

# WAITING FOR SERVICES

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Analyzing the impact of  
Nebraska's developmental  
disabilities waiting list

October 2019

**Disability Rights Nebraska**

Protection and Advocacy for People with Disabilities



Nebraska Consortium for Citizens with Disabilities

*"Advancing the rights of all people with disabilities in Nebraska"*

## Executive Summary

Developmental disability services help nearly 5,000 Nebraskans live, function, and work in the state who otherwise would struggle to. They do this by providing residential care, day services that help people with developmental disabilities improve skills for functioning, employment services, and various other services.

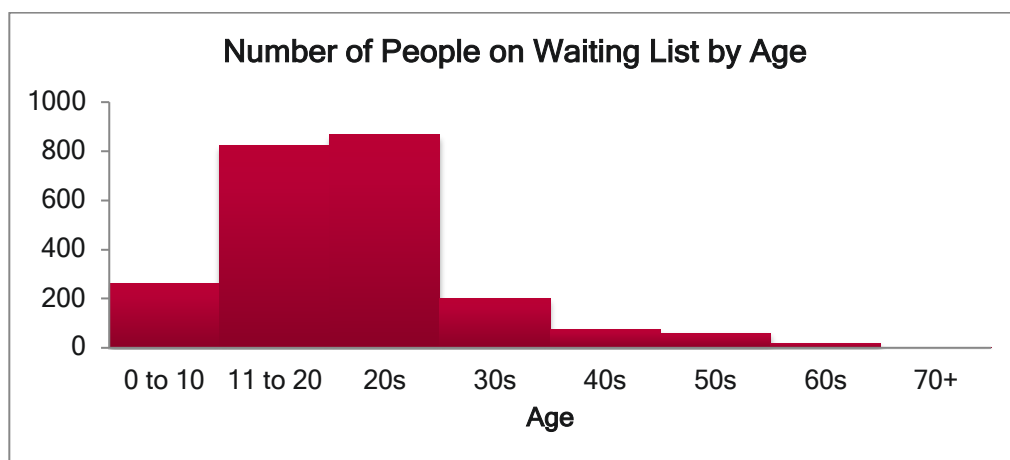
Due to budget constraints, over 2,300 Nebraskans are sitting on a waiting list past their date of need, not receiving services from the state. Nebraska has a large waiting list compared to other states and spends less per capita than comparable states on services. This has led to middling outcomes for Nebraskans with developmental disabilities, especially in fostering independence and quality of life.

Nebraska has options to improve its disability aid program. By promoting in-home services, prioritizing job services and services for young children, and intentionally providing funding to reduce the waitlist, Nebraska can build a developmental disability aid program that promotes independence, improves quality of life, and benefits the economic situation of people with disabilities.

## The Waiting List for Services in Nebraska

While almost 5,000 Nebraskans received developmental disability services in 2018, another 2,300 sat on the state waiting list not receiving services.<sup>1</sup>

The state waiting list is a list of people with developmental disabilities who have requested services from the state and have a need for these services, but cannot receive services primarily due to a lack of funding.<sup>2</sup> 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.<sup>3</sup>



*Smith, Letter to Senator Lynne Walz, 2019.*

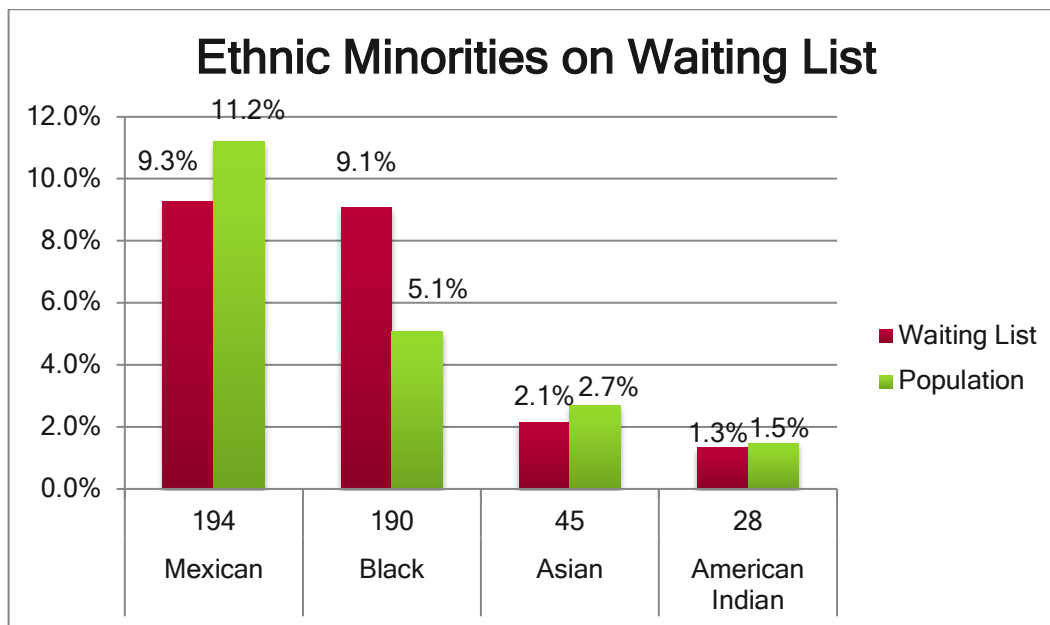
<sup>1</sup> Smith, Letter to Senator Lynne Walz, 2019. This letter is printed in full in Appendix A.

<sup>2</sup> O'Hare, Mary, "Nebraska Legislative Resolution 156: Addressing the Waiting List for Persons with Developmental Disabilities and Rate Methodology," Legislative Resolution 156 Workgroup, December 2008, p. 10.

<sup>3</sup> Smith, Letter to Senator Lynne Walz, 2019.

## Waiting for Services: Nebraska's DD Waiting List

The proportion of White (78%), Asian (2.1%), and American Indian (1.3%) people on the waiting list come close to the racial composition of the state of Nebraska.<sup>4</sup> People of “Mexican” heritage (as defined by the Nebraska Department of Health and Human Services) are underrepresented on the waiting list and Black/African American people appear more on the waiting list than they do in the general population.



*Smith, Letter to Senator Lynne Walz, 2019.*

The waiting list is not one that moves quickly, either. While best-case people with disabilities are able to get off the waiting list in a month or so, 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.<sup>5</sup>

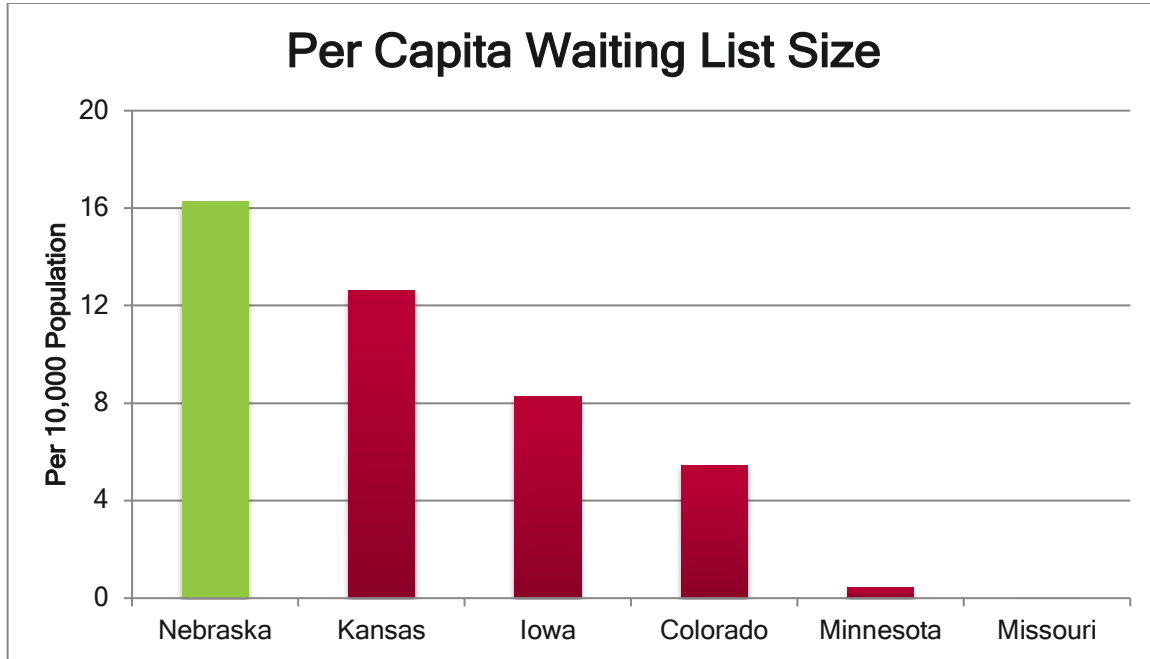
Comparative state data tells us that Nebraska’s developmental disabilities waiting list was longer than any of five comparison states besides Kansas in 2017, the most recent year comparative data is available.<sup>6</sup> On a per capita basis, the size of Nebraska’s waiting list is long, with more Nebraskans on the waiting list per capita than all comparison states and three times the people on its waiting list than the average comparison state.<sup>7</sup>

<sup>4</sup> Ibid., “Quickfacts: Nebraska, Population Estimates, July 1, 2018,” Census.gov.

<sup>5</sup> Smith, Letter to Senator Lynne Walz, 2019.

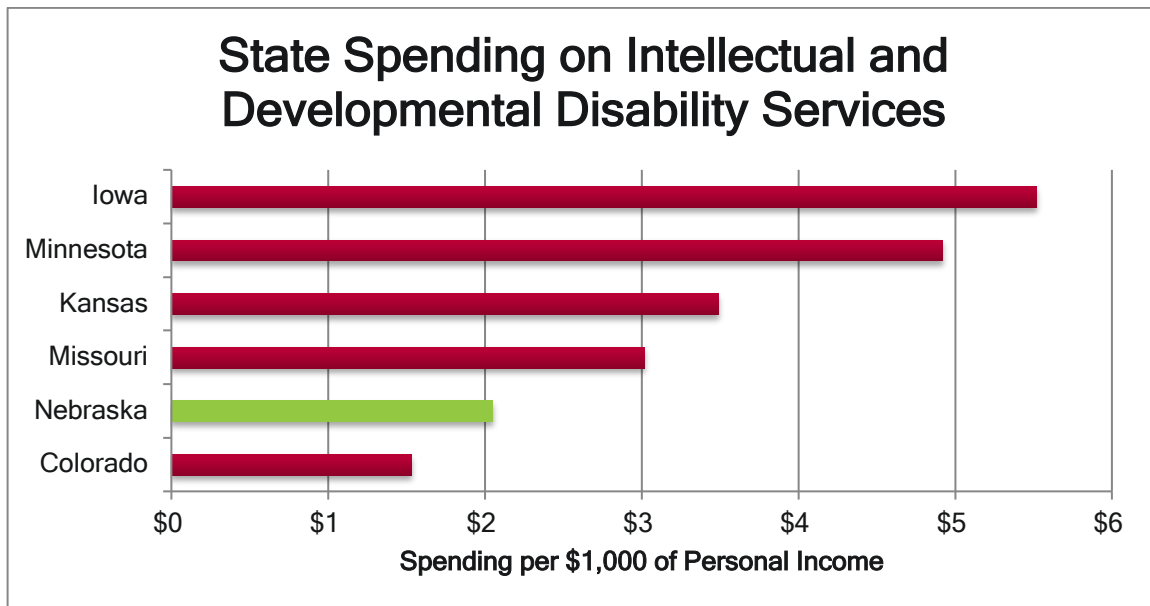
<sup>6</sup> “Waiting List Enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers,” State Health Facts, Kaiser Family Foundation, 2017; These comparison states were chosen to reflect the past waiver study: “Nebraska Waiver Study,” Arc of Nebraska, Fall 2019, [https://www.arc-nebraska.org/nebraska\\_waiver\\_study](https://www.arc-nebraska.org/nebraska_waiver_study)

<sup>7</sup> “Annual Estimates of the Resident Population for the United States, Regions, States, and Puerto Rico: April 1, 2010 to July 1, 2018”. United States Census Bureau.



Kaiser Family Foundation, United States Census Bureau.

Nebraska also tends to use less of its resources on developmental disability services, ranking 39<sup>th</sup> nationally in spending as a percentage of personal income and spending less than all comparison states besides Colorado.<sup>8</sup> Iowa and Minnesota spend two and a half times what Nebraska spends per \$1,000 of personal income on intellectual and developmental disability services.



"I/DD Spending per \$1,000 of Personal Income," Case for Inclusion.

<sup>8</sup> "I/DD Spending per \$1,000 of Personal Income," The Case for Inclusion: Serving at a Reasonable Cost, <http://www.caseforinclusion.org>

## *Waiting for Services: Nebraska's DD Waiting List*

Despite its long waiting list and low levels of spending on developmental disabilities, Nebraska falls in the middle of the pack nationally when it comes to promoting community inclusion for people with developmental disabilities, ranking 23<sup>rd</sup> among states in the 2019 “Case for Inclusion” rankings. Nebraska was rated highly for its employment services but docked for its family stability policies and had middling rankings in independence, quality of life, coverage, and overall ranking. Among comparison states, Nebraska is also middle of the pack, falling behind Missouri and Minnesota and ranking ahead Colorado, Kansas, and Iowa.

### **2019 “Case for Inclusion” Rankings**

<b>State</b>	<b>Independence</b>	<b>Quality of Life</b>	<b>Family Stability</b>	<b>Employment</b>	<b>Coverage</b>	<b>Overall</b>
Missouri	18 <sup>th</sup>	4 <sup>th</sup>	10 <sup>th</sup>	20 <sup>th</sup>	13 <sup>th</sup>	4 <sup>th</sup>
Minnesota	31 <sup>st</sup>	11 <sup>th</sup>	9 <sup>th</sup>	26 <sup>th</sup>	45 <sup>th</sup>	21 <sup>st</sup>
<b>Nebraska</b>	<b>29<sup>th</sup></b>	<b>21<sup>st</sup></b>	<b>42<sup>nd</sup></b>	<b>14<sup>th</sup></b>	<b>27<sup>th</sup></b>	<b>23<sup>rd</sup></b>
Colorado	10 <sup>th</sup>	40 <sup>th</sup>	50 <sup>th</sup>	4 <sup>th</sup>	21 <sup>st</sup>	27 <sup>th</sup>
Kansas	39 <sup>th</sup>	30 <sup>th</sup>	40 <sup>th</sup>	27 <sup>th</sup>	26 <sup>th</sup>	37 <sup>th</sup>
Iowa	37 <sup>th</sup>	46 <sup>th</sup>	47 <sup>th</sup>	30 <sup>th</sup>	17 <sup>th</sup>	45 <sup>th</sup>

*Case for Inclusion Rankings 2019, <http://www.caseforinclusion.com>*

In 2008, the Nebraska Legislature appointed a workgroup to recommend a strategic plan for reducing the state waiting list for developmental disability services.<sup>9</sup> The workgroup’s final report outlined the state’s challenges in projecting future utilization of developmental disability services and provided the Nebraska Legislature with a preferred option and a second-best option for reducing the waiting list.

1. (Preferred): Appropriate funds, in the upcoming fiscal year, necessary to provide services for all eligible individuals with developmental disabilities who are past their need date. Once those individuals have been funded, provide funding for all eligible individuals as they reach their need date.
2. Incrementally provide services to individuals on the waiting list by offering funding for two years of service requests in each year from 2009 until 2014 and, from that point forward, fund all eligible individuals on their need date.

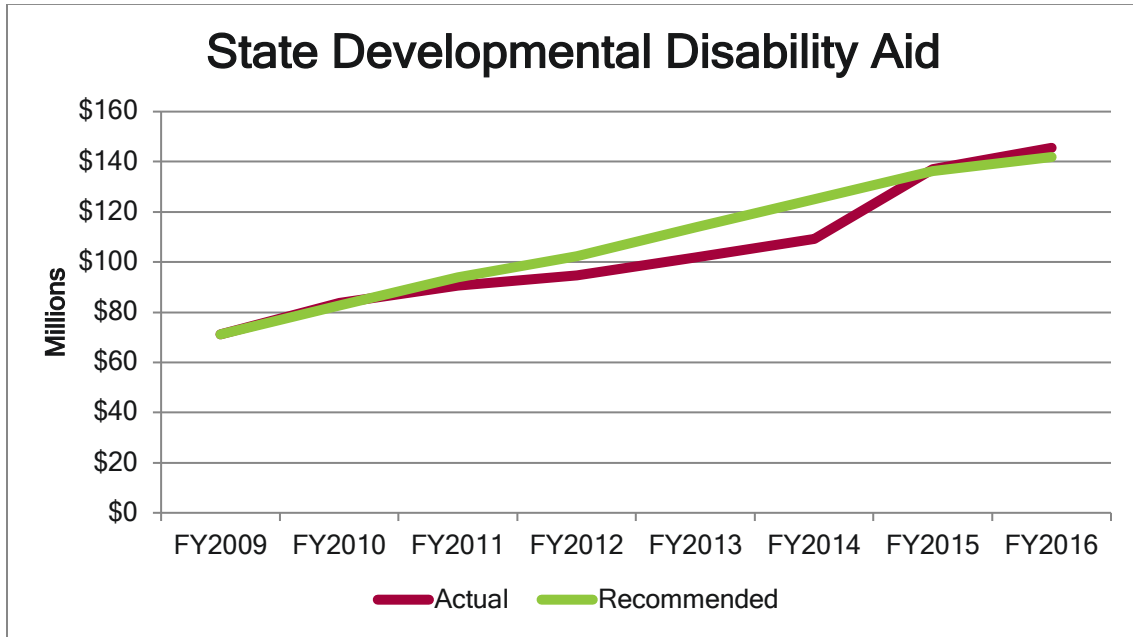
The Nebraska Legislature opted for option two, making disability aid a top-12 line item increase each year from 2010 until 2016. While legislative spending matched the workgroup recommendation in Fiscal Year 2010, the Legislature underspent compared to workgroup recommendations from Fiscal Year 2011 to Fiscal Year 2014.<sup>10</sup> The Legislature caught up with

<sup>9</sup> O’Hare, “Nebraska Legislative Resolution 156,” 2008.

<sup>10</sup> “Biennial Budget Reports: 2009-2016,” Nebraska Legislature, [nebraskalegislature.gov](http://nebraskalegislature.gov).

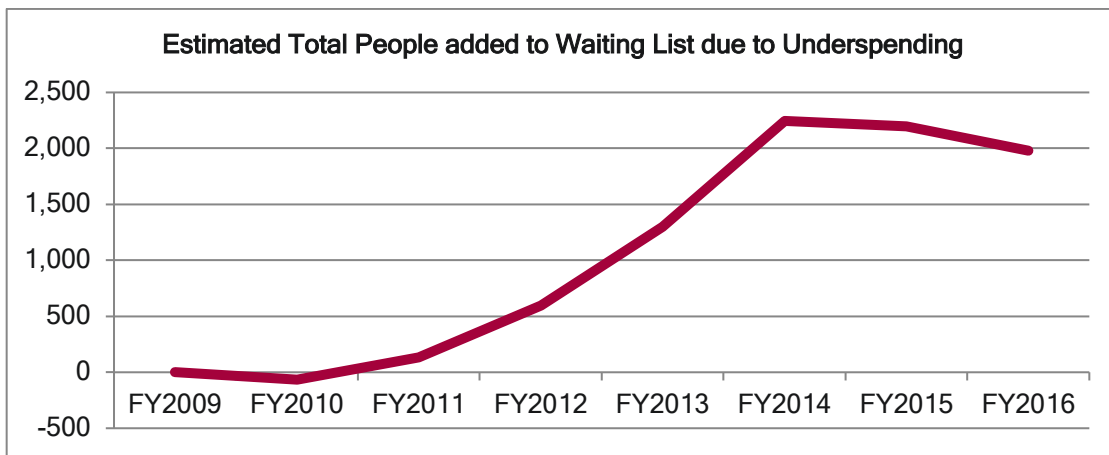
## Waiting for Services: Nebraska's DD Waiting List

recommendations in Fiscal Years 2015 and 2016, but the “catch-up” time period led to a \$33 million cumulative shortfall in spending from Fiscal Year 2010 to Fiscal Year 2016.



*“Biennial Budget Reports: 2009-2016,” Nebraska Legislature  
O’Hare, “Nebraska Legislative Resolution 156”*

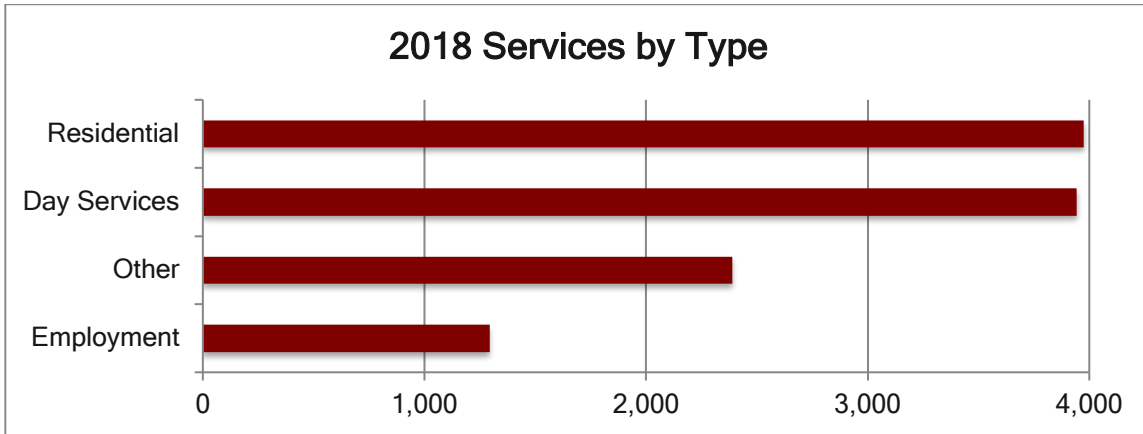
Since the workgroup recommended a cumulative \$71 million in new annual spending to provide services to about 4,200 requests, the average request was projected to cost about \$17,000 in state funds. Thus, the shortfall in disability aid expenditures of \$33 million would have led to about 2,000 individuals not being served, which explains about 85% of the current waiting list. The remaining 350 people on the waiting list were due to underestimates by the workgroup due to unanticipated community need.



*“Biennial Budget Reports: 2009-2016,” Nebraska Legislature  
O’Hare, “Nebraska Legislative Resolution 156”*

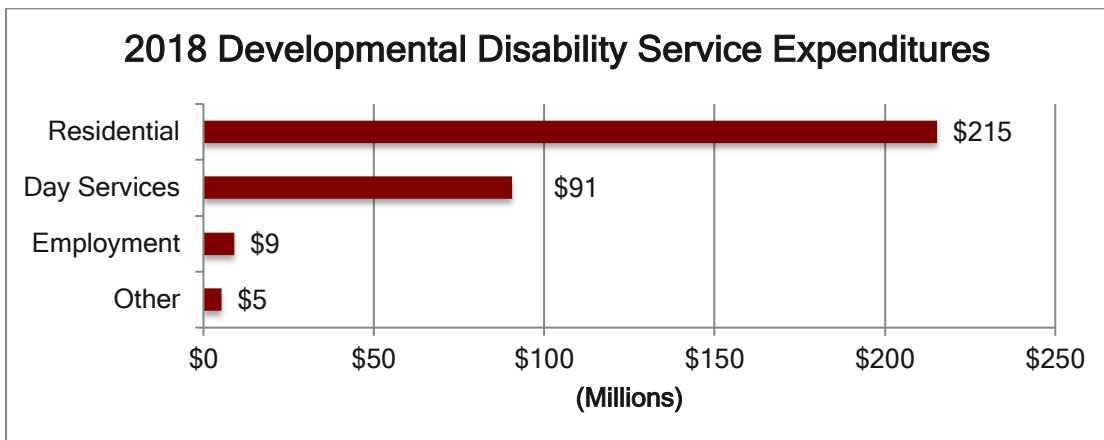
### Developmental Disability Services: Living, Functioning, and Working

In 2018, the state of Nebraska provided services to assist 4,835 Nebraskans with disabilities through developmental disability waivers.<sup>11</sup> Of these nearly 5,000 Nebraskans, 3,975 received residential services, 3,934 received day services, 1,468 received employment services, and up to 1,445 received other services.<sup>12</sup>



Smith, Letter to Senator Lynne Walz, 2019.

These services amounted to a total of \$320 million in total spending in 2018 and ranged from residential services to day services to employment.<sup>13</sup> Two-thirds of these funds were spent on residential services and about a quarter were spent on day services. While employment and other services made up almost a third of total services provided, they amounted to only \$14 million, less than five percent of total expenditures.



Smith, Letter to Senator Lynne Walz, 2019.

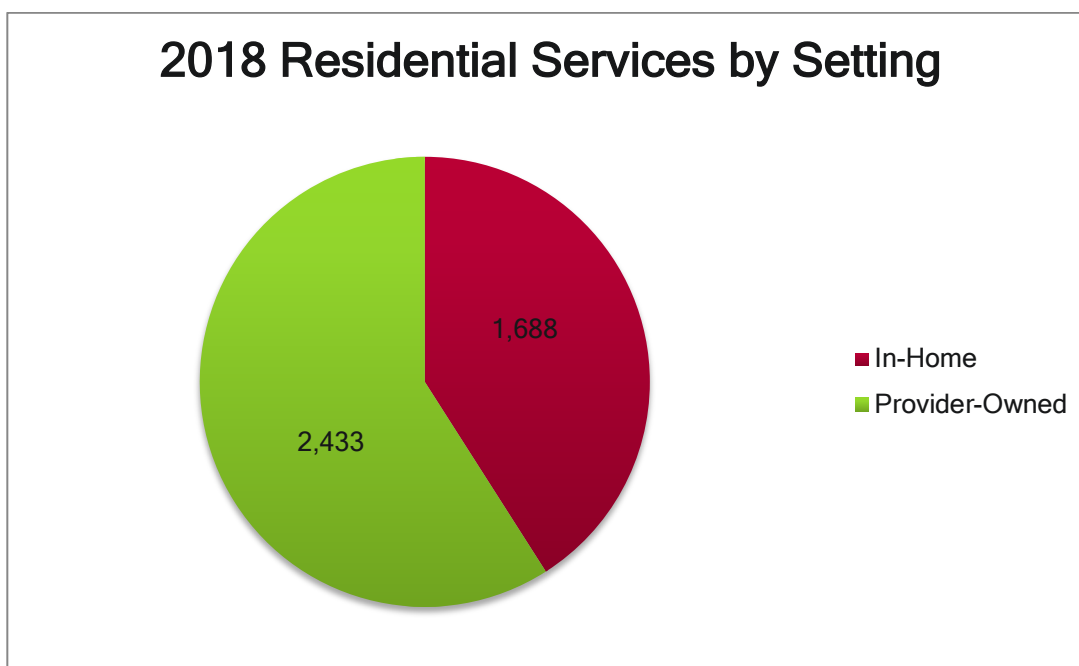
<sup>11</sup> Smith, Dannette, Letter to Senator Lynne Walz, Table 5 August 1, 2019. The sum of these numbers exceed 4,835 since individuals often receive multiple types of services.

<sup>12</sup> Ibid.

<sup>13</sup> Ibid.

Residential services represented the majority of state spending on developmental disability services through waivers, making up about two-thirds of all such spending and serving almost four thousand individuals.<sup>14</sup> Residential services are services designed to assist a Nebraskan living with a developmental disability in living in the community.<sup>15</sup> Residential services range from assistance provided in a person's own home to full-time assisted living in provider housing.

The Nebraska Department of Health and Human Services splits funding for residential services into two categories: (1) in-home services, which are provided to people living with developmental disabilities in their own home or with family, and (2) services provided to people living with developmental disabilities in provider-owned, operated, or otherwise-controlled residences.<sup>16</sup> In 2018, about 1,700 (41%) of residential services were provided in a home setting and 2,400 (59%) were provided in provider-owned settings.<sup>17</sup>



*Smith, Letter to Senator Lynne Walz, 2019.*

<sup>14</sup> Ibid.

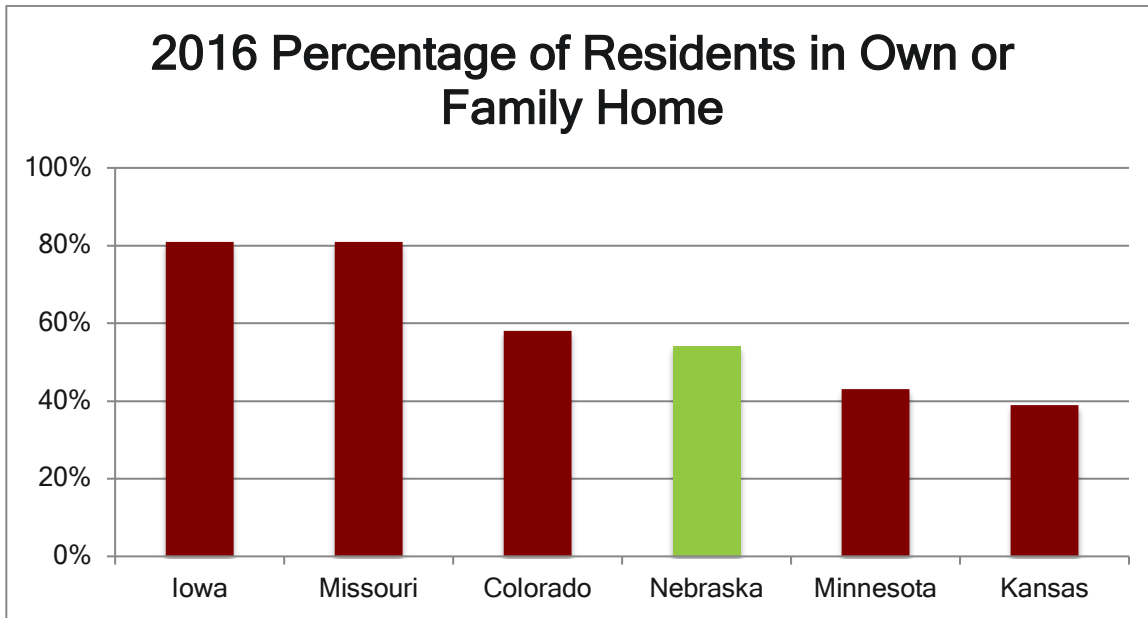
<sup>15</sup> O'Hare, Mary, "Nebraska Legislative Resolution 156: Addressing the Waiting List for Persons with Developmental Disabilities and Rate Methodology," Legislative Resolution 156 Workgroup, December 2008, p. 10.

<sup>16</sup> "Title 403: Medicaid Home and Community-Based Waiver Services (HCBS) for Individuals with Developmental Disabilities – Chapter 5: Comprehensive Developmental Disabilities Services Waiver," Nebraska Department of Health and Human Services, Rules and Regulation, p. 11,13. For the purposes of this report, we use the phrase "in-home" to refer to "in-home residential habilitation services" as defined by the Nebraska Department of Health and Human Services and "provider-owned" to refer to "residential habilitation services" as defined by the Nebraska Department of Health and Human Services.

<sup>17</sup> Smith, Letter to Senator Lynne Walz, 2019.



According to research by the ANCOR Foundation, Nebraska is rather middle of the road in its breakdown of in-home versus provider-owned residential services.<sup>18</sup> In 2016, Nebraska had a slightly higher percentage of people with disabilities living at home than Minnesota and Kansas, a slightly lower percentage of people with disabilities living at home than Colorado, and a much lower percentage of people with disabilities living at home than Iowa and Missouri.<sup>19</sup>



*Case for Inclusion*

Research comparing in-home residential services to provider-owned residential services in the state of Oregon found that people living in-home were more likely to take part in community activities and have an active social life than those in institutional settings.<sup>20</sup> Studies on deinstitutionalization in the UK have found similar community integration advantages associated with in-home care.<sup>21</sup> Recent research suggests that shifts from large institutional settings to smaller residential settings nationwide have been associated with greater choice for participants in regard to where and with whom they would live, where they went during the day, who their case manager was, and who their staff was.<sup>22</sup> Evidence

<sup>18</sup> "The Case for Inclusion Report 2019," ANCOR Foundation, 2019, <http://caseforinclusion.org/>.

<sup>19</sup> These comparison states were chosen to reflect the past waiver study: "Nebraska Waiver Study," Arc of Nebraska, Fall 2019, [https://www.arc-nebraska.org/nebraska\\_waiver\\_study](https://www.arc-nebraska.org/nebraska_waiver_study)

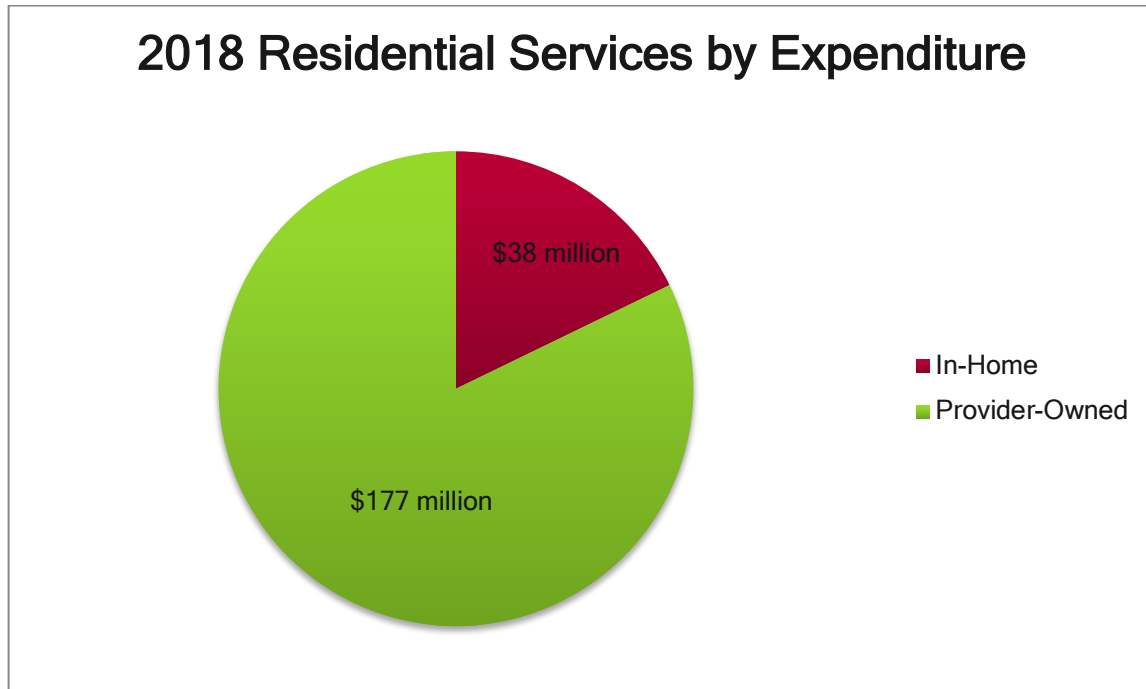
<sup>20</sup> Howe, John, Robert H. Horner, and J. Stephen Newton. "Comparison of supported living and traditional residential services in the state of Oregon." *Mental Retardation* 36, no. 1 (1998): 1-11.

<sup>21</sup> Emerson, Eric, and Chris Hatton. "Deinstitutionalization in the UK and Ireland: Outcomes for service users." *Journal of Intellectual and Developmental Disability* 21, no. 1 (1996): 17-37.

<sup>22</sup> Houseworth, J., Tichá, R., Smith, J., & Ajaj, R. (2018). Developments in living arrangements and choice for persons with intellectual and developmental disabilities. Policy research brief, 27(1), University of Minnesota, Institute on Community Integration.

also suggest that families of people with developmental disabilities are satisfied with community care.<sup>23</sup>

One potential additional benefit of in-home residential services over services in provider-owned settings is cost of care to the state. While provider-owned services made up 59% of all residential services provided in Nebraska in 2018, they also made up 82% of all costs.<sup>24</sup> On average, the state spent three times as much on a per-service basis in provider-owned settings than it did in in-home settings.



*Smith, Letter to Senator Lynne Walz, 2019.*

Shifting services from provider-owned to in-home settings should be approached with caution. Service allocation by setting is responsive to needs of individuals and incorrect placement could lead to negative results for service recipients and wasted public dollars. Some studies find that differences in spending between in-home and provider-owned services can be explained by needs of recipients, suggesting costs could be driven by providers being responsive to individual needs rather than inefficient spending.<sup>25</sup>

<sup>23</sup> Jones, Jennifer L., and Kami L. Gallus. "Understanding deinstitutionalization: What families value and desire in the transition to community living." *Research and Practice for Persons with Severe Disabilities* 41, no. 2 (2016): 116-131.

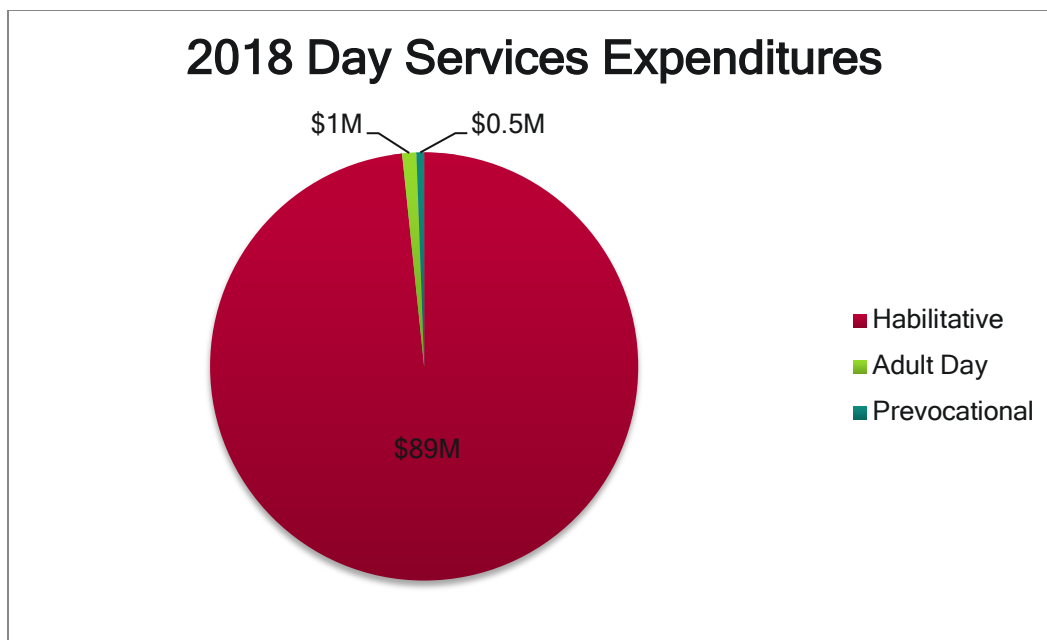
<sup>24</sup> Smith, Letter to Senator Lynne Walz, 2019.

<sup>25</sup> Emerson, Eric, Janet Robertson, Nicky Gregory, Chris Hatton, Sophia Kessissoglou, Angela Hallam, Krister Järbrink, Martin Knapp, Ann Netten, and Patricia Noonan Walsh. "Quality and costs of supported living residences and group homes in the United Kingdom." *American Journal on Mental Retardation* 106, no. 5 (2001): 401-415.

Trends in home and community-based services in other states demonstrate that there is a wide range of different state approaches being used to address the needs of people with developmental disabilities. If reallocation of funds from provider-owned settings to in-home settings could be achieved with similar or better quality outcomes for service recipients, it would lead to large savings for the state. For instance, if Nebraska had a percentage of residents living at home on par with Iowa or Missouri's at current costs of in-home and provider-owned residential services, the state would save \$82 million a year, over a quarter of the current HCBS budget.

The second major category of service spending in 2018 was day services. Day services are nonresidential services to help participants keep, learn, or improve skills and functioning for daily living or provide other supports for participants.<sup>26</sup> 94% of these services are habilitative services of some sort, working to improve functioning for participants.<sup>27</sup> Habilitative services could be physical therapy, addressing physical impairment, or occupational therapy, addressing barriers to environmental functioning.<sup>28</sup> The remainder of day services provided were adult day services, close-contact services focused on meaningful day activities, and prevocational services providing broad career planning, job search, and employability training.<sup>29</sup>

The \$89 million in habilitative services spending in 2018 was the largest single category of HCBS spending for the state outside of its residential services in provider-owned settings, making up over a quarter of the HCBS budget and 98% of all day services expenditures.<sup>30</sup>



Smith, Letter to Senator Lynne Walz, 2019.

<sup>26</sup> "Habilitative/Habilitation Services," Healthcare.gov, 2019.

<sup>27</sup> Smith, Letter to Senator Lynne Walz, 2019.

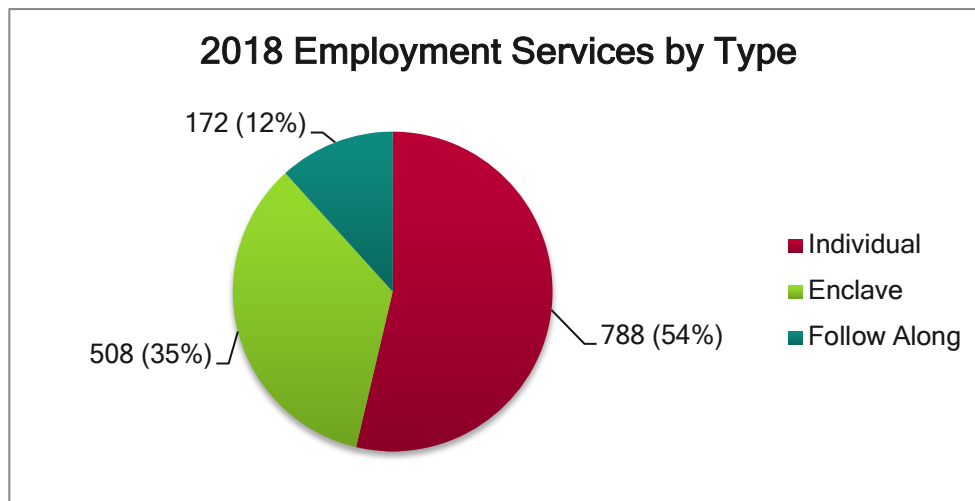
<sup>28</sup> National Academies of Sciences, Engineering, and Medicine. *Opportunities for improving programs and services for children with disabilities*. National Academies Press, 2018.

<sup>29</sup> "Title 403," Nebraska Department of Health and Human Services.

<sup>30</sup> Smith, Letter to Senator Lynne Walz, 2019.

A third category of services provided via waivers are employment services, provided to about 1,300 Nebraskans with disabilities in 2018.<sup>31</sup> People with developmental disabilities face lower levels of labor force participation than any other disability group and policy researchers stress shared goals with integrative responses to help people with developmental disabilities overcome barriers.<sup>32</sup> Supportive employment services are an evidence-based practice that has been shown to increase employment among participants with certain types of developmental disabilities.<sup>33</sup> In 2010, a national study of vocational rehabilitation agencies found that Nebraska had the **most cost-efficient supported employee program in the country**, returning \$2.77 to the state in savings from alternative programs and new tax revenue for every \$1 invested in the program.<sup>34</sup> Thus, while the overriding policy rationale for developmental disability services is equity, employment services provide a strong economic efficiency rationale as well.

Over half of employment services are individualized programs designed to help participants obtain and maintain competitive employment.<sup>35</sup> Another third are “enclave” programs, a setting where a participant works with a group of other participants in a regular business or industry setting. The remainder are “follow-along” programs, which resemble individualized programs with closer supervision.



*Smith, Letter to Senator Lynne Walz, 2019.*

<sup>31</sup> Ibid.

<sup>32</sup> Khayatzadeh-Mahani, Akram, Krystle Wittevrongel, David B. Nicholas, and Jennifer D. Zwicker. "Prioritizing barriers and solutions to improve employment for persons with developmental disabilities." *Disability and rehabilitation* (2019): 1-11.

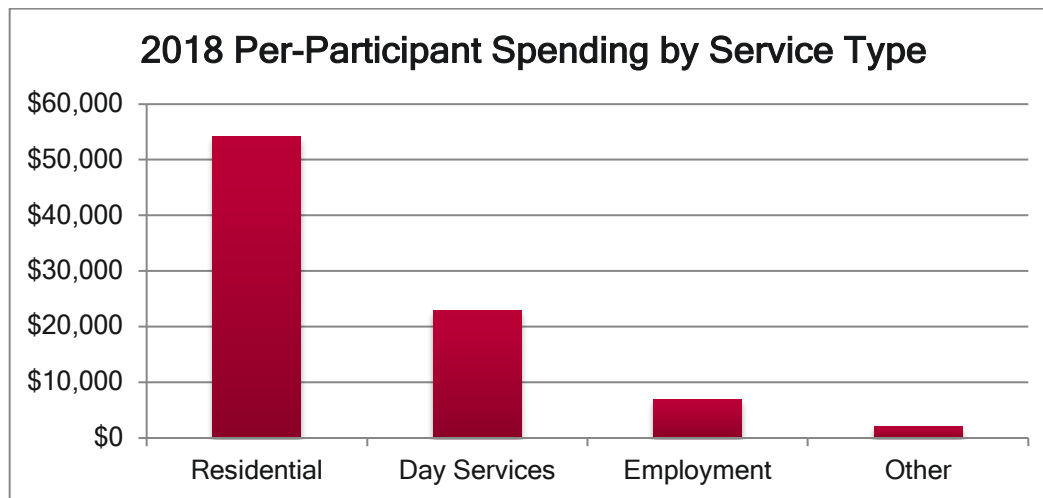
<sup>33</sup> Wehman, Paul H., Carol M. Schall, Jennifer McDonough, John Kregel, Valerie Brooke, Alissa Molinelli, Whitney Ham et al. "Competitive employment for youth with autism spectrum disorders: Early results from a randomized clinical trial." *Journal of autism and developmental disorders* 44, no. 3 (2014): 487-500.

<sup>34</sup> Cimer, Robert E. "National cost efficiency of supported employees with intellectual disabilities: 2002 to 2007." *American Journal on Intellectual and Developmental Disabilities* 115, no. 1 (2010): 19-29.

<sup>35</sup> "Title 403," Nebraska Department of Health and Human Services; Smith, Letter to Senator Lynne Walz, 2019.

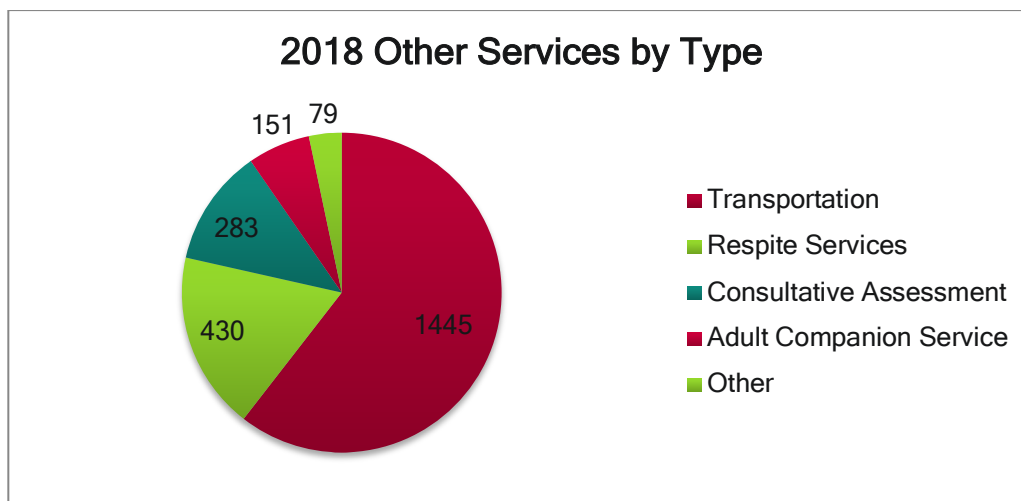
## Waiting for Services: Nebraska's DD Waiting List

Employment services spending in 2018 was \$9 million, only 3% of total HCBS spending.<sup>36</sup> Nonetheless, employment services made up 11% of total services. This is because the state spent an average of \$7,000 per service on employment compared to \$23,000 per service on day services and \$54,000 per service on residential services.<sup>37</sup>



*Smith, Letter to Senator Lynne Walz, 2019.*

The remaining 20% of services only make up 1.6% of the HCBS budget (\$5.2 million), mainly composed in number of participants in and gross spending on transportation services (\$3.5 million) to access program services.<sup>38</sup> Other services include short-term respite services for caregivers, assessment services to determine participant needs, “adult companion” short-term habilitative services, and miscellaneous emergency and technical services.



*Smith, Letter to Senator Lynne Walz, 2019.*

<sup>36</sup> Ibid.

<sup>37</sup> Ibid.

<sup>38</sup> Ibid.

## Policy Implications

Disability is a natural part of the human experience: one in six Americans have a developmental disability.<sup>39</sup> In order to live at home, be involved in the community, and work, those with developmental disabilities need more support than those without them. Because of this, a capability approach to public policy would prioritize the needs of those with developmental disabilities as a population that needs support to achieve minimum functioning enjoyed by others.<sup>40</sup>

The Nebraska Legislature has acknowledged the importance of supporting those with developmental disabilities, with its developmental disabilities line item ranking in the top fifteen line item increases in the state budget in eight of the past ten years.<sup>41</sup> That being said, the state has still not kept up with the demand for services over that time period, allowing the waiting list to balloon. In the past three years, the legislature has slowed spending on developmental disability aid, even reducing spending in Fiscal Year 2019.<sup>42</sup>

Assuming a 6% annual growth of people needing services and a 5% growth in per-person costs per year, the state will need to increase its annual spending on developmental disabilities by \$113 million in the next five years. Under the same conditions, the state would have to spend an additional \$67 million in 2024 to eliminate the waiting list, though costs would be lower in earlier years depending on the phase-in.

The state's recent creation of a vocational rehabilitation waiting list is a case of forgone revenue for the state.<sup>43</sup> With 2,400 people on a waiting list for vocational rehabilitation, the state is potentially forgoing millions of dollars in savings from alternative program costs and new tax revenue. People on the vocation waiting list receiving other services are especially costing the state and prioritizing getting them vocational services would create more revenue for the state. Nebraska Vocational Rehabilitation has said 1,300 people have been taken off the vocational rehabilitation list since July.<sup>44</sup>

On a broader scale, the state does not need to break the bank to provide essential services to people with developmental disabilities. Creating an ongoing monitoring system similar to that executed by the state from 2010-2016 to ensure the state is keeping up with demand for services would be an important first step. Also, the state can free up funds while also fostering independence by encouraging in-home services for those who could benefit from them rather than residential services in provider-owned settings.

<sup>39</sup> "Facts About Developmental Disabilities," Centers for Disease Control and Prevention, <http://www.cdc.gov>, September 26, 2019.

<sup>40</sup> Nussbaum, Martha C. *Frontiers of justice: Disability, nationality, species membership*. Harvard University Press, 2009.

<sup>41</sup> "Biennial Budget Reports: 2010-2019," Nebraska Legislature, [nebraskalegislature.gov](http://nebraskalegislature.gov).

<sup>42</sup> *Ibid.*

<sup>43</sup> "Nebraska Waiver Study," The Arc of Nebraska, Fall 2019.

<sup>44</sup> Foley, Lindy. (VR Director, State of Nebraska). October 23, 2019. Email communication.

Developmental disability services can yield economic gains as well. Early intervention in particular can reduce state costs and, if services yield the outcomes that have been found in other states, would increase future incomes for a total net lifetime benefit of \$650,000 to \$1.1 million per child served in 1998 dollars.<sup>45</sup> With 260 children on the waiting list, interventions such as these could reap substantial economic benefits for the state.

Lastly, developmental disability services can be a tool for fighting poverty. High rates of unemployment among those living with developmental disabilities demonstrate that people living with developmental disabilities encounter significant barriers to generating income.<sup>46</sup> More than a quarter of children with disabilities nationwide live in families under the federal poverty level, even though less than one in five children overall live in families under the poverty line.<sup>47</sup> In addition, their needs for support at home and in community activities mean people with developmental disabilities need more resources to experience the same quality of life as those not living with these disabilities.

Developmental disability aid is a key state tool for ensuring human rights, growing the economy, and fighting poverty. The Nebraska Legislature has the chance to tackle these goals in the upcoming years by creating a plan to promote independence, reduce the waiting list, and get services to those who need it most.

### Acknowledgements

Policy analysis support and drafting provided by Scioto Analysis. Learn more at

<http://www.sciotoanalysis.com>.



<sup>45</sup> Jacobson, John W., James A. Mulick, and Gina Green. "Cost-benefit estimates for early intensive behavioral intervention for young children with autism—general model and single state case." *Behavioral Interventions: Theory & Practice in Residential & Community-Based Clinical Programs* 13, no. 4 (1998): 201-226.

<sup>46</sup> Khayatzadeh-Mahani, Akram, Krystle Wittevrongel, David B. Nicholas, and Jennifer D. Zwicker. "Prioritizing barriers and solutions to improve employment for persons with developmental disabilities." *Disability and rehabilitation* (2019): 1-11.

<sup>47</sup> Hughes, Carolyn, and Selete K. Avoke. "The elephant in the room: Poverty, disability, and employment." *Research and Practice for Persons with Severe Disabilities* 35, no. 1-2 (2010): 5-14.

**Appendix A: HHS CEO Dannette Smith's Memo to Senator Lynne Walz**

**NEBRASKA**

Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES



Pete Ricketts, Governor

August 1, 2019

Senator Lynne Walz, District #15  
State Capitol  
PO Box 94604  
Lincoln, NE 68509-4604

RE: LR216

Dear Senator Walz:

Thank you for your recent letters concerning the Department of Health and Human Services and funding of the Medicaid Home and Community-Based Services waiver. I have provided answers to your questions below.

Response to letter addressed to Director Miller

- 1) The number of individuals currently on the Medicaid Home and Community-Based Waiver waiting list.

As of 7/22/2019, there were 2,326 individuals on the waiting list for Medicaid Home and Community-Based (HCBS) Waivers for the Developmentally Disabled (DD Waivers). Of these:

- 586 are receiving services on the DD Adult Day Waiver and are waiting for residential services on the DD Comprehensive Waiver.
- 262 are receiving services on the Aged & Disabled Waiver and are waiting for services on the DD Adult Day Waiver and/or the DD Comprehensive Waiver.

- 2) A breakdown of any and all available population demographic information such as age, race, gender, marital status, income, education, and employment status for those individuals residing on the waiting list.

The tables below provide the available demographic information of individuals on the waiting list for Medicaid HCBS DD Waivers that is maintained by the Division. All of the tables reflect data from 7/22/2019.

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Table 1: Distribution of Individuals on waiting list for DD Waivers by Age

Age Range	Individuals on Wait List
0-10	263
11-20	824
21-30	867
31-40	203
41-50	78
51-60	63
61-70	23
70+	5

Table 2: Distribution of Individuals on waiting list for DD Waivers by Race

Race	Individuals on Wait List
American Indian	28
Asian	45
Black/African American	190
Mexican	194
White	1638
Declined Response	231

Table 3: Distribution of Individuals on waiting list for DD Waivers by Gender

Gender	Individuals on Wait List
Male	1,400
Female	926

Table 4: Distribution of Individuals on waiting list for DD Waivers by Marital Status

Marital Status	Individuals on Wait List
Divorced	8
Married	15
Never Married	2197
Widowed	1
Declined Response	105

- 3.) An analysis of the healthcare services being provided to individuals currently on the HCBS waiver.

Individuals on Medicaid HCBS DD (DD) Waivers receive services both through the DD waiver and through their Heritage Health Medicaid Plan. The tables below provide utilization statistics for calendar year 2018 (CY2018). The timeframe of CY2018 rather

## Waiting for Services: Nebraska's DD Waiting List

than state fiscal year 2018 (SFY2018) was chosen for analysis because of two considerations:

- 1) Providers have 6 months to bill for Medicaid services in accordance with 471 NAC 3-002, therefore this time period represents the most recent year for which DHHS has complete utilization data.
- 2) The DD waivers were amended just before SFY2018. The amendment included changes to the services offered through DD waivers that took effect during SFY2018 which would make an analysis and presentation of service utilization more complex for comparison.

**Table 5: Service Utilization on the DD Waivers - Includes Claims Paid through 7/15/2019 for Dates of Service between 1/1/2018 and 12/31/2018**

Service Category	Service	Participants	Total Expenditures	% Total Expenditures
Residential	IN-HOME RES HABILITATION	1,688	38,337,196	12.0%
	RESIDENTIAL HABILITATION	2,433	176,900,403	55.3%
<b>All Residential Services</b>		<b>3,975</b>	<b>215,237,598</b>	<b>67.2%</b>
Employment	ENCLAVE	508	2,999,503	0.9%
	SUPPORTED EMPLOYMENT-FOLLOW ALONG	172	121,773	0.0%
	SUPPORTED EMPLOYMENT-INDIVIDUAL	788	5,870,761	1.8%
<b>All Employment Services</b>		<b>1,294</b>	<b>8,992,037</b>	<b>2.8%</b>
Day Services	ADULT DAY SERVICES	137	969,804	0.3%
	HABILITATIVE COMMUNITY INCLUSION	2,758	35,151,532	11.0%
	HABILITATIVE WORKSHOP	2,892	53,944,029	16.9%
	PREVOCATIONAL SERVICES	202	522,006	0.2%
<b>All Day Services</b>		<b>3,934</b>	<b>90,587,372</b>	<b>28.3%</b>
<b>All Employment and Day Services</b>		<b>4,318</b>	<b>99,579,408</b>	<b>31.1%</b>
Other Waiver Services	ADULT COMPANION SERVICE	68	228,826	0.1%
	ADULT COMPANION SERVICE IN-HOME	83	430,001	0.1%
	ASSISTIVE TECHNOLOGY AND SUPPORTS	2	3,335	0.0%
	CONSULTATIVE ASSESSMENT SERVICE	283	250,507	0.1%
	CRISIS INTERVENTION SUPPORT	2	5,704	0.0%
	EMERGENCY RESPONSE SYSTEM	25	11,121	0.0%
	ENVIRONMENTAL MODIFICATION ASSESSMENTS	19	19,000	0.0%
	HOME MODIFICATIONS	17	76,587	0.0%
	HOMEMAKER - INDEPENDENT	11	43,980	0.0%
	RESPIRE - AGENCY	186	328,223	0.1%
	RESPIRE - INDEPENDENT IN-HOME	146	222,607	0.1%
	RESPIRE - INDEPENDENT-OUT	98	142,322	0.0%
	TRANSPORTATION	1,445	3,465,509	1.1%
VEHICLE MODIFICATIONS	3	21,790	0.0%	
<b>All Other Services</b>		<b>-</b>	<b>5,249,511</b>	<b>1.6%</b>
<b>Total Served on Waiver:</b>		<b>4,835</b>		
<b>Total DD Waiver Expenditures:</b>			<b>320,066,518</b>	
<b>Annual Expenditures per Person:</b>			<b>66,198</b>	

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**Table 6: Service Line Utilization of Medicaid State Plan Services for Individuals on DD Waivers - Includes Claims Paid through 6/30/2019 for Dates of Service between 1/1/2018 and 12/31/2018**

ServiceType	Individuals	Payments to Providers
Dental	3,156	739,309
Drugs/Pharmacy	3,923	10,488,066
Early Periodic Screening Diagnosis and Treatment	131	16,617
Home Health	100	1,910,919
Inpatient – Hospital	455	881,255
Outpatient	3,532	2,949,209
Practitioner/provider fees	4,696	8,037,961
<b>TOTAL</b>		<b>25,023,336</b>

3.) The range and average time an individual resides on the waiting list before moving onto the HCBS waiver in addition to a more detailed breakdown as could reasonably be provided.

The Division generally does not track the average length of time an individual is on the wait list as a whole. This is because the number in and of itself would not be a representative value since individuals may move up the list and receive an offer based on a prioritization category. Another factor is when an individual is offered a DD Adult Day Waiver slot under Priority 4, they may choose to remain on the wait list with the application date for the DD Comprehensive Wavier under Priority 6. A better representation is the average wait list time for a Priority 6 funding offer for an individual.

Since July 1, 2017, the Division has made 561 funding offers under Priority 6 as defined in Nebraska revised statute 83-1216. Table 7 provides several descriptive statistics, including the range and the average, for the individuals that received these offers.

**Table 7: Descriptive Statistics for Individuals on the Waiting List who received a Funding Offer Corresponding to the Sixth Priority in Nebraska Revised Statute 83-1216 in SFY2017 or SFY2018**

<b>Total Priority 6 Offers</b>	<b>561</b>
<b>Descriptive Statistics for Years on Waiting List</b>	
<b>Average</b>	<b>6.6</b>
<b>Min</b>	<b>0</b>

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- 4) Any further information you can provide that would give a more thorough understanding.

The Division received 567 applications for Medicaid HCBS DD Waiver services in state fiscal year 2018 and 435 applications in state fiscal year 2019.

The table below shows the DD waiver funding offers made in SFY2017 and SFY2018. Funding offers were made in late SFY2017 in part due to additional appropriations for waitlist reduction in LB327 (2017). This appropriations bill included an additional \$1,697,234 General Funds for SFY2018 and \$3,474,752 General Funds for FY2019 to serve individuals on the waiting list.

**Table 9: Funding Offers made for DD Waivers in SFY2017 and SFY2018 by Priority in Nebraska**

83-1216 Priority	Description	SFY2017 Offers	SFY2018 Offers
<b>First</b>	Emergency (Priority)/DDCA	40	52
<b>Second</b>	Transition of Institutional Persons	4	7
<b>Third</b>	Transition from Foster Care System	29	5
<b>Fourth</b>	Transition for High School (Graduates)	193	175
<b>Fifth</b>	Dependent of member of Armed Forces	0	0
<b>Sixth</b>	Date of Application (Waitlist)	559	2
<b>TOTAL</b>		<b>825</b>	<b>241</b>

**Table 10: Funding Offers made for DD Waivers in SFY2017 and SFY2018 by Priority in Nebraska Revised Statute 83-1216**

		SFY2017	SFY2018
<b># of Individuals who left DD Waiver Services (Attrition)</b>	Day Waiver	33	43
	Comprehensive Waivers	137	122
	<b>Total For DD Waivers</b>	<b>170</b>	<b>165</b>
<b>Estimated Annual Cost of DD Waivers for those who left DD Waiver Services (Attrition Savings)</b>	Day Waiver	529,355	657,151
	Comprehensive Waivers	9,594,034	8,953,509
	<b>Total For DD Waivers</b>	<b>10,123,389</b>	<b>9,610,660</b>

## Waiting for Services: Nebraska's DD Waiting List

The Division currently has Medicaid HCBS DD Waiver application amendments pending with CMS. The current and proposed rates are not adjusted to exclude the costs associated with maintenance and supervision provided for under the foster care arrangement as these are considered a state obligation. The Division expects the directive from CMS through a corrective action plan to adjust the service definitions and rates applicable to children in foster care. Research and review of other states' policies and rate structures is already underway for timely resolution. As I have shared with the DD agencies at a recent Nebraska Association of Service Providers meeting, I do not have any reason to believe at this time that the rate adjustments would be an overall reduction to their payment to serve these children but there will be a change from one to two payment sources.

### Response to letter addressed to Director Wallen

- 1) The number of DHHS wards who are deemed eligible for services from the Division of Developmental Disabilities (DD), reported by service area.

The table below shows the 68 state wards, by CFS service area, on the waiting list for Medicaid Home and Community-Based Services Developmentally Disabled Comprehensive Waiver (DD Waiver) as of July 22, 2019.

Service Area	State wards on Waiting List
Central Service Area	7
Eastern Service Area	42
Northern Service Area	4
Southeast Service Area	14
Western Service Area	1

- 2) The number of DHHS wards who are deemed eligible for DD services and are currently not receiving services under the waiver because of insufficient emergency slots, reported by service area.

All of the 68 state wards identified in the previous question meet eligibility requirements for DD waiver services.

To clarify, insufficient emergency slots is not the reason state wards are not receiving services under the DD waiver. Due to federal rules and regulations state wards do not meet the criteria for the first priority category in state law, which is reserved for persons with developmental disabilities in immediate crisis due to caregiver death, homelessness, or a threat to the life and safety of the person. This is because, as a state ward, the state has the legal responsibility to ensure health and safety of the child and meet their needs through another federal funding source. To address the needs of this population, the state was able to establish a prioritization category and the legislature deemed it the third funding priority in Nebraska Revised Statute 83-1216.

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## Waiting for Services: Nebraska's DD Waiting List

<b>Max</b>	7.9
<b>First Quartile</b>	6.3
<b>Second Quartile (Median)</b>	6.7
<b>Third Quartile</b>	7.1

- 3) The number of individuals and the monetary amount dedicated to each of the different funding priorities.

There are no specified numbers of individuals or earmarked dollars in statute dedicated for each of the funding priorities. The state has estimated numbers of individuals for reserved capacities in the waivers to allow for prioritization of waiver offers, or slots, as funding becomes available. These estimates are set conservatively (i.e. they represent the highest anticipated number of individuals that may become eligible in a waiver year, accounting for year-to-year variation in historical data) and are found in Appendix B of the Medicaid HCBS DD Waiver applications. The estimates were set in accordance with the *Application for a 1915(c) Home and Community-Based Waiver Instructions, Technical Guide and Review Criteria* published by CMS in January 2015. There is not a federal penalty if reserved slots are not all utilized within a waiver year.

The table shows cost statistics for entrants to the DD waivers in SFY2018.

**Table 8: Cost Statistics for Entrants to DD Waivers in SFY2018 by priority in Nebraska Revised Statute 83-1216**

<b>83-1216 Priority</b>	<b>Description</b>	<b>Number of Individuals</b>	<b>Actual Cost in SFY2018</b>	<b>Estimated Annual Cost</b>	<b>Estimated Average Annual Cost Per Individual</b>
<b>First</b>	Emergency/DDCA (Priority)	32	\$1,253,132	\$4,309,025	\$134,657
<b>Second</b>	Transition of Institutional Persons	4	\$184,450	\$439,430	\$109,857
<b>Third</b>	Transition from Foster Care System	24	\$584,375	\$2,337,794	\$97,408
<b>Fourth</b>	Transition for High School (Graduates)	138	\$1,197,667	\$2,704,172	\$19,595
<b>Fifth</b>	Dependent of member of Armed Forces	-	-	-	-
<b>Sixth</b>	Date of Application (Waitlist)	381	\$5,692,757	\$12,866,570	\$33,771

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## Waiting for Services: Nebraska's DD Waiting List

3.) The estimated average daily cost of services for this population, reported by service area.

The table below shows the estimated daily costs reported by service area for this population. The total costs are for services paid for each state ward from July 1, 2018 to June 30, 2019.

Service Area	Number of Individuals	Total Costs	Average Costs/Day
Central Service Area	7	\$ 192,680.69	\$ 75.41
Eastern Service Area	42	\$ 3,192,362.35	\$ 208.24
Northern Service Area	4	\$ 109,269.05	\$ 74.84
Southeast Service Area	14	\$ 431,413.77	\$ 84.43
Western Service Area	1	\$ 10,042.98	\$ 27.52
<b>Total</b>	<b>68</b>	<b>\$ 3,935,768.84</b>	<b>\$ 158.57</b>

4.) The current adoption and/or guardianship stipend that is available to families who are standing ready to provide permanency.

The table below displays the daily rates negotiated with families for Adoption and Guardianship Assistance Agreements:

Child Age 0-5	Daily \$13.78 - \$35.60
Child Age 6-11	Daily \$15.29 - \$38.65
Child Age 12-18	Daily \$17.67 - \$40.70

To receive a stipend for an adoption or guardianship, the child first has to be eligible for an Assistance Agreement, then DHHS negotiates the daily rates based off the family need and the child's needs.

Sincerely,



Dannette R. Smith, MSW  
Chief Executive Officer  
Department of Health and Human Services

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