

**Position Paper on the Closing of Intermediate Care  
Facilities for Persons with Intellectual and/or  
Developmental Disabilities in Nebraska**

Disability Rights Nebraska

May 9, 2017

## Table of Contents

<b>Executive Summary .....</b>	<b>3</b>
<b>Background.....</b>	<b>4</b>
<b>Community Inclusion in Nebraska.....</b>	<b>9</b>
<b>Community Integration is a Civil Right .....</b>	<b>11</b>
<b>Recommendations .....</b>	<b>14</b>

## Executive Summary

Disability Rights Nebraska, the designated Protection and Advocacy system for persons with disabilities in Nebraska<sup>1</sup>, is guided by a vision where Nebraskans with mental or physical disabilities are valued within their communities, have control over their own lives, and have the necessary resources available to experience a life of quality. As such, we firmly believe that all people with disabilities should be afforded every opportunity to live in their community of choice with dignity and equality.

We were pleased to support Legislative Bill 895<sup>2</sup> in the legislature. We supported the bill's intent to analyze and plan for the future of the Beatrice State Developmental Center (BSDC) and the Bridges program. Given the decreasing census at BSDC, the ongoing significant operational costs, and the continued reliance on isolated and congregated institutional settings over community-based placement, such an examination is long overdue. While these are compelling reasons to assess the value of BSDC in 2017, it and all Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities (ICF/IDD) should be closed. Closure is the right thing to do. BSDC is but one ICF/IDD that is part of a larger issue of institutional segregation, congregation, and isolation. As such, we urge the legislature to build upon the foundation of LB 895 to expand its analysis towards the future of all ICF/IDDs in Nebraska.<sup>3</sup>

As of 2014, 15 states report having no state operated ICF/IDD institutions.<sup>4</sup> ICF/IDDs isolate, congregate, and segregate individuals with intellectual and/or developmental disabilities (I/DD) from the rest of society. These facilities are the remnants of a time when abuse, neglect and stigmatization occurred behind closed doors. Today Nebraska agrees that people with I/DD should no longer live as second-class citizens and should be afforded the same opportunities as all Nebraskans. This is why Disability Rights Nebraska believes in and supports the phased closure of all ICF/IDDs.

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<sup>1</sup> 42 U.S.C. § 15001 *et seq.* (DD Act), Neb. Rev. St. § 20-161 *et seq.*

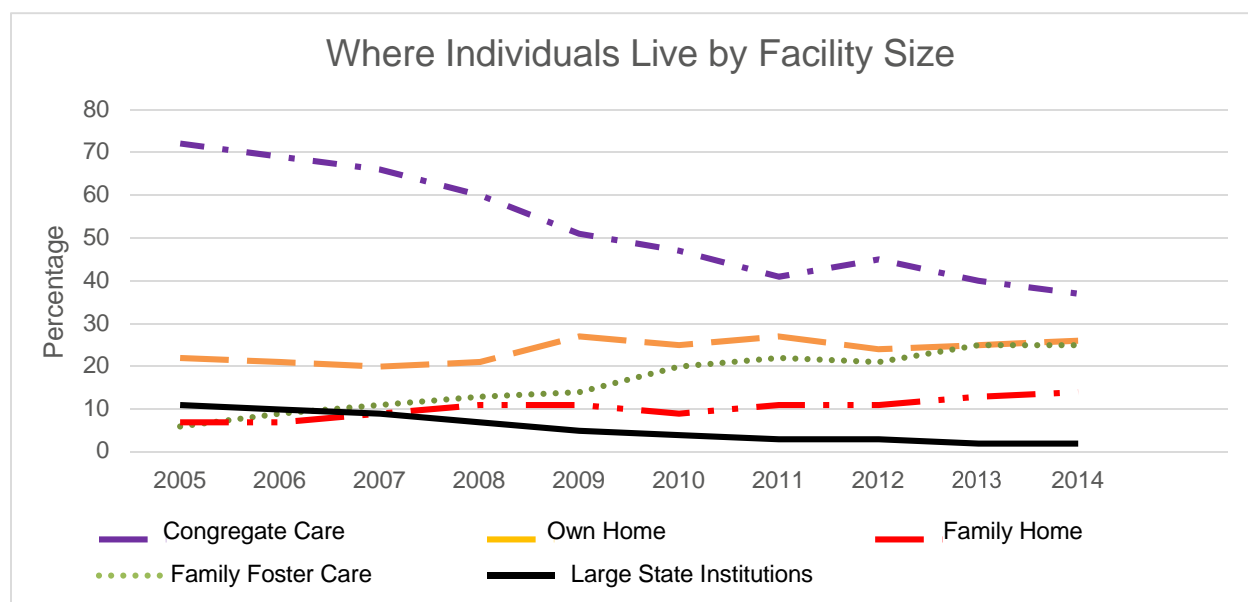
<sup>2</sup> Neb. Rev. Stat. §83-1227.

<sup>3</sup> Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities (ICF/IDD) is an optional Medicaid benefit that enables states to provide comprehensive and individualized health care and rehabilitation services to individuals to promote their functional status and independence, *Medicaid.gov Intermediate Care Facilities for Individuals with Intellectual Disabilities*, <https://www.medicaid.gov/medicaid/ltss/institutional/icfid/index.html>

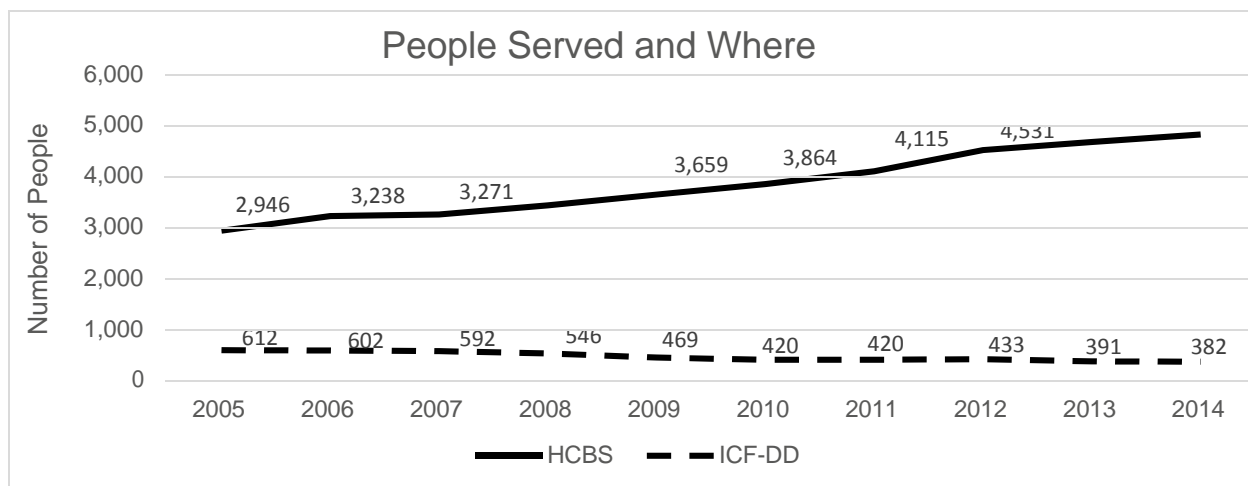
<sup>4</sup> Tarren Bragdon, *The Case for Inclusion 2016: 2016 Report*, United Cerebral Palsy, 8, 29, (2016), available at <http://cfi.ucp.org/wp-content/uploads/2014/03/Case-for-Inclusion-2016-FINAL.pdf>, last visited May 2, 2017.

## Background

According to a national report issued by United Cerebral Palsy<sup>5</sup>, since 2005, the trend in Nebraska has moved away from congregate care and large state institutions.



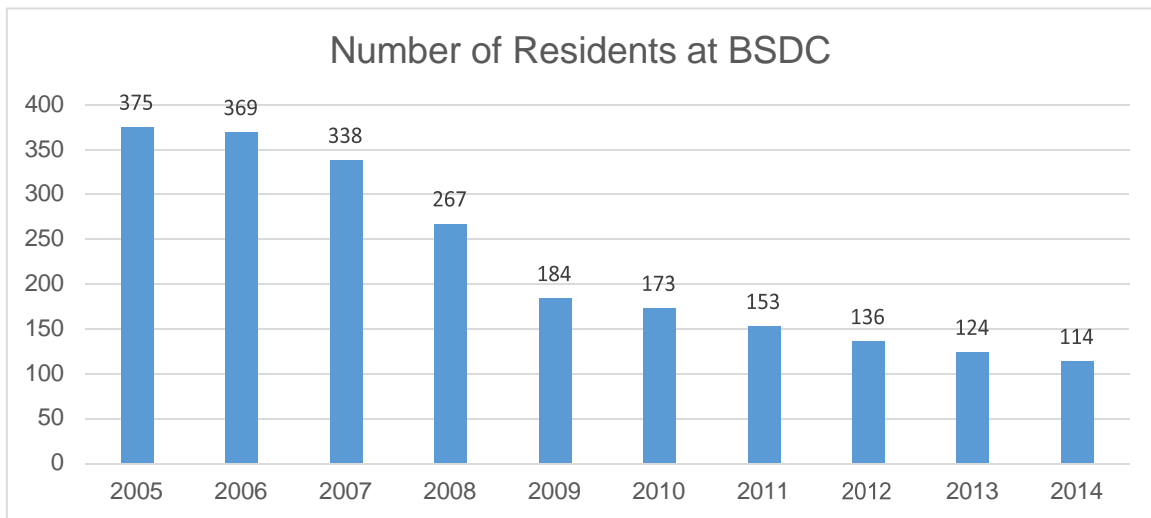
Source: United Cerebral Palsy, *The Case for Inclusion: State Scorecards* (2016)



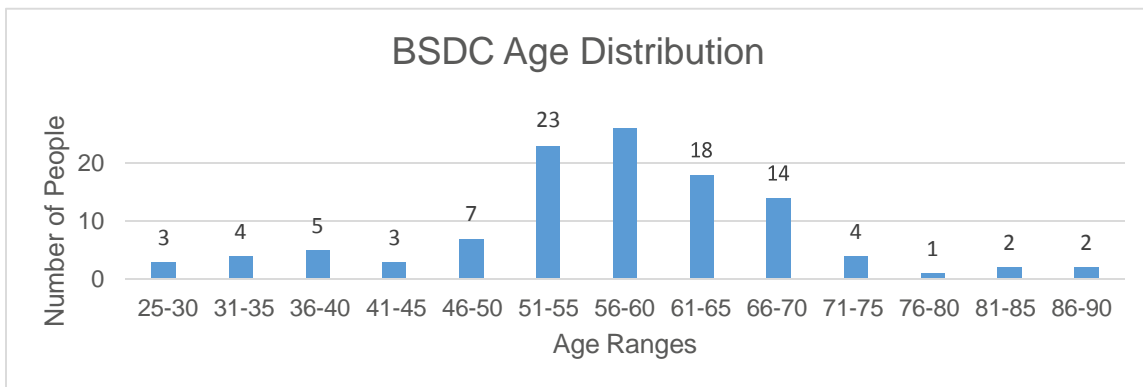
Source: United Cerebral Palsy, *The Case for Inclusion: State Scorecards* (2016)

<sup>5</sup> United Cerebral Palsy, *The Case for Inclusion: State Scorecards* (2016) available at: <https://cfi.ucp.org/state-scorecards/> (last visited May 3, 2017).

In 1966, before the development of community-based services in Nebraska, the population living at BSDC peaked at 2,236 residents.<sup>6</sup> The current census at BSDC is approximately 112 residents. Their ages range from 25 to 87 with an average age of 57 years.<sup>7</sup> Apart from having a disability, a young 25 year-old has little in common with someone at the age of 85. Nevertheless, they are congregated together.



Source: United Cerebral Palsy, *The Case for Inclusion: State Scorecards* (2016)



Source: Letter from Courtney Miller

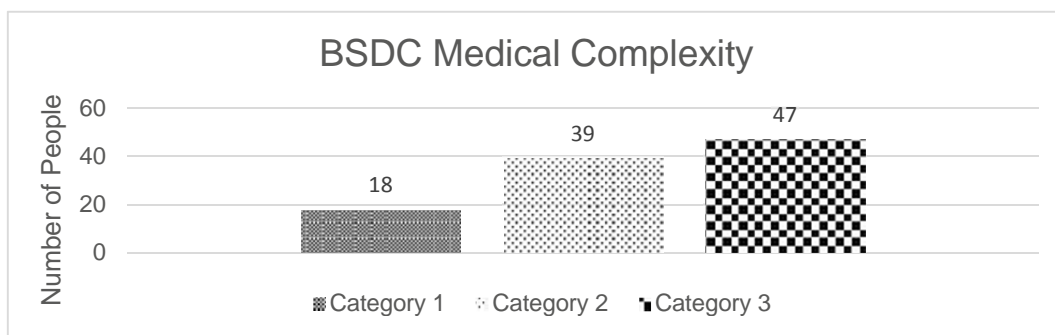
<sup>6</sup> Gaul, Kate, *Department of Health and Human Services Frequently Asked Questions About Nebraska's Largest Agency*, Legislative Research Office, (March 2015), available at <http://nebraskalegislature.gov/pdf/reports/research/hhsfaq2015.pdf>.

<sup>7</sup> Letter from Courtney Miller, Director of the Nebraska Department of Health and Human Services Division of Developmental Disabilities, to Eric Evans, CEO of Disability Rights Nebraska, Request for Information regarding ICF/IDDs (Feb. 7, 2017) (on file with author).

Residents of BSDC represent approximately 2.8% of the total population of individuals who receive developmental disability (DD) services.<sup>8</sup> The Nebraska Division of Developmental Disabilities has explained the medical complexity of individuals who currently reside at BSDC from a primary care standpoint. The description used to explain “Medically Complex” is divided into three categories:

1. Complex medical conditions requiring multiple outside consults. This means frequent exacerbations of chronic conditions requiring more frequent monitoring, assessment and changes to plan of care, possible psychiatry clinics and other meetings;
2. Complex medical conditions with occasional exacerbations requiring changes to plan of care and assessment at primary health care provider, with a routing number of meetings between 5-8 a year;
3. Routine care with infrequent visits to primary health care provider and routine number of meetings 5 or fewer a year.<sup>9</sup>

The following chart illustrates the distribution of individuals residing at BSDC who fall into the three different categories: 18 individuals in category 1, 39 individuals in category 2, and 47 in category 3.<sup>10</sup> There are 8 individuals who are not identified to meet the medically complex criteria.<sup>11</sup> Each of these individuals could live in the community with the proper supports and the same necessary medical services; they should not be congregated based on this.



Source: Letter from Courtney Miller

<sup>8</sup> Miller, *supra*, at 9.

<sup>9</sup> Letter from Courtney Miller, Director of the Nebraska Department of Health and Human Services Division of Developmental Disabilities, to Eric Evans, CEO of Disability Rights Nebraska, Request for Information regarding ICF/IDDs (Feb. 7, 2017) (on file with author).

<sup>10</sup> *Id.*

<sup>11</sup> *Id.*

BSDC operates a sheltered workshop that paid approximately 49 residents a sub-minimum wage during the previous year.<sup>12</sup> Sub-minimum wage represents a view that some people do not deserve a base wage to which anyone without a disability would be legally entitled. Moreover these sub-minimum wage positions take place on campus. An individual who receives much of his or her medical treatment on campus at BSDC, and also works a sub-minimum wage job on that same campus has little opportunity to participate in the rest of society, to explore his or her interests, or to interact with people without disabilities. Payment of sub-minimum wage is yet another example that illustrates the continued isolation and segregation occurring at BSDC.

Although BSDC is the only state-run ICF/IDD, two large private ICF/IDD facilities owned and operated by Mosaic are located in Axtell, NE and Beatrice, NE. The Axtell facility is licensed to serve 112 individuals and the Beatrice/Mosaic facility is licensed to serve 132 individuals.<sup>13</sup> Both facilities operate sheltered workshops that pay their workers sub-minimum wage: 56 residents from Axtell and 33 residents from Beatrice/Mosaic.<sup>14</sup> This again shows the low expectations and continued repetition of archaic policies and practices that are imposed on people with I/DD.

The federal government has limited the use of sub-minimum wage through passage of the Workforce Development Innovative Opportunity Act.<sup>15</sup> Provisions of this law require a series of steps to be taken before an individual under the age of 24 can be placed in a job paying less than minimum wage (almost all of which are either in sheltered workshops or enclaves operated by community rehabilitation providers).<sup>16</sup> This provision also includes language that prohibits schools from contracting with sub-minimum wage providers.<sup>17</sup>

The federal government has signaled that the use of sub-minimum wage and other practices that segregate, congregate, and isolate individuals with disabilities into “separate” and “other” settings will face greater scrutiny. Ultimately, we believe these practices should be abandoned entirely and ICF/IDDs that also operate a sheltered workshop should be studied closely because both institutions are a direct impediment to community integration. Now that Nebraska has committed to plan for the future of BSDC, it also has the opportunity to review the use of discriminatory practices in other ICF/IDDs.

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<sup>12</sup> U.S. Department of Labor, Wage and Hour Division, <https://www.dol.gov/whd/specialemployment/PatientWorkerList.htm>.

<sup>13</sup> State of Nebraska Roster, <http://dhhs.ne.gov/publichealth/Documents/ICFDDRoster.pdf>.

<sup>14</sup> *Id.*

<sup>15</sup> US Department of Labor Wage & Hour Division - Field Assistance Bulletin No. 2016- 2 - WHD Enforcement of WIOA Limitations on Payment of Subminimum Wages under FLSA Section 14(c), July 27, 2016. [https://www.dol.gov/whd/FieldBulletins/fab2016\\_2.htm](https://www.dol.gov/whd/FieldBulletins/fab2016_2.htm)

<sup>16</sup> *Id.*

<sup>17</sup> *Id.*

The Nebraska Division of Developmental Disabilities took an important first step to end discrimination and promote community integration when it closed the Bridges program in Hastings, Nebraska.<sup>18</sup> The Division should continue down this path and plan for the closure of BSDC and all ICF/IDDs in Nebraska.

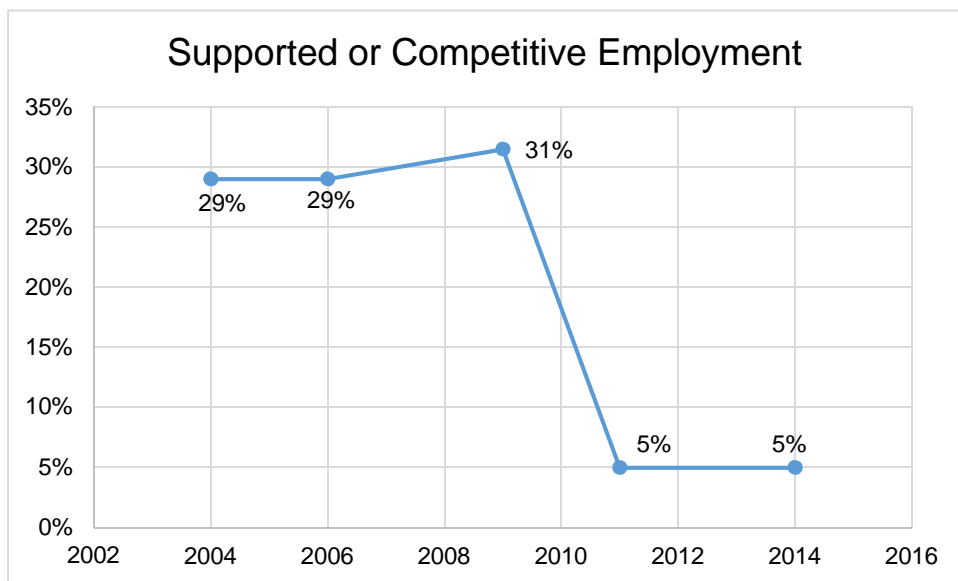
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<sup>18</sup> Young, Joann, BSDC laying off 39 workers; “Bridges Program in Hastings Closing,” Lincoln Journal Star, March 7, 2017. Last visited, 5/2/2017. [http://journalstar.com/news/state-and-regional/govt-and-politics/bsdc-laying-off-workers-bridges-program-in-hastings-closing/article\\_dc07a642-b15b-5e11-8770-418c65d044e2.html](http://journalstar.com/news/state-and-regional/govt-and-politics/bsdc-laying-off-workers-bridges-program-in-hastings-closing/article_dc07a642-b15b-5e11-8770-418c65d044e2.html).



## Community Inclusion in Nebraska

Nebraska must make community inclusion a priority. In United Cerebral Palsy's 2016 report on inclusion, it ranked Nebraska 41<sup>st</sup> among the 50 states and the District of Columbia.<sup>19</sup> This was down from Nebraska's 2015 ranking at 37<sup>th</sup>.<sup>20</sup> At one point in time, Nebraska was a state that made significant progress towards inclusion among individuals with intellectual and/or developmental disabilities. Unfortunately, this report demonstrates that much work remains to be done and that we should reverse this downward trend. Indeed, 80% of states have done a better job of inclusion than Nebraska. For example, our supported or competitive employment drastically declined between 2009 and 2012 and remained at a mere 5% through 2014.<sup>21</sup> Forty-six states currently have Employment First policies in which states commit to integrated employment through publicly-financed day and employment services.<sup>22</sup> Integrated employment requires that employees are paid directly by employers at competitive wages—and not subminimum wage. Nebraska is not among these 46 states,<sup>23</sup> and could go far in promoting inclusion through the creation of an Employment First policy.



Source: United Cerebral Palsy, *The Case for Inclusion: State Scorecards* (2016)

<sup>19</sup> Bragdon, *supra* at 4.

<sup>20</sup> *Id.*

<sup>21</sup> *Id.*

<sup>22</sup> Bragdon, at 4.

<sup>23</sup> See Derek Nord, Ph.D. & David Hoff, MSW, *Employment First Across the Nation: Progress on the Policy Front*, Policy Research Brief, Vol. 24, No. 1 (2014) available at <http://www.apse.org/wp-content/uploads/2014/01/activity.html> (last visited May 3, 2017).

While Nebraska's ranking declined between 2015 and 2016, states like Missouri and South Dakota increased their ranking by double digits over the last decade. Missouri alone increased their ranking by 33 places by increasing the portion of resources dedicated to people in the community. Where 50% of their resources had been dedicated to inclusive resources, Missouri increased this number to 88%. They also increased the number of people served in home-like settings from 75% to 84% and closed the last two state institutions.<sup>24</sup> Our neighbors were able to achieve this through a concerted effort and so can we by shifting our resources from institutional settings like BSDC and other ICF/IDDs to integrated community-based services.

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<sup>24</sup> *Id.* at 17.

## Community Integration is a Civil Right

In 1990, Congress enacted the Americans with Disabilities Act (ADA) “to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.”<sup>25</sup> In passing the ADA, Congress recognized that “historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.”<sup>26</sup> A core purpose of the ADA is to “assure equality of opportunity, full participation, independent living, and economic self-sufficiency” for individuals with disabilities.<sup>27</sup> Therefore, the ADA and its Title II regulations require public entities to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”<sup>28</sup> The preamble to the “integration mandate” regulation explains that “the most integrated setting” is one that “enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible . . . .”<sup>29</sup>

The United States Supreme Court held in *Olmstead v. L.C.*, that the ADA prohibits unjustified segregation of people with disabilities and described the harms of segregation, “institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life and that confinement in an institution severely diminishes the everyday life activities of individuals . . . .”<sup>30</sup>

In *Olmstead*, the Supreme Court, interpreting the ADA and its integration mandate, held that Title II of the ADA prohibits the unjustified segregation of individuals with disabilities. The Court held that public entities are required to provide community-based services to persons with disabilities when (a) such services are appropriate; (b) the affected persons do not oppose community-based treatment; and (c) community-based services can be reasonably accommodated, taking into account the resources available to the entity and the needs of others who receive disability services from the entity.<sup>31</sup> However, courts have repeatedly and soundly rejected the argument that *Olmstead*

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<sup>25</sup> 42 U.S.C. § 12101(b)(1). Section 504 of the Rehabilitation Act of 1973 similarly prohibits disability-based discrimination. 29 U.S.C. § 794(a) (“No otherwise qualified individual with a disability . . . shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance . . . .”). Claims under the ADA and the Rehabilitation Act are generally treated identically.

<sup>26</sup> 42 U.S.C. § 12101(a)(2).

<sup>27</sup> 42 U.S.C. § 12101(a)(7) (2009).

<sup>28</sup> 28 C.F.R. § 35.130(d) (the “integration mandate”).

<sup>29</sup> 28 C.F.R. pt. 35, app. B (addressing § 35.130(d)).

<sup>30</sup> *Olmstead*, 527 U.S. at 600-01.

<sup>31</sup> *Olmstead*, 527 U.S. at 607.

gives an individual the right to remain in an institution if the State decides to close the institution.<sup>32</sup>

Under the Obama administration, the federal government was heavily involved in *Olmstead* enforcement and technical assistance in a variety of contexts.<sup>33</sup> Indeed, the reach of *Olmstead* and the ADA's Integration Mandate extends well beyond institutions themselves.<sup>34</sup> Effective March 17, 2014, the U.S. Department of Health and Human Services Centers for Medicare and Medicaid Services (CMS) promulgated final regulations impacting all Medicaid home and community-based services.<sup>35</sup> The rule reinforces established public policy that residential settings should be smaller, within inclusive communities, and support control and decision-making by the people who live in those settings.<sup>36</sup> The policy makes clear that any residential settings supported with CMS funds must be inclusive and assure that those being supported have control and decision-making authority about such aspects of daily life as having guests and when to eat.<sup>37</sup> The home and community-based services final regulations require that settings be integrated in, and support full access to, the greater community, including opportunities to seek employment, engage in community life, control personal resources, and receive services.<sup>38</sup>

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<sup>32</sup> *IL League of Advocates for the Developmentally Disabled v. Quinn*, (IL) 2013 WL 3168758 (N.D. Ill. 6/20/2013) District Court; *Sciarilla v. Christie* (NJ), 2013 WL 6586569 (D.N.J. Dec. 13, 2013); *Richard S. v. Department of Developmental Services* (CA), 2000 WL 35944246 (C.D. Cal. March 2000); *Richard C. v. Houstoun* (PA), 196 F.R.D. 288, 292 (W.D. Pa. 1999).

<sup>33</sup> See e.g., U.S. Dep't of Justice, *Statement of the Department of Justice on Application of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C. to State and Local Governments' Employment Service Systems for Individuals with Disabilities* (Oct. 31, 2016) available at [https://www.ada.gov/olmstead/olmstead\\_guidance\\_employment.pdf](https://www.ada.gov/olmstead/olmstead_guidance_employment.pdf) (last visited May 7, 2017), providing technical assistance on integrated employment); see also U.S. Department of Health and Human Services, *OCR Olmstead Enforcement Success Stories: Preventing Discrimination Against People with Disabilities in Health Care and Social Services* available at <https://www.hhs.gov/civil-rights/for-providers/compliance-enforcement/examples/olmstead/index.html#top> (last visited May 7, 2017), providing an extensive list of *Olmstead* enforcement cases and their dispositions; U.S. Dep't of Justice, *Olmstead: Community Integration for Everyone, Olmstead Enforcement*, available at [https://www.ada.gov/olmstead/olmstead\\_cases\\_list2.htm](https://www.ada.gov/olmstead/olmstead_cases_list2.htm) (last visited May 7, 2017), providing a list of cases in which the DOJ has been involved.

<sup>34</sup> See e.g., Robert Dinerstein, *The Olmstead Imperative: The Right to Live in the Community and Beyond* (August 14, 2015), *Inclusion*, 2016, Vol. 4, No. 1, 16-20; American University, WCL Research Paper No. 2016-11, available <https://ssrn.com/abstract=2749372> (last visited May 7, 2017), providing a brief history of *Olmstead* enforcement and its reach.

<sup>35</sup> 42 C.F.R. §§ 430-431; 42 C.F.R. §§ 435-436; 42 C.F.R. §§ 440-441; 42 C.F.R. §447, see also <http://www.aucd.org/docs/policy/HCBS/references/final-rule-fact-sheet-%20self%20directed.pdf>

<sup>36</sup> Office of the Federal Register, <https://www.federalregister.gov/documents/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider>

<sup>37</sup> <http://www.aucd.org/docs/policy/HCBS/references/hcbs-setting-fact-sheet.pdf>

<sup>38</sup> *Id.*

People with I/DD can and should receive services in the community. Assumptions that they require constant supervision or support, group employment, and group living are derived from low expectations of people with I/DD and unsupported by research.<sup>39</sup> Indeed, the research demonstrates that people attain better outcomes when they live in smaller community-based settings that promote control, choice, and opportunities.<sup>40</sup>

People with intellectual and developmental disabilities have a legal right to live and to receive necessary services and supports in their community. Life in the community provides opportunities for dignity, freedom, choice, and a sense of belonging that are not possible in an institutional environment. This is the most important reason ICF/IDDs should be closed.

Closure of current ICF/IDDs will not be easy and need not be immediate. Rather, a plan should be developed that includes input, collaboration, and direction from individuals with I/DD, their families, and advocates. Such a plan must outline the necessary steps and timelines so that closure is implemented and ultimately achieved within a reasonable timeframe so that people with I/DD living in institutions can successfully transition to high-quality, safe, and person-centered living situations in the community.

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<sup>39</sup> *Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community*, National Council on Disability. (February 24, 2015) at pg. 57. also available at: [http://www.ncd.gov/rawmedia\\_repository/HCBS%20Report\\_FINAL.pdf](http://www.ncd.gov/rawmedia_repository/HCBS%20Report_FINAL.pdf); K. Charlie Lakin et al., *Behavioral Outcomes of Deinstitutionalization for People with Intellectual and/or Developmental Disabilities: Third Decennial Review of U.S. Studies 1977-2010*, Research And Training Center On Community Living, a review of 45 studies finding “consistent evidence of benefits accruing to people with ID/DD from movement from institutions to community.”; The American Association on Intellectual and Developmental Disabilities and the Association on University Centers on Disabilities published “Community Living and Participation for People with Intellectual and Developmental Disabilities: What the Research Tells Us,” available at [http://aucd.org/docs/publications/2015\\_0723\\_aucd\\_aaidd\\_community\\_living3.pdf](http://aucd.org/docs/publications/2015_0723_aucd_aaidd_community_living3.pdf); see also ODEP, *Integrated Employment Toolkit*, available at <https://www.dol.gov/odep/ietoolkit/researchers.htm> and <https://perma.cc/7PCU-NFLM> (last visited May 7, 2017), providing additional research citations that show individuals with I/DD are capable of working in community-settings, outcomes, and best practices.

<sup>40</sup> *Id.*

## Recommendations

Disability Rights Nebraska recommends the following:

1. Continue to prohibit new admissions to BSDC;
2. Establish a task force that will work in conjunction with the Olmstead stakeholder advisory committee to develop a three-year plan to close BSDC;
3. Develop and implement a high-quality, multi-layered system of quality assurance to ensure safe supports and services in the community that are outcome driven;
4. Examine and expand the capacity of services and supports that will be needed in the community as individuals transition to the community;
5. Seek guidance from states who have successfully developed and implemented plans for closure of their state institutions;
6. Eliminate ICF/IDDs as a state option in Nebraska's State Medicaid Plan and develop a plan for their closure;
7. Strengthen and increase opportunities for competitive employment and adopt Employment First policies;
8. Ensure that individuals are not transitioning to private ICF/IDDs.