

# Disability Rights Nebraska

Protection and Advocacy for People with Disabilities

**Testimony on LB 376  
Before the Health and Human Services Committee  
Nebraska Legislature**

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**Bradley A. Meurrens  
Public Policy Director  
Disability Rights Nebraska**

Good afternoon Senator Walz and members of the committee. For the record my name is Brad B-R-A-D Meurrens M-E-U-R-R-E-N-S and I am the Public Policy Director at Disability Rights Nebraska. We are the designated Protection and Advocacy organization for persons with disabilities in Nebraska, and I am here today in support of LB 376.

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 provide to eligible families an additional \$12,000 to help 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 unexpected expenses. Parents have described to us: “It’s like having to hold your breath all the time...

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<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>3</sup> “Nebraska Families Say Change To Medicaid Waivers Removes Kids With Disabilities From Needed Coverage”, *Omaha World Herald*, September 14, 2019, available at [https://omaha.com/livewellnebraska/nebraska-families-say-change-to-medicaid-waivers-removes-kids-with-disabilities-from-needed-coverage/article\\_eab10c89-dacb-5f00-ae54-f563583a3077.html](https://omaha.com/livewellnebraska/nebraska-families-say-change-to-medicaid-waivers-removes-kids-with-disabilities-from-needed-coverage/article_eab10c89-dacb-5f00-ae54-f563583a3077.html)

you don't plan or budget for your car breaking down" and "All it takes is one major unplanned expense and the financial house of cards comes crashing down; living precariously".

We support LB 376 because it supports families of children with disabilities.

We recommend LB 376 be advanced.

For further information or comment, please contact me at your convenience: [brad@drne.org](mailto:brad@drne.org) or 402-474-3183.