

Disability Rights Nebraska

Protection and Advocacy for People with Disabilities

**Testimony on LB 1204
Before the Health and Human Services Committee
Nebraska Legislature
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Good afternoon Senator Howard 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 strong support of LB 1204.

Disability, while a natural part of the human experience, is expensive. Disabilities exact significant direct and indirect financial costs from individuals and families who experience disability. Direct costs include purchasing disability-related goods/services. Indirect costs include reducing hours worked to provide care for a child with a disability. Even with Medicaid or Medicare, co-pays for doctor visits or prescriptions can be costly, considering that a child's disability may mean multiple doctors/specialists, multiple treatments, and/or multiple prescriptions.

“Direct costs of care include therapies, preventive and emergency care, home modification, special educational services, adaptive equipment and supplies, and respite care. These expenses are not fully covered by U.S. public health insurance systems such as Medicaid or the State Children’s Health Insurance Programs, or by private insurance. As a result, families bear significant financial burdens for out-of-pocket payments.”¹

¹ 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

Stabile and Allen (2012) estimate the additional annual cost per family with children with disabilities is around \$10,830 (includes direct monetary costs and indirect costs).² All of these costs “have a deleterious long-term impact on family finances, including later life asset accumulation and financial security”.³

Many families with children with disabilities relayed during the Division of Developmental Disabilities listening sessions last year that they either are in desperate need of additional supports or services to ensure the health, safety, and livelihood of their children, or they face substantial financial difficulties in providing care and services for their child(ren) with a disability.

Developing a waiver such as proposed in LB 1204 is a step in the right direction, even if it requires additional tweaking. Furthermore, it is another opportunity to address the implications of the Waiting List. If parents were able to access additional funding (and services) as proposed in LB 1204, perhaps Nebraska could reduce the growth of or reduce the numbers of families waiting for services on the waiting list.

This bill is at least a starting point for the necessary larger discussion about how Nebraska can further support families who have children with disabilities. We would be happy to work with the Department of Health and Human Services, the Legislature, and all pertinent stakeholders to develop a mechanism to provide families the supports and services they need.

Disability Rights Nebraska recommends that LB 1204 be advanced.

² Stabile, M. & Allin, S. (2012). “The Economic Costs of Childhood Disability”, *The Future of Children*, v. 22, pp. 65-96

³ Supra note 1.