



For Immediate Release

Press Conference

Thursday May 27, 2021 11:00

Nebraska Capitol Rotunda

### **No Funding for Children with Disabilities Again This Year**

05/24/2021

Lincoln- Last week, a small group of Nebraska Legislators killed LB 376, a bill introduced by Senator Machaela Cavanaugh to support children with Developmental Disabilities. The bill would look to deal with Nebraska's waiting list for Developmental Disability Services of over 3,000 people. Wait time is 6-8 years on average and radically growing. Because of the long-term critical underfunding and a service model that has not been updated for decades, Nebraska has seen a tremendous amount of need and struggle.

The bill passed General reading without a single vote in opposition, but on the next Select Round faced a vicious filibuster. This bill would have bridged the coverage gap that exists in our state for children with disabilities due to our current waiting list, which prevents families from accessing services for their child with disabilities. 1100 of those families on the current waiting list are children birth to 21. By creating services for these families, Nebraska could have significantly brought down the average cost of services. To take action advocates urge citizens to sign their petition at <https://www.arc-nebraska.org/familysupportwaiver>

"We heard from legislators that they wanted a smart option, so we responded with an option that would serve more people, more effectively, and bring down the cost. Without these preventive services, children with disabilities have more medical emergencies and use more expensive care averaging over \$230,000 per individual per year. With these types of supports the average cost of services is shown to reduce to \$63,000 per person per year. We realized children need a different set of services that can prevent higher costs later on. So we proposed an option that would have a capped cost of \$10,000 per individual per year." Edison McDonald Executive Director The Arc of Nebraska.

"We lose a lot of fights in the disability world when it comes to politics, but this one is stinging hard. Children with Down syndrome with higher medical needs like a feeding tube, supplemental oxygen, etc. who have been struggling would have been offered a pathway to the basic supports they need." Leah Janke Executive Director Down Syndrome Association of the Midlands. "The state has disenfranchised kids like mine. We just want access to vital therapies,

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home modifications, and support that help keep our children alive. The current average extra cost is unrealistic for the majority of people to keep their kid alive without support.”

“The changes the family support waiver could make would help families provide care at home with services designed to help the disabled child develop to their fullest potential. For some, that would eventually mean being able to live independently,” Senator Machaela Cavanaugh stated. “I will continue to fight for these kids and families who desperately need our help.”

“The state has disenfranchised kids like mine. We just want access to vital therapies, home modifications, and support that help keep our children alive. The current average extra cost is unrealistic for the majority of people to keep their kid alive without support.” Shonda Knop Parent of Child on the Waitlist

#### Contacts

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