

Disability Rights Nebraska

Protection and Advocacy for People with Disabilities

March 19, 2020

Dear Senators:

Disability Rights Nebraska is the designated Protection and Advocacy organization for people with disabilities in Nebraska, writes to support consideration of LB 994.

The National Council on Disability conducted a study of the discrimination claims regarding organ transplants and people with disabilities.¹ Their study found that:

“...many organ transplant centers have policies that bar or caution against placing people with HIV, psychiatric disabilities, or intellectual and developmental disabilities (I/DD) on the waiting list to receive an organ transplant.” (see page 1 “Letter of Transmittal”)

Moreover, the Washington Post reveals in 2017² that people with disabilities encounter discrimination in some transplant programs, given the wide latitude these programs enjoy regarding who shall receive an organ transplant:

“In fact, mentally disabled people are turned down for organ transplants often enough that their rights are a rapidly emerging ethical issue in this corner of medicine, where transplant teams have nearly full autonomy to make life-or-death decisions about who will receive scarce donor organs and who will be denied.

Beyond some restrictions imposed by laws such as the Americans With Disabilities Act, the doctors, nurses, psychologists and social workers at 815 U.S. transplant programs are free to take neurocognitive disabilities such as autism into consideration any way they want.

As a result, there is wide variation from program to program. Some teams weigh mental and psychological issues heavily in deciding whether someone should be eligible for the precious gift of a heart, liver, kidney or lung. Others do not. A few even admit that they automatically rule out people with certain disabilities. Some patients are rejected at one medical center but accepted at another.” (emphasis added)

Disability Rights Nebraska recommends advancing LB 994; at a minimum, given the unique nature of this truncated session, the legislature should give robust discussion of the proposal components in a subsequent session or over the interim. The Unicameral is in a unique position to answer the question(s) about how transplant recipients are decided and the extent to which Nebraskans with disabilities encounter discrimination regarding organ transplants.

If there are further questions or comment, please feel free to contact me at your earliest convenience: brad@drne.org or 402-474-3183.

Sincerely,

Bradley A. Meurrens, MPA

Public Policy Director

¹ National Council on Disability (2109). *Organ Transplant Discrimination Against People with Disabilities*, September 25, 2019. Available at https://ncd.gov/sites/default/files/NCD_Organ_Transplant_508.pdf

² Bernstein, L. “People with autism, intellectual disabilities fight bias in transplants”, Washington Post, March 4, 2017, available at https://www.washingtonpost.com/national/health-science/people-with-autism-intellectual-disabilities-fight-bias-in-transplants/2017/03/04/756ff5b8-feb2-11e6-8f41-ea6ed597e4ca_story.html

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