

## House Health and Human Services SB 2305 March 12, 2025

Chairwoman Lee and Members of the Senate Human Services Committee, I am Kirsten Dvorak, Executive Director of The Arc of North Dakota, supporting individuals with intellectual and developmental disabilities since 1958. We empower families and foster inclusive communities throughout the state. I stand in support of Senate Bill No. 2305.

The 2023 FINDS (Family and Individual Needs for Disability Supports) Community Report, created by the Institute on Community Integration at the University of Minnesota in partnership with The Arc of the United States, reveals the significant challenges faced by families caring for individuals with disabilities. These families contend with substantial financial strains and difficulty accessing essential services needed for the care of their loved ones. The report highlights the pressing need for policy initiatives like Senate Bill No. 2305 to alleviate these issues and ensure families receive the support they need.

- **Financial Hardship**: 41% of family caregivers have quit their jobs to provide care. This issue isn't about compensating parents for staying home; it highlights that many have lost their jobs because of the extensive care requirements of their children. These families face significant financial pressure as they attempt to cover the long-term caregiving expenses needed for their loved ones.
- **Limited-Service Availability**: Many individuals with disabilities remain on waiting lists for essential services, such as in-home support, respite care, and specialized therapies, placing enormous pressure on families who must take on caregiving responsibilities with little to no external support.
- Caregiving Demands: Family caregivers often dedicate over 40 hours per week
  to providing care, impacting their health and ability to maintain employment.
  Research has shown that prolonged caregiving without support can lead to
  increased rates of stress, anxiety, and even physical health issues such as high
  blood pressure and chronic fatigue.
- Cost of Institutionalization vs. Home Care: Studies have shown that homebased care is significantly more cost-effective than institutional care. On average, institutionalization can cost two to three times more than providing care within the home. By supporting family caregivers, we can help individuals with disabilities remain in a stable and familiar environment while reducing the overall financial burden on the state.

Senate Bill No. 2305 presents vital assistance through the Family Paid Caregiver Service Pilot Project, designed to reward family caregivers who deliver outstanding care to qualified Medicaid 1915(c) waiver recipients. This legislation guarantees compensation for caregivers who provide care beyond typical daily living activities necessary to prevent institutionalization. The Department of Health and Human Services will oversee the program, ensuring accurate eligibility assessments and avoiding duplicate payments from other services. Moreover, the Cross-Disability Advisory Council will advise on the program's implementation and future Medicaid waiver initiatives. The legislature will receive ongoing reports on the program's effectiveness, utilization, and expenses to ensure transparency and effectiveness. Additionally, a one-time funding of \$7.3 million from the general fund will support this initiative for the two years from July 1, 2025, to June 30, 2027.

At The Arc of North Dakota, we believe that while financial assistance to family caregivers is essential, it should not replace comprehensive support systems. Investments in home-based services, respite care, and community programs remain crucial to ensuring that individuals with disabilities receive high-quality care that supports them and their families.

This bill represents a step toward recognizing and alleviating the burden carried by countless families in our state. By supporting SB 2305, we can empower families with the resources they need to provide the best care possible while maintaining their well-being.

On behalf of The Arc of North Dakota and the families we serve, I urge you to support Senate Bill No. 2305. Thank you for your time and consideration. I am happy to answer any questions.

Sincerely, Kirsten Dvorak Executive Director, The Arc of North Dakota