North Dakota Centers for Independent Living

To: North Dakota Senate Appropriations

From: North Dakota's Four Centers for Independent Living

Subject: Funding for Independent Living Programing in HB 1012

Date: 3/11/21

Chairmen Holmberg and Members of the Committee,

My name is Scott Burlingame, I am the Executive Director of Independence, Inc. a Resource Center for Independent Living located in Minot. I am here today to speak in support of the full funding for Independent Living Programing in HB 1012.

The funding for independent living services in the last biennium was \$73,756 towards a federal match, and \$1,675,406 in general funds for a total of \$1,749,163.

In your handout (see figure 4) you can see a map of the four Centers for Independent living in our state, and the area they serve. As you can see, Dakota Center for Independent Living serves the southwestern part of the state, Freedom Resource Center serves the southeastern area, Options Interstate Center serves the northeastern part, and at Independence, Inc., we serve the northwestern quadrant.

All Centers for Independent Living are required to provide five core services, which are: Independent Living Skills Training, Individual and Systems Advocacy, Peer Counseling, Information and Referral, and Transition from institutional settings to community living, as well as for youth who are out of school. We also provide community services such as systems advocacy, community education, accessibility consultations and outreach.

One of the most important things to understand about the value of Independent Living is we are, at our core, people with disabilities serving other people with disabilities. Over half of our staff are persons with disabilities. We are people who have faced obstacles and barriers, fought back, overcame them, and have now dedicated our lives to doing our part to help others achieve their dreams.

Centers for Independent Living are peer driven and peer led. In addition to our staff, over half of our management and board of directors are also persons with disabilities. Our disabilities are as varied as those of the people we serve, but make no mistake, our staff are also trained and capable professionals. The average Independent Living staff in North Dakota has 11 years of experience. Our staff have college degrees in areas like Social Work, Education, Rehabilitation Counseling, Vocational Evaluation, Developmental Disabilities, Psychology, Communication and more.

As we talk about our need for funding, please remember our network has never been fully funded. According to a study we commissioned back in 2015, it would take over \$8,000,000 to fully fund our network and meet the needs of every person with a disability in our state. The fact that we are so far from that number means each of our local Centers must make decision on how best to spend our limited resources and to provide the best impact for our investment in our individual communities.

The funding provided by the state of North Dakota has been a game changer in our ability to serve North Dakotans with disabilities. We have presented you with a map with a pin showing the address of each of the people served by a Center in the past two years (see figure 1). As you can see, despite our limited funding, we have been able to provide a variety of services across the state.

Without the state funding, most of those pins will disappear.

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Our local Centers have the ability to respond to our unique community needs. This means we can help a senior in High School with a learning disability in Crosby to pass his driver's test, or we can help a Senior Citizen from Grand Forks County who wants a ramp for their church. We can help a woman with a new physical disability in Wahpeton to find accessible housing or we can help a 40-year-old with a brain injury in Bismarck to learn to pay his bills,

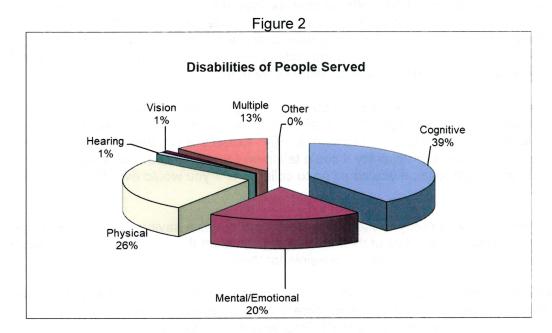
Our local controls mean we can be partners in building local communities as well. A few of the many things we have done is helped the Grand Forks and Jamestown Airports to accommodate people with disabilities in their emergency preparedness, provided trainings to landlords on accessible housing, taught disability awareness to elementary age students, and held a public forum on overcoming the stigma around mental health and addiction.

In the past two federal fiscal years, our CIL's have prevented 41 persons from entering nursing homes or other institutions and assisted in relocating 54 people from institutional care. According to our estimates (see figure 5), this outcome has the potential to save the state \$6,239,505.00, and even more the longer people are able to stay in their own home.

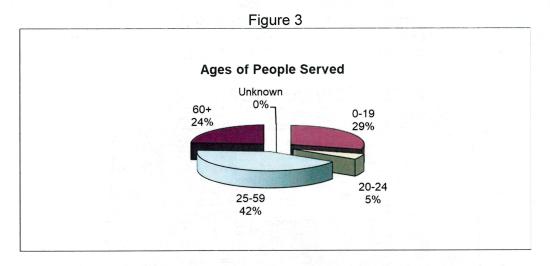
As you listen to the testimony on all the programing in HB 1012 it has to seem overwhelming and at times be difficult to understand all the programs and services available to North Dakotans. As I am sure you have discovered, the services and supports available to people with disabilities vary greatly depending on age and medical diagnosis.

That is not true at Centers for Independent Living.

At Centers, we serve and all types of disabilities (see figure 2). In the past two years, 39% of the people we serve have cognitive disabilities, such a learning disabilities or autism, 26% people are people with physical disabilities, such as spinal cord injury, arthritis, or cerebral palsy, 20% are people with mental health type disabilities, like depression, substance abuse disorder, or bipolar disorder, and about 1% each are who are Deaf/hard of hearing or Blind/visually impaired. Around 13% of the people we served reported multiple disabilities.



We also serve all ages (see figure 3). This includes 29% under the age of 19, 5% age 20-24, 42% between the ages of 25-59, and 24% age 60 or over.



Eligibly for Independent Living is not based on disability type or age. It is based on very simple criteria:

- Are you a person with a disability?
- Does that disability affect one or more of your major life areas?
- Do you want Independent Living Services?
- Are you willing to set a goal and do your part to achieve that goal?

It is the self-determination that is inherent in how we do things that makes our programing so successful. There is much focus on Person Centered planning as a best practice in today's service delivery model, however, without solid self-determination, Person Centered planning will never succeed.

Here is an example, a long time ago, I was a student on an Individualized Education Plan (IEP). I went to meetings at my school, with my parents, teachers, special education teachers, school counselors, and other professionals. As a student who was struggling with how to write, that was a pretty intimidating room. You could have built the programing around my needs, and it may have helped, but I was not able to truly overcome my disability until I accepted it and was confident enough to request the type of help I really need.

Two years ago, I had the opportunity to go into the High School in Velva and work with kids who were a lot like I was at their age. When I talked to them, I was able to tell them I knew what it was like to struggle in school, to sit through an IEP, to feel like you were going to be defined for the rest of your life by your disability. I could tell them I remembered what it was like to not be sure if you would graduate, if you could go to college, or if you would ever find a successful career.

I have to tell you; I was pretty excited when I received a notice saying these students had graduated on time with the rest of their class. I am confident they are now entering adulthood with a better understanding of what is possible for them.

Independent Living is cost effective and a smart investment for the state. It is part of the solution to the ever-increasing costs of long-term care, it is an alternative to the high cost of dependency, and it is the right thing to do. People who live independently live longer, they are happier, and it saves the taxpayer money.

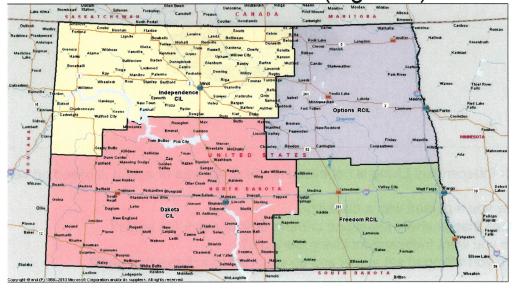
I would gladly answer any questions you may have.

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Center Service Areas (Figure 4)



(Figure 5)

POTENTIAL INSTITUTIONAL CARE COSTS SAVED BY NORTH DAKOTA CENTERS FOR INDEPENDENT LIVING

Part of the Core Services of Independent Living Centers is to assist persons with disabilities in either leaving or preventing their placement in institutions. This effort by the four Centers for Independent Living in North Dakota has the potential to Save the state

\$6,239,505.00. This potential savings is the difference between what it costs for individuals to live independently using the average monthly cost rate compared to institutional care average rates. Nursing Home cost rates were reported by CMS, for Older Adults and people with disabilities, (CMS Data by State & Waiver Program Page 1 table 43, 2015) compared to the average nursing home cost, (personal communication ND DHS, Aging Division, Money Follows the Person Program) The institutional care rate was adjusted for room and board. The information is for the time period FYs 19 and FY 20.

- \$ 9,523.00 AVERAGE NURSING HOME COST PER MONTH
 - **x 70%** ADJUSTMENT FOR ROOM AND BOARD @ 20%
- \$ 6,666.00 ADJUSTED COST PER DAY FOR NURSING HOME CARE
- \$ 6,666.00 ADJUSTED NURSING HOME RATE
 - \underline{x} 12 DAYS OF THE YEAR
 - \$ 79,992.00 COST PER YEAR FOR NURSING HOME CARE
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- 14,313.00 AVERAGE COST PER YEAR (waiver Program Expenditures OlderAdults & PD, CMS data 2015 COST SAVINGS
- x 95 PEOPLE WITH DISABILITIES

\$ 6,239,505.00 TOTAL POTENTIAL SAVINGS

Note: Centers for Independent Living reported Independent Living Services prevented 41 persons from entering nursing homes or other institutions during the last budget period and assisted in relocating 54 people from institutional care.

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