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# Testimony of Sheldon Toubman before the Public Health Committee in Support of SB1, with Amendments

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Senator Abrams, Rep. Steinberg and Members of the Public Health Committee:

My name is Sheldon Toubman and I am an attorney in the benefits and elder law units of New Haven Legal Assistance Association, where I mostly represent low income health care consumers. I am here to support SB1 intended to address health disparities, disparities which were always present but became painfully illuminated by the pandemic. While I overall strongly support SB 1, I have three concerns discussed below.

First, advocates for peer support services urge the striking of Section 2. They instead support the passage of HB 6588, which will allow for a meaningful and representative process that will inform further development of the peer workforce in Connecticut.

Second, there is concern with community representation on the reparations commission. For a group with such a mandate to have credibility, such representation is imperative.

Third, and what I will spend most of my time on, is what is **missing** from the bill, specifically, the needed mandate for DPH to finally issue long overdue guidance prohibiting the discriminatory rationing of healthcare in times of crisis.

- Some history: Beginning on March 25, 2020, early in the COVID-19 pandemic, groups representing people with disabilities formally requested that the Governor and the Department of Public Health issue uniform statewide guidance to all hospitals prohibiting discrimination in the rationing of health care, should that become necessary, in accordance with guidance issued by the U.S. Department of Health and Human Services Office for Civil Rights, and in light of the developing demand on hospitals.
- Because DPH failed to act, several Connecticut hospitals, acting to fill the void, issued their own highly problematic guidelines, which effectively discriminated against people with disabilities, older adults, and Black, brown, indigenous and Asian people.
- Some of the discriminatory provisions adopted by CT hospitals included: (1) the application of tests of likely survival for **five years** after discharge, a test directly discriminating against older people and Black and brown people with inherently shorter lifespans; and (2) the addition of extra points to triage scores (higher scores meaning lower priority to receive life-sustaining treatment) because an adult needed assistance with all activities of daily living or had a severe and irreversible neurological condition, or a child had a progressive neurological disorder.
- Once it was learned that hospitals were adopting rationing criteria which also disadvantaged older adults and Black, brown, indigenous and Asian people, other CT advocacy groups beyond disability advocates also called on DPH to issue uniform statewide anti-discrimination guidance. They also were concerned with hospitals issuing **no** guidance, and thus allowing implicit bias to drive decision-making in crisis situations.
- Despite repeated requests from now 39 advocacy organizations across Connecticut – some dating back nearly a year – DPH continues to refuse to act, potentially putting lives in danger in the absence of clear, consistent, uniform guidelines to prevent discrimination

in the event that rationing of life-sustaining treatments becomes necessary due to a vaccine-resistance variant of COVID-19 or other pathogen.

- While DPH suggested last summer and fall that some statewide guidance would be issued in March 2021, DPH now is merely suggesting the *possibility* of getting to it by the "end of 2021." The reasons provided by DPH for refusing to act have been inconsistent and implausible, from the demands of the pandemic making it difficult to act to an assertion there was no need for guidance because the worst of the pandemic had passed. They even included a claim made in January, 2021 that it would not be "rushed" into doing this—**10 months after it was first asked to act.**
- Most other states long ago, either before or shortly after the start of the pandemic, issued the kind of statewide guidance advocates are requesting of DPH. This includes states as diverse as California, Utah and Tennessee.
- While one CT hospital has adopted guidelines which address all of the advocates' concerns, the latest information provided by CT hospitals to DPH and shared with advocates shows the disparities and dangers of lack of a uniform state policy, with nearly two-thirds failing to include adequate policies to protect against discriminatory practices.
- Some hospitals have affirmatively discriminatory written guidelines, e.g., one declares that someone with "[a]dvanced or irreversible neurologic event or condition" does "not qualify for the provision of critical care or other scarce resources under consideration including the utilization of a mechanical ventilator," an express discrimination on the basis of disability.
- Based on this history, it is clear that, without a legislative mandate, no timely action will be taken by DPH to issue statewide guidance ensuring that uniform anti-discrimination protections are adopted by all state hospitals.
- The attached proposed language from the broad coalition working on issuance of this guidance addresses all of these concerns, and includes protections already adopted in other states and by one of CT's leading hospitals.

I urge you to pass favorably on SB1, but with Section 2 removed, the attached language requiring DPH to finally issue statewide anti-discrimination guidance added, and the membership of the reparations committee strengthened with community representation.

Thank you for the opportunity to speak with you today.

**New Language for SB 1 Requiring Department of Public Health Guidance Prohibiting Discriminatory Rationing of Healthcare by Hospitals**

Proposed New Sections:

**Section 1**. The Department of Public Health shall, *no later than July 1, 2021*, issue guidance to all Connecticut hospitals which shall require each hospital to promptly develop and place on its website within 15 days thereafter hospital-wide guidelines providing, in the event rationing of life-saving healthcare should become necessary for any reason, that:

a) consideration of disability, age, race or ethnicity is prohibited, independent of its impact on immediate survivability, as a factor in triage scoring protocols or in deciding who receives treatment.

b) age may not be used as a tie-breaker in considering such decisions.

c) consideration is only allowed regarding imminence of mortality in the hospital following treatment for the immediate acute crisis, with consideration of likely survival after discharge from the hospital prohibited.

d) all individuals must be deemed qualified for, and eligible to receive, lifesaving care, regardless of pre-existing medical conditions, disabilities or co-morbidities which do not bear on immediate survivability.

e) criteria that erect extra burdens on the ability of people with disabilities to access care, on the basis of their diagnosis or need for assistance with activities of daily living, are prohibited.

f) consideration of "quality of life" or "worth" of people with disabilities, or any other group of patients, is prohibited.

g) all decisions based on a Sequential Organ Failure Assessment (SOFA) or other triage scoring protocols must result from individualized assessments based on available objective medical evidence.

h) the SOFA or other triage scoring protocols must include reasonable accommodations/ modifications of the protocols for people with disabilities in order to ensure that they are evaluated based on their actual immediate mortality risk

i) resource-intensity and duration of need on the basis of age or disability may not be used as criteria for the allocation or re-allocation of scarce medical resources

j) removal of medical equipment belonging to a patient upon admission, for reallocation to another patient, is prohibited.

k) patients may not be steered into agreeing to the withdrawal or withholding of life-sustaining treatment as a condition of receiving services; patients shall receive information on the full scope of available life-saving treatments; and hospitals may not impose blanket "Do Not Resuscitate" policies for reasons of resource constraints.

l) there shall be a well-publicized appeals process available for any patient or their representative in disagreement with the results of a treatment rationing determination made with respect to that patient, with life-saving treatment provided during the pendency of any appeal, and a decision rendered within three days of the filing of the appeal.

m) the patient and known representative of the patient shall be notified immediately whenever a determination to deny treatment is made pursuant to the SOFA or any other triage scoring protocols, which notification shall include information about the means to access the appeals process.

**Section 2.** Prior to issuing the guidance provided for in the above section, the Commissioner of Public Health shall review guidance issued by the U.S. Department of Health and Human Services' Office for Civil Rights and by other states for best practices and shall consult with advocates for older adults, people with disabilities and Black, brown, indigenous and Asian health consumers in the state for input on the details of the guidance document.