

3/27/2025

Senator Donna Bailey, Chair Representative Kristi Mathieson, Chair Joint Standing Committee on Health Coverage, Insurance and Financial Services Cross Office Building, Room 220 Augusta, Maine 04333

Re: Testimony in Support of LD 1055, An Act to Prohibit Discrimination in Access to Anatomical Donations and Organ Transplants

Dear Senator Bailey, Representative Mathieson, and Members of the Joint Standing Committee on Health Coverage, Insurance and Financial Services:

My name is Barrett Littlefield and I am a senior staff attorney at Disability Rights Maine. DRM is Maine's designated Protection and Advocacy Agency, and our mission is to advance justice and equality by enforcing rights and expanding opportunities for people with disabilities in Maine. Thank you for this opportunity to provide testimony in support of LD 1055.

Persons with disabilities encounter widespread stigma and prejudice. While the Rehabilitation Act of 1973 prohibits discrimination on the basis of disability by federally-funded entities, and the Americans with Disabilities Act of 1990 expanded the scope of said protection, ableism continues to permeate medical decision-making, making the often Sisyphean task of accessing necessary medical treatment all the more difficult, and occasionally unreachable, for persons with disabilities. Evidence of such ableism in the organ transplantation system has been well documented.¹ Self-advocates' have made significant progress in the push to end disability discrimination in the aforementioned area of medical decision-making;² their efforts have supported the

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¹ National Council on Disability, *Organ Transplant Discrimination Against People with Disabilities*. 25 Sept. 2019, www.ncd.gov/report/organ-transplant-discrimination-against-people-with-disabilities.;

Ne'eman, Ari, et al. "Organ Transplantation and People With I/DD: A Review of Research, Policy and Next Steps." *ASAN*, policy brief, 2013, <u>www.autisticadvocacy.org/wp-content/uploads/2013/03/ASAN-Organ-</u> <u>Transplantation-Policy-Brief</u> 3.18.13.pdf.

² Bunici, Ashley. "A Conversation with Charlotte Woodward: Disability Policy Trailblazer." *NACDD*, 4 Sept. 2024, <u>www.nacdd.org/a-conversation-with-charlotte-woodward-disability-policy-trailblazer</u>.

passage of largely bipartisan legislation aimed at preventing said discrimination in forty states. Nonetheless, negative biases and erroneous assumptions about the worth and quality of life of persons with disabilities continue to prevent persons with disabilities from receiving equal access to life-saving organ transplantation. LD 1055—by defining how and under what circumstances a person may commence a civil action for injunctive or equitable relief when faced with disability discrimination while navigating or seeking to access the organ transplant system—ensures person who are subjected to said discrimination by a health care facility of provider have a clearer path towards justice.

For the foregoing reasons, DRM supports LD 1055, and we urge this Committee to vote ought to pass. Thank you for your time and consideration.

Sincerely,

RH L+l

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