Defending Disabled Life: Community Response to Crisis Standards of Care

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Introduction

- This is a story about 2020 and 2021, but it started **long before** and it is still playing out today.
- On the surface it was about resource management. In reality, it is about a fundamental moral question: does society believe that the lives of people with disabilities are **worth saving?**
- **Personal background:** in 2020 I was less than a year into my tenure as Executive Director of Disability Policy Consortium, where I started as an organizer in 2014. Pre-COVID, I'd be fighting the use of QALYs (more on them later) for a couple of years.

Before 2020: Singer, Transplants, and DNRs

- The **Crisis Standards of Care (CSC)** fight thrust issues into the spotlight that had been discussed in the health policy and health ethics fields for decades.
- Some philosophers like **Peter Singer** have long argued for healthcare rationing, based on assumption that life with a disability is less worth living.
- Treatments like **organ transplants** frequently **denied** based on unrelated disability, especially intellectual disability and mental health diagnosis.
- Some providers **pressure** disabled patients to sign DNRs, on the theory that some people might be better off not being kept alive

Before 2020: Quality Adjusted Life Years (QALYs)

- **Mathematical measure** used to establish the value of healthcare treatments. Used most frequently in drug pricing.
- Discounts years of **survival** using "disability weights"—ratio of assumed quality of life with a given condition to life with no disability. Determined by surveying general public, not people with the disability
- **Example:** A year of life with severe epilepsy (1 or more seizures per month) is weighted at 55% of the value of a nondisabled year[1]. A treatment that let someone live ten years longer with severe epilepsy would get credit for saving 5.5 QALYs.
- **The more disabled someone is judged to be, the less extending their life is worth**

1: Liu et al, "Estimated disability weights for the severity of health outcomes: a systematic review and meta-analysis" 2025

COVID-19 Onset: Shortfalls and Potential Rationing

- When the pandemic hit in earnest in 2020, it immediately became clear that supply of ventilators and ICU beds **might not be enough**.
- Immediate question: **who** would get turned away if some people had to be?
- **Scramble** to establish rationing criteria. Sometimes at individual hospital level, but states eventually step in.
- Committees established: physicians, medical ethicists, policymakers. Initially **no representation** from people with disabilities or patient groups.
- Different states go in different **directions**

The Key Question: What is the Goal?

- Are states trying to **maximize** fairness? Trying to prioritize saving certain groups? Are they trying to save the most lives? Are they judging some lives as more valuable than others?
- Fairest system is a **lottery,** but few people want this.
- Most people agree **saving children** is a priority. Some people also prioritize by profession, especially saving healthcare workers themselves
- Prioritizing by short-term survival: **save the most lives.** Assess who is most likely to survive with a ventilator but die without one and allocate accordingly. Does not consider long- term survival, but does still disadvantage some people with disabilities if they'd be less likely to survive with a ventilator.

Are Some Lives Worth More Than Others?

- Some states, including MA, go further, prioritizing ***long-term survival.*** Saving the most ***life years,*** not lives.
- Older people would be **deprioritized**
- People with disabilities/comorbid conditions that reduce their life expectancy would be deprioritized—**not** because they were less likely to survive COVID, but because they were assumed to have less long to live even if they fully recovered. Everything from diabetes and heart disease to paralysis and MS could reduce your chances.
- Some states go even further; Alabama standards **deny** all ICU COVID treatment to people with intellectual disabilities

Legal Challenges

- Disability rights orgs and civil rights organizations **file immediate legal challenges** against various states' standards to the Office of Civil Rights in the Department of Health and Human Services, alleging crisis standards violate the ADA. Most extreme ones lilke Alabama's are immediately overturned.
- Special credit goes to MA's own **Center for Public Representation**, which wins victories in multiple states.
- Threat of legal action also **bolsters** community action

Community Pressure

- Here in Massachusetts, **DPC** and **Disability Law Center** went on record in early March, **warning** healthcare policymakers that the community will not stand for discrimination.
- We worked through the media and elected officials to **draw attention** to discrimination. Credit to Congresswoman Pressley, who uses her position to call for the standards to be changed.
- **We mobilized community members** to contact healthcare policymakers to demand change.
- First standards were repealed without being used. Tweaked second version was reintroduced, but still **de-prioritized** those judged to have less than five years to live.

Community Victory

- Advocates and lawyers continued to **push back** against the 2nd version of standards as still discriminatory.
- We **demanded a voice** in deciding whether our lives will be protected
- After legal victory against another state with similar standards, MA's 2nd standards were also pulled.
- I, and other disability advocates were appointed to the committee that determines the 3rd standards. Discussions were tense; some members **genuinely did think our lives were less valuable.**
- Ultimately, 3rd standards only considered whether someone has six months to live or less. Added in important disability protections
- While MA activated standards, no one was actually denied care based on them. Some people are denied in other states

Michael Hickson Case and DNR Pressure

- **Michael Hickson** was a quadriplegic black man in Texas. His wife wanted to keep him on life support but was overruled by his doctor and a court because his quality of life was judged to be too low. She records him saying ***Michael might be better off dead than living in his present condition.***
- People with disabilities in multiple states are **pressured** to sign **Do Not Resuscitate** orders, waiving lifesaving treatment. Oregon actually has to pass a guardrail law because its so rampant
- In MA, we encountered a case of a woman whose doctor **unsuccessfully pressured her children** to sign a DNR for her and then got her to sign it without understanding what it was.

Vaccine Rollout

- Similar discussion happens in reverse for limited initial supply of COVID-19 vaccines: having been initially deprioritized for ventilators, would people with disabilities be **prioritized** for vaccines?
- Despite repeated requests from advocates, state initially used **extremely limited CDC list** for prioritization. **Excludes** things like spinal cord injury, cystic fibrosis, all IDD except for Down Syndrome, while including smoking and weight
- Policy **finally changed** a few weeks before being made available to general public.
- On the positive side, vaccination process was **much more accessible** thanks to community pressure. In-home options, accessible sites with interpreters

Where Do We Stand Today?

- **No guarantee** what standards would be used in the next crisis
- People with disabilities still get **discriminated** against for treatment
- **No legal guardrails** against pressure to sign DNRs
- Still calls to use **QALYs** to price treatments, can still be used by insurers to **deny care**

Solution: Healthcare Discrimination Legislation

- **S.869, An Act relative to preventing discrimination against persons with disabilities in the provision of health care.** First introduced in 2021 and reintroduced every subsequent session. Direct response to what we learned during the pandemic.
- Bans any **future crisis standards** from discriminating
- Bans the **use of QALYs** for healthcare decision-making while allowing alternative metrics.
- Bans **denying or deprioritizing** someone for treatment **based on disability**
- Introduces **DNR guardrails**
- Was favorably voted out of **Healthcare Financing**, but needs support

The CSC Ethos and Medicaid Cuts

- On a larger level, what we saw in HR1 and the rhetoric from the administration since is a **cruder version of the same thinking** behind the Crisis Standards of Care.
- Congress **slashed billions from Medicaid** while knowing that HCBS for people with disabilities would be cut.
- Targeting disability programs as wasteful and saying families should provide care for free is **equal (=)** to saying that our lives are not worth saving.
- The difference is that COVID was an actual emergency; there really were potentially not enough ventilators to go around. This is a **policy choice.**
- State legislatures still get to **decide what to do.** Their choices will be telling.

What Can We Learn From All This?

- **Many** healthcare policymakers—elected and appointed officials, medical ethicists, hospital officials, and even some doctors—do not think our lives are as worth living as the lives of nondisabled people.
- Healthcare is a **scarce resource** that can be denied to us if we don’t fight for it.
- Fighting **works**. Even in the midst of an unprecedented crisis, we took on the state and won. We can do that **again**.
- We must **frame the debate** in these terms. This is not an apolitical question of resource allocation. It is not about waste, or about tax savings. It is about whether policymakers think keeping us alive is worth the cost—and whether they can get away with saying no.