How Crisis Standards of Care Can Ensure Equity for People with Disabilities

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Disclosures

We have no financial relationships to disclose.
Outline

What are Crisis Standards of Care?
Why do we need them?
How do CSC work?
The problem: How might CSC perpetuate inequity?
Best practices and next steps
Questions and discussion

Objectives

Explain why we need CSC
Identify three ways in which existing CSC may discriminate against marginalized populations
Identify three ways in which to ensure greater equity in CSC-guided decisions
What are Crisis Standards of Care?

CSC “provide a roadmap for medical decision-making during catastrophic events”

-ASPR TRACIE

Why do we need CSC?

First come, first served
Provider choice
Status of CSC by state, as of August 2020

How do CSC work?

- **Exclusion**
  - Who is considered eligible

- **Acuity**
  - Who needs the scarce resource the most (SOFA, MSOFA)

- **Reallocation**
  - Likelihood of benefit
  - Who will benefit the most from receiving resources

- **Allocation**
  - Re-scoring at timed intervals
The problem: How might CSC perpetuate inequity?

Where are CSC most likely to be needed?
The problem: How might CSC perpetuate inequity?

Who is likely to be sicker on arrival?

Re-consider “objective” measurements of sickness:
How can SOFA be discriminatory?

The problem: How might CSC perpetuate inequity?

Who is less likely to survive >5 years?
What to do?

Best practices: How can CSC promote equity?

- **PLAN**
  - Coordinate

- **ACCESS**
  - Limit exclusion criteria

- **SCORING**
  - Use disease-specific measures of acuity
  - Consider disabilities
  - Omit long-term survival

- **TIE-BREAKERS**
  - Use a lottery
Best practices: How can CSC promote equity?

Coordinate
- Limit exclusion criteria
- Use disease-specific measures of acuity
- Consider disabilities
- Omit long-term survival
- Use a lottery

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Best practices:
How can CSC promote equity?

Use disease-specific measures of acuity

Coordinate Limit exclusion criteria Consider disabilities Omit long-term survival Use a lottery

Best practices:
How can CSC promote equity?

Consider disabilities (and SDOH)

Coordinate Limit exclusion criteria Use disease-specific measures of acuity Omit long-term survival Use a lottery
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What is the actual question?

Crisis Standards of Care are not a utility maximization problem.

They are an answer to one basic question: whose lives do we value?
Society systemically de-values the lives of people with disabilities

- Discrimination in housing, employment, and education
- Half of police killings, overrepresented in domestic violence
- Blocked from receiving organ donations
- QALYs literally devalue our lives.

Some state CSC blatantly discriminated

- Alabama: All people with ID/DD denied ventilators
- Utah, Tennessee: People with ALS, MS, SMA, Cystic Fibrosis denied ICU admission.
- Florida: Anyone with a neurological disorder requiring “lifelong assistance with most basic activities of daily living” excluded from all hospital admission.
- New York: Policy allowed seizure of disabled patients’ personal ventilators.
Some states were more subtle

Misuse of short-term metrics
   Glasgow Coma Scale
   Kidney function tests

Unjust long-term metrics: what are we trying to save?

Saving lives is equitable.
Saving life-years is not.
Saving lives is equitable. Saving life-years is not.

- Preserving years of life is superficially appealing
- Two major problems:
  - Metrics are wildly inaccurate
  - Short life expectancy is often the result of discrimination
- Result: in MA, thousands of people with disabilities would have been de-prioritized because of age or disability

The Community Fights Back

In MA, we objected early, often, and loudly.

Brought together disability and racial justice advocates.

Threats of legal action & national coordination forced two repeals of standards.

We finally got to the table.
Basis of non-discriminatory standards

A fair goal: **Save The Most Lives.**

Prioritize based on likelihood of Survival to Discharge.

No consideration of age or comorbidity except in as much as survival to discharge is affected.

CSC are far from the only problem

Discrimination was rampant at the provider and system level
Michael Hickson Case
Systemic discrimination in Oregon
Lack of Vaccine Priority

Ableism is rampant among physicians
Spinal cord injury study
Lisa Iezzoni Study
Standards must be **anti-discriminatory**

- Forbid consideration of “quality of life.”
- Institutionalize safeguards and provide for appeal
- Protect communication access
- Mandate bias training

**What Now?**

- Legislate before the next pandemic
- Forbid other forms of healthcare discrimination
- Start working *now* to address bias within the system.
References


Letter from the Massachusetts Coalition on Health Equity to Secretary Marylou Sudders calling for the reconsideration of the Massachusetts Crisis Standards of Care, April 17, 2020.


References (cont.)


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Questions? Discussion?

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