## **Disability Rights Nebraska**

Protection and Advocacy for People with Disabilities

May 11, 2021

Dear Senators:

Disability Rights Nebraska supports the underlying bill LB 376 and the Committee Amendment AM 1307.

Living with a disability is expensive. Some have estimated the annual cost per family with children with disabilities is approximately \$10,830<sup>1</sup> and these costs can have "a deleterious long-term impact[s] on family finances, including later life asset accumulation and financial security"<sup>2</sup>. Many families who have children with disabilities rely on Nebraska's Medicaid waivers to sustain the health and life of their child. Beyond the direct impact on the health and safety of the child, the importance of the Medicaid waiver for these families cannot be overstated: "Henning said losing waiver services could force her family to make tough decisions, such as whether to divorce or quit working so the whole family could qualify for Medicaid. Another option would be to admit Connor to a nursing home or to leave Nebraska altogether."<sup>3</sup>

Disability Rights Nebraska supports LB 376 as it would help families supplement the services received through the waiver. Additionally, the bill would re-orient the test of eligibility to the child's assets/income not the parents'-- the method originally used to determine waiver eligibility. When Nebraska changed this eligibility evaluation to the parents' income, many families were deemed ineligible for waiver services, and as a result were left scrambling to cobble together the services that vanished; many had to face choices similar to Mrs. Henning's above.

With limited cash assistance, higher unemployment rates, and significant disability-specific expenses, many families with children who have disabilities have little to no financial "cushion" to absorb significant care expenses.

We recommend LB 376 be amended with AM 1307 and be advanced.

For further information or comment, please contact me at your convenience: <u>brad@drne.org</u> or 402-474-3183.

Sincerely,

Brad Meurrens Public Policy Director

<sup>&</sup>lt;sup>1</sup> Stabile, M. & Allin, S. (2012). "The Economic Costs of Childhood Disability", *Future Child*, Spring v.22(1): 65-96 <sup>2</sup> Ghosh, S. et al (2015), "Deprivation Among U.S. Children with Disabilities Who Receive Supplemental Security Income", *Journal of Disability Policy Studies*, Vol. 26, No. 3, p.174

<sup>&</sup>lt;sup>3</sup> "Nebraska Families Say Change To Medicaid Waivers Removes Kids With Disabilities From Needed Coverage", Omaha World Herald, September 14, 2019.