

Testimony on Legislative Resolution 216
Before the Health and Human Services Committee
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Good morning Senator Howard and members of the Committee. My name is Eric A. Evans, Ph.D. (E-R-I-C E-V-A-N-S) and I serve as the Chief Executive Officer at Disability Rights Nebraska. We are the designated Protection and Advocacy System under the federal Protection and Advocacy for People with Intellectual/Developmental Disabilities Act and we work to protect and advocate for the legal and human rights of Nebraskans with developmental disabilities. I am here today to discuss with the committee our recent report on the waiting list and provide a long-view perspective on the waiting list.

I first want to thank Senator Walz for introducing LR 216. It identifies a number of significant issues regarding developmental disabilities services that need to be addressed to maximize the potential for community inclusion of Nebraskans with developmental disabilities. We appreciate this opportunity to begin a serious discussion about how Nebraska can move forward to address system inefficiencies and barriers involving multiple perspectives: policy makers, parents, people with intellectual/developmental disabilities, and advocates.

During the forty-six years I have worked in the intellectual/developmental disabilities field I have appeared before the legislature on at least six separate occasions and participated on numerous work groups that were formed to study the waiting list issue. Over the years several reports have been produced and, on occasion, the Legislature acted on recommendations from the reports that led to movement of people off the waiting list. Unfortunately, these actions were generally only partial in nature and the waiting list problem has existed for over three decades during which time it has continued to balloon.

As part of our preparation for this hearing, Disability Rights Nebraska and the Nebraska Consortium for Citizens with Disabilities contracted with Scioto Analysis to conduct an analysis of Nebraska's waiting list for individuals with intellectual/developmental disabilities. I have brought hard copies of the report for members of the committee. I want to highlight briefly several of the general findings from our study:

- While almost 5,000 Nebraskans received developmental disability services in 2018, another 2,300 sat on the state waiting list not receiving services.

- Of those on the waiting list, about three quarters are between the age of 10 and 30, while only about one in six are over age 30.
- The typical person pulled off the waiting list in 2017 or 2018 was on the waiting list for **six to seven years**, with some having waited almost eight years.
- Nebraska tends to use less of its resources on developmental disability services compared to other states, ranking 39th nationally in spending as a percentage of personal income
- In the past three years, the Nebraska legislature has slowed spending on developmental disability aid, even reducing spending in Fiscal Year 2019.

Typically, during past efforts to address the problem, one of the major roadblocks to addressing the waiting list was cost. This is not to say that the Legislature hasn't acknowledged the importance of supporting people with intellectual/developmental disabilities. The data clearly shows that developmental disabilities expenditures have been in the top fifteen line-item increases in the State budget in eight out of the past ten years. The data clearly also shows what is likely to happen if we don't act on the waiting list in a timely manner: during the course of the next five years the State would need to increase its annual spending on developmental disabilities by \$113 million to account for annual growth in service costs [approximately a 50-50 split between state and federal funds]. In terms of the cost to eliminate the waiting list by 2024, the State would have to allocate an additional \$67 million [approximately a 50-50 split between state and federal funds] (see page 14). However, this estimate also assumes that we continue to provide services in the same way that we currently do. This also raises the question as to whether the current system of services and supports allows us to utilize funds in the most efficient and effective way.

The recent changes to the Medicaid Waiver programs requiring that waiver services and supports be provided in the most integrated settings, and the efforts of the Social Security Administration to move toward the elimination of sheltered workshops, Nebraska has a prime opportunity to reform our approach to providing services and supports to people with intellectual/developmental disabilities. Our report emphasizes that it is not necessary to "break the bank" to provide essential services and initiate a systematic approach to reduce the waiting list.

The report offers several recommendations to help start the conversation:

- Create an ongoing monitoring system to ensure the State is keeping up with the demand for services.
- Encourage in-home services for those who can benefit from them instead of providing residential services in costlier provider-owned settings.
- Expand employment opportunities so that people can move from Day Service programs to competitive employment.

- Expand early intervention services for children since there are approximately 260 children on the waiting list.
- Reframe our thinking about intellectual/developmental disability services as a tool for fighting poverty.
- Develop the understanding that State and federal funding for intellectual/developmental disability services is a key tool for ensuring human rights, promoting independence, enabling self-sufficiency and growing the economy.

Our report shows that Residential Services account for the largest service expenditure for nearly 4,000 out of the 5,000 individuals with intellectual/developmental disabilities who receive publicly funded services at a cost of \$215 million per year (see pages 7-9). When we look at the data on where people with intellectual/developmental disabilities live, 59% of those receiving services were in provider-based settings at a cost of \$177 million per year, while 41% were receiving services in their own home or family home at a cost of \$38 million per year. The average annual costs per individual for residential services is \$54,000. Our research shows that there are clear benefits to people living in their own homes when compared with people living in provider based residential settings as well as potential cost benefits to the State (see pages 9-11).

The second largest service expenditure for people with intellectual/developmental disabilities receiving publicly funded services is for Day Services and close to 4,000 individuals receive these services at a cost of \$91 million per year. In contrast, approximately 1,300 individuals Employment Services at a cost of \$9 million per year. The average cost for Day Services is about \$23,000 per individual compared with \$7,000 per individual for Employment Services (see pages 11-14).

So, from our perspective, there is clearly an economic argument that we could obtain a savings in service costs that could be reallocated to service those individuals who are currently on the waiting list. When we compared costs for services in surrounding states we found that the potential cost saving could be as much as \$82 million per year (page 11). Of course, it is always difficult comparing what happens in one state with what happens in another state, but the prospect of such potential savings suggests that we should give serious consideration to doing things differently in Nebraska.

But cost savings is not the only economic argument. State and federal funding for services and supports to individuals with intellectual/developmental disabilities and their families has a direct impact at the local community level. These funds are used to hire staff to provide services, rent facilities, pay utilities, and purchase goods and services. In turn, this helps to improve local economies, especially in rural areas, as well as contribute to tax revenue at all levels. In this sense there is a direct economic benefit much like other governmental economic development efforts.

Before closing I think it is also important to understand that there is a compelling moral argument for addressing the waiting list. Nebraska was the first state in the nation to make the commitment to serve people with intellectual/developmental disabilities in the

community and this idea has spread world-wide. We were also among the first states to pass legislation requiring schools to open their doors to students with disabilities-- two years before the passage of federal legislation. We have a system of medical, social and educational services for infants, children and youth with disabilities, from the date of diagnosis through age 21. Yet, we have approximately 2,300 people on the waiting list who need services but cannot obtain them. How can we justify providing the services and supports to individuals over many years, and at significant cost, only to abandon them because they don't qualify for an existing service or they have aged out of the educational system? We must do more than offer them a hollow promise of the good life. We have a moral obligation to do so.

Thank you for your attention and the opportunity to begin this important conversation. I truly hope that Nebraska will be able to find the will and the way to eliminate the waiting list once and for all. I'd be happy to answer any questions at this time and, if I'm not able to provide one for you today, I'll work to follow-up with a written answer.