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**Testimony of Holly Simone**  
**Joint Committee on Health Care Financing**  
**Tuesday, November 9, 2021**  
**S. 745/H. 1256 An Act relative to preventing discrimination against**  
**persons with disabilities in the provision of health care**

Good Morning Chair Lawn, Chair Friedman, and Honorable Committee Members.

My name is Holly Simone I serve as the Chairperson of the Massachusetts Developmental Disabilities Council. The Council an independent state agency that is federally mandated by the Developmental Disabilities Assistance and Bill of Rights Act to empower intellectually and developmentally disabled people and their families to help shape policies that impact them. I am a Mother of two disabled children, and also a Commissioner for the Somerville Commission for Persons with Disabilities. I am here because this bill, S. 745/H. 1256 An Act relative to preventing discrimination against persons with disabilities in the provision of health care, would make a profound difference in preventing discrimination in the Commonwealth and all that flows from it.

Between May 2020 and March 2021, the lives of my daughter Elizabeth, my mother Sybil, and my father Kemon tragically ended. In their lives and deaths, they all experienced discrimination related to health care, including basic diagnostic testing and treatments during the surge of COVID 19. They suffered painful inhumane deaths, and they were all disabled. This bill is one step towards shifting societal biases and ensuring disabled people are treated with dignity and not denied essential medical care because of their disabilities.



*My two daughters, Ava and Elizabeth*

**Discrimination towards disabled people in the provision of health care was happening years before the pandemic.** My daughter Elizabeth was non-verbal, deaf-blind, and required 24/7 nursing to support her complex medical needs and afford her the opportunity to thrive in her



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community. She was gifted in many ways, yet her access to quality health care was repeatedly withheld during her 18 years of life. She was denied quality health care because of the inherent bias towards disabled persons in the medical community.

Many years before her death, Elizabeth was in excruciating pain that triggered long and repetitive seizures. Gallstones were found, yet the lab results did not support emergency surgery, and her disposition to pain was not to cry or express outward feelings of distress. Based on these datapoints we were told she would have to wait for the procedure. When I challenged the decision of the surgical team; the attending surgeon abruptly walked into Elizabeth's ICU room and screamed at me: "This is not an emergency therefore I will not perform emergency surgery today." I pleaded to discuss this further explaining to the doctor about her inability to express pain and that not having baseline lab comparisons should not rule her out for surgery. He then repeated what he said before adding "and Lady, I don't fix crazy!" Elizabeth's nurse and another doctor were in her room during this exchange.



*Elizabeth during a hospitalization*

Due to scheduling errors and pushback from her urologist, Elizabeth was discharged home in unbearable pain, and experienced elevated seizures. By the time the gallbladder was removed a month later, there were so many stones that they were growing outside of her gallbladder and impairing her liver.

**Massachusetts' Crisis Standards of Care would have discriminated against my daughter because of her disability.** We are beyond lucky that the crisis standards of care Massachusetts adopted never went into effect, even the version revised in response to advocacy from the disability community and BIPOC advocates. The October 2020 Massachusetts crisis standards of care described health care providers "choose" who is worthy of critical care and scarce resources. Had they gone into effect, the standards would have required triage teams to predict individual patients' likelihood of death within one year.<sup>1</sup> People would then have been placed in color coded groups that determine what priority they got.

**On a good day, Elizabeth's disabilities would have prevented her from receiving critical care under the crisis standards of care that Massachusetts adopted. But my daughter's life was worth saving.** Life is precious and everyone deserves joy. Under the Massachusetts standards, Elizabeth would have been labeled "Yellow" and denied critical care. The fact that the state would even have this crisis standards of care policy and be prepared to use it suggests my daughter's life

<sup>1</sup> Mass. Dept. of Pub. Health, Exec. Office of Health & Hum. Servcs, *Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic* April 7, 2020 (revised April 20, 2020; October 20, 2020), at 11 <https://www.mass.gov/doc/crisis-standards-of-care-planning-guidance-for-the-covid-19-pandemic/download> ("Patients who are more likely to survive with intensive care are prioritized over patients who are less likely to survive with intensive care. Patients who are not expected to die within one year due to advanced underlying medical conditions are given priority over those who are expected to die within one year due to such advanced conditions.").

was not valued, not because of her individual situation but because of false assumptions about the quality of her life and inaccurate, biased convictions about her diagnosis.

**Even *without* the crisis standards of care technically in effect, Elizabeth was treated as if they were and was denied medical care during her last hospital admission in spring of 2021.** They let her die and she didn't have to – she had been sicker than she was during this admission for years. Her symptoms during her final hospital admissions during the pandemic were treatable, but she didn't get the treatment.

This was Elizabeth's path during her final hospitalization: Overnight she was given a toxic dose of a medication to reduce her seizures, which caused her to stop breathing. I was never informed about the decisions made following this event. I watched in shock as gloves were removed from her room and staff no longer wore PPE around her, though they continued to do this everywhere else in the hospital. They even told us they were running out of gloves and we cannot have gloves in the room any more. Lab testing reduced from twice daily to none due to lack of supplies, and I had to advocate for treatment based on the results that were coming in. When I asked why they stopped doing labs they said they had to conserve lab resources due to COVID and they additionally refused to send out the genetic testing that was being recommended by her geneticist to improve her care. X-Rays and ultrasounds stopped, and eventually she was sent home to reserve ICU beds for COVID cases. In person hospice care at home became very limited and they were unable to even get me needed supplies. I spent the morning of her death fighting with a pharmacy over a billing confusion for a medication to ease her pain. I had no warning and hospice did not tell us her death was imminent. I missed the opportunity to hold her that day.

Even though the crisis standards of care were not technically being used by the hospital, I believe that because of the pandemic Elizabeth did not receive the proper care and treatment because of her disability and that this contributed to her death. **A child who was disabled died during COVID because of her disability.**

**S. 745/H. 1256 would prevent discrimination like Elizabeth experienced in her life and death in the future, and would help would make sure people like my daughter are not wrongfully denied access to lifesaving treatment in a crisis, or in her lifetime.** This has far-reaching implications for the disability community and for BIPOC communities who are at risk of being denied life-saving care under crisis standards of care<sup>2</sup> as others testifying today will describe in detail. Though data is scarce and inconsistent, we know that developmentally disabled people are at higher risk for COVID-19.<sup>3</sup> If developmentally disabled people and BIPOC communities are at

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<sup>2</sup> See, e.g., *Crisis Standards of Care in the USA: A Systematic Review and Implications for Equity Amidst COVID-19* Emily C. Cleveland Manchanda, Charles Sanky and Jacob M. Appel, [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7425256/pdf/40615\\_2020\\_Article\\_840.pdf](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7425256/pdf/40615_2020_Article_840.pdf) (“[Crisis Standards of Care] may disproportionately impact disadvantaged populations due to inequities in comorbid condition prevalence, expected lifespan, and other effects of systemic racism.”).

<sup>3</sup> Asst. Sec. Planning & Evaluation, U.S. Health. Hum. Servs., *COVID-19 Data On Individuals With Intellectual And Developmental Disabilities*, Jul. 2021, [https://www.aspe.hhs.gov/sites/default/files/2021-07/COVIDIDDIB\\_0.pdf?\\_ga=2.23697274.1577210359.1627308546-1609936077.1583937637](https://www.aspe.hhs.gov/sites/default/files/2021-07/COVIDIDDIB_0.pdf?_ga=2.23697274.1577210359.1627308546-1609936077.1583937637) (“Individuals with intellectual and developmental disabilities (ID/DD) are at greater risk for infection and adverse health outcomes due to COVID-19 than individuals without ID/DD for a variety of reasons, including a high prevalence of underlying medical conditions; difficulties accessing information, understanding or practicing preventative measures, and communicating symptoms of illness; and residing in a congregate care setting.”).

greater risk of severe COVID-19, they will get fewer resources under crisis standards of care, deepening inequities for all.

I am angry that my vocabulary now includes the term “life-cycle-based allocation.” All I see is Yellow. I will conclude by sharing what I see as the most unforgivable rationale for devaluing life – using disability as a benchmark of non-survival. Elizabeth’s life was measured by quality not quantity. She was deserving of care.

Sincerely,

/s/

Holly E. Simone  
Chairperson



*Together with Elizabeth.*