders. While more difficult, policy-maker mediation is superior to expert delegation, for it offers a more transparent and accountable process with a greater likelihood of accounting for distributional consequences to marginalized groups.

The unprecedented public visibility given to CSCs as a result of the COVID-19 pandemic may have begun such process shifts, prompting a “change of venue” for bioethics policy making, but they are unlikely to end there. Policy makers that may have previously seen delegation to experts as a safe avenue for avoiding responsibility for difficult choices found themselves facing public backlash and potential legal liability for the CSCs they had previously endorsed. Deference to expert judgment on resource allocation will no longer seem the safe option it once was, even post-COVID-19. We theorize that when public backlash mitigates the political benefit of expert delegation, policy makers are more willing to directly mediate policy disputes between experts and consumer stakeholders, resulting in policy changes more closely aligned with the latter’s views.

While further research is necessary to validate these ideas, the process of change in state CSCs is consistent with them. Categorical exclusions, the most visible form of disability discrimination, were quickly removed from existing plans and left out of most new ones as media attention increased during the early phase of the pandemic, even though they

had been central to pre-pandemic CSC planning. Other disability rights priorities, such as prohibiting prioritization based on resource intensity and requiring reasonable modifications, were more common in plans issued later in the pandemic, after stakeholder groups developed greater expertise to influence policy makers. Regardless, CSC revisions regarding disability were almost always in favor of greater alignment with disability rights positions, suggesting that stakeholder engagement proved an effective avenue for modifying policies that were previously the exclusive domain of experts.

Subsequent inquiries should more closely examine public opinion and the process of bioethics policy change at the micro-level, looking closely at different venues for debate. Various experimental methods, such as conjoint analysis, may help explain the salience of different diagnoses and their intersection with other forms of marginalized identity.

COVID-19 has provided a vivid illustration of the stakes of bioethics policy. Our review suggests that the disability rights movement has had increasing success in influencing CSC policy as the pandemic has proceeded, though some of this influence is not yet reflected in plans that have not been recently updated. Further research should explore the process of bioethics decision making and the ways in which experts and other stakeholders conflict and collaborate in shaping policy.

■ ■ ■

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