



Commonwealth of Massachusetts
Massachusetts Developmental Disabilities Council

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Testimony: Lydia Brown
To the Joint Committee on Public Health
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H 3271: An Act concerning nondiscrimination in access to organ transplantation

Dear Chairpersons and Committee Members,

Thank you for giving me the opportunity to address you on H 3271: An Act concerning nondiscrimination in access to organ transplantation. My name is Lydia Brown and I am the Chairperson for the Massachusetts Developmental Disabilities Council. The Council is federally mandated to educate policy makers on both the state and federal level about the intent of legislation and its impact on people with developmental disabilities. In addition, the Council works to improve the system of supports for individuals with developmental disabilities and their families by bringing together lawmakers with advocates to make sure people with developmental disabilities are included in decisions about public policy.

People with disabilities face pervasive stigma and prejudice—in the world of disability activism, we call this insidious phenomenon “ableism.” Like other forms of institutionalized prejudice, ableism is a system of values about which bodies and minds should be considered “normal,” “healthy,” and “desirable” and conversely, which bodies and minds should be considered defective, inferior, unhealthy, and undesirable. This value system does not rely on any individual person’s explicit, conscious, or malicious intent toward people with disabilities. Instead, it is institutionalized within unquestioned attitudes and assumptions that inform medical, legal, and social policies and procedures.

In March 2013, the Autistic Self Advocacy Network (ASAN) published a report documenting widespread discrimination against disabled people in need of life-saving organ transplants. Doctors whose first and foremost concern ought to be the holistic wellbeing of their patients are subject to the same prejudices as the rest of society. Based on prejudicial stereotypes and assumptions about the quality of life that disabled people experience, doctors may make discriminatory decisions at every stage of a patient’s experiences with the organ transplantation process. From consultation to referral all the way to determination of eligibility and placement on waiting lists, people with disabilities face a terrifying reality—that their healthcare providers, charged with their treatment and care, may decide that they should not access this lifesaving treatment or that they have less right than people without disabilities.



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In the same month as the ASAN report, the United Kingdom released the final report of a three-year study on medical discrimination resulting in premature and preventable deaths of people with mental disabilities. Their investigative team uncovered over 1,200 cases where doctors made more rapid life-and-death decisions for patients with mental disabilities or else issued do-not-resuscitate orders solely on the basis of disability status. In Massachusetts, our own Brandeis University's Lurie Institute on Disability Policy has long researched disparities in healthcare service delivery and outcomes for people with disabilities. Even the most well-intentioned doctors who harbor no conscious bias toward people with disabilities are susceptible to socially pervasive ableist attitudes that can and do unduly influence medical decisions.

Unfortunately, many people with disabilities who experience discrimination, abuse, and neglect in medical settings never have the opportunity to share their stories or have their voices heard. Nevertheless, we know of many cases in which people with disabilities have been unjustly denied access to lifesaving organ transplants. We know of Mia Rivera, a toddler who was initially denied a kidney transplant in January 2012 because she has an intellectual disability; Paul Corby, who was denied a heart transplant in August 2012 because he is autistic in a decision that was never reversed; and Anthony Stokes, who was initially denied a heart transplant in August 2012 because he was labeled "noncompliant," potentially due to learning disabilities.

Some unscrupulous medical professionals may raise concerns that people with certain disabilities, particularly those who have significant cognitive and intellectual disabilities, may be unable to fully participate in decision-making processes about their medical treatment, or to comply with post-transplantation treatment regimens. Others may speculate about the capacity of the potential transplant recipient to contribute to society. These concerns are rooted in baseless and outdated assumptions about people with disabilities. With appropriate supports and accommodations, people with disabilities can participate in their own treatment decisions and manage their own post-surgical treatment regimens. Given the supports and services necessary to maintain a lifestyle in accordance with an individual's own goals and desires, people with disabilities can participate fully and equally in their own communities and society at large.

Based on the Massachusetts Developmental Disabilities Council's analysis, H. 3271 would amend our current laws on organ transplantation by explicitly prohibiting discriminatory decisions on the basis of disability status, except in the few cases where a person's specific disability has a direct bearing on their medical suitability as a transplant candidate. While legislation cannot eliminate discriminatory attitudes or unconscious and implicit biases, this bill could potentially save the lives of people with disabilities in need of lifesaving organ transplantation by creating legal protections for those most in need of equal access and opportunity. I appreciate the opportunity to educate Committee members about the intent of H. 3271 as it impacts people with disabilities. The Council welcomes the opportunity to schedule a follow up meeting with members if additional questions arise.

Thank you,
Lydia Brown
Chairperson
The Massachusetts Developmental Disabilities Council