

March 16, 2021

RE: HF 1080 Written Testimony

Chair Stephenson, Vice Chair Kotyza-Witthuhn, and members of the House Commerce Finance and Policy Committee:

“Organ transplants save lives. But for far too long, people with disabilities have been denied organ transplants as a result of unfounded assumptions about their quality of life and misconceptions about their ability to comply with post-operative care” I didn’t write this quote – The National Council on Disabilities did in their September 2019 report entitled “Organ Transplants and Discrimination Against People with Disabilities” This report was the first in a five-report series on the intersection of disability and bioethics.

Just this January, the Office of Civil Rights announced an issuance of a Request for Information on disability discrimination in health care stating they’d become aware that significant discrimination on the basis of disability may still exist – among other things, it identified organ transplantation discrimination and value assessment methodologies, including by use of measures that assign percentage values to the lives of individuals or groups of individuals with disabilities due to their disability or judgments regarding quality or relative worth of life”

Minnesotans facing organ transplant discrimination on the basis of disability should have some recourse at the federal level because of American with Disabilities Act and other federal legislation, however they’d have to fight that fight in federal court...a process that can take years....time is a luxury that potential transplant recipients do not have. A Minnesota law would allow individuals facing discrimination to challenge the discrimination in local court, and get priority on the docket.

16 states have already passed similar legislation. 17 others are trying to pass legislation this year. We would like Minnesota to be one of them.

The most appropriate considerations for organ transplant are organ and patient survival. Research shows there is no substantial difference in patient or organ survival between those with and without intellectual or developmental disabilities. Multiple studies have shown that patients with developmental or intellectual disabilities and appropriate post-transplant support have outcomes comparable to those of children without disabilities.

Thank you,

Sarah Curfman

Executive Director of the Down Syndrome Association of Minnesota