



August 3, 2022

Dear Chairman Wyden and Ranking Member Crapo:

On behalf of the Down syndrome community, we wish to thank you for holding a hearing on addressing the organizational failures of the United States' organ procurement and transplantation network. We look forward to working together to address this critical issue, particularly as it affects individuals with intellectual and developmental disabilities. As you consider improvements to the system, we urge you to recognize that the lives of individuals with disabilities have equal value to the lives of people without disabilities, so they deserve equal access to organ transplants. We ask that you advance meaningful solutions to address systemic discrimination against individuals with disabilities found at all levels of the organ procurement and transplantation network.

Organ transplants are a key part of our nation's health care system. They save lives every day. Unfortunately, people with disabilities have consistently been denied organ transplants in the United States based on unfounded assumptions on their quality of life and ability to comply with post-operative care. This is in direct violation of the Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973, and Section 1557 of the Affordable Care Act, which prohibit discrimination on the basis of disability.

Despite these existing overarching protections, real-world discrimination persists. The National Council on Disability (NCD) recently reviewed applicable federal and state laws, the disability-related policies of various organ transplant centers, and policies of the Organ Procurement and Transplantation Network and issued a report in September 2019.¹ The report found that people with disabilities are frequently denied access to organ transplants based on written and unwritten policies excluding people with disabilities as organ transplant candidates, even in the nine states that, at the time, had state laws in place prohibiting such practice. Furthermore, some medical professionals even refused to evaluate a patient's medical suitability for organ transplant because of their disability.

In our community, the threat of discrimination in organ transplantation presents a real-world danger. About 50% of all people born with Down syndrome have congenital heart disease, which often requires heart surgery and, if unsuccessful, can lead to the need for transplantation. Last year, NDSS learned of Zion Sarmiento, a baby born in June with Down syndrome in Florida. Zion had a congenital heart defect and underwent multiple surgeries, but ultimately, he needed a transplant to survive. Despite Florida having passed a state-law prohibition of disability discrimination in organ transplantation, effective July 1, 2020², Zion was unable to access a transplant and tragically passed away in October. He was less than four months old.

While progress has been made since NCD issued their report, including the passage of laws in 34 states,³ this patchwork does not adequately ensure individuals with disabilities are protected because the organ transplant ecosystem, as a whole, is firmly interstate. **We therefore strongly urge the Committee to support consideration and passage of the Charlotte Woodward Organ Transplant Discrimination Prevention Act**

¹ National Council on Disability. (2019). *Organ transplant discrimination against people with disabilities*. Retrieved from https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf

² Florida CS/HB 1179 (2020) <https://www.myfloridahouse.gov/Sections/Bills/billsdetail.aspx?BillId=69420>

³ National Down Syndrome Society. (2022). *Organ transplant discrimination state laws*. Retrieved from https://www.ndss.org/advocacy#p_health

(S.3301), which would prohibit discrimination against people with disabilities who need organ transplants, upholding, clarifying, and building upon rights established in the Americans with Disabilities Act of 1990, Sec. 504 of the Rehabilitation Act of 1973, and Sec. 1557 of the Affordable Care Act. This commonsense legislation is bipartisan in both chambers (with H.R.1235) and has no fiscal impact.

NDSS is eager to partner with you as the Committee explores and develops meaningful policies to improve the nation's organ transplant ecosystem, including protecting the civil rights of individuals with disabilities. For more information, please contact Bartholomew N. Devon, senior director of public policy, at bdevon@ndss.org.

Sincerely,

A handwritten signature in black ink that reads "Kandi Pickard". The signature is fluid and cursive, with a large loop at the end of the last name.

Kandi Pickard
President and CEO

The National Down Syndrome Society (NDSS) is the leading human rights organization for all individuals with Down syndrome. NDSS envisions a world in which all people with Down syndrome have the opportunity to enhance their quality of life, realize their life aspirations, and become valued members of welcoming communities.