



March 17, 2021

House Committee on Commerce Finance and Policy
509 Rev. Dr. Martin Luther King Jr. Blvd
St Paul, MN 55155

Re: HF 1080

Dear Chair Stephenson, Vice Chair Kotyza-Witthuhn and Members of the Committee:

As the leading human rights organization for all individuals with Down syndrome, the National Down Syndrome Society (NDSS) strongly supports the passage of HF 1080 which will ensure fairness in organ transplants for people with disabilities.

Despite federal protections, such as the Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1973, people with disabilities still face discrimination determining eligibility to receive organ transplants. Providers often have a misconception that people with disabilities, especially those with intellectual and developmental disabilities (IDD), are unable to manage complicated post-operative treatment. Providers may also assume that people with disabilities have a lower quality of life than those without disabilities and would not benefit from life-saving transplants.

A study by Stanford University showed that 85 percent of pediatric transplant centers consider intellectual or developmental disabilities when determining eligibility for transplants. Additionally, 71 percent of heart programs also consider disabilities as a factor.¹

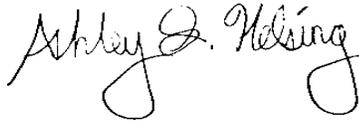
This crucial legislation clarifies that doctors, hospitals, transplant centers and other health care providers are prohibited from denying access to necessary organ transplants solely based on a qualified individual's disability. Additionally, this bill requires that, when evaluating the likelihood of a transplant's success, health providers consider the full range of supports available to help a person with a disability manage their post-operative care. The bill also includes a fast-track procedure for challenging discrimination to ensure that people in urgent need of an organ transplant obtain timely resolutions to their claims.

There are currently laws against organ transplant discrimination in the states of California, Delaware, Florida, Indiana, Iowa, Kansas, Louisiana, Maryland, Massachusetts, New Jersey, Ohio, Oregon, Pennsylvania, Virginia and Washington.

¹ Richards CT, Crawley La Vera M, Magnus D. Use of neurodevelopmental delay in pediatric solid organ transplant listing decisions: Inconsistencies in standards across major pediatric transplant centers. *Pediatric Transplantation* 2009;13:843–850

We hope that Minnesota is committed to eliminating discrimination based on disability. This bill is a positive step in that direction and will save so many lives. Thank you for your leadership.

Sincerely,

A handwritten signature in black ink that reads "Ashley S. Helsing". The signature is written in a cursive style with a large, looping initial 'A'.

Ashley Helsing
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