

***Olmstead* Barriers in Ohio:  
The Problems faced by People with Disabilities in Ohio  
in Achieving Community Integration**

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An Ability Center of Greater Toledo White Paper  
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**THE ABILITY CENTER**  
GREATER TOLEDO • OTTAWA COUNTY • BRYAN

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The Ability Center of Greater Toledo is a Center for Independent Living, established in 1920, serving seven counties in northwest Ohio. Our mission is to assist people with disabilities to live, work, and socialize within a fully accessible community. We exercise our core values of consumer control and community inclusion; advocacy; establishing high expectations for success among people with disabilities; and forming partnerships and positive public relations to deliver best practice programs that assist people with disabilities in achieving community integration.

This white paper and other Ability Center policy advocacy can be found on our website, [www.abilitycenter.org](http://www.abilitycenter.org).

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## **I. Introduction**

Sixteen years ago, in *Olmstead v. L.C.*, the U.S. Supreme Court held that a state's duty to refrain from discrimination under the Americans with Disabilities Act included an affirmative mandate to allow people with disabilities to live "in the most integrated setting appropriate."<sup>1</sup> In that decision, the Supreme Court required states to support the deinstitutionalization of people with disabilities and their transition into living and working in an inclusive community.

The Ability Center of Greater Toledo is dedicated to removing barriers to equal opportunity and community inclusion and has a commitment to change systems, public policies, and attitudes that prevent people with disabilities from living, working, and socializing in their communities. The focus of this paper is an overview of the public policy and legal bases for community inclusion and some of the barriers to community inclusion that the Ability Center of Greater Toledo<sup>2</sup> has identified among its consumers.<sup>3</sup> While in the past fifteen years, Ohio has taken steps to implement the *Olmstead* decision, its policies have lagged behind those of other states and consumers with disabilities in Ohio continue to be subject to discrimination in the form of institutionalization and segregation from the greater community.

## **II. Background and Historical Perspective**

### **A. Asylums and Institutions**

Both Title II of the Americans with Disabilities Act and the Supreme Court's *Olmstead* decision were a reaction to the pervasive segregation and institutionalization of people with disabilities in early America. Early discrimination against people with disabilities was, in great part, defined by the

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<sup>1</sup> *Olmstead v. L.C.*, 527 U.S. 581, 594 (1999), available at <http://www.law.cornell.edu/supct/html/98-536.ZS.html>.

<sup>2</sup> The Ability Center of Greater Toledo is a Center for Independent Living serving the Northwest Ohio area that actively partners with community organizations and supports individuals with disabilities and their families to achieve their vision of independent living. We are dedicated to assist people with disabilities to live, work, and socialize within a fully accessible community and have a commitment to changing systems, public policies, and attitudes that prevent people with disabilities from living, working, and socializing in their communities.

<sup>3</sup> The conclusions in this paper are based on data and the observations of the Ability Center, which has worked to assist the state in implementation of *Olmstead* programs; has direct, daily contact with consumers; and also has exposure to the issues on a policy level.

decision to house people with disabilities in state sponsored asylums and institutions. In very early colonial America between 1492 and 1700, families cared for those unable to care for themselves due to physical, developmental, or mental health disabilities on an individual basis.<sup>4</sup> However, from the civil war period through the 1890s, the population of the U.S. grew and concentrated in cities, and the federal government expanded. Those conditions resulted in a generalized treatment of those with disabilities based on federal policy and law.<sup>5</sup> Too often, governmental treatment of disability involved segregation and institutionalization.<sup>6</sup> Insane asylums developed quickly across the U.S. alongside schools for the "idiots, deaf, and blind" and other institutions that solely served people with disabilities.<sup>7</sup>

Initially, many of these institutions were focused on transition from segregated settings to independence, but as time went on, institutions moved from places focused on transition to places that were simply custodial.<sup>8</sup> People with disabilities living in institutions were forced to live in appalling conditions, were subjected to abusive treatment,<sup>9</sup> and their behavior, including their day-to-day choices, were controlled by a doctor's orders.<sup>10</sup> Many residents were subject to commonplace use of physical restraints, brutality, starvation, and non-consensual sterilization.<sup>11</sup>

After decades of advocacy, disability rights activists eventually exposed the conditions in institutions and succeeded in creating a federal policy favoring deinstitutionalization. In the 1970s, the movement towards deinstitutionalization focused on transitioning people with disabilities from asylums

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4 Kim E. Nielsen, *A Disability History of the United States*, 25(Beacon Press 2012). A 1694 Massachusetts statute guaranteed that each community had the responsibility "to take effectual care and make necessary provision for the relief, support, and safety of such impotent or distracted person."

5 *Id.* at 91-93.

6 *Id.*

7 *Id.* at 94-98.

8 *Id.* at 118.

9 *Id.* at 113, 116-117; see also *Buck v. Bell*, 274 U.S. 200 (1927) (Supreme Court decision affirming a Virginia statute that allowed the sterilization of inmates of institutions supported by the state where they are "found to be afflicted with a hereditary form of insanity or imbecility"), available at <http://www.law.cornell.edu/supremecourt/text/274/200>.

10 *Id.* at 119.

11 *Id.* at 144.

to independent living centers, group homes, and community based mental health centers.<sup>12</sup> From 1965 to 1980, the number of people institutionalized in public asylums fell by 60%.<sup>13</sup> Unfortunately, the focus on releasing people from asylums did not provide enough community supports, and many people let out of asylums ended up homeless or in jail.<sup>14</sup> This initial push for deinstitutionalization did not accomplish what many hoped and advocated for because it was not supported by the means necessary to achieve it.<sup>15</sup> However, advocates made great strides in changing public perception and national policy regarding treatment of people with disabilities.

**B. The Americans with Disabilities Act and *Olmstead v. L.C.***

During this period of time, the federal government recognized institutionalization as, like racial segregation, a form of discrimination that causes inequality and a lack of opportunity and created laws that made institutionalization unlawful and counter to public policy. Specifically, Congress passed the Rehabilitation Act of 1973<sup>16</sup> and the Americans with Disabilities Act (ADA)<sup>17</sup> in 1990. These laws made disability discrimination a violation of federal law.<sup>18</sup> Additionally, in a decision that has been referred to as the *Brown v. Board of Education*, the hallmark desegregation case, for disability rights, in 1999 the Supreme Court held in *Olmstead v. L.C.* that the anti-discrimination provisions of the ADA prohibited states from isolating the disability community through unnecessary institutionalization.<sup>19</sup> The Court found that "unjustified isolation \* \* \* is properly regarded as discrimination based on disability," and that this discrimination violated federal law.<sup>20</sup> The holding of the *Olmstead* case mandated states to assist people with disabilities in avoiding "unjustified isolation" or unnecessary institutionalization.

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<sup>12</sup> *Id.* at 164.

<sup>13</sup> *Id.*

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

<sup>15</sup> *Id.*

<sup>16</sup> 29 U.S.C. 701, *et seq.*

<sup>17</sup> 42 U.S.C. 12101, *et seq.*

<sup>18</sup> Nielson, *supra* note 4 at 164.

<sup>19</sup> *Olmstead v. L.C.*, 527 U.S. 581, 593 (1999).

<sup>20</sup> *Id.* at 597.

In *Olmstead*, the Atlanta Legal Aid Society sued the state of Georgia on behalf of Lois Curtis and Elaine Wilson, two women with developmental disabilities and mental illness who were patients in Georgia psychiatric hospitals.<sup>21</sup> Both women lived in psychiatric treatment facilities for many years beyond their requests to leave.<sup>22</sup> The Atlanta Legal Aid Society claimed that the two women's institutionalization violated Title II of the ADA and its implementing regulations.<sup>23</sup>

The Legal Aid Society argued that Georgia's failure to transition the two women into the community violated the ADA's requirement that, "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by such an entity."<sup>24</sup> Likewise, Georgia violated the ADA implementing regulations requiring public entities to, "administer services, programs, and activities in *the most integrated setting appropriate* to the needs of qualified people with disabilities."<sup>25</sup>

In response, the state of Georgia admitted that the ADA required people to be served in the most "integrated setting appropriate", but argued that it would be too expensive to provide supports in a community setting to every eligible individual.<sup>26</sup> It claimed that its failure to provide Curtis and Wilson with community placements would, "fundamentally alter the nature of the service, program, or activity."<sup>27</sup> In short, it argued that to move them from the state-sponsored institutional settings to state-sponsored community settings would be so expensive that it would be prohibitive.

*Olmstead* eventually went to the U.S. Supreme Court on the question of whether a lack of state

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21 *Id.* at 593; Judge David L. Bazelon Center for Mental Health, *The Olmstead Decision*, available at <http://www.bazelon.org/Where-We-Stand/Community-Integration/Olmstead-Implementing-the-Integration-Mandate/The-Olmstead-Decision-.aspx> (accessed May 29, 2014).

22 Nielson, *supra* note 4 at 593.

23 *Olmstead*, 527 U.S. 581 at 594.

24 *Id.*; 42 U.S.C. 12132, *emphasis added*.

25 *Id.*; 28 C.F.R. 35.130(b)(7)(1998), *emphasis added*.

26 *Id.*

27 *Id.*; 28 C.F.R. 35.130(b)(7)(1998).

funding fell under the "fundamentally alter" exception.<sup>28</sup> Rather than agreeing that a lack funding was an excuse for unnecessary institutionalization, the Court affirmatively held that, under Title II of the ADA, states were *required* to provide community based treatment for persons with disabilities where the state's treatment professionals determined that such placement was appropriate, the affected persons did not oppose such treatment, and the placement could be reasonably accommodated taking into account the resources available to the state and the needs of others with mental disabilities.<sup>29</sup>

The Court held that the state must take into account its *duty* to meet out a range of services provided to those with disabilities equitably against the expense of services.<sup>30</sup> The Court also stated that lower courts may require states to show that they have a plan for moving people to less restrictive settings and a waiting list that moves at a reasonable pace not controlled by a state's attempt to keep its institutions fully populated when states claim that deinstitutionalization is too expensive.<sup>31</sup>

Finally, the Supreme Court emphasized two federal policy considerations in its *Olmstead* decision: 1) unnecessary institutionalization perpetuates myths that people with disabilities are incapable of participating in community life; 2) and confinement severely diminishes the everyday life activities of people with disabilities including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.<sup>32</sup> In effect, the Supreme Court directed states to end the systemic unwarranted confinement of people with disabilities in state hospitals, nursing facilities, intermediate care facilities, and residential treatment centers and create a system where states supported such people in community living.<sup>33</sup>

### **C. The Institutional Bias in Medicaid.**

States primarily use the federal Medicaid system to care for people with disabilities, so

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<sup>28</sup> *Id.*

<sup>29</sup> *Id.* at 607.

<sup>30</sup> *Id.* at 597.

<sup>31</sup> *Id.* at 605-606.

<sup>32</sup> *Id.* at 607.

<sup>33</sup> Jennifer Mathis, *Community Integration of Individuals with Disabilities: An Update on Olmstead Implementation*, 35 Clearinghouse Review 395 (Nov.-Dec.2001).

*Olmstead* compliance is largely focused on creating exceptions to the institutional bias present in the Medicaid system. On July 30, 1965, the Social Security Amendments of 1965 (Title XIX) established two related national health insurance programs for the aged, i.e. Medicaid and Medicare, that updated and improved the already-existing old-age, survivors, and disability insurance program.<sup>34</sup> The legislation was referred to casually as “hospital insurance” because it was designed primarily to provide insurance for hospital stays and limited post hospital home health services.<sup>35</sup> Given the focus of the legislation, a number of provisions were placed in the act to make it easier for the elderly and disabled to obtain needed hospital care.<sup>36</sup> Mandatory coverage of long-term care services was limited to care provided in skilled nursing facilities for people 21 years or older.<sup>37</sup> Prior to 1981, the only comprehensive, long-term care that was reimbursed by Medicaid was care in an institutional setting, such as a nursing facility, hospital, or an intermediate care facility.<sup>38</sup>

In response to the push for care in a community setting, in 1981, Congress authorized the waiver of certain Medicaid requirements to enable a state to provide home and community based services (HCBS) to people who would otherwise require services provided in institutional settings.<sup>39</sup> Medicaid Home-and-Community Based Waivers (Waivers) were established under section 1915(c) of the federal Social Security Act and were intended to correct the bias towards institutional care in the Medicaid program.<sup>40</sup> To participate, states received approval from the Department of Health and Human Services to institute a waiver program.<sup>41</sup> Waivers are only one of three ways in which states

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<sup>34</sup> Wilbur J. Cohen; Robert M. Ball, *Social Security Amendments of 1965: Summary and Legislative History*, 3(September 1965), available at <http://199.173.225.5/policy/docs/ssb/v28n9/v28n9p3.pdf> (accessed October 2014).

<sup>35</sup> *Id.* at 3.

<sup>36</sup> *Id.* at 8.

<sup>37</sup> Gary Smith; Janet O’Keefe; Letty Carpenter; Pamela Doty; Gavin Kennedy; Brian Burwell; Robert Mollica; and Loretta Williams; U.S. Department of Health and Human Services, *Understanding Medicaid Home and Community Based Services: A Primer*(October 2000), available at <http://aspe.hhs.gov/daltcp/reports/primer.pdf> , (accessed October 2014).

<sup>38</sup> Danyell Punelli, *Medicaid Home-and Community Based Waiver Programs*,2 (November 2013), available at Minnesota House of Representatives <http://www.house.leg.state.mn.us/hrd/pubs/waiver.pdf> (accessed October 2014).

<sup>39</sup> *Smith, et al., supra* note 37, at 13.

<sup>39</sup> *Punelli, supra* note 38, at 2.

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

<sup>41</sup> *Id.*

have provided HCBS through the Medicaid laws. Otherwise, states can provide HCBS under 1915(I) state plan services or 1915(k) community first choice authorities.<sup>42</sup>

Because of the design of the Social Security Act, a 1915(c) waiver can provide services not usually covered by the Medicaid program, as long as the services are necessary to keep a person from being institutionalized.<sup>43</sup> Services include case management, homemaker, home health aide, personal care, adult day health, habilitation, respite care, day treatment or other partial hospitalization services, psychosocial rehabilitation services, clinic services for people with chronic mental illness, other such services requested by states that may be approved.<sup>44</sup> In effect, Medicaid is the primary drivers of states' systems to provide services for those with disabilities and, in many ways, the services they offer dictate where a person with disabilities is able to live, work, and otherwise spend their days.

Much of the control of these policies is in the hands of states. Broad national guidelines are established by Federal statutes, regulations, and policies, but each state establishes its own eligibility standards; determines the type, amount, duration, and scope of services; sets the rate of pay for services; and administers its own program.<sup>45</sup> Medicaid payments are made directly to the state providers of covered services.<sup>46</sup> Thus, state's Medicaid systems must be operated in way that complies with the *Olmstead* mandate.

### **III. Federal Implementation of *Olmstead v. L.C.***

Since 1999, the federal government has actively applied and expanded the *Olmstead* mandate. Federal courts have required states to take affirmative action to implement plans to deinstitutionalize the state. Courts have consistently held that the *Olmstead* decision does not just apply to persons who

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<sup>42</sup> Centers for Medicare and Medicaid Services, *Fact Sheets: Home and Community Based Services* (January 10, 2014), available at <http://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2014-Fact-sheets-items/2014-01-10-2.html> (accessed January, 2014).

<sup>43</sup> *Smith, et al., supra note 37* at Chapter 1.

<sup>44</sup> *Id.*

<sup>45</sup> Centers for Medicare and Medicaid Services, *Medicaid Information by Topic*, available at <http://medicaid.gov/medicaid-chip-program-information/by-topics/by-topic.html> (accessed January 2014).

<sup>46</sup> *Id.*

are institutionalized but those "at risk" of institutionalization.<sup>47</sup> In *Makin v. Hawaii*, a district court held that *Olmstead* required Hawaii to modify its Medicaid system where access to waivers required long waiting lists and where there were caps on the number of waiver slots.<sup>48</sup> In *Townsend v. Quasim*, the Ninth Circuit held that Washington was required to expand its community based nursing home waiver program to include "medically needy" Medicaid recipients unless it could prove that doing so would require cutbacks to other recipients.<sup>49</sup> In *Fisher v. Oklahoma Health Care Authority*, the Tenth Circuit held that Oklahoma was required to provide additional prescription services in its community based nursing home waiver program unless it could show that such services would require cuts.<sup>50</sup>

Courts have required states to have strategic, time-specific plans to further the *Olmstead* decision. In *Frederick v. Department of Welfare*, the Third Circuit held that states cannot rely on past progress to show their compliance with the *Olmstead* decision but must have a plan showing "commitment by [the state] to take all reasonable steps to continue that progress."<sup>51</sup> While the District Court of Maryland declined to require Maryland to make immediate changes to its system where people with traumatic brain injury were unnecessarily institutionalized, the decision was based on Maryland's systemic plan that would expand services to those people over several years.<sup>52</sup> While the fundamental alteration defense still exists, it has not been successful as a defense to a state's failure to actively implement a plan that will allow people to choose to move from an institutional setting into the community.

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47 *Fisher v. Oklahoma Health Care Authority*, 335 F.3d 1175, 1185 (10th Cir.2003), available at <http://www.clearinghouse.net/detail.php?id=12669>.

48 *Makin v Hawaii*, 114 F.Supp.2d 1017, 1034(D.Haw.1999); *Lewis v. New Mexico Department of Health*, 275 F.Supp.2d 1319,1346 (D.N.M.2003)(length of the waiting lists kept plaintiffs from receiving Medicaid waivers with reasonable promptness) available at <http://law.justia.com/cases/federal/district-courts/FSupp2/275/1319/2463337/>; *Bryson v. Vailas*, 114 F.Supp.2d 1017 (D. New Hampshire 1999), available at [http://nh.findacase.com/research/wfrmDocViewer.aspx/xq/fac.20040326\\_0000193.DNH.htm/qx](http://nh.findacase.com/research/wfrmDocViewer.aspx/xq/fac.20040326_0000193.DNH.htm/qx).

49 *Townsend v. Quasim*, 328 F. 3d 511,517- 519 (9th Cir. 2003) DOJ brief available at <http://www.dphhs.mt.gov/Portals/85/dsd/documents/DDP/SELN/DOJSupports.pdf>.

50 *Fisher* at 1177-78.

51 *Frederick v. Department of the Public Welfare of the Commonwealth of Pennsylvania*, 364 F.3d 487, 500 (3d Cir.2004) available at <http://www2.ca3.uscourts.gov/opinarch/031461p.pdf>.

52 *Williams v. Wasserman*, 164 F.Supp.2d 591,638(D. Md. 2001).

The executive branch of the federal government has also consistently supported, encouraged, and offered guidance on *Olmstead* implementation. In 2001, President George W. Bush issued an executive order supporting swift implementation of *Olmstead*.<sup>53</sup> In 2009, President Barak Obama launched the "Year of Community Living" directing all relevant federal agencies to work together to make the promise of *Olmstead* a reality.<sup>54</sup> Additionally, the Department of Health and Human Services issued a series of five letters to state Medicaid directors providing guidance for the requirements of *Olmstead*.<sup>55</sup>

As part of the presidential mandate, from 2009 to 2014, the Department of Justice (DOJ) has been involved in more than fifty investigations and court cases in twenty-five states regarding *Olmstead* implementation.<sup>56</sup> In public statements, the DOJ has expressed the policy that: 1) people with disabilities should have opportunities to live life like people without disabilities; 2) people with disabilities should have opportunities for true integration, independence, recovery, choice, and self-determination in all aspects of their lives including where they live, spend their days, work, and participate in their community; and 3) people with disabilities should receive quality services that meet their individual needs.<sup>57</sup> It also recognized that it is not enough to move people out of institutions and that states must ensure that people have the support and services that they need to lead successful lives in the community.<sup>58</sup>

The DOJ has targeted states who have failed to deinstitutionalize specific populations from nursing homes, group homes, and segregated day activities and those who have unnecessarily delayed

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<sup>53</sup> George W. Bush, *Executive Order, Community Based Alternatives for Individuals with Disabilities* (June 18, 2001), available at <http://www.accessiblesociety.org/topics/programs-policy/olmsteadexecordertext.htm> (accessed January 6, 2015).

<sup>54</sup> Thomas E. Perez, *Olmstead Enforcement Update: Using the ADA to Promote Community Integration*, 10 (June 21 2012) available at the Department of Justice website, <http://www.nasddds.org/resource-library/ada-olmstead/federal-policy-documents/olmstead-enforcement-update-using-the-ada-to-promote-community-integration/> (accessed January 6, 2014).

<sup>55</sup> *Mathis*, *supra* note 33 at 15.

<sup>56</sup> United States Department of Justice Civil Rights Division, *Olmstead Litigation in the 12 U.S. Circuit Court of Appeals*, [www.ADA.gov/olmstead/olmstead\\_enforcement.htm](http://www.ADA.gov/olmstead/olmstead_enforcement.htm), (accessed July 10, 2014).

<sup>57</sup> *Perez*, *supra* note 54 at 2.

<sup>58</sup> *Id.*

or put people at risk of institutionalization through waiting lists, limiting funding, and a failure to provide appropriate services. For example, the DOJ sued the state of Rhode Island for unnecessarily segregating people with disabilities in sheltered workshops and facility based day programs.<sup>59</sup> The DOJ found that Rhode Island over-relied on segregated day settings to the exclusion of integrated alternatives such as supported employment and integrated day services.<sup>60</sup> In a consent decree, Rhode Island was required to engage in transition planning for supported employment; cease funding for and placement in sheltered workshops; conduct assessments assuming that persons with severe disabilities can engage in supported employment; and phase out all current employment at sheltered workshops.<sup>61</sup>

The DOJ filed a lawsuit against Florida for failing to evaluate children entering nursing homes for community based supports; limiting the availability of home-based supports prescribed by a physician; making substantial cuts to community based services programs while enhancing payment for certain institutional settings; and maintaining years-long waiting lists for community services.<sup>62</sup>

The DOJ also entered into a settlement agreement with New York to resolve charges that it had violated the ADA by unnecessarily segregating people with mental illness in Adult Homes, defined as for-profit institutions where over 25% of the residents had a mental health disability.<sup>63</sup> These people ended up in Adult Homes after hospitalization or homelessness because there were no available placements in community settings.<sup>64</sup> The consent decree required the state of New York to fund subsidized scattered site housing in an amount to allow every Adult Home resident to transition to such housing; provide appropriate assessments for each Adult Home resident that begin with the presumption that they belong in supported housing; develop a person-centered care plan for each

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<sup>59</sup> *U.S. v. Rhode Island*, 1:14-cv-00175 (D.R.I.2014) consent decree available at <http://www.ada.gov/olmstead/>.

<sup>60</sup> U.S. Department of Justice, *United States' Title II Investigation of Employment, Vocational, and Day Services for Persons with Intellectual and Developmental Disabilities in Rhode Island*(January 6, 2014) available at [http://www.ada.gov/olmstead/documents/ri\\_lof.pdf](http://www.ada.gov/olmstead/documents/ri_lof.pdf) (accessed July 10, 2014).

<sup>61</sup> Consent Decree, *U.S. v. Rhode Island*, 1:14-cv-00175(D.R.I.2014), p 4-8.

<sup>62</sup> DOJ: Civil Rights Division, *United States' Investigation of the State of Florida's Service System for Children with Disabilities who have Medically Complicated Conditions* (2012) available at [www.ada.gov](http://www.ada.gov) (accessed July 10, 2014).

<sup>63</sup> Complaint, *O'Toole v. Cuomo*, E.D.N.Y., CV 13-4165, July 23,2013, available at [www.ada.gov/olmstead/olmstead\\_cases\\_list2.htm](http://www.ada.gov/olmstead/olmstead_cases_list2.htm). (accessed July 10, 2014).

<sup>64</sup> *Id.* at 36.

person assessed; provide training to those running Adult Homes and housing contractors; and provide community services.<sup>65</sup> These lawsuits, and others, evaluated states' plans for deinstitutionalization and targeted holes in state's plans that allowed people to be unnecessarily institutionalized or at risk of unnecessary institutionalization.

#### **IV. Olmstead in Ohio**

##### **A. *Olmstead* Implementation in Ohio**

Like other states, Ohio has taken steps to implement the *Olmstead* decision through policy task forces and implementing a Medicaid waiver system that provides HCBS as an alternative to institutionalization. Ohio has also instituted a number of federally-backed programs that have assisted in transitioning people from institutional settings into the community and is working on several new initiatives to decrease the numbers of people living in institutional settings. However, this paper focuses on the problems that still exist in the Ohio system. Primarily, the institutional settings still relied on in Ohio are intermediate care facilities for people with intellectual disabilities (ICF/IID); nursing facilities (NF); and children's residential facilities.<sup>66</sup>

Ohio has implemented ten 1915(c) waivers to provide HCBS to people requiring long term care.<sup>67</sup> Three provide services for people with physical disabilities below the age of 60 (OH Home Care Waiver, OH Assisted Living, OH Integrated Care Delivery System (ages 18-64)); five provide services to people over the age of 60 (OH PASSPORT (65 years+ and physically disabled 60-64); OH Choices (65 years+ and physically disabled 60-64); OH Assisted Living (65 years+ and physically disabled 60-64); OH Transitions Aging Carve-Out (65 years+ and physically disabled 60-64); OH Integrated Care Delivery System); and three provide services for people who meet an ICF level of care (OH SELF, OH

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<sup>65</sup> Consent Decree, *O'Toole v. Cuomo*, E.D.N.Y., CV 13-4165, July 23, 2013, available at [www.ada.gov/olmstead/olmstead\\_cases\\_list2.htm](http://www.ada.gov/olmstead/olmstead_cases_list2.htm) (accessed July 10, 2014).

<sup>66</sup> Centers for Medicare and Medicaid Services, *Intermediate Care Facilities for Individuals with Mental Retardation*, available at <http://www.medicare.gov/medicaid-chip-program-information/by-topics/delivery-systems/institutional-care/intermediate-care-facilities-for-individuals-with-mental-retardation-icfmr.html> (accessed July 7, 2014).

<sup>67</sup> Centers for Medicare and Medicaid Services, *Waivers*, available at [http://www.medicare.gov/medicaid-chip-program-information/by-topics/waivers/waivers\\_faceted.html](http://www.medicare.gov/medicaid-chip-program-information/by-topics/waivers/waivers_faceted.html) (accessed July 7, 2014).

Level One, and Individual Options).<sup>68</sup> There are no waivers in Ohio directed towards people with mental illness. Each waiver specifies both the amount of money and the services available under the waiver. Ohio has increased waivers and implemented transition programs with federal monetary support such as the Home Choice Program.<sup>69</sup> While Ohio has moved towards *Olmstead* implementation, many people with disabilities still lack the choice or appropriate supports to live in the community rather than an institutional setting.

### **B. Challenges to Ohio's Implementation of *Olmstead*.**

In the twenty years since *Olmstead*, Ohio's slow pace and seeming reluctance to change have been challenged in federal court. In 1989, the Ohio Legal Rights Service (now Disability Rights Ohio, DRO) filed the class action lawsuit *Martin v. Taft* based on *Olmstead*, challenging Ohio's status as one of the largest users of congregate care in the United States for people with developmental disabilities.<sup>70</sup> *Martin* highlighted Ohio's wavier waiting lists, which, at the time, contained 1600 people under the age of 60 and 20,000 people with developmental disabilities.<sup>71</sup> DRO argued that, while the number of community waiver *slots* had increased, in practice, residential placements in the community were scarce.<sup>72</sup> In 2004, the parties a court-approved consent decree increasing the number of waivers, designating a certain number for people living in institutional settings, and increasing funding towards HCBS.<sup>73</sup>

More recently, on July 1, 2014, DRO requested a meeting with Governor John Kasich, John

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<sup>68</sup>*Id.*

<sup>69</sup> Ohio Department of Medicaid, *Home Choice: Helping Ohioans Move, Expanding Choice*, available at <http://medicaid.ohio.gov/FOROHIOANS/Programs/HomeChoice.aspx> (accessed in January, 2015). In August, Ohio transitioned its 5,000<sup>th</sup> individual from a long-term care facility into the community. Catherine Candisky, *State moves 5,000 from nursing homes to their Own Homes*, The Columbus Dispatch, available at <http://www.dispatch.com/content/stories/local/2014/08/17/state-moves-5000-from-nursing-homes-to-their-own-homes.html> (accessed August 17, 2014).

<sup>70</sup> Plaintiffs' Memorandum Contra Defendants' Motion for Summary Judgment, 8, *Martin v. Taft*, 222 F.Supp.2d 940 (S.D.Ohio 2002), available at [http://www.disabilityrightsohio.org/sites/default/files/ux/MartinvTaftPlaintiffMemo8\\_2006.pdf](http://www.disabilityrightsohio.org/sites/default/files/ux/MartinvTaftPlaintiffMemo8_2006.pdf) (accessed July 2014).

<sup>71</sup> *Id.* at 10.

<sup>72</sup> *Id.*

<sup>73</sup> Consent Order, *Martin v. Taft*, 222 F.Supp.2d 940 (S.D.Ohio 2002), available at <http://www.disabilityrightsohio.org/martin-proposed-consent-11-06> (accessed July 2014).

Martin, the Director of the State Department of Developmental Disabilities, and John McCarthy, Director of the State Department of Medicaid, to discuss Ohio's current lack of progress in de-institutionalizing those with developmental disabilities.<sup>74</sup> The problems they cited included the continued construction of new ICFs, the practice of moving people with developmental disabilities from larger ICFs to smaller ICFs, and Ohio's failure to have a system that enables people to move toward supported employment and integrated day settings.<sup>75</sup> Director Martin responded with a letter dated July 31, 2014 inviting DRO to meet with them regarding the issues.<sup>76</sup> DRO warned in its response letter that "the state's current initiatives will not be enough to forestall legal action."<sup>77</sup> Since that time, we have been informed that the state has had regular meetings with DRO and is attempting to come to an agreement that will address those concerns.

Finally, earlier this year, the federal Department of Health and Human Services created a new rule requiring all states to ensure that Medicaid waiver funds are being used in community based settings.<sup>78</sup> Mainly, the federal rule establishes a new definition of home and community based settings and requires states to create a transition plan to comply with that definition.<sup>79</sup> The new definition requires that waiver services be provided in settings that support:

full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.<sup>80</sup>

Ohio has since created a draft plan for compliance with that rule that will change Ohio's system of providing care. It is still during the comment period on that plan.

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<sup>74</sup> Disability Rights Ohio, *DRO Warns that Current State Initiatives Will not be Enough to Forestall Legal Action* (August 1, 2014) available at <http://www.disabilityrightsohio.org/news/dro-warns-current-state-initiatives-will-not-be-enough-forestall-legal-action> (accessed January 6, 2015).

<sup>75</sup>*Id.*

<sup>76</sup>*Id.*

<sup>77</sup>*Id.*

<sup>78</sup> Centers for Medicare and Medicaid Services, *Fact Sheet: Home and Community Based Services* (January 10, 2014) available at <http://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2014-Fact-sheets-items/2014-01-10-2.html> (accessed January 6, 2015).

<sup>79</sup>*Id.*

<sup>80</sup>*Id.*

## C. Fundamental Problems

It is the experience of the Ability Center and its clients that Ohio's system still contains barriers to a society where people with disabilities live, work, and socialize in the most integrated setting appropriate. A large number of people with disabilities locally, and statewide, still live, work, and spend their time in segregated facilities without any option to choose to be more integrated in the community.

Broadly, the percentage of Medicaid dollars in Ohio dedicated to HCBS has only increased from 11.4% to 32.4% in the sixteen years since *Olmstead*.<sup>81</sup> That is behind the national *average* of 38.8% in 2012, and behind states that budget 60%- 65% to HCBS such as Oregon and Minnesota.<sup>82</sup> More specifically, the Ability Center, as a Center for Independent Living, hears often from consumers who struggle to live in community settings and has identified some of the barriers they face to achieving that goal.

### I. **The current system makes it easier to receive services in an institutional, rather than a community-based, setting.**

#### A. **People with developmental disabilities continue to face long waiting lists, and difficulty getting, waivers.**

Ohio fails to meet its *Olmstead* mandate when people with disabilities are unable to receive HCBS due to long waiting lists and poorly implemented assessments. Access to institutional settings is not limited through waiting lists, but waiver enrollment is capped.<sup>83</sup> Thus, people can gain entrance to institutional settings at any time, but because waiver enrollment is capped, even when an individual meets the requirements for a waiver, a slot may not be available.<sup>84</sup>

This problem is especially present in the Department of Developmental Disabilities (DODD) system. The DODD provides HCBS waivers to approximately 32,200 people with disabilities, but as of

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<sup>81</sup> *Id.*

<sup>82</sup> *Id.*

<sup>83</sup> *Id.*

<sup>84</sup> Health Policy Institute of Ohio, *Health and Disabilities Basics: Overview of Health Coverage, Programs, and Services*, 6 (March 2014) available at <http://www.healthpolicyohio.org/category/policy-basics> (accessed January 19, 2015).

June, 2013, there were 41,260 people on the wavier waiting list.<sup>85</sup> The median wait time for a DODD waiver is over thirteen years.<sup>86</sup> Ability Center staff members have worked with DODD consumers who were required to wait up to 20 years for HCBS.

Locally, the Lucas County Board of Developmental Disabilities reports 2627 people on the list for Individual Options Waivers and 1652 people on the waiting list for Level One Waivers as of April, 2014. In May, 2013, the waiting lists contained 2635 people for the Individual Options Waiver and 1701 people on the waiting list for Level One Waivers. Thus in a year, the number of people with disabilities in Lucas County waiting for DODD waivers only decreased by around 60 people.

**B. Poor implementation of assessments for aging and other waivers for the physically disabled cause delays in the receipt of services that often result in institutionalization or risk of institutionalization.**

Though smaller, there are currently 2,713 people on waiting lists for PASSPORT waivers and 1,123 people on waiting lists for Assisted Living waivers statewide. The assessment process and local implementation of aging waivers causes delays in transition, or, at times, transition from nursing facilities without services. Ability Center staff members have observed through implementing the Home Choice Program that those eligible for Home Choice waivers often face long waits to be assessed by a case management agency for a waiver prior to discharge and again for HCBS to begin after they are found eligible for a waiver.<sup>87</sup> Once an individual is approved for a Home Care Waiver, it can take six weeks after their assessment to get approval for the waiver to be activated when that individual has a designated Ability Center nursing home transition coordinator. However, staff

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<sup>85</sup> *Id*; Ohio Colleges of Medicine Government Resource Center, *What are we waiting for? Waiver Supported Services Needed by Individuals and their Caregivers* (February 2014) available at <http://www.ddc.ohio.gov/pub/waiting-list-study-2-21-14.pdf> (accessed January 19, 2015).

<sup>86</sup> *Id*; Disability Rights Ohio *supra*note 74.

<sup>87</sup> These delays were also noted in the 2007 evaluation of Ohio's Assisted Living Medicaid Waiver Program created by the Margaret Blenkner Research Institute. Heather Menne; Farida Ejaz, *Evaluation of Ohio's Assisted Living Medicaid Waiver Program: Assessment and Service Plan Development Process*, 15 (June 2007) available at <http://www.benrose.org/research/Benjamin%20Rose%20Case%20Study%20Piece.pdf> (accessed January 19, 2015) and a study done on the PASSPORT waiver by the Miami University Scripps Gerontology Center, William Ciferri; Suzanne Kunkel; Kathryn McGrew; Shahla Mehdizadeh; Jane Straker; and Valarie Wellin, *Program Evaluation of PASSPORT: Ohio's Home and Community Based Medicaid Waiver, Final Report*, 39(May 15 2007) available at <http://www.ohiomemory.org/cdm/ref/collection/p267401ccp2/id/3061> (accessed January 19, 2015).

members are required to have housing and supports in place within 30 days of a person's referral. The delay prevents people from transitioning into the community.

Discharge from nursing facilities without an assessment leads people who could otherwise live in the community with supports to be re-admitted to a nursing facility. Many people want badly to transition but cannot secure affordable housing or are not provided with enough services to survive in the community. Ability Center staff members have encountered individuals who were repeatedly discharged and re-admitted into nursing facilities over the course of years before finally being assessed for a waiver and transitioning successfully with the assistance of a transition coordinator.

**II. At the same time, Ohio lags behind other states in re-designing and decreasing its reliance on institutional settings.**

**A. The primary type of care facility in Ohio for people with developmental disabilities is still ICF/IID.**

The primary type of care facility in Ohio for people with developmental disabilities is still an ICF/IID. ICFs/IIDs are specifically designed to solely house people with developmental disabilities.<sup>88</sup> There are about 432 facilities, including ten operated by the Department of Developmental Disabilities (DODD), serving 7,000 Ohioans.<sup>89</sup> 6000 people in Ohio are institutionalized in private ICFs/ IIDs and almost 1000 more are in developmental centers.<sup>90</sup> As of 2011, no other state has large private ICFs/ IID beds (defined as fifteen or more beds) as Ohio.<sup>91</sup> The national trend over the past 10 years reflects a 33% decrease in the number of people living in large ICFs/ IID, but Ohio has experienced a 6% increase with a total of over 3400 beds in large private ICFs.<sup>92</sup>

In 2007, Lucas County contains 18 certified ICF/ IID facilities.<sup>93</sup> Some are small facilities with four or five beds, but four of those contain twenty or more beds. One is an ICF/ IID facility run by the

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<sup>88</sup> Health Policy Institute of Ohio *supra* note 84 at 5.

<sup>89</sup> *Id.*

<sup>90</sup> Disability Rights Ohio *supra* note 74 at 3.

<sup>91</sup> *Id.* at 3.

<sup>92</sup> *Id.*

<sup>93</sup> Index to Residential Facilities Guide (August 17, 2007) available at <http://www.longtermcareohio.com/downloads/Licensed-Facilities-index%5B1%5D.pdf> (accessed January 19, 2015).

state Department of Developmental Disabilities, the Northwest Ohio Developmental Center, which houses 101 people.<sup>94</sup> A full 386 people with developmental disabilities in Lucas County still live in ICF/ IID. In addition, four residential facilities receiving waiver funding have eight or more beds.<sup>95</sup>

**B. Funding favors institutional placements in ICF/ IID facilities and nursing facilitates.**

On a state level, there is still inequality in funding that incentivizes placement in an institution over community based placements. Institutional placements at state developmental centers or private ICFs/IID are funded with a combination of state and federal Medicaid dollars while placement in Medicaid waiver programs providing home and community based services for people with developmental disabilities must be matched with county funds.<sup>96</sup> Thus, there is an incentive for county boards to preference the placement of people with developmental disabilities in institutional settings, which are paid for without county funds.

Likewise, the Ohio Department of Aging's Annual Report listed \$577,417, 356 for Long- Term Care and Supports and \$119,369,840 towards HCBS.<sup>97</sup> Overall, 31.4% of Medicaid and state long term supports and services spending in Ohio goes towards HCBS for older people and adults with physical disabilities in comparison to 65.4% in top states.<sup>98</sup> As of 2011, Ohio still had more nursing homes per capita than any other state.<sup>99</sup>

The Lucas County Jobs and Family Services' report for 2013 reports that Lucas County has 37

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<sup>94</sup> The statistics regarding individuals with Developmental Disabilities in Lucas County came from the database of the Lucas County Board of Development Disabilities.

<sup>95</sup> Index to Residential Facilities Guide, August 17, 2007.

<sup>96</sup> *Id.*

<sup>97</sup> *Id.*

<sup>98</sup> Susan C. Reinhard; Enid Kassner; Ari Houser; Kathleen Ujvari; Robert Mollica; Leslie Hendrickson, *Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* (2014) available at [http://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/ltc/2014/raising-expectations-2014-AARP-ppi-ltc.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2014/raising-expectations-2014-AARP-ppi-ltc.pdf) (accessed January 19 2015).

<sup>99</sup> Reginald Fields, *Gov. John Kasich and Nursing Home Lobby Battle Over Proposed Budget Cuts*, The Plain Dealer (May 2011).

nursing homes and 16 residential care facilities or assisted living facilities.<sup>100</sup> According to the Area Office on Aging, from August, 2013 through July, 2014, there were 4950 requests for nursing home placement in the ten county, northwest Ohio area. During that period, the Area Office on Aging enrolled 148 persons on a waiver transitioning out of nursing facilities. Total, 848 people enrolled in an Area Office on Aging waiver during that time. There are currently 80 people in Lucas County on waiting lists for a PASSPORT waiver and 6 on a waiting list for an Assisted Living waiver.

**C. People with developmental disabilities are often placed in segregated day facilities without the option of transitioning into supported employment.**

It is currently much easier under Ohio's system for people with developmental disabilities to receive day services in segregated settings rather than integrated settings. Ohio will be rolling out its Employment First Program,<sup>101</sup> but the policy has not yet been instituted. Currently, Ohio funds 93% of its employment services in sheltered work or enclave settings; nearly 17,000 people in Ohio receive services in sheltered workshops, which is more than in any other state.<sup>102</sup> Nearly all 14,000 people receiving day habilitation services are in congregate facility based settings based on state and county funding directed to those areas.<sup>103</sup> Some ICF/ IID provide day habilitation services on the premises, and there, people live day-to-day without even leaving the confines of the center. Developmental centers, sheltered workshops and facility based day habitation programs are currently the mainstay of the Ohio system.

While Lucas County has also recently began to implement Ohio's Employment First Program, currently 1622 people with developmental disabilities are enrolled in sheltered workshops, 147 are in enclaves,<sup>104</sup> and only 143 people have reported community-supported employment. In the most recent

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<sup>100</sup> Ohio Jobs and Family Services, *Lucas County Profile: Statistical and Demographic Data* (2013) available at <http://jfs.ohio.gov/county/cntypro/pdf13/Lucas.stm> (accessed January 19, 2015).

<sup>101</sup> See Ohio's Employment First website, [www.ohioemploymentfirst.org](http://www.ohioemploymentfirst.org) (accessed January 19, 2015).

<sup>102</sup> Disability Rights Ohio *supra* note 74; Ohio Department of Developmental Disabilities, OPRA Spring Conference power point (April 18, 2012) available at [dodd.ohio.gov/newsroom/Documents/Director Martin](http://dodd.ohio.gov/newsroom/Documents/Director%20Martin) (accessed January 19, 2015).

<sup>103</sup> *Id.*

<sup>104</sup> An enclave is supported employment services provided to individuals who work as a team, generally at a single worksite of a host community business or industry, with initial training, supervision, and ongoing support provided by on-site

DODD audit of the Lucas County Board of Developmental Disabilities, it was noted that many people in county board operated day programs stated that they did not feel they had enough meaningful activities, and several people stated that they would like to work in the community.<sup>105</sup> As part of a plan of correction, staff was required to undergo additional training on those issues.<sup>106</sup> There is a need for state and local agencies to support options for people with disabilities who wish to spend their days in integrated employment engaging in meaningful activities for a fair wage.

**III. Once people with disabilities are found eligible for HCBS, it is difficult to receive, and maintain, all the services needed by each person to remain living in the community.**

**A. Waivers often do not provide adequate supports for people to live in the community.**

Ohio fails to meet its *Olmstead* mandate where restrictions on HCBS create a situation where people cannot receive enough services to live in the community or are unable to receive services at all. The waiver restrictions on the level and types of services that people can receive often make people ineligible for needed services.<sup>107</sup> For example, the DODD waivers currently do not provide nursing services. The Individual Options waiver, designed for people with cognitive impairment, does not cover nursing services or intensive behavior supports.<sup>108</sup> The SELF and level one waiver programs have strict cost caps and can only support people with minimal needs.<sup>109</sup> Generally, administrative billing requirements and assessments focus on financial considerations rather than actual needs.<sup>110</sup> As it stands, people with disabilities get a larger number of hours of care in institutional settings than they do in community based settings.

Likewise, the waiver system is fragmented and fails to provide for those with severe or mild

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staff. R.C. 5123:2-9-16(B)(18). Generally, community supported enclaves still pay individuals less than minimum wage and limit work to groups of individuals with disabilities rather than in integrated employment.

<sup>105</sup> Ohio Department of Developmental Disabilities, Lucas County Board of Developmental Disabilities Audit, *Compliance Summary*, 6/17/14-6/19/14.

<sup>106</sup> *Id.*

<sup>107</sup> Disability Rights Ohio, *supra* note 74.

<sup>108</sup> *Id.*

<sup>109</sup> *Id.*

<sup>110</sup> *Id.*

physical disabilities. Due to caps on the dollar amount of services under PASSPORT,<sup>111</sup> many people with severe physical disabilities cannot receive enough HCBS to survive in their homes. As people age, they can even lose services due to the larger amount of services available under the Home Care Waiver rather than PASSPORT. For those with a mild disability that does not meet an institutional level of care, there is no waiver that will provide that level of service. Though Ohio has implemented a limited-time program called Recovery Requires a Community, there is also no Ohio waiver directed towards those with mental health disorders. The differing amounts of care and services provided under different waivers often fail to meet the needs of people with dual or multiple disabilities. Likewise, the state's tendency is always to cut services for people in a manner unrelated to their disabilities in order to save costs.

In 2014, the AARP ranked Ohio 44<sup>th</sup> out of 50 states in their scorecard of long term services and supports.<sup>112</sup> While Ohio was ranked 27<sup>th</sup> in terms of effective transition, it was ranked 42<sup>nd</sup> in affordability and access; 39<sup>th</sup> in quality of life and quality of care; 39<sup>th</sup> in support for family caregivers; and 32<sup>nd</sup> in choice of setting and providers.<sup>113</sup> 27.9 percent of home health patients in Ohio end up with a hospital admission in comparison to 18.9 percent in top states.<sup>114</sup> 69.2 percent of people 18+ were usually or always getting needed support in comparison to 79.1 percent in top states.<sup>115</sup> Service recipients and their families noted, overall, no change in performance indicators from 2011 through 2014.<sup>116</sup>

Likewise, in a 2014 needs assessment by the Area Office on Aging of Northwest Ohio (AOoA

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<sup>111</sup> Service needs must not exceed the six-month cost cap of \$17,797.00 or \$35,594.00 annually. ProSeniors, *Passport & Other Home Care Alternatives*, available at [www.proseniors.org/pdfdocs/medicaid/passport.pdf](http://www.proseniors.org/pdfdocs/medicaid/passport.pdf) (accessed July 17, 2014).

<sup>112</sup> Susan C. Reinhard, et al., *supra* note 98.

<sup>113</sup> *Id.*

<sup>114</sup> *Id.*

<sup>115</sup> *Id.*

<sup>116</sup> AARP, *Ohio: 2014 State Long-Term Services and Supports ScoreCard Results* (January 1, 2014), available at <http://www.longtermscorecard.org/~media/Microsite/State%20Fact%20Sheets/Ohio%20Fact%20Sheet.pdf> (accessed January 6, 2015).

NW Ohio), 74.7% of those surveyed noted in-home care services was an unmet need.<sup>117</sup> For rural areas, 79.9% reported in-home care services as an unmet need.<sup>118</sup> The number one activity of daily living that seniors identified needing assistance with was not medical services, but chore services, a HCBS.<sup>119</sup> AOoA NW Ohio found that those who do not qualify for a Medicaid waiver often cannot afford HCBS at all.<sup>120</sup> Elderly adults with severe disabilities also lack day facilities.<sup>121</sup> Ability Center staff members have encountered young individuals with no family support and severe disabilities, such as those who are paralyzed, who are unable to receive enough services to transition into the community despite repeated requests to leave a nursing facility. They have also encountered people with disabilities too mild to qualify for a waiver, such as slight memory loss from a stroke, that leave them at-risk of re-institutionalization once they are back in the community because they do not qualify for HCBS.

**B. Eligibility and assessments for waivers are inconsistent and unrelated to people's individual needs.**

It has been the experience of the Ability Center staff members that assessments and eligibility for waivers are inconsistent, leaving the question of whether an individual qualifies for a waiver to be partly based on location and the person who conducts the assessments. Due to subjective differences in the conduct of assessments, two people with identical needs may have different assessment outcomes. One individual may qualify for a waiver while another does not, or one individual may qualify for a waiver immediately while another has to wait for services.

In Ability Center staff member's experience, whether an individual is determined to need HCBS depends on the person doing the assessment. Some assessors ask pre-determined questions and fail to even review people's charts while others spend time determining what an individual needs during his or

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<sup>117</sup> *Id.*

<sup>118</sup> *Id.*

<sup>119</sup> *Id.*

<sup>120</sup> *Id.*

<sup>121</sup> *Id.*

her assessment. Many people do not understand the questions or fear that they will not be discharged if they ask for help, and their needs are not uncovered. Then they receive limited HCBS or none at all; experience a medical emergency; and are re-admitted to a nursing facility. These gaps and inconsistencies in the provision of waiver services place people at risk of institutionalization or cause people to be unnecessarily institutionalized.

### **C. The low wages and benefits of in-home providers cause unavailability and frequent turn-over of in-home providers.**

People with disabilities who receive HCBS rely on in-home providers for their day to day personal care, and in order for HCBS to allow a person to maintain life in the community; they must be available, dependable, and trustworthy. However, the industry has a wage structure on par with, or below, that of the fast food industry.<sup>122</sup> Most aides make between \$8.00 and \$11.00 per hour.<sup>123</sup> Wages actually decreased from 2003-2013 for personal care aides, home health aides, and nursing assistants.<sup>124</sup> 44 percent of direct care workers in Ohio rely on public assistance.<sup>125</sup> Aides also use their own vehicles, pay for their own gas, and generally, do not get to stay on the clock between clients.<sup>126</sup> The average turn-over rate is 31%, which is closer to 36% in the state's metro areas.<sup>127</sup>

Ohio is one of eight states that don't require home health agencies to be licensed, and yet aides must have 60 to 75 hours of training and 16 clinical hours in order to enter the field.<sup>128</sup> The high-training, low-wage structure results in the high turnover and a lack of home healthcare aides. This acts as a barrier to the *Olmstead* mandate of providing services in the most integrated setting appropriate. In its needs assessment, the AOoA NW Ohio noted a lack of availability of home health care aides

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<sup>122</sup> Rita Price, Ben Sutherly, *Home Care for Vulnerable Ohioans Leans Hard on Poorly Paid Workers*, The Columbus Dispatch (December 15, 2014).

<sup>123</sup> *Id.* See also PHI, *State Data Center*, available at <http://phinational.org/policy/states/ohio/> (accessed January 26, 2015).

<sup>124</sup> PHI *supra* note 123.

<sup>125</sup> *Id.*

<sup>126</sup> Price, Sutherly, *supra* note 122.

<sup>127</sup> *Id.*

<sup>128</sup> Price, Sutherly *supra* note 122; PHI *supra* note 123.

generally, and a greater need in the rural areas, especially Ottawa County.<sup>129</sup>

**D. The absence of supports and safe, affordable housing for people experiencing mental illness places them at risk of institutionalization.**

While Ohio has worked to deinstitutionalize psychiatric hospitals, many people with severe mental illness end up in nursing homes or prisons due to a lack of sufficient community supports.<sup>130</sup> Without a dual diagnosis, people with mental health disorders do not qualify for any waiver services<sup>131</sup> and, thus, while many people with mental health disorders transitioning from nursing homes and psychiatric institutions into the community need additional supports, there is a lack of services available to keep them in the community.<sup>132</sup> Most supports needed by people with mental illness to live independently are not covered by Medicaid such as family counseling, intensive home-based services, and supportive housing.<sup>133</sup> In addition to that, many people with mental illness do not qualify for Medicaid services.<sup>134</sup>

There is also a lack of safe, affordable housing available to people with mental illness.<sup>135</sup> Subsidized housing stock is low, many older buildings are not accessible, and many people are ineligible for subsidized housing due to criminal histories or drug use. Often people with mental illness have no choice but to rely on group homes or nursing facilities. In fact, some nursing facilities advertize that they will take any person, even with a criminal history, in order to fill beds with people with mental health disorders. As nursing facilities are successful if their beds are full, they have little incentive to assist these people in transitioning back into the community once they have entered. The

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<sup>129</sup> Area Office on Aging NWO, Inc., *Program Year 2015-2018, Strategic Area Plan for Programs on Aging*, 19 available at <http://www.areaofficeonaging.com/strategic.pdf> (accessed January 19, 2015).

<sup>130</sup> Susan Ackerman, The Center for Community Solutions, *Ohio's Community Mental Health System at a Crossroads*, 5(2010) available at [www.communitysolutions.com](http://www.communitysolutions.com) (accessed January 19, 2015).

<sup>131</sup> Recently, Ohio has instituted the Recovery Requires a Community Program designed to offer those with mental illness community supports. It is too soon to have an evaluation of this program. See [http://disabilityrightsohio.org/sites/default/files/sites/default/files/u62/FAQ\\_Recovery\\_Requires\\_a\\_Community.pdf](http://disabilityrightsohio.org/sites/default/files/sites/default/files/u62/FAQ_Recovery_Requires_a_Community.pdf).

<sup>132</sup> Susan Ackerman *supra* note 128.

<sup>133</sup> *Id.*

<sup>134</sup> *Id.*

<sup>135</sup> Jessie Balmert, *Housing options for people with mental health issues vary greatly across Ohio*, [www.thenews-messenger.com](http://www.thenews-messenger.com) (June 14, 2014)(accessed January 19, 2015).

lack of available programs for people with mental illness places them at risk of institutionalization and unnecessarily confines them in group homes and nursing homes.

The Lucas County Mental Health and Recovery Service Board underwent an intensive gap analysis for people with mental illness in 2014 where they researched needs and held stakeholder forums.<sup>136</sup> Both the forums and the Board identified housing and supported employment as two significant gaps in current services offered in the county.<sup>137</sup> They noted that those with a criminal background and those transferring from long-term-care were especially difficult to house.<sup>138</sup>

#### **IV. Recommendations and Next Steps**

Our vision of an inclusive Ohio is one where community based care is standard practice and institutional care the exception. Our goal is to advance community based care to the greatest extent possible. To do this, Ohio needs to remove the current barriers that keep people with disabilities in institutions or living at risk of institutionalization. Based on the experience and research done by the Ability Center, we make the following recommendations on a federal, state, and local level.

##### **A. Direct at least 60% of Medicaid funds to (Home and Community Based Services (HCBS) and health care in people's homes.**

As noted earlier, several states have devoted at least 60% of Medicaid funding to HCBS and health care in the home. Ohio continues to treat home and community based care as an exception, or part of a continuum, and that funding structure needs to be reversed. The current model views HCBS as a solution only for those with few needs and as a cost cutting measure. Transferring more funds into HCBS would open home and community based care to more people and assist in ending the long waiting lists and delays in receiving services.

##### **B. Direct additional funding towards creating more inclusive, accessible affordable housing.**

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<sup>136</sup> Mental Health and Recovery Services Board of Lucas County, *2014 Gaps Analysis*, available at <http://co.lucas.oh.us/index.aspx?nid=430> (accessed January 19, 2015).

<sup>137</sup> *Id.*

<sup>138</sup> *Id.*

Recent years have brought deep cuts in federal funding for the U.S. Department of Housing and Urban Development, leaving it severely underfunded.<sup>139</sup> Yet, to implement the *Olmstead* mandate, federal and state budgets need to focus on creating more inclusive, accessible, affordable housing and vouchers for all people with disabilities that is scattered throughout differing communities. Many people with disabilities rely on affordable housing to live in the community and maintain their own homes. To support this need there should be an increase in vouchers for inclusive, affordable housing throughout the community.

**C. Adopt a system that provides HCBS and increase access to home nursing services directly through Medicaid rather than through waivers.**

Currently, people must apply for a waiver to receive HCBS and struggle to survive in the community with the limited home health services provided under the state plan. HCBS should be available under Ohio's state plan through Section 1915(i) of the Social Security Act.<sup>140</sup> State plan HCBS should be designed so that anyone eligible for Medicaid would be able to receive HCBS based on an individualized needs assessment. That assessment should be completed prior to entering into an institutional setting. State plan services should be designed so that people do not have to meet an institutional level of care in order to receive HCBS. Additionally, the number of hours of nursing services available under state plan services should be increased to match the hours of services available under the Ohio Home Care Waiver.

**D. Adopt one common assessment tool HCBS based on individual needs, including non-medical needs.**

Ohio needs to streamline its assessment process to be sure that people who wish to transition out of institutions into the community are receiving consistent assessments that result in them receiving all HCBS services necessary to meet their needs. Assessors should be trained and incentivized to

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<sup>139</sup> Douglas Rice, Center on Budget and Policy Priorities, *House HUD Bill Would Cut Assistance to Low-Income Renters: Would Stall Recent Progress in Reducing Homelessness* (May 22, 2014), available at <http://www.cbpp.org/cms/?fa=view&id=4148>(accessed January 26, 2015).

<sup>140</sup> Currently, California, Colorado, Connecticut, D.C., Florida, Idaho, Indiana, Iowa, Louisiana, Maryland, Michigan, Mississippi, Montana, Nevada, Oregon, and Wisconsin offer some form of a 1915(i) state plan HCBS.

conduct thorough, prompt, and consistent assessments.

**E. Create policies that increase the number and reliability of in-home providers.**

The federal and state government should encourage workers to enter into the home health care field by reducing training requirements, increasing provider compensation in a way that doesn't affect the amount of services received by the recipient of HCBS. Also, where HBSC is not provided family and friends of those with disabilities should be allowed to act as their home health care aide.

**F. Appoint local administrators of disability agencies that have a background in *Olmstead* issues or provide extensive training in *Olmstead* issues.**

One of the main issues facing *Olmstead* implementation is a lack of understanding among administrators of local disability agencies. Where administrators are appointed to direct agencies that provide services for those with disabilities, they should have a background in, or extensive training in, *Olmstead* issues in order to advance the implementation of the mandate.

**G. Create specific benchmarks and models for community living for state and local disability agencies.**

Local agencies should be given specific numeric benchmarks to move those receiving services in institutional settings into their own homes on a specific time line. For example, a certain percentage of people living in institutional settings should be served in their own homes at 1 year, 2 years, 5 years, and 10 years. Additionally, state and local disability agencies should be given models of best practices for transitioning people into their own homes and providing services in that environment.

Similar benchmarks should be implemented for moving people into supported employment, and models of best practices for supported employment and inclusive day services should be provided to state and local disability agencies. Where a person has skills, or can develop skills, that would allow them to work in a job in the community, they should not be permitted to be paid sub-minimum wage for utilizing those skills.

**VI. Conclusion**

The Supreme Court decided *Olmstead v. L.C.* sixteen years ago, but the federal government,

and Ohio, have been slow to change the model of placing people with disabilities in segregated, congregate care where they have few opportunities to make decisions or direct the path of their lives. As noted by the Supreme Court in *Olmstead*, institutional care only serves to encourage the myth that people with disabilities have little to offer, that they are unable to survive without being shut away, and that they must be completely dependent on others throughout their entire lives. Additionally, a system dependant on congregate care deprives people with disabilities of the opportunity to live full and meaningful lives. *Olmstead v. L.C.* created a promise that people with disabilities would no longer have to live in such a system, Ohio must re-direct its system of providing care in order to the fulfill that promise.