

House Appropriations - Human Resources Division HB 1012 February 5th, 2025

My name is Kirsten Dvorak, Executive Director of The Arc of North Dakota, an organization dedicated to promoting and protecting the human rights of individuals with intellectual and developmental disabilities (IDD). For 65 years, we have advocated for inclusive services that empower individuals with disabilities to lead meaningful, independent lives in their communities.

In 1980, The Arc of North Dakota and four courageous families took a stand against the horrific conditions at state-run facilities, notably San Haven and Grafton State School, now called the Life Skills and Transition Center (LSTC). These institutions faced issues of overcrowding, neglect, and abuse, trapping individuals with disabilities in unsafe, unsanitary environments without adequate medical care or educational opportunities. Reports documented the use of physical restraints due to inadequate staffing and resources, illustrating a grim picture of widespread mistreatment.

The 16-year legal battle that followed exposed these injustices and led to critical reforms, ensuring that individuals with disabilities were no longer warehoused in inhumane conditions or stripped of their basic rights. While significant progress has been made, the history of these institutions is a stark reminder of why continued investment in community-based services is essential. Without proper funding and oversight, we risk regressing into outdated practices that isolate and fail individuals with disabilities. We must remain vigilant in protecting their right to live with dignity and full participation in their communities.

We appreciate the remarkable turnout at Disability Awareness Day. However, while raising awareness is important, it must be paired with concrete action. Individuals with exceptional needs—including those who require personalized support, crisis intervention, and ongoing assistance—cannot thrive on awareness alone. They need dedicated staff, comprehensive services, and sufficient funding to succeed within the community.

According to the latest U.S. Census data, approximately 12% of North Dakotans have a disability, highlighting the urgent need for strong support systems. Data from the Department of Health and Human Services shows an increasing demand for developmental disability (DD) services. As of 2024, more than 8,400 children and adults are receiving case management services, and this demand continues to rise. Without adequate staffing, individuals with disabilities risk losing their ability to live independently, work in their communities, and engage in meaningful activities.

It is particularly concerning that involuntary discharges due to "inability to meet needs" continue. Between July and December 2024, nine individuals were involuntarily discharged, some due to behavioral or medical challenges and others because of staffing shortages. These are real people—our neighbors, friends, and family members—who found themselves without the services they rely on simply because there wasn't enough staff to support them. A critical approach to addressing this crisis involves securing adequate funding. The executive budget request outlines a 1.5% inflationary increase for providers; however, this is inadequate. Direct Support Professionals (DSPs) form the foundation of community-based services, facilitating individuals with disabilities in leading fulfilling and independent lives. Their wages must remain competitive to attract and retain a proficient workforce. Without substantial investment in provider rates, we risk increased staff shortages, involuntary discharges, and the deterioration of essential services.

We fully support the proposal for \$9 million to expand the Autism Waiver. This funding is essential for delivering timely and appropriate services to children and adults with autism, reducing long waitlists, and improving access to necessary therapies and support programs, such as ABA.

We support the state's commitment to the Cross-Disability Waiver, which ensures individuals with diverse disabilities receive the services they need. Last week, we testified in strong support of the \$5 million request to hire experts and refine the level of care framework. This funding is crucial to creating an accurate, equitable system that fairly assesses individuals' needs and provides them with appropriate support.

The Arc of North Dakota is encouraged by the recent decrease in population at LSTC, reflecting progress toward community-based care and independent living. However, we remain deeply concerned about the continued placement of youth at LSTC. Institutional settings are not appropriate for young individuals with disabilities, particularly those with a dual diagnosis who require specialized, community-based support. Sustainable funding solutions must be found to expand community services, ensuring that no child is forced into an institution due to a lack of appropriate resources.

Vocational Rehabilitation (VR) services are essential for helping individuals with disabilities achieve employment and independence. These services provide job training, skill development, and workplace accommodations, enabling individuals to contribute actively to the workforce. A major concern is the implementation of Order of Selection, a federally mandated process that limits services when funding is insufficient. If enacted in North Dakota, this would create a system where only those with the most severe disabilities receive immediate assistance. In contrast, others are placed on a waiting list with no clear timeline for support. We strongly oppose implementing Order of Selection and urge full funding for VR services to ensure all eligible individuals receive timely support.

The State Hospital has long played a vital role in providing services for individuals with developmental disabilities and mental health needs. Developing a new State Hospital presents a crucial opportunity to modernize care, enhance accessibility, and ensure comprehensive, person-centered support. We strongly support the establishment of this new facility and urge the state to prioritize funding that sustains and expands access to these essential services.

I respectfully urge this committee to recognize the long-term benefits of investing in Home and Community-Based Services (HCBS) and provider rates. As demographic trends indicate, an aging population coupled with increasing disability rates will significantly amplify the demand for services. Proactive investment in community-based care is not only necessary but also cost-effective. Supporting individuals in community settings is far less expensive than institutional care and helps prevent costly crisis interventions and unnecessary institutional placements. This funding is not merely a financial consideration but a commitment to upholding the dignity, independence, and well-being of individuals with disabilities. By prioritizing these essential investments, we can establish a sustainable system that ensures individuals with disabilities have access to the care and support they need to thrive in their communities.

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I have included a link to *Abolition of Shame*, a documenty by The Arc of Upper Valley that details the lawsuit: https://youtu.be/LBMBx6UFyC0?si=HsYqlZ8D5Jth-TZb

The language used to describe individuals with disabilities has evolved significantly. Some once-common terms are now considered offensive and dehumanizing. While specific historical terms are referenced in this program due to their relevance to the lawsuit, The Arc does not use or condone any derogatory language. This includes the R-word, which was previously part of The Arc's name but has since been removed to reflect a commitment to respect and dignity. Moving forward, The Arc should always be referenced as The Arc, not as an acronym (ARC or The ARC). It is a name that signifies advocacy and inclusion, and it should be recognized as such in all contexts.