

**Home and Community-Based Services:  
Creating Systems for Success at Home, at Work and  
in the Community**

## **Acknowledgements**

The National Council on Disability (NCD) expresses appreciation to the National Association of State Directors of Developmental Disabilities Service (NASDDDS) for working collaboratively to develop this report. The individual and collective contributions of these professionals have been essential throughout the partnership: Project Manager, Charles Moseley, Ed.D., former Associate Executive Director, NASDDDS; Pamela D. Walker, Ph.D., Center on Human Policy, Syracuse University; Ben Cichocki, ScD, CRC, CPRP, Research Associate, Human Services Research Institute; Renáta Tichá, Ph.D., Research Associate, Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota ; Steven J. Taylor, Ph.D., Director, Center on Human Policy, Syracuse University; and Mary P. Sowers, Director of Special Projects, NASDDDS.

## **Dedication**

This report honors the memory of Dr. Steven J. Taylor from Syracuse University, a scholar, visionary leader, researcher, and prolific author who was one of the report developers. Throughout an illustrious career he advocated for the rights of people with disabilities, including living in the community, accessible public transportation, school inclusion, integrated employment, a home of their own, and community supports for their families. He was truly one of the “giants” in the Intellectual and Developmental Disabilities field. Both a mentor and a friend to an array of professionals who became peer collaborators, he also provided invaluable guidance and assistance in the preparation of this report. Dr. Taylor passed away in November 2014, while the report was in its final phase.

# Table of Contents

I.	EXECUTIVE SUMMARY .....	5
II.	BACKGROUND .....	10
	HCBS Overview .....	10
	The Changing Structure of Service Delivery .....	11
	The Americans with Disabilities Act and the <i>Olmstead</i> Ruling .....	12
	Growth of Home and Community-Based Services .....	14
III.	COMMUNITY OUTCOMES RESEARCH.....	17
	Research Focus and Methodology .....	20
	Research Findings and Themes: Setting Size and Outcomes .....	22
	Residence Size .....	26
	Adaptive Behavior.....	30
	Satisfaction, Well-being and Loneliness .....	31
	Health Care.....	32
	Choice/Self-determination .....	33
	Residential Settings of Different Types and Configurations.....	36
	Organizational and Environmental Issues .....	42
	Service Setting Costs.....	43
	Staffing .....	45
	Level of Disability .....	48
	State Variation.....	50
	Summary of Research Findings .....	51
IV.	POLICY AND PRACTICE .....	51
	Civil Rights.....	52
	Federal Regulatory and Policy Environment.....	54

	Self-Advocacy as a System Driver.....	56
V.	SUMMARY, CONCLUSIONS AND RECOMMENDATIONS.....	57
	NCD’s Recommendations for the Federal Government:.....	59
	NCD’s Recommendations for States:.....	60
VI.	APPENDICES.....	62
	Appendix A. Intellectual and Developmental Disabilities Studies: The chart lists 44 total reports of studies (single and mega analyses) reviewed from research performed mostly in the United States (reports =27); others were in the United Kingdom (reports = 7), Wales (reports = 3), Australia (reports = 3), and the reports for United States & Ireland, Isreal, England & Wales were single instances). In four of the total 44 reports the number of study participants was “unknown.” The remaining studies in this portion of the review reported subject numbers ranging from n=10 to n= 12, 236. ....	62
	Appendix B. Mental Health Studies Chart: The research literature review in the chart below presents information from 32 mental health studies. Among themes/topics are: residence type and/or size, choice, environment, staffing, cost, adaptive behavior, and others. While one study location was listed as unknown, one study each occurred in Canada, and Isreal, there were two studies in British Columbia and Australia. The majority of participants were adults with mental illnesses residing in the United States (n=26 of the total 32 mental health reports addressing community outcomes). ....	75
	Appendix C. Supplemental Information: Selected Terminology and Descriptions .....	81
VII.	ENDNOTES .....	87

## I. EXECUTIVE SUMMARY

A Right Not a Privilege. The legal mandate shifting the foundation of service delivery for people with disabilities to home and community settings is unequivocal. Yet, transition from traditional congregate settings and service delivery approaches to the individualized, person-centered alternatives that facilitate full integration continues to challenge policymakers, providers, and other stakeholders alike. This National Council on Disability (NCD) report examines the research on the impact of the size and types of community settings on the individual and service-related outcomes of people with disabilities who live in those settings. The research findings are set against the current public support framework for people with disabilities as circumscribed by key judicial, legislative, and regulatory provisions that have been put into place over the past several years. This report reviews the implications of the 1999 Supreme Court *Olmstead*<sup>1</sup> decision and related enforcement activities by the U.S. Department of Justice (DOJ); provides an overview of the recently finalized regulations governing home and community-based services (HCBS) furnished under Medicaid State Plan and waiver programs;<sup>2</sup> and offers perspectives from self-advocates and disability thought leaders. Although the research clearly documents the superior outcomes achieved by people with disabilities in integrated person-centered settings, the need to deliver services in the community is driven by much more than research. The opportunity to choose to receive supports in order to have a home, family, friends, a job, and a regular life in the community is not a privilege—but a right.

It's the Law. The Americans with Disabilities Act (ADA),<sup>3</sup> with further clarification through the *Olmstead*<sup>4</sup> decision, affirmed that people with disabilities have the same rights as all citizens: to live with their families and friends in local neighborhoods and towns, to be employed in regular jobs at competitive wages, and to participate in community affairs. However, the opportunity for a person with disabilities to participate in society is highly dependent on the nature and extent of the supports he or she receives. Noting the pivotal role public services play in assuring access to the benefits of community living by people with disabilities, in *Olmstead* the Supreme Court ruled that such supports must be furnished in the most integrated settings appropriate to each person's needs in order

to prevent their exclusion from the rights of citizenship.<sup>5</sup> Over the past two decades, these and other judicial actions have been followed by state and federal initiatives to expand access to community resources. As a result, the nature of long-term services and supports for individuals with disabilities is changing: appropriate and increasing pressure on state systems attempts to ensure that services are made available which enable individuals with disabilities to fully engage in their communities -- with a home of their own, work, family, and friends.

Regulating Home and Community Services. Public services for people with disabilities in the United States (U.S.) are organized and delivered through a variety of state, federal, and local resources. The majority of the public supports people receive are funded by a combination of state and federal dollars through the Medicaid program.<sup>6</sup> Federal Medicaid regulations provide broad standards and expectations across all states, but the responsibility for determining eligibility, access, and the nature, type, scope, and duration of services rests primarily with state agencies. Typically, services are administered through state agencies with expertise in one or more disability populations -- people with intellectual and developmental disabilities, mental health disabilities,<sup>7</sup> physical disabilities, sensory disabilities, or other chronic or long-term conditions. Due to statutory and organizational differences between states, the character of services and supports differs from one jurisdiction to the next, depending on the population of people with disabilities being served.

Effective March 17, 2014, the U.S. Department of Health and Human Services Centers for Medicare and Medicaid Services (HHS/CMS) promulgated final regulations impacting all Medicaid Home and Community Based Services (HCBS) authorities.<sup>8</sup> The new HCBS regulations include requirements related to person-centered planning, conflict-free case management, quality, and the nature and characteristics of settings that may be considered “home and community-based” for the purpose of funding and service delivery. Only those settings meeting the HCBS characteristics established in the new regulations and guidance will be eligible for federal financial participation (FFP) under the various Medicaid HCBS authorities. The HCBS final regulations<sup>9</sup> 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. Settings must ensure individuals’ rights of privacy, dignity and respect, freedom from coercion and restraint, and must optimize individual autonomy and choice. The regulations also require that individuals in provider-owned or -operated settings be supported to control their own schedules and activities, including access to food and visitors, that they choose and at times of their choosing.

This national policy shift in favor of integrated supports and services presents a number of challenges to the state agencies and providers that have been furnishing supports through traditional mechanisms. Prior to HHS/CMS promulgation of the current rules on implementing HCBS, DOJ created a “technical assistance guide” to help individuals with disabilities understand their rights and to ensure that public entities understand their obligations under the ADA and *Olmstead*.<sup>10</sup> Now research findings which document improved outcomes achieved by people with disabilities who receive integrated supports and services can contribute to the knowledge base and enhance the efforts of the states working alongside people with disabilities and their advocates. Such collaborations restructure their support systems both to align with the *Olmstead* decision and to comply with the requirements of the HCBS regulations addressing:

- physical size and structure;
- rights and self-determination;
- qualities and attitudes of providers;
- access to community life; and
- the meeting of support and access needs.

Revealing Strong Research Trends. The preponderance of research reviewed for this NCD report -- regarding HCBS beneficiary outcomes information -- supports the conclusion that smaller, more dispersed and individualized community settings further integration and positive outcomes for individuals with disabilities. Strong trends are found in the data on the impact of setting size and type for people with intellectual and

developmental disabilities and for individuals with mental health disabilities. The trends reveal factors such as greater individual choice, satisfaction, housing stability, and higher levels of adaptive behavior and community participation associated with living in residential settings of smaller size.

The literature review reveals that the available research addressing setting-related outcomes tend to focus on the experiences of people with intellectual and developmental disabilities and adults with mental health disabilities. No studies were located that address the same research review parameters among individuals with physical disabilities or people with traumatic brain injury (TBI). Studies that were identified for people with physical disabilities or TBI were not designed to compare—and so, did not provide sufficient information on—the differences in outcomes related to setting size or type; rather, these studies addressed quality of life in different areas, such as access to health care, employment, or physical or psychological well-being.

The conclusions of this NCD report, then, are based largely on research outcomes of people with intellectual and developmental, or mental health disabilities. Although support needs may differ according to the nature of a person's disability and environmental factors, the results and data trends identified in the current study address quality of life and community participation issues that are common to people with disabilities of any kind living in the community. Public policy decisions must reflect information that is drawn from a broad array of individual, administrative, and political sources in addition to data generated by published research and peer-reviewed studies. The materials were from an array of sources, including “gray” literature (documents distributed by non-commercial publishers), position papers from organizations and thought-leaders, and first-person accounts from self-advocates, families, or others. Sources also include public comments submitted in response to the new HCBS regulations and position papers such as *Keeping the Promise*<sup>11</sup> prepared by individuals and advocacy groups. These additional materials can provide valuable information regarding the impact of policy changes on individuals and are crucial to informing any consideration regarding appropriate system design for community-based services.



While the findings of this report generally apply to all entities receiving federal funding, the scope of work does not include singling out various population groups by factors of age or ethnicity. NCD recognizes, for example, that people residing on tribal lands and U.S. territories often present different and relatively unique needs and issues. NCD's ongoing assertive outreach to vulnerable populations and direct stakeholder interaction through other processes will continue to inform the overall work of the agency.

This NCD report concludes with a series of recommendations for federal and state entities. At the federal level, the recommendations are for HHS/CMS to take appropriate and effective actions that call for: (1) full regulatory implementation; (2) identifying and sharing promising practices; (3) making toolkit sources useful for effective regulatory compliance; (4) self-assessment by federal fund administrators; (5) effective federal monitoring and enforcement; and (6) establishing definitions and requiring measurement of service and support quality. Recommendations for states address the actions that are needed in the areas of: (1) limiting residence setting size; (2) quality management; (3) financial alignment across current funding, resource and rate setting, setting of system goals, and the current HCBS regulations; (4) assuring stakeholder engagement throughout the planning and implementation of plans, processes, and programs; (5) oversight that enhances provider expectations about qualifications, training, and giving necessary services and supports; and (6) expansion of opportunities that promote self-determination and consumer control in living alternatives across the broad array of people with disabilities receiving federal benefits.

The recommendations in this report are based primarily on a review of the legal and regulatory home and community-based services framework outlined by the ADA and the new HCBS regulations. These recommendations also are informed by research documenting the impact of setting size and configuration on the outcomes achieved by people with intellectual and developmental disabilities and individuals with mental health disabilities receiving supports in home and community-based arrangements.

## II. BACKGROUND

### HCBS Overview

Public services for people with disabilities in the U.S. are organized and delivered through a variety of state, tribal, and federal mechanisms. Most supports, including those furnished to people with disabilities living on their own or with their families, are funded by a combination of state and federal dollars through states' Medicaid programs. Additional services are supported through state general revenues, Medicare, and a variety of other state, federal, and local sources. Services frequently are comprehensive and life-long in nature. Federal regulations provide broad consistent standards and expectations across all states, but responsibility for determining eligibility, access, and the nature, type, scope, and duration of services rests primarily with state agencies. Statutory and organizational differences across states mean that the services and supports vary from one state to the next, depending on the population of people with disabilities being served and the funding available.

The traditional organization of public support systems for people with disabilities has changed in recent years, as states have sought to decrease service costs and to improve administrative efficiencies by reducing reliance on costly and segregated institutional facilities and by introducing, instead, managed care concepts and tools. Long used in the medical care arena, the application of managed care strategies to the organization and delivery of long-term disabilities services (Managed Long Term Services and Supports—MLTSS) is not well established in the majority of states.<sup>12</sup> States are implementing MLTSS through existing state or local government agencies or are contracting with private health care corporations to administer, fund, and ensure service delivery. For certain disability groups, this represents a significant shift in the service delivery model. Such changes do not come easily. People with disabilities, families, advocates, and disability professionals have expressed serious concerns over the limited experience managed care organizations have in the design, management, and provision of lifelong supports to people with intellectual, developmental, and other disabilities.<sup>13</sup>

## The Changing Structure of Service Delivery

Traditionally, long-term services and supports for people with disabilities have been organized as a continuum of program alternatives with more intensive and restrictive programs at one end and less restrictive and intensive services at the other. The idea of the service continuum was based to a large extent on the concept of the least restrictive environment (LRE) proposed in the 1960s in the fields of special education<sup>14</sup> and developmental disabilities.<sup>15</sup> At its base, the principle seeks to affirm the entitlement of individuals with disabilities to receive needed services and supports in a manner that “least intrudes upon or restricts individual rights.”<sup>16</sup> The LRE principle has since been incorporated in judicial rulings as well as in state and federal legislation. The rights of people with mental illnesses and people with intellectual disabilities to receive needed supports in environments that offer the least restrictive conditions necessary for habilitation was underscored by the federal court’s landmark ruling in *Wyatt v. Stickney* in 1972.<sup>17</sup> The concept was endorsed at the federal level when it was included by reference<sup>18</sup> in the Developmentally Disabled Assistance and Bill of Rights Act of 1975<sup>19</sup> and later, in the Supreme Court’s ruling in *Pennhurst State School and Hospital v. Halderman*.<sup>20</sup>

The LRE principle laid the foundation for the development of a progression of program models arranged on the basis of their restrictiveness. A residential and/or a vocational continuum can range from institution to community or family living, theoretically designed to offer increasing independence and community integration to the person receiving support while decreasing restriction of rights as he or she gains new skills. The Residential Continuum span is from public institution, private institution, nursing home or intermediate care facility to large community group home, small community group home, foster home, family home, semi-independent or independent living. The Vocational Continuum span is from day treatment, day habilitation, psycho-social rehabilitation, sheltered work to transitional employment, enclave/work station, job placement with support, and integrated employment.<sup>21</sup>

Although the continuum concept offered a reasonable way to conceptualize service system organization in the 1970s, the expansion of community support alternatives and a decreasing reliance on segregated institutional models—following the establishment of the Home and Community-Based Services (HCBS) Medicaid waiver program in 1981—made it clear that people with even the most intensive service needs could effectively be supported in small, non-restrictive integrated community settings.<sup>22</sup> The financial and operational flexibility of the HCBS waiver program fueled significant changes in the organization of disability services, as state after state launched initiatives to deinstitutionalize their systems, diverting funding and services to smaller, less costly settings. The availability of federal funding for institutional options remains intact. Settings not meeting the new HCBS requirements may be eligible to receive federal support as nursing facilities, intermediate care facilities for people with intellectual and developmental disabilities, or other institutional programs.

### **The Americans with Disabilities Act and the *Olmstead* Ruling**

As large facility-based programs closed and increasing numbers of individuals with disabilities were supported in local communities, policymakers began to understand what people with disabilities, families, and advocates had been saying for years. Essentially, the goals of community inclusion and integration could not be achieved without significant changes in the manner in which public services were provided to people with disabilities—and, indeed, in society itself. In 1990, recognizing that the historical isolation and segregation of people with disabilities continued to be "a serious and pervasive social problem," President George H. W. Bush signed the Americans with Disabilities Act (ADA).<sup>23</sup> A key focus of this landmark legislation was on government itself, prohibiting discrimination by any public entity and ensuring that no qualified individual with a disability would, "... 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 any such entity."<sup>24</sup> In addition to defining disability, the ADA prohibits discrimination on the basis of disability in employment, public services provided by state and local governments, public services

operated by private entities, transportation, commuter authorities, or telecommunications.

A number of the most noteworthy outcomes of the ADA have resulted from the U.S. Supreme Court's 1999 decision in *Olmstead v. L.C.* regarding the delivery of publicly financed services and supports.<sup>25</sup> The Court held that public entities must provide community-based services to people with disabilities when: (a) such services are appropriate; (b) the affected individuals do not oppose community-based treatment; and (c) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.<sup>26</sup> The Supreme Court explained that its holding "reflects two evident judgments." First, "institutional placement of [people] who can handle and benefit from community settings perpetuates unwarranted assumptions that [people] so isolated are incapable or unworthy of participating in community life." And second, that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."<sup>27</sup>

The ADA's "integration mandate," as described in the *Olmstead* ruling, requires states to fund, operate, and administer programs and services to people with disabilities in a manner that does not result in their unjustified segregation or exclusion from society through: (a) the direct or indirect operation of facilities, programs or services; (b) the financing of the delivery of services in private facilities; or (c) the promotion or reliance on the segregation of individuals with disabilities in private facilities or programs as a result of the state's planning, service system design, funding choices, or service implementation practices.<sup>28</sup>

The ADA's integration mandate has significant implications not only for segregated institutional services, but also for home and community-based supports that function, through their design or delivery, to exclude or segregate people receiving supports from society at large. Under the ADA, all relevant public entities must ensure the services and supports they provide to people with disabilities afford each person the same

opportunities as people without disabilities for integration, independence, recovery, choice, and self-determination in all aspects of life, including in the settings in which they live, work, engage in other activities, and seek access to the community.<sup>29</sup>

In 2009, the Obama Administration launched the “Year of Community Living” as a major national initiative and directed the federal government to undertake a strong *Olmstead* enforcement effort to ensure that states were meeting their obligations under the ADA and the Supreme Court’s decision.<sup>30</sup> By the end of 2012, the DOJ Civil Rights Division was involved as an amicus or interested party in over 40 *Olmstead* related matters in 25 states.<sup>31</sup> These actions resulted in a number of states, by court order or settlement agreement, undertaking fundamental changes in the manner in which they offered services to individuals with disabilities to further opportunities for meaningful community integration.

### **Growth of Home and Community-Based Services**

The Omnibus Budget and Reconciliation Act of 1981 (OBRA '81)<sup>32</sup> added Section 1915(c) to Title XIX of the Social Security Act. Section 1915(c) permits states to waive provisions of the Medicaid statute in order to furnish HCBS to eligible individuals who would otherwise receive institutional care. Today, the 1915(c) waiver program is the primary mechanism for publicly funded community-based long-term services and supports for people with disabilities in the United States. The HCBS waiver program has grown dramatically since 1981. Initially used by states to fund community services for people with intellectual and developmental disabilities (IDD) as alternatives to more costly institutional care, the program has since expanded to include individuals who are aging, people with physical disabilities, and, more recently, and people with mental health disabilities. By the end of FY 2011, a total of 325 1915(c) programs operated across 47 states<sup>33</sup> and the District of Columbia serving over 1.3 million individuals.<sup>34</sup>

HCBS programs furnish an array of community-based residential, day, employment, therapeutic, and ancillary services to assist individuals with intensive needs remain in the community and avoid institutionalization. Statutory provisions added to the Social

Security Act in recent years have increased HCBS opportunities provided under state Medicaid plans to more disability groups and people in need of support. Provisions, included under Sections 1915(i), 1915(j), and 1915(k) of the Social Security Act make available significant alternatives to states interested in expanding community supports to people with disabilities.<sup>35</sup> These programs can be offered by states as separate benefits or in tandem with other HCB services. More information about Sections 1915 (j), and (k) is in Appendix C of this report. States also may pursue more broad based system change initiatives through demonstration waiver programs offered under Section 1115 of the Social Security Act.<sup>36</sup>

Regulating Home and Community-Based Services. New HCBS federal regulations became effective on March 17, 2014.<sup>37</sup> The provisions and requirements address areas of person-centered planning, conflict-free case management, service quality, and the nature and characteristics of settings that may be considered “home and community-based” for the purpose of funding and service delivery. Settings that meet the HCBS standards and guidance will be eligible for federal funding. The impetus for the HCBS rule was twofold: (1) to better align Medicaid funding and program requirements with the civil rights protections afforded to individuals with disabilities under the ADA, and (2) to address concerns that current Medicaid HCBS mechanisms were being used in some states to fund institutional-style settings that did not afford individuals the opportunities necessary to engage meaningfully in their communities.

The new Medicaid HCBS rule does not directly address the size of settings. Instead, it identifies the qualities and characteristics of HCB settings and services that must be met by states and providers, regardless of the number of individuals being supported. HHS/CMS has provided preliminary implementation guidance to states related to settings in which residential supports are delivered and has announced that additional guidance related to the application of these rules to non-residential settings is forthcoming. Specifically, the rule provides that, to qualify as “Home and Community-Based,” a setting must, among other requirements: (a) be integrated in, and support full access of individuals to, the greater community, including employment; (b) be selected

by the individual from among setting options; and (c) ensure an individual's right to privacy and freedom from coercion.<sup>38</sup>

The HCBS rules have the potential to make significant changes to the nature of the services offered by states in home and community-based systems, as traditional programs give way to flexible funding and support designed to maximize choice and opportunities for community engagement. Although newly promulgated HCBS regulations closely approximate the goals and civil rights requirements of the ADA, there are differences. Research analysis finds that the ADA requirements stand separate from additional specific regulations and service-related requirements of Medicaid programs provided by states under Title XIX of the Social Security Act.<sup>39</sup> A state may operate HCBS and supports in a manner that fully complies with federal Medicaid regulations. That same state might violate the ADA's integration mandate—if service outcomes result in unnecessary segregation or exclusion from the mainstream of society. States must ensure that their Medicaid and other publicly funded programs not only meet federal regulatory requirements, but are also consistent with the ADA's integration mandate.

System Change. The final HCBS regulations require that settings be integrated in and support full access to, the greater community. Individuals who receive Medicaid HCBS must have opportunities to seek employment, to engage in community life, to control personal resources, and to receive services in the community to the same degree as individuals not receiving Medicaid HCBS. Furthermore, settings must ensure individuals' rights of privacy, dignity and respect, freedom from coercion and restraint, and must optimize individual autonomy and choice. The regulations also require, in provider-owned or operated settings, that individuals are supported to control their own schedules and activities, including access to food and visitors that they choose and at times of their choosing. These requirements are far more challenging to accommodate when many people, with different preferences, styles, and support needs receive services in the same setting. The provisions also will lead to significant changes in the structure and functioning of state disability systems. Currently, state agencies are



performing self-assessments to determine changes needed to reduce setting size and shift resources away from facility based service models. State also must restructure staffing patterns to enable people receiving services to access the community on their own terms, defining for themselves the roles that services and service providers will play in their lives.

Public policy managers, like clinical practitioners, have a professional responsibility to acquire and apply the best available knowledge and evidence in their professional roles, and in their efforts to develop and improve services and supports for individuals with disabilities.<sup>40</sup> As described below in the community outcomes research section, the evidence strongly suggests that compared to people living in larger settings that they do not control, people with disabilities living in small family-scale settings that they control are more likely to experience positive personal outcomes, participate in community activities, be employed, have friends, have privacy, and enjoy all of the other liberties afforded citizens in this country.<sup>41</sup>

This NCD report is written to provide evidence about individual and support outcomes associated with programs, services, and settings of different size and configuration. The information is primarily for use by state and federal policymakers, people with disabilities, families, providers, and other stakeholders.

### **III. COMMUNITY OUTCOMES RESEARCH**

A considerable body of research has accumulated data showing improved individual, behavioral, and support outcomes among people living in community rather than in segregated institutional programs and nursing homes. Appendix A presents more details about a growing body of research involving people with intellectual and developmental disabilities. See Appendix B with regard to a small number of community outcomes studies on people with mental health disabilities.

The data clearly indicate that community-based supports facilitate a person's integration into society<sup>42</sup> and result in better quality of life outcomes across a wide range of areas,

such as personal and support-related choice,<sup>43</sup> community participation, and housing stability. While numerous studies document improved individual and support outcomes associated with community living, it must be remembered that inclusion is a right. People with disabilities are entitled under Title II of the ADA to receive public services and supports in the most integrated settings appropriate to their needs. Unjustified segregation is prohibited regardless of research evidence favoring one treatment approach over another.

As both state and federal policy regarding long-term service delivery shifts in favor of support models that furnish individualized assistance in small homes and local neighborhoods, it is important to note that there is no uniform set of services, but rather a wide array of funding and support alternatives. Community residential services, for example, vary significantly in size and configuration among states and across disability populations.

Community Residential Settings may be of differing size:

- a. Self-directed, where the person with disabilities contracts with others to provide necessary assistance and support at home, in the community, or on the job;
- b. Individualized, supporting 1-3 individuals living in individual homes, apartments, shared living, host home, or adult foster care situations in which the person's residence is owned or leased either by the provider or by the individual receiving support;
- c. Group, serving 4-6 people in group-homes, community residences, "family care," supportive housing [mental health], or other similarly sized settings;
- d. Large Group, serving 7-15 people in larger congregate settings; or
- e. Family living, where adults live in the home of a biological family member or guardian.

Settings exist in different configurations, types, or arrangements that support individuals or groups of people with disabilities in a variety of non-normative settings including:

- a. Dispersed, small homes, condominiums, or apartments scattered within a large residential complex designed for people with and without disabilities;
- b. Section 811, the Supportive Housing for Persons with Disabilities program including alternatives organized around the goal of providing permanent supportive housing to people with mental health needs;
- c. Single Room Occupancy or “extended stay” housing for people with mental illnesses; and
- d. Clustered housing or “campus” models in which people with disabilities live and receive services in homes and settings that are designed for the exclusive use of people with disabilities. Such settings may be located in proximity to local communities or neighborhoods, but they typically retain an institutional organizational structure, centralizing administration of all residential, day, employment, health, therapeutic, and ancillary services under a single controlling authority.

In addition to the “community” settings noted above, there also are smaller institutional settings serving 4-15 individuals. Settings in which individuals may receive services can be certified as Intermediate Care Facilities for Individuals with Intellectual Disabilities ((ICF/IID)).<sup>44</sup> More information about the ICF/IID terminology is in Appendix C. Other residences with services are designed to support people with mental health needs.

States have utilized Medicaid home and community-based service funding to support individuals living in many of the group and clustered settings described above. While this practice has been permissible in the past, many of the programs do not exhibit the characteristics of community settings and are unlikely to comport with the HCBS settings requirements as set forth in the new regulations.

As noted above, a considerable amount of research has examined differences in individual outcomes which people with disabilities achieve in institutional versus

community settings. Comparatively little research, however, has assessed outcomes across the various types of home and community-based residential settings.

Furthermore, the focus of research on community living differs by disability group. The size of residential setting has been an important issue for people with intellectual and developmental disabilities and the systems that support them, but there has been less research regarding the size of setting for services for people with mental health disabilities and for people with physical disabilities. Setting size is but one of several variables that must be taken into consideration in any assessment and analysis of an individual's quality of life. However, as described below, the data make it clear that individual and family-scale settings are significantly more likely to be community-based, while larger and congregate settings are likely to be institutional in nature.

## **Research Focus and Methodology**

This report examines the nature, extent, and conclusion of research evidence comparing the outcomes and documenting the experiences of people with disabilities in residential and other service settings of differing size and configuration as described in Section III above. The studies and reports were selected for review based on the following criteria: (a) focus primarily on U.S. services; (b) address the outcomes and experiences of adults with intellectual and developmental disabilities, adults with mental illnesses, and to the extent that the information is available, people with physical disabilities, traumatic brain injuries (TBI) and other conditions; (c) address adaptive behaviors, challenging behaviors, choice, social networks, community participation, and related activities; (d) include contrast group studies comparing outcomes of people who moved from one type of non-institutional community setting to another, to the extent that they have been performed; and (e) use information drawn from existing data and data-sets such as the National Core Indicators (NCI) and other information gathered by HHS/ Substance Abuse and Mental Health Services Administration (SAMHSA) projects. Strategies were developed to aid in determining the relevance of the evidence gathered, accounting for differences in the nature and type of data reported, and evaluating the

direction and magnitude of reported outcomes. Additional methods were used to compare research findings, results, and conclusions across studies and resources utilizing different research designs and methodologies. This latter point was particularly challenging because of the nature of the research question.

This NCD analysis focuses primarily on peer reviewed research published in scientific journals but additionally utilizes evidence from credible “gray literature” sources including, “[T]hat which is produced on all levels of government, academics, business and industry in print and electronic formats, but which is not controlled by commercial publishers.”<sup>45</sup> Gray literature typically includes technical reports, working papers, conference proceedings, analyses, program descriptions, and whitepapers produced and published by governmental agencies, organizations, and other credible sources.<sup>46</sup>

Evidence was identified through the following methods and strategies: (a) review of existing related databases such as Education Resources Information Center (ERIC) for articles published between 1990 and 2013; (b) review of key journals such as the *Journal of Intellectual and Developmental Disabilities*, the *American Journal on Intellectual and Developmental Disabilities*, *Journal of Policy and Practice in Intellectual Disabilities*, and other journals using the ancestry approach; Internet-based keyword searches for related documents and materials, reviews of reports, accounts, and other documents prepared by state and federal agencies, provider entities and national associations, such as the National Association of State Directors of Developmental Disabilities Services, the National of State Mental Health Directors, the ArcUs, the Autism Self-Advocacy Network, the National Alliance on Mental Illness, etc. The literature review also included articles and documents on key individual and support variables that can be expected to affect individual outcomes—including the meaning and definition of choice, informed choice and self-direction, and recovery in the context of long-term support.

Several challenges were encountered during the analysis for this NCD report. No studies, reports or analyses were identified that were based on randomized control group interventions or experimental designs. No studies, reports or analyses were found

that utilized matched comparisons where the characteristics of people with different levels of severity of disability are taken into account. Several qualitative studies examining the experiences and perspectives of people in inclusive, supported living and related settings were identified and included in the analysis, but few, first-hand accounts by people with mental health disabilities living in the community were identified during this review that specifically addressed the issue of size of the residential setting. However, anecdotal data from people with intellectual disabilities who moved from large homes and settings to smaller more individualized arrangements were identified and are included. Conceptual articles examining the implications of choice, self-determination or self-direction, person-centered planning and service delivery, individual control, etc. were reviewed and included in the analysis and report where appropriate.

### **Research Findings and Themes: Setting Size and Outcomes**

The research evaluating the impact of the size or configuration of community residential settings on the ability of people with disabilities living in those settings to achieve personal and support outcomes is limited and uneven across disability groups. NCD found relatively few studies conducted in this area. The available research almost exclusively focuses on the experiences of individuals from two disability groups—people with intellectual and developmental disabilities and those with mental health disabilities. Research designs and analytical strategies have tended to reflect the nature and priorities of the service population. For example, size of residential setting has long been an area of concern for developmental disabilities services. Research on the impact of residential settings for people with mental health disabilities more often has addressed the nature and configuration of the setting and the types of services offered.

Although the research base is small, the data sets that are available document clear trends in increased choice, satisfaction, and personal outcome achievement associated with homes and residential settings of smaller size. Comprehensive analysis of 80 peer reviewed research studies and reports published since 2000 revealed a number of key themes and conclusions with respect to the impact of the size of the setting in which services are delivered—which can provide important guidance for states and

organizations in their efforts to design and operate person-centered systems of supports and services.

Overview of Intellectual and Developmental Disabilities. The past 30 years has witnessed a substantial decrease nationally in the size of residential settings for individuals with intellectual and developmental disabilities (IDD). As reported by researchers at the Research and Training Center on Community Living, in 1977 the average residential setting size was 22.5 people, while in 2002 the average size was 3.1 people per setting and, by 2011 that number had decreased to 2.3. These data also reveal considerable state to state variability. In 2011, for example, four states supported more than 90 percent of all residential service recipients with IDD in settings of 3 or fewer (Kentucky, New Hampshire, New Mexico, and Vermont). By contrast, five states supported less than 30 percent of people in settings of 3 or fewer individuals (Illinois, Mississippi, New Jersey, New York, and South Carolina).<sup>47</sup>

45 peer reviewed research studies, meta-analyses, policy reports, and other documents were examined for inclusion in this paper. A clear trend in the findings of these pieces is that people with disabilities living in smaller settings are more likely to achieve positive outcomes and to experience an improved personal and support-related quality of life than are individuals who live in larger settings. Taken as a group, these studies provide strong evidence suggesting that individuals with IDD living in smaller settings on average experience superior quality of life outcomes across all domains, than do people with IDD living in larger settings. People with IDD who lived in a home of their own, with their families, in shared living situations, or in provider supported alternatives with one or two roommates consistently scored higher in terms of individual outcome achievement than did people living in moderate (four to six individuals) and large (15 or more residents) residential programs and facilities. There was some variability on specific outcomes. Not surprisingly, people with IDD living in small homes operated by provider agencies scored higher in terms of preventative health care than did individuals living on their own or with families. Positive (i.e., healthier) outcomes with regard to not putting on unnecessary weight were more likely to be associated with people living in

group or agency settings than among individuals living on their own. However, positive outcomes around those issues most directly relevant to the new settings regulation – choice, control, privacy, and related areas – are higher in smaller and non-provider controlled settings.

Other NCI-based studies have reported more positive individual and support-related outcomes associated with smaller, more family-scale settings. For instance, Stancliffe et al., found greater loneliness in larger settings (seven to 15 people) than in smaller settings (one to two, and three to six).<sup>48</sup> Two additional studies by Stancliffe and colleagues conducted in Minnesota documented greater adaptive behavior and less challenging behavior among people living in smaller settings.<sup>49</sup> In a 2005 study, Gardner and Carran reported that “in general, comparisons indicate a lower level of outcome attainment in larger settings than in moderate-sized settings.” The authors noted that, for people with IDD, outcome achievement was additionally related to the person’s level of disability, underscoring the importance of the availability of community supports for people living in small settings.<sup>50</sup>

Overview of Mental Health Disabilities. Thirty-five research studies, meta-analyses, and policy papers were reviewed addressing setting related outcomes among people with mental health disabilities. While no studies identified during this literature search explicitly tested the effect of size of residence on outcomes for individuals with mental health disabilities, a number utilized research designs that compared individual outcomes achieved by people in residential settings of different size along with other service-related variables. As a result of possible interactions between variables, findings in the mental health data cannot be attributed to the size of the residence alone. Still, taken as a whole, the studies reviewed suggest that smaller residence size is more beneficial for individuals with mental health disabilities.

Housing programs serving individuals with mental health disabilities have been undergoing what some have argued is a transformative shift in the nature and delivery of services.<sup>51</sup> This transformation has entailed a move away from large, congregate, custodial residential settings, where staff members are viewed as providers of care,



toward the use of independent apartments integrated into the community—where members of staff are viewed as facilitators supporting the achievement of individualized goals with choice by the individuals being served paramount.<sup>52</sup> Not all of the approaches identified in an earlier NCD report have been widely replicated, yet a growing body of research evidence shows the applicability of several alternative programs, such as supported housing. Therein people choose where they live rather than being required to live in a place because of their disabilities.<sup>53</sup>

The option of moving to “permanent supported housing,”<sup>54</sup> of which the “Housing First” model is a prominent approach, might hold promise for some individuals with psychiatric disabilities. In a 2009 quantitative synthesis of the evidence, Leff and colleagues at the Human Services Research Institute conducted a meta-analysis across 44 housing interventions with a combined sample of 13,436 individuals. They found that interventions using a permanent supported housing approach had the largest impact on outcomes such as housing stability, reduction in hospitalization, and housing satisfaction.<sup>55</sup> Less is known, however, about the contributions various factors have on the outcomes achieved by the people living in those homes. Examples are residence size, type, organizational or environmental variables, program costs, staffing, choice and self-direction, adaptive behavior, level of disability, or variation by state. The recent literature (2000-present) reviewed for information about the link between these factors and outcomes is summarized below.

The following sections describe the impact of key factors such as setting size on personal and support outcomes related to satisfaction, well-being and loneliness, access to health, care community participation, and others. Each section summarizes related research findings for people with intellectual disabilities and individuals with mental health disabilities, the two groups for which sufficient data could be identified and gathered. As noted above, although the research findings related to the two population groups cannot be directly compared they do reveal comparable trends and lead to similar conclusions.

## Residence Size

Intellectual and Developmental Disabilities. The preponderance of research on the impact of setting size on individual and support outcomes among people with IDD has utilized NCI survey data. In an overview of NCI studies published between 2008 and 2012, Tichá and colleagues examined outcomes achieved by people with IDD in relation to seven different types of residential settings: one's own home, family, host family, agency-owned or operated with one to three residents, agency with four to six residents, agency with seven to 15 residents, and agency with 16 or more residents. Agency with 1-6 residents typically refers to either a group home or an agency-owned apartment. The outcomes examined included choice, health, obesity, loneliness, wellbeing and satisfaction, and expenditures. The authors compared outcomes achieved by people living in each of the seven types of residential settings identified above against the agency operated home of one to three residents as the statistical referent. Overall the most positive outcomes were for individuals with IDD living in their own homes (owned or rented) —except for the category of obesity. In addition, living with family or host family produced better results with respect to making choices, resident wellbeing, and satisfaction than did living in an agency setting.<sup>56</sup>

A separate study by Tichá and colleagues found that living in an agency-operated setting of one to three residents or in a family or host family is better for the individuals with IDD than living in an agency home with more than three residents, in terms of the outcomes noted above in the previous study. Living in an agency setting with one to three people was additionally found to be less costly than with living with a family or host family. Residents received better preventative health care when living in an agency-operated setting with one to three residents than when living with family, or on their own, or in an agency with four to 15 residents.<sup>57</sup>

A recent research-policy brief written by Nord and his colleagues examined the general trends in the relationship between residential setting size/type and outcomes for people with IDD based on the NCI studies.<sup>58</sup> The residential settings compared were: own home, family, host family, small agency (one to three people), moderate agency (three

to six people), large agency (six or more people), and institution (16 or more people). The outcomes examined were: greater choice, greater preventative health care, greater satisfaction, lower overweight or obesity, and lower expenditures. Outcome results were ranked by type of residential setting. The results indicated that on average, people with IDD achieved the best outcomes living in their own homes or in small agency settings, followed closely by those living with their families or with host families. The worst settings for all outcomes combined were large agency-operated programs. With respect to personal choice, greater choice-making was found among people with IDD residing in their own homes, small agency settings, host families, and families—with significantly less choice experienced by individuals living in moderate sized agency settings (three to six people), larger agency (six or more people), and institutions. Family settings were most conducive of satisfaction of people with IDD, followed by small agency, moderate agency, host family, and living on one's own. When expenditures were compared, living with family and living with host family ranked higher than living in a small agency and living on one's own. Preventative health care and overweight or obesity showed a pattern of results that differed from the other outcomes. Examples such as improved preventative healthcare outcomes and obesity scores were more evident among people with IDD in agency-operated or supervised settings compared to those living on their own or with family.<sup>59</sup> However, on measures of choice, control, privacy, and other issues relevant to the new HCBS settings regulation, outcomes were better for people living on their own or with their families.

Mental Health Disabilities. No studies identified during the literature search for this NCD project explicitly tested the effect of size of residence on outcomes for individuals with mental health disabilities. However, there were a number of studies which, as part of their design, compared outcomes between people living in one size of residence to people living in a residence of a different size. Unfortunately, the interventions or services offered often varied between the settings of different size, making the results impossible to attribute to the size of the residence alone. Taken as a whole, however, the studies reviewed seem to indicate that smaller residence size (five or fewer individuals) is more beneficial than larger residence size (six or more individuals) for

individuals with mental health disabilities. Also, though considerations remain, it does appear that supported housing provided in larger residences is better than no provision of supported housing at all.

The majority of U.S. studies in this review reported that programs utilizing individualized apartments or smaller residence sizes were associated with “better” outcomes, such as longer housing tenure, less service use, and more consumer choice in comparison to programs utilizing larger residences. A number of these studies found positive effects on housing tenure. Lipton and colleagues followed 2,937 individuals in high, moderate, and low-intensity housing over a span of five years and found that for individuals in the high-intensity housing group, the people in non-congregate living arrangements or what were defined as medium-sized units (28 to 99 beds) had longer housing tenures than others.<sup>60</sup> Tsemberis and Eisenberg (2000) compared 242 individuals in a Housing First program (independent apartments) to 1600 individuals in larger congregate settings and found that individuals in the Housing First program were more likely to remain in their homes for up to four and a half years.<sup>61</sup> Finally, Stefancic and Tsemberis studied 260 individuals in a Housing First program using independent housing or a control group largely housed in congregate settings and found that people in the program that emphasized independent apartments were still in their homes at 20 months.<sup>62</sup>

Another theme of the U.S. studies reviewed was that smaller residence sizes were associated with better service outcomes. In a study of a Housing First intervention program involving 206 individuals, Tsemberis, and colleagues reported that those individuals living in independent apartments had significantly less use of substance abuse services, in addition to more choice, more stability in choice, and more housing stability.<sup>63</sup> Another study reported that use of substance abuse services was greatly reduced (10 times less likely) for 75 people in a comparison of a Housing First program to a “Treatment First” approach in a large residential setting.<sup>64</sup>

Housing First programs are similarly associated with increased independence, self-sufficiency, and better functioning by those individuals being served—resulting in less need for services. Gulcur and colleagues reported significantly less time spent in the

hospital in their study comparing 225 individuals in a Housing First program to those in the regular continuum of care, which often consists of larger residential settings.<sup>65</sup> Finally, less use of crisis services, greater autonomy, and increased economic satisfaction were also reported for individuals living in independent apartments as compared to those receiving services provided in congregate settings.<sup>66</sup>

Similarly, a qualitative study of 80 individuals in supported housing reported mostly positive outcomes for residents of independent apartments, such as feelings of increased privacy, independence, and freedom to pursue interests.<sup>67</sup> Participants indicated that living alone in an apartment was a major adjustment from homelessness and that the sense of "fitting in" was lower for those in the smaller independent apartments vs. larger staffed residences.<sup>68</sup> These studies underscore the importance of promoting community interaction.

Studies conducted outside of the U.S., though fewer in number, also support the use of smaller residences. Warren and Bell (2000) conducted a qualitative study of 10 individuals currently receiving mental health services in Australia, and found that they preferred smaller independent apartments to larger congregate residences.<sup>69</sup> Echoing the findings of some of the U.S. studies, Patterson and colleagues examined the relationship between housing program type and outcome for 497 individuals randomly assigned to Housing First programs in Vancouver, British Columbia. The authors reported that assignment to a Housing First program, either scattered site or congregate, predicted greater perceived quality of life compared to those not in a supported housing program at all.<sup>70</sup>

Two studies conducted outside of the U.S. examined sense of community, belonging, and social inclusion, though the findings appeared to differ from those in the US. Patterson, Moniruzzaman, and Somers examined the concepts of psychological and physical community integration for individuals randomly assigned to Housing First or treatment as usual (usually large congregate settings) in Vancouver, British Columbia.<sup>71</sup> De Heer-Wunderink and colleagues reported similar findings in their 2012 study of 255 individuals in supported housing compared to those in group residences in the

Netherlands. In both studies independently living service users were found to be more likely than those in the group residences to be socially included.<sup>72</sup> Though the amount of evidence is limited, such findings suggest that differences between cultures should also be considered when implementing supported housing programs.<sup>73</sup>

### **Adaptive Behavior<sup>74</sup>**

Intellectual and Developmental Disabilities. Within the U.S., studies by Stancliffe and colleagues have consistently documented better adaptive behavior outcomes to be associated with smaller settings. For example, the authors found that people living alone exhibited the best-developed adaptive behavior and the least challenging behavior, and participants from four-person units the poorest. They concluded that larger size settings predicted poorer adaptive behavior.<sup>75</sup>

Many studies have documented the influence of adaptive behavior on outcome achievement.<sup>76</sup> Stancliffe and colleagues reported a clear relationship between adaptive behavior and personal control. In a 2002 study, Stancliffe and colleagues demonstrated that adaptive behavior actually decreased challenging responses among individuals living in intermediate care facilities (ICF/IID), concluding that the results showed that individuals with shorter periods of institutionalization, who subsequently lived in smaller community settings and experienced larger increases in community participation, had higher adaptive behavior scores. The authors concluded that these data provide further evidence of the need to reform or convert intermediate care facilities and expand HCBS.

Similarly, Woolf documented co-relationships between adaptive behavior and residential independence. Individuals living independently displayed the highest adaptive behavior, followed by those in supported living, group homes, and ICFs. The authors conclude that programs that promote adaptive behavior and skills are important to achieving greater independence.<sup>77</sup>

Mental Health Disabilities. The concept of adaptive behavior is primarily related to IDD services and not generally used to guide research on services for people with mental

health disabilities. A single study was identified in the review of the mental health literature which appeared to address adaptive behavior and services. Wright and Kloos (2007) studied 249 individuals in a supported housing program and assessed the relationship between apartment-level and neighborhood-level environmental factors and various outcomes.<sup>78</sup> One of the outcomes that they assessed was a construct they identified as adaptive functioning, defined as “social and vocational functioning as well as the client’s ability to cope effectively with their mental illnesses and other life circumstances” and which was rated by case managers. The researchers found that the apartment-level environmental factors explained only two-percent of the variance in reported adaptive functioning, and that the neighborhood-level environmental factors did not explain any additional variance in the outcome. These findings indicate a weak effect of environmental factors on adaptive functioning among people with mental health disabilities.<sup>79</sup>

### **Satisfaction, Well-being and Loneliness**

Intellectual and Developmental Disabilities. In a study published in 2007 based on the NCI data, Stancliffe et al. found a significant difference in loneliness by residence size, with larger settings associated with more loneliness. While no difference was found between settings of one to two and three to six, there was a difference in settings of eight to 15. Overall, they reported that “greater loneliness was significantly positively correlated with residence size, being afraid at home and afraid in one’s neighborhood. Significant negative correlations were reported with social contact (friends, family) and liking where one lives.<sup>80</sup> Then, in a 2009 study, Stancliffe and colleagues found greater satisfaction and sense of well-being among residents of smaller settings. For example, residents of settings of seven or more reported significantly more loneliness than residents of smaller settings.<sup>81</sup> Additionally, significantly more residents of smaller settings reported liking where they live. They concluded that:

Comparisons by residence size yielded a more consistent picture, with more negative findings always associated with larger residence size...Self-reported well-

being and satisfaction findings document the benefits of residential support provided in very small settings with choice of where and with whom to live...<sup>82</sup>

## **Health Care**

Intellectual and Developmental Disabilities. A few studies address health care and type of residence, though not size. For instance, the work of Stancliffe et al., (2011) focuses on overweight and obesity among adults with intellectual disabilities in 20 states, based on the NCI data.<sup>83</sup> They found the highest rates of obesity among adults living in their own homes, and the lowest among adults living in institutions. Foster homes and group homes had a significantly lower rate of obesity than agency apartments, own homes, and family homes. The authors noted the wealth of evidence that small, less regulated settings provide better overall outcomes in terms of choice and well-being and emphasized that “a return to institutions or institution-like controls” as a solution to obesity is out of the question. Additionally, the same researchers noted that “once the interaction between the type of residence and level of intellectual disability is taken into account, some of the differences between settings are no longer relevant.”<sup>84</sup>

Mental Health Disabilities. A very limited number of studies identified addressed health outcomes for individuals with mental health disabilities in housing programs. One study took place in the United States, and one in Canada. In the U.S. study, Nath, Wong, Marcus, and Solomon examined frequency and mix of service contacts and found that those receiving case management, coupled with weekly contact with residential support services, visited a general health practitioner more frequently than those with fewer support services.<sup>85</sup> In the Canadian study, Grant and Westhues found positive changes in perceptions of physical health between baseline and 12 months for the group receiving the intervention with higher supports compared to those receiving less support. Though the amount of evidence is very limited, these two studies suggest that program staffing levels may be related to the use of physical health services as well as to the perception of physical health for individuals with a mental health disability.<sup>86</sup>



## Choice/Self-determination

Intellectual and Developmental Disabilities. Several studies addressed choice and self-determination in community settings. Lakin and colleagues conducted a comprehensive 2008 study of 2,398 adults with intellectual and developmental disabilities using HCBS and Intermediate Care Facility (ICF) services in six states.<sup>87</sup> They investigated choice in everyday and support-related decisions. In essence, people stated that they regularly made choices relative to the services they receive and the activities in which they engage at home, work and in the community. The same authors found that everyday choice and support-related choice was “considerably higher on average” among people living in HCBS settings as compared to those living in intermediate care facilities. However, overall, they found that “choice was more strongly associated with living in a congregate setting than whether that setting was HCBS- or ICF/IID financed.”<sup>88</sup> (Institutionally financed settings are institutional in nature and generally much larger than HCBS settings.) Data regarding setting size and level of intellectual disability also were analyzed. The research report indicates that:

For [people] with mild intellectual disabilities, those living in places of one or two residents had more everyday choice than did those from larger settings. For individuals with severe or profound IDD, there was significantly less everyday choice for those in settings of nine or more, but relatively little difference among smaller settings.<sup>89</sup>

Further study of everyday choice and support-related choice (Tichá et al., 2012) documented choice across different types of settings. The research found that for people with mild intellectual disabilities, the best place for making support-related choices is clearly (significantly) when living on their own, followed by either living with a family, or in an agency setting of one to two, four to six, or seven to 15. Individuals with all levels of intellectual disability living in their own homes had significantly more support-related choice than people in any other residential arrangement. In terms of everyday choice, people with mild and moderate IDD had more control when living in

their own homes, whereas people with severe and profound IDD had more control when living in agency homes of three or fewer residents. Overall, Tichá and colleagues<sup>90</sup> found that people report having more choice in their own homes and in small agency settings than in family-based settings. The authors suggest: “Since family-based arrangements are among the fastest growing, there is a need to investigate what might promote more choice in these arrangements.” Similarly, Tichá and colleagues reported that those in settings of 16 or more had less everyday choice than residents of smaller community settings.<sup>91</sup>

Lakin and colleagues<sup>92</sup> documented that HCBS residents had more choice and that there was less choice in larger settings, whether ICF/IID or HCBS. The authors concluded, however, that many people across all settings still have very little choice. Findings from the NCI data brief support this conclusion. Many respondents reported that they did not have input in major life decisions, while a higher proportion reported having input into everyday decisions.

Self-determination and control have been found to contribute to more satisfaction and less loneliness. For instance, Stancliffe and others found that subjects with no choice of living companions-- and those with no choice of where to live -- were both significantly more likely to feel lonely and/or unhappy, and to dislike their home.<sup>93</sup> In a subsequent study, Stancliffe and colleagues investigated choice of living arrangements. They reported a “strong and significant” relationship between choice of where to live and with whom to live and level of ID; the less severe the ID, the more likely to have choice. They also found a strong association between current place of residence and participation in choosing that place. People living in their own homes had the most choice. Similarly, people living in their own homes participated most in choosing housemates or deciding to live alone.<sup>94</sup>

Overall, across the studies on choice and self-determination, a common finding is that people in parental homes or their own homes have more choice and self-determination than those in group homes. Also, as researchers have documented, it is critical to also take into account differences based on level of intellectual disability.<sup>95</sup>

Mental Health Disabilities. There were four U.S. studies that explicitly measured consumer choice and examined the relationship between consumer choice and outcomes. All studies that explicitly tested consumer choice found a significant relationship between it and outcomes, indicating that consumer choices are critical in the provision of supported housing. NCD has conducted extensive research related to housing options for individuals with disabilities and in series of earlier reports set forth a livable community framework.<sup>96</sup> The reports propose necessary changes in public policies regarding self-determination and choice related to housing; reliable and accessible transportation; accessible environments for work, education, and health care; and opportunities for participation in civic, social and recreational activities.<sup>97</sup>

In their comparison of programs utilizing smaller versus larger residences, Siegel and colleagues<sup>98</sup> found that people in a supported housing program experienced significantly more autonomy, defined as the “levels of independence and physical autonomy afforded by the housing,” than those in the larger residences.<sup>99</sup> Tsemberis and colleagues found that those in the supported housing group they studied experienced significantly more choice and a more stable pattern of choice over time compared to those in the “treatment as usual” residential continuum of care group.<sup>100</sup> Additionally, Yanos and colleagues found that perceived choice was related to type of housing (favoring independent apartments) and reaction to housing, with those responding positively to housing perceiving more choice.<sup>101</sup> In a 2012 study by Tsai and Rosenheck of 534 chronically homeless adults with serious mental illnesses placed in supported housing, domains of consumer choice assessed weakly predicted psychological well-being and subjective quality of life, but not housing outcomes.<sup>102</sup> Overall in these studies, individuals in programs that utilized smaller, independent housing experienced more choice.

There were also a few studies reviewed that were conducted in the U.S. that did not explicitly test consumer choice, but still address the construct tangentially through the nature of the housing programs they are testing. Tsemberis and Eisenberg, in their 2000 study of Housing First, found significantly better housing outcomes for residents

of the experimental program (that has consumer choice as a core tenant) in comparison to residents in the group utilizing the traditional linear residential treatment.<sup>103</sup> In their qualitative study, Tsai and colleagues found that generally, independent housing was more desired than supervised, and that one of the core reasons for preferring independent housing was autonomy.

## **Residential Settings of Different Types and Configurations**

Intellectual and Developmental Disabilities. As noted above there has been a steady decrease in the average number of residents in state-funded residential settings over the years. The NCI surveys provide basic information on the nature and types of residential settings used by people with IDD.<sup>104</sup>

Few studies were identified in the NCD review that specifically addressed residential size as a variable. The majority of the research focused on differences between ICF/IID facilities and HCBS settings; people living in supported or semi-independent living and people residing in fully staffed group homes; and outcomes achieved by people living in clustered versus dispersed housing. Generally, these studies do not specifically address the impact of residential size on outcome achievement.

Studies that compare outcomes among people living in settings of differing size report that people living in HCB settings experienced greater control over the decisions that affect their lives; more choice of where to live, and with whom to live; and more choice of the staff who worked with them than did people residing in ICF/IIDs. While people living in HCB settings evidenced greater choice generally, the data show that one-third (33.8 percent) reported not having choice in the selection of direct support staff.<sup>105</sup> In another study addressing personal control, Stancliffe and colleagues found that individuals supported by semi-independent living exercised more personal control than did those living in HCB services, which in turn enjoyed more personal control than ICF/IID residents.<sup>106</sup>

In semi-independent living the atmosphere was more conducive to individualization and consumer and staff autonomy; staff members were more skilled, but provided fewer hours of support per resident, and residents had more money for discretionary spending.” Overall, they conclude: “This study points to the poorer outcomes and likely need for reform of traditional community living services, notably those funded under the ICF program.<sup>107</sup>

In a related study Stancliffe (2011) reported that residents of institutions, nursing facilities, and group homes had little choice irrespective of their level of disability. Also, people with severe disabilities had little choice irrespective of their residence type.<sup>108</sup>

Gardner and Carran studied outcomes through personal outcome interviews with people living in a variety of settings, including supervised living, supported living, independent living, and natural and foster families.<sup>109</sup> Overall, people in ICF/IIDs achieved poorer than people did individuals in HCBS or state-funded service. The differences were statistically significant. People in independent living had greater personal outcomes than did people in other settings; outcomes were higher for people in supported living than for those residing with natural and foster families. In supervised living the outcomes were lower than in the other settings. All of the differences were statistically significant.<sup>110</sup>

In another study investigating differences in community setting across a wide variety of dimensions, David Felce *et al.* conducted an in-depth comparison of semi-independent living and fully staffed group homes in England and Wales.<sup>111</sup> All of the settings were for four or fewer residents. The researchers reported that:

- Group size was greater in fully staffed homes than in semi-independent living;
- Fully staffed homes and semi-independent settings were similar with respect to implementation of procedures for individual planning, staff training and supervision, and planning for staff support;
- Procedures for behavioral assessment and implementing teaching programs and for planning service user activities were more common in fully staffed settings;

- Compared to fully staffed settings, people in semi-independent settings had greater money management problems, had poorer health care related to lifestyle threats, and undertook a lower variety of community activities;
- People in semi-independent living took part in more community activities independently, were more likely to have people other than family and staff in their social networks, participated more in domestic household activities, and exercised greater choice; and
- Total costs of care were almost three times less in semi-independent living than in group homes.<sup>112</sup>

Felce and his colleagues concluded that:

In terms of current policy goals, independence, choice, and social inclusion, semi-independent living was either superior to or similar to fully staffed, suggesting that a conclusion of cost effectiveness might be reached in its favor. Semi-independent living seems to offer certain lifestyle advantages, at lower cost, namely greater self-determination and independence of activity in the community. Indicators of inclusion were no better in semi-independent living than in fully staffed homes. Discovering how to organize and deliver support so that it results in increased social inclusion remains an important research and service development objective.<sup>113</sup>

Similarly, in a study based in Australia, researchers studied outcomes in matched pairs of people with IDD living in group homes and in semi-independent living. On 22 outcomes, the two groups did not differ significantly; however, on five outcomes there were significant differences that favored semi-independent living. Individual resident interviews show that semi-independent living settings had better outcomes than group homes for social satisfaction and empowerment. Based on staff interviews, semi-independent living settings have better outcomes for frequency of use of community places, number of community places used without staff support, and participation in domestic tasks.<sup>114</sup>

In relation to personal control and self-determination skills, Stancliffe and colleagues reported that people living in semi-independent living have higher outcomes than those in ICFs. However, in a study of satisfaction some years later, Stancliffe and colleagues found few significant differences between HCBS and ICF. The same authors suggested that “this finding may reflect the fact that some HCBS congregate services are, like ICFs, neither individualized nor flexible.”<sup>115</sup>

In 2009, Mansell and Beadle-Brown reviewed literature related to dispersed housing versus clustered housing. At that time, they found no U.S. studies related to this topic. Based on review of 19 studies in other countries, they concluded that dispersed housing appeared to offer advantages over clustered housing on the majority of quality indicators used in the study. Further, the authors reported finding no evidence that clustered housing alternatives were able to furnish the quality of life that was provided by dispersed housing at a lower cost.

Finally, a study of people who owned their own homes versus those who did not found that homeowners had more control over their residence (e.g., having a key, making house rules, privacy), and had more independence (e.g., choosing support staff, what they do during the day, choice of friends, how money is spent).<sup>116</sup>

Mental Health Disabilities. Similar to the review for residence size, the literature search identified no studies that explicitly tested the effect of different types of residence on outcomes for individuals with mental health disabilities (i.e., by comparing the same programs with only residential type differing between the programs). Such a design would have allowed for a direct assessment of the effects of residential type. However, there were a number of studies which compared outcomes between those in one type of residence to those of another, though often the interventions or services offered varied between the different residence types as well. This means that any differences between the programs may have been due to the residence type, but also possibly could have been due to other differences between the programs. Some of the studies reviewed for residence size could also be viewed as addressing residence type, as there is often a strong relationship between the type of residence and size of residence.

For example, in most cases independent apartment/individualized residence sizes correspond to a dispersed or scattered site residence type, while most of the larger residence size or congregate housing corresponds to what might be called a community institution housing type or residential treatment. Consequently, the conclusions and themes identified within the literature for residence type largely mirror those for residence size.

Other studies support the conclusion that a more dispersed housing type is associated with a longer housing tenure in comparison to those in more residential treatment-type settings,<sup>117</sup> as well as resulting in improved service outcomes.<sup>118</sup> Similarly, other researchers found that receipt of a rental subsidy or Section 8 Housing Choice Voucher,<sup>119</sup> more common with dispersed or scattered residence types, was significantly associated with housing tenure for 655 Veteran's Administration survey respondents.<sup>120</sup>

Some of the studies conducted in the U.S. suggest that community integration involves more than just living in small homes dispersed throughout the community.<sup>121</sup> A study of community integration among 124 individuals in dispersed housing types,<sup>122</sup> compared people with mental health disabilities to people living in similar residence types without mental health disabilities. Not surprisingly, the individuals in the supported housing program had less community integration than other community members, but the differences were small and attributed to length of time in community, not to psychiatric diagnoses.<sup>123</sup> Similarly, Tsai, Bond, Salyers, Godfrey, and Davis conducted a qualitative study of 40 individuals in either independent housing (apartments, majority dispersed) or more supervised, congregate settings.<sup>124</sup> Most of the clients residing in apartments either interacted only with other clients who were also living there or kept to themselves, while nearly all of the individuals in supervised housing reported a sense of community among the other tenants. As with residence size, such findings indicate that programs emphasizing dispersed or scattered site housing might also consider emphasizing activities or strategies that promote interaction within the community. In turn, such



interaction might help individuals feel they belong and are a part of the larger community.<sup>125</sup>

Studies conducted outside of the U.S., though fewer in number,<sup>126</sup> appeared to support the use of more dispersed residential alternatives.<sup>127</sup> In addition to studies previously reviewed, Lambert, Ricci, Harris, and Dean compared results of a survey of the housing needs of 101 people with mental illnesses. Comparisons of data from participants treated by the Central Western Area Mental Health Service with data from the 1994 Australian Housing Study show that individuals with mental illnesses want housing similar to Australians in general (independent homes, home ownership), and individuals' satisfaction with their housing environments provided support for housing integrated into the community as opposed to institutional settings.<sup>128</sup> Another study, conducted in the UK, compared outcomes for 37 women in either "step down" community housing or a psychiatric institution and found that those in the program that was less institutional had better psychological well-being and fewer security needs.<sup>129</sup> Taken as a whole, these studies provide strong evidence that more dispersed and less institutional residence types are associated with better outcomes outside of the U.S. as well.

A couple of studies conducted in the Netherlands<sup>130</sup> and Vancouver British Columbia<sup>131</sup> also examined sense of community, belonging, and social inclusion, though again the findings appeared to differ from those in the US. These studies found a relationship between more community integration and what could be considered programs using more dispersed residential types in comparison to programs using more residential congregate types. However, one study showed similar findings to the US: Weiner and colleagues<sup>132</sup> compared 97 individuals in Israel living in either scattered independent supportive housing or in group residences. They did not find any differences between the two groups in degree of loneliness, quality of life (QOL), or psychiatric symptoms, but that residents of the group homes had more social support.<sup>133</sup>

## **Organizational and Environmental Issues**

Intellectual and Developmental Disabilities. A few researchers have gone beyond only size and type, to focus on specific organizational and environmental variables that may have an impact on outcomes. For example, in a study of environmental variables, in particular, autonomy and control, Stancliffe and colleagues reported that most environmental variables differed significantly by size of setting, with one-person homes the most favorable and four-person the least. Additionally, the environmental variables differed significantly by type of residence, with more favorable scores for semi-independent settings and lower scores for ICFs. Heller and colleagues concluded that specific features of the environment could influence well-being. These include: opportunities to make choices, the physical attractiveness of the setting, and the extent of family involvement.<sup>134</sup> In a study based in Wales, Perry and Felce found that environmental/organizational variables such as staff performance, working methods, and the internal organization of the setting are important to outcomes. However, they did not find size to have any significant influence on outcome (within a study of small homes, with one to five residents).<sup>135</sup> Finally, Gardner and Carran focused on organizational size, and found the best outcomes were achieved by individuals in mid-size organizations, versus those in very large or very small organizations. There is need for much further study that focuses on specific aspects of residential settings, in order to more fully understand what makes a difference in terms of outcomes.<sup>136</sup>

Mental Health Disabilities. A handful of studies identified during the course of the literature search discussed environmental factors related to housing for individuals with psychiatric disabilities. Overall, the literature indicates that both apartment-level and neighborhood-level environmental factors are of importance, though studies testing the impact of these factors on outcomes were largely lacking.

In the U.S., a couple of studies explored apartment-level environmental factors. Lipton and colleagues looked at the relationship between intensity of housing type and tenure, and found that, for those in the low-intensity housing type (more independent), tenure was longer in settings in which studio floor plans predominated.<sup>137</sup> In their qualitative

study referenced earlier, Tsai and colleagues found that clients in both independent and supervised housing favored having their own space and keys, their own bathroom, and a kitchen for cooking. Compared to those in supervised housing, more of those in independent apartments described having privacy in their settings. Overall, all of these apartment-level factors are largely found in smaller, more independent housing settings.<sup>138</sup>

Additional studies in the U.S. focused more on neighborhood-level environmental factors. Wright and Kloos examined the effects of perceived housing environment on well-being outcomes for 249 individuals in a supported housing program. They found that ratings of the physical quality of the apartment were significantly associated with well-being outcomes such as recovery and housing satisfaction—though not as strongly as with neighborhood-level ratings. Neighborhood-level ratings consisted of evaluations of both the physical quality of the neighborhood and the social environment, and self-reported ratings of the social and interpersonal relationships at the neighborhood-level (the sense of community) was consistently the strongest single predictor variable regardless of the outcome examined.<sup>139</sup> Following up on these findings, Townley and Kloos sought to explain the factors associated with sense of community by exploring unique factors related to serious mental illnesses and neighborhood experiences among 402 individuals using supported housing and mental health services. They reported that neighbor relations, neighborhood satisfaction, housing type, and community tolerance for mental illnesses all significantly predicted sense of community, with congregate housing type also significantly predicting sense of community, as discussed earlier.<sup>140</sup>

### **Service Setting Costs**

Intellectual and Developmental Disabilities. Numerous studies have focused on the relationship between costs of care, outcomes, and quality of life but they generally address type of setting rather than size. Felce and colleagues, for example, found that costs are three times less in semi-independent settings as compared to fully staffed group residential alternatives.<sup>141</sup> Robertson and colleagues concluded that non-congregate supports may be more cost effective. They state: “The main argument in

support of congregate services is more efficient use of resources; however, at least one-third of participants had no written treatment program; specialist expertise in congregate facilities appears to be restricted to use of medications and use of physical restraint. Congregate settings have higher staffing ratios and better quality internal working practices for person-centered planning, assessment, and teaching, activity planning, and staff support for residents. However, these inputs do not appear to translate into improved outcomes (emphasis added).<sup>142</sup> Finally, in a study based in Australia, Stancliffe and Keane documented that staffing costs and total costs were both significantly higher for group homes. They conclude that the very large cost and staffing differences between group homes and semi-independent living suggest that participants' accommodation services were not needs based, given that support needs did not differ significantly by group.<sup>143</sup>

Mental Health Disabilities. A limited number of studies were identified that addressed costs for housing programs for individuals with mental health disabilities. However, those studies appear to indicate positive cost outcomes associated with the provision of supported housing, which typically consists of smaller, independent housing versus traditional housing approaches, which rely more on larger, congregate-type settings. Stefancic and Tsemberis studied 260 individuals in either a Housing First program using independent housing or in a control group largely housed in congregate settings.<sup>144</sup> In addition to finding more individuals housed in the Housing First program, the researchers also calculated costs of \$20,410 per client per year compared to a range of \$24,269 to \$43,530 per client per year for shelter reimbursement. This indicates a sizeable costs savings for programs utilizing more individualized housing approaches.<sup>145</sup> Likewise, in a comparison of Housing First programs to Treatment First programs, Gulcer and colleagues noted that there was a significant effect of program assignment on costs with the control group costing significantly more than the experimental group overall.<sup>146</sup> Finally, Chalmers-McLaughlin was able to map the service usage of 268 homeless individuals in costs categories such as: mental health care, substance abuse treatment, community support, prescription drugs, ambulance calls, police contact, jail night stays, housing costs, shelter night stays, hospital

emergency room visits, and public transportation. They compared the costs for those that received supported housing services to the costs for those that did not. Not only were costs savings observed in eight of 11 service categories, but even with the costs of housing accounted for (such as costs of rental supports), the total savings to the system was \$584,907 after 12 months in housing.<sup>147</sup> This represented an average savings of \$2,182 per participant, which, while smaller than that found by the Stefancic and Tsemberis study discussed above,<sup>148</sup> still represents a significant cost advantage favoring programs utilizing a supported, individualized approach.

There was only a single study identified outside of the U.S. that examined costs. Siskind and colleagues studied 252 individuals in Australia in either a Transitional Housing program or in a control group, and calculated the number of bed-days averted by each group. They found that the housing program cost less per participant (\$14,024) than the bed-days averted (\$17,348) in Australian dollars, representing a cost savings per participant in the same general ballpark as costs observed in the U.S. focused studies.<sup>149</sup> Taken together, these studies indicate that there may be significant cost savings associated with the use of smaller, more individualized supported housing programs compared to traditional housing programs.

## **Staffing**

Intellectual and Developmental Disabilities. Few studies have focused on the relationship between the role of staff and the achievement of outcomes among people receiving support. The studies that have examined this issue have not placed any particular emphasis on setting size,<sup>150</sup> or have reported that the staff ratio was not significantly related to outcomes.<sup>151</sup> In a study of loneliness in residential settings, Stancliffe and colleagues found that the amount of paid support was not significantly related to loneliness. The authors suggested that, rather than the number of staff, it may be what staff do while present that can have an impact on loneliness.<sup>152</sup> Other research has concluded that people living with only partial staff support appear to conduct their lives more independently than do people living with constant staff support—suggesting that the presence of staff may actually inhibit the expression of their independence.<sup>153</sup>

Mental Health Disabilities. A number of studies involving people with mental health disabilities examined differences in staffing intensity, availability of different types of staff for support, and degree of staff integration. Results of studies examining differences related to staffing were somewhat mixed overall, with some showing better outcomes and some not, though the range of outcomes examined varied significantly. This pattern of mixed results was the same in both the U.S. and in international studies, suggesting that this topic may be a particularly rich area for future study. The research should focus on sorting out which outcomes are seemingly affected and what staffing characteristics and patterns seem to contribute most to those outcomes.

In the area of intensity of staffing for people with psychiatric disabilities, Lipton and colleagues followed clients in housing settings of varying intensity (structure and amount of independence).<sup>154</sup> Individuals placed in the high-intensity settings accounted for most of the increased hazard of becoming discontinuously housed during the first 120 days after placement. Assuming that the more structured settings relied on more staff to provide the monitoring and structure, this finding indicates that more independence from staff may be associated with better outcomes within supported housing programs.<sup>155</sup> Similarly, Yanos and colleagues compared the responses of people with mental health needs in independent apartments to those of people in staffed apartments, and found that people in the apartments without staff frequently indicated feelings of increased privacy, independence, and freedom to pursue interests.<sup>156</sup> On the other hand, in their study of veterans in supported housing described earlier, Mares and colleagues found that more intensive case management was associated with a greater likelihood of successful completion of treatment and with being independently housed upon leaving the program.<sup>157</sup> Burt similarly reported a positive effect of staffing intensity in her study of 471 individuals enrolled in a high- or regular-intensity homelessness and employment support program. She found that individuals in the high-intensity program did significantly better than the regular-intensity participants for all housing and employment outcomes.<sup>158</sup>

Other studies conducted in the U.S. focused on differences in program access or the availability of various types of staff as part of the interventions tested. For example, Clark and Rich compared outcomes for 152 individuals receiving either a comprehensive housing program (housing, housing support services, and case management) or a second program that consisted of case management only. They found that that better housing outcomes were achieved by people in the program with access to more staff, but only for individuals with a high amount of psychiatric symptoms and substance abuse, with no differences between the programs for other clients.<sup>159</sup> Nath and colleagues classified 252 individuals receiving supported housing into four different groups—by frequency and mix of contacts—and examined the use of physical health services, finding that individuals receiving case management coupled with weekly contact with residential support services visited a general health practitioner more frequently than people with access to less support staff.<sup>160</sup>

One study examined the effect of degree of staff integration. McHugo and colleagues in 2004 randomly assigned 121 individuals to either an integrated housing program, where case management and housing services were provided by the same agency and closely coordinated, or to a parallel housing program, where case management was provided by mobile ACT teams and housing services were provided by community landlords. They found that both programs reduced homelessness and increased time in stable housing, and that both groups improved symptoms, general life satisfaction, and experience of interpersonal violence/victimization, drug and alcohol use.<sup>161</sup>

Results related to staffing variation outside of the U.S. also were mixed. As noted earlier, Barr and colleagues compared individuals in a community-based step down program—with less staffing and more independence—to individuals remaining in an institution in the UK and found improved outcomes for individuals in the program that made use of less intensive staffing.<sup>162</sup> On the other hand, Grant and Westhues, in their 2010 study of 27 individuals, found no significant differences between people in a high-support housing program compared to people in a low-support housing program in Canada after a correction for the number of statistical tests used was made.<sup>163</sup>

## Level of Disability

Intellectual and Developmental Disabilities. Level of disability also has a powerful influence on outcomes, and a number of studies<sup>164</sup> have documented that individuals with severe/profound intellectual disability had significantly lower outcomes.<sup>165</sup> In addition, multiple studies based on the NCI data have consistently found level of intellectual disability to be a significant predictor of outcomes for people with IDD, including different types of choice.<sup>166</sup> In these studies, level of intellectual disability was significantly related to residential size.

In their 2011 study, Stancliffe and colleagues found a strong and significant relationship between choice of where to live and with whom to live and level of intellectual disability. Overall, they found that people with severe disabilities are “far more likely to live in congregate settings.”<sup>167</sup>

Kim and Dymond (2012) found that people with severe disabilities tend to live in more restrictive and traditional living arrangements; thus, they assert that the full spectrum of supported living services is not available for people with severe disabilities.<sup>168</sup>

In two other studies, Lakin<sup>169</sup> and Tichá<sup>170</sup> found that level of intellectual disability is a significant predictor of everyday and support-related choice that interacts with the type and size of residential setting. People with more severe disabilities tended to have fewer opportunities to make both types of choice. For a person with a profound intellectual disability, there were no significant differences found for making support-related choice in any of the settings—apart from living in an agency with four to six people where the opportunities are much worse. For people with severe intellectual disabilities, the results suggest that there is not a significant difference in everyday choice between any of the settings except for living in an institution, where everyday choice-making opportunities are worse. For people with profound ID, the settings most conducive to making everyday choices are: living with host family, living on their own, and living in a small or medium-size agency; and the setting least conducive to making everyday choices is living in an institution.



Mental Health Disabilities. In a sense, the rise of supported housing models is a repudiation of the idea that level of impairment or disability influences housing outcomes. For example, one of the key defining features of the Housing First model is that housing is provided first, separating clinical and treatment issues from the provision of housing. As noted earlier, the weight of the evidence strongly supports such approaches.<sup>171</sup> Still, our search identified a limited number of studies conducted in the U.S. that addressed level of disability among participants living with mental illnesses.

Researchers Clark and Rich conducted a subgroup analysis that used propensity scoring methods to classify individuals into high-, medium-, and low-impairment groups on the basis of psychiatric symptoms and degree of alcohol and illegal drug use.<sup>172</sup> They found that better housing outcomes were achieved for people in the high-impairment subgroup in the more comprehensive housing program than with just case management alone, however no differences were found between programs for the other subgroups.<sup>173</sup> Schutt and Goldfinger studied 118 individuals in either supported housing or in group home settings, and found that functional ability (as measured with the Life Skills Profile) did not influence what were posited to be the fundamental causes of housing loss, but did have an independent effect on housing retention.<sup>174</sup> Mares and colleagues<sup>175</sup> did not explicitly test level of disability, but examined whether the receipt of residential treatment in the six months prior to program entry influenced outcomes for veterans placed into supported housing and found that it did not. In the traditional continuum of care, residential treatment is usually recommended for people experiencing the most severe impacts on functioning, meaning that receipt of residential care could be viewed as a sort of proxy for level of disability.<sup>176</sup>

There was a single study identified during our literature review that addressed level of disability outside of the U.S. Patterson and colleagues stratified their 497 participants by level of need (either “high” or “moderate”) before random assignment, but did not note any differences in findings based on level of need. They found that outcomes improved for both the groups receiving supported housing compared to those receiving treatment as usual.<sup>177</sup>

In summary, though the amount of literature reviewed was limited, it does not appear that level of disability is consistently related to outcomes for individuals with mental health disabilities in housing programs, as studies of outcomes for supported housing models such as Housing First<sup>178</sup> would suggest.

## **State Variation**

Intellectual and Developmental Disabilities. Some of the U.S. studies that were included in the review of literature reveal significant differences in outcomes by state. For example, Lakin and colleagues found significant differences in choice by state.<sup>179</sup> Similarly, Tichá and colleagues reported that “the state in which people lived was notably predictive of support-related choice.”<sup>180</sup> Thus, the researchers conclude:

...although personal and environmental factors were substantially associated with opportunities to exercise choice, the culture, expectations, resources, and available accommodation options established within individual state IDD service systems have significant effect on the extent to which people are actually afforded significant say in the decisions that affect their lives.<sup>181</sup>

Stancliffe and Lakin reported important differences by state in consumer outcomes and ethnic status.<sup>182</sup> Data from the NCI surveys reveal significant state variation in self-direction (e.g., ranging from 12.5 percent in Ohio to zero percent in Indiana and Oklahoma). It seems that further study of state policies and practices in relation to outcomes is warranted. These findings with regard to state variation also support the value of establishing and maintaining national data sets.

Mental Health Disabilities. There were no studies identified that addressed variation in state service delivery systems, financing, statewide outcomes, or the like.

## **Summary of Research Findings**

The research findings and conclusions included in this report paint a clear picture of the benefits people with intellectual, developmental, and mental health disabilities derive from living in community settings that are: (1) small and family-scale (supporting one to three individuals) and (2) integrated into the mainstream of society (facilitating access to friends and families, employment in typical businesses, and participation in local affairs and activities).

Individual and support-related outcomes are maximized when people have a home of their own, along with the appropriate assistance to design the supports they need and to determine the roles that support providers will play in their lives. The research data show that size and configuration of settings within which services are delivered/made available to the person can have a pervasive impact on:

- the outcomes the person is able to achieve; and
- the extent to which he or she is able to fully access and take advantage of the benefits of community living.

Small, personalized, settings increase opportunities for personal satisfaction, choice, self-determination, community participation, and feelings of well-being. Small settings are similarly associated with decreases in (1) the use of services, (2) feelings of loneliness, and (3) service-related personnel and other costs. These findings have major implications for both state and federal policymakers as they develop and implement new services to respond to new federal regulations and existing ADA requirements.

## **IV. POLICY AND PRACTICE**

The research is compelling, with the strong and collective evidence, that smaller settings provide the greatest opportunities for positive individual outcomes. Policymakers must consider additional programmatic, financial, operational, and political

variables in their determination of the structures, policies, and practices that will further opportunities for meaningful community integration of individuals with disabilities. Still, the law of the land, federal policy, and the perspectives of individuals most directly impacted by such policies must all take preeminence in decisions regarding services and supports for individuals with disabilities.

## **Civil Rights**

Living in the community with family and friends, working at a typical job in a regular business, and participating in community affairs is a right of citizenship, not a privilege, for individuals with disabilities, as for all Americans. This right was confirmed with the passage of the Americans with Disabilities Act in 1990, affirmed with the 1999 Supreme Court's *Olmstead* decision, and repeatedly reaffirmed in the years since that landmark decision. Court decisions, settlement agreements, and consent decrees are all actions that have directly impacted state system design of HCBS to ensure that individuals with disabilities have access to quality services in the community.

Indeed, the law itself recognized and sought to address the long entrenched systems that have perpetuated barriers to full community integration, as writer Sam Bagenstos notes:

Importantly, the statute takes the concept of forbidden discrimination beyond intentional and overt exclusion; it also treats as discrimination the failure to provide 'reasonable accommodations' to people with disabilities. In a single legislative act, Congress recognized that society's institutions and structures have been designed without people with disabilities in mind, and that justice requires society to make changes today to include them fully in the life of the community.<sup>183</sup>

Similarly, Chas Moseley aptly states, in his 2013 paper related to *Olmstead* and Medicaid, that:

[a]lthough service delivery approaches have changed, reflecting a greater emphasis on integrated community-based services, federal funding mechanisms and states' systems of support for people with disabilities have continued to be anchored in traditional service models that result in unnecessary segregation of individuals with disabilities and their exclusion from society. The passage of the ADA and the *Olmstead* ruling recognizes in law the obsolescence of traditional non-integrated approaches and provides a broad system change framework for public entities to follow to improve service delivery and the lives of people receiving supports and carry out Congress' [integration mandate].<sup>184</sup>

DOJ has repeatedly and successfully put forth the expectation that state systems providing services to individuals with disabilities make available opportunity for meaningful community engagement, in all aspects of life. In fact, in a 2010 letter<sup>185</sup> of findings to the Commonwealth of Virginia, DOJ notes that "*Olmstead* therefore makes clear that the aim of the integration mandate is to eliminate unnecessary institutionalization and enable individuals with disabilities to participate in all aspects of community life."<sup>186</sup> Similarly, the State of Delaware and DOJ agreed in the 2011 settlement agreement in *United States v. Delaware* that

...the ADA, the Rehabilitation Act, and implementing regulations at 28 C.F.R. Part 35, and 45 C.F.R. Part 84 ("Section 504"), [which] require, among other provisions, that, to the extent the State offers services to individuals with disabilities, such services shall be provided in the most integrated setting appropriate to meet their needs. Accordingly, throughout this document, the Parties intend that the principles of self-determination and choice are honored and that the goals of community integration, appropriate planning, and services to support individuals at risk of institutionalization are achieved.<sup>187</sup>

As illustrated in case after case, individuals with disabilities have the unequivocal civil right to live, work, and develop relationships with people in the community. This right is most commonly realized when the supports available enhance, not hinder, such engagement. States that are aggressively working to redesign their service delivery

system to comply with the law and to ensure their citizens' civil rights are offering models of services in small, individualized settings, dispersed throughout communities.

## **Federal Regulatory and Policy Environment**

As the case law has increasingly and consistently established the obligations of states to ensure that HCBS are delivered in a manner to support community integration, so too have Federal policies been evolving. Beginning soon after the *Olmstead* decision, HHS/CMS —then called the Health Care Financing Administration—began publishing a series of technical guidance letters<sup>188</sup> in January 2000 to State Medicaid Directors to encourage proliferation of HCBS nationally. Those HHS/CMS letters, known collectively as the “*Olmstead* Letters,” provided advice on strategies for designing individualized services for individuals with disabilities to enable them to remain in or return to their communities, consistent with Medicaid requirements. As noted in *Olmstead* Letter #2:

...the *Olmstead* decision challenges States to prevent and correct inappropriate institutionalization of [people] with disabilities and to review intake and admissions processes to assure that [people] with disabilities are served in the most integrated setting appropriate.<sup>189</sup>

Similar federal policy efforts have continued in the ensuing time, culminating in the 2014 publication of the final rule for HCBS. The regulations define expectations for settings in which HCBS and supports are delivered, requiring optimal community integration for individuals served through those programs. As the preamble declares:

A state's obligations under the ADA and section 504 of the Rehabilitation Act are not defined by, or limited to, the services provided under the State's Medicaid program. However, the Medicaid program can support compliance with the ADA, section 504 of the Rehabilitation Act, and *Olmstead* through the provision of Medicaid services to Medicaid-eligible individuals in integrated settings.<sup>190</sup>

To recap, the requirements of this final rule include expectations of conflict-free case management, person-centered approaches to planning and service delivery, and they also provide important guidelines related to the settings in which federally funded HCBS services can be delivered. These regulations recognize the importance of the service delivery setting and its characteristics in ensuring the optimization of community engagement for individuals with disabilities.<sup>191</sup>

In addition to the evolution of Medicaid policy related to community integration for individuals with disabilities, there is a growing Federal recognition that the responsibility for optimizing opportunities for community engagement lies not just with Medicaid. In fact, Section 2402(a) of the Affordable Care Act requires, among other provisions, that the Secretary of Health and Human Services promulgate regulations to ensure that state systems “provide the support and coordination needed for a beneficiary in need of such services (and their family caregivers or representative, if applicable) to design an individualized, self-directed, community-supported life.”<sup>192</sup>

This provision spans beyond Medicaid, recognizing the need for states to provide supports to take into consideration how such systems will enable individuals to live, work, and love in their homes and communities.

These federal policies reflect both the civil rights of individuals with disabilities and the opinions of individuals, families, and advocates, from across the nation, regarding the manner in which supports should be made available. As noted NCD’s 2008 publication, [f]or the promise of full integration into the community to become a reality, people with disabilities need safe and affordable housing; access to transportation; access to the political process; and the right to enjoy whatever services, programs, and activities are offered to all members of the community by both public and private entities.<sup>193</sup>

## Self-Advocacy as a System Driver

Throughout the past twenty-five years, the voices most critical to the civil rights and public policy considerations have been those of the individuals most directly impacted by the service delivery system. In fact, the *Olmstead* decision is the prime example of the power of self-advocacy, as two women, Lois Curtis and Elaine Wilson, through self-advocating, have changed the lives of individuals nationally and impacted the manner in which systems support individuals with disabilities.

Individuals with disabilities have been instrumental to the shaping of federal policy, particularly around Medicaid. Developed at a summit of leaders from the Autistic Self Advocacy Network, the National Youth Leadership Network, Self-Advocates Becoming Empowered, and allies, the publication *Keeping the Promise* sought to provide HHS/CMS with a definition of "community" that captures the most vital elements of community life. This publication provided self-advocate perspectives on policy issues in the areas of housing, education, employment, and transportation.<sup>194</sup> Elements of the paper clearly are evident in the final regulations, highlighting the prominent voice that individuals with disabilities can have in shaping public policy and service delivery systems.

*Keeping the Promise* included a number of critical policy guidelines for HHS/CMS consideration. These recommendations are essential for state policy makers as well. Among the guidelines were the following, highlighting the importance of supports and services being offered in settings of individuals' choice, dispersed throughout the community, in sizes where choice and control are optimized:

Large Size: A large congregate care facility is not a home in the community. If a half dozen or more people live in a provider-owned group home, it is almost never controlled by the people who live there;

- Policy Guideline: A home should not be considered "in the community" if more than four unrelated people live there;



- Policy Guideline: We should live in apartments, houses, condominiums, trailers, etc. located in rural, urban, or suburban communities with typical public resources such as shops, houses of worship, places to work, and accessible transportation systems. We have the right to live in a safe community among people with and without disabilities.<sup>195</sup>

No choices: When we have no or limited choices. People make decisions for us and limiting choices about where to live, food, clothing, health care, and spending money.

- Policy Guideline: We must have a right to privacy. We must be able to have time to ourselves and have a private space with a door that can be locked against intrusion by staff or housemates.
- Policy Guideline: We must have rights of freedom of mobility, choice, and association. Staff cannot set rules about: a) where we go and when, b) when and what we eat or drink, and c) who may be invited into our home and at what time.<sup>196</sup>

## V. SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Based on the literature review, there are several key findings:

1. Overwhelmingly, research demonstrates that people attain better outcomes when they live in smaller community-based settings that promote control and choice. A relatively small number of studies compare outcomes across different sizes of settings. Based on the studies that do exist, however, it is clear that small size alone is insufficient to ensure that people receiving support are able to achieve good outcomes.
2. Program and funding models alone are insufficient to ensure that positive personal outcomes are achieved. While HCBS service approaches are flexible and can be

tailored to the specific needs of each person, few research studies specifically identify the qualities or features of small settings that reliably promote good outcomes. A significant need exists for further research that seeks to identify key funding and support variables that are associated with positive individual, organizational and systems outcomes across settings.

3. Health outcomes are not always better in small, community-based settings, though this is typically outweighed by improvements in choice, control, safety, and quality of life. This suggests a need, however, to explore ways to promote better outcomes within community settings.
4. Outcomes with regard to choice and control have been found to be better in smaller, community-based settings. At the same time, it has also been found that even in these smaller, community-based settings, a relatively small proportion of people have significant choice and control, particularly with regard to major life decisions (e.g., where and with whom to live).
5. The outcomes achieved by individuals in community settings are highly related to their levels of disability. Although research demonstrates that people with the most severe disabilities make significant improvements in small settings, they are more likely to be placed in larger groups. Policies should promote equal access and opportunities for community living, choice, and individual control among all people with disabilities receiving services, including individuals with the most intensive support needs.
6. There is significant state-to-state variation in outcomes across community settings. These findings point to the necessity of sharing state policies and practices that promote better outcomes in the community.

## **NCD's Recommendations for the Federal Government:**

1. Full Regulatory Implementation. HHS/CMS, through its regulation of Home and Community-Based Services (HCBS) and its review of state transition plans, should provide specific guidance to states regarding the requirement that services: (a) ensure full community integration, participation, and access; (b) facilitate equal access to employment, community activities, and the benefits of community living; and (c) be delivered in typical individual and family-scale settings of three or fewer individuals. Such oversight will establish federal expectation that HCBS must be individualized, person-centered, and self-directed.
2. Promising Practices. HHS/CMS and the Administration for Community Living, should identify, for state and federal policymakers, promising HCBS models, approaches, and operational strategies with evidence documenting: (a) the optimization of personal and support outcomes; (b) consistency with the ADA integration mandate and related legal precedent; and (c) acceptance by individuals receiving support, by self-advocates, and by advocacy groups of these models, approaches, and strategies as appropriate as examples of best or preferred practice.
3. Tool Identification. HHS/CMS should provide technical guidance to states on policy development, service design, operational methods, and financial and payment strategies—to assist in replicating promising practices and to support models with evidence of effectiveness and regulatory compliance.
4. Outcome Assessment. HHS/CMS and other HHS funding entities should require states to regularly assess and report on the personal and support-related outcomes, which individuals with disabilities achieve through publicly supported home and community services, with the use of standardized, population-based, valid, and reliable assessment tools such as the National Core Indicators.
5. Ongoing Enforcement. HHS/CMS should ensure that states are fully implementing the provisions of the final HCBS regulations through the review and approval of state

plans and waiver applications, the review of required state reporting on adherence to their approved plans and application, and through on-going monitoring.

6. Defining and Measuring Support Quality. HHS/CMS should require states to develop and implement a quality management plan and a strategy that includes performance measures and outcomes – in order to assess personal experience and support quality at the individual and systems levels.

### **NCD's Recommendations for States:**

1. Limit Size of Residential Settings. Revise or restructure existing funding and support policies to limit the size of residential settings for people with disabilities to homes and living arrangements that are of individual and family scale, consumer controlled, and non-stigmatizing. Prohibit clustered or campus-style housing where people with disabilities are segregated from the rest of society. For people with mental health disabilities, as well as for people with physical disabilities, traumatic brain injury, sensory and other disabilities, expand access to independent apartments in integrated community settings with access to on-going support and follow up services as necessary to increase likelihood of positive individual choice, control, and outcomes.
2. Quality Measurement. Implement new or expand existing performance measurement, data collection, and management systems to document and track individual and system performance outcomes achieved by people with disabilities in housing of differing size and configuration.
3. Financial Alignment. Review current funding, resource allocation, and rate setting methodologies to align provider reimbursement practices with system goals and the new Medicaid HCBS regulations that support service delivery in the most integrated settings.

4. Stakeholder Engagement. Establish ongoing relationships with individuals receiving supports and their families, as well as with disability advocates, to gather input and advice on key policy and practice issues regarding the structure, operation, and funding of services and supports.
5. Provider Expectations. Ensure that the staff who support individuals with disabilities in community residential and other settings have received adequate training to provide effective services that lead to improved individual outcomes; boost provider qualifications, training, and oversight.
6. Develop Individual and Relationship-Based Service Alternatives. Expand opportunities for self-directed, consumer controlled living alternatives that furnish supports to people in their own homes, and for relationship-based living arrangements with families, friends, partners, or shared living.

## VI. APPENDICES

**Appendix A. Intellectual and Developmental Disabilities Studies:** The chart lists 44 total reports of studies (single and mega analyses) reviewed from research performed mostly in the United States (reports =27); others were in the United Kingdom (reports = 7), Wales (reports = 3), Australia (reports = 3), and the reports for United States & Ireland, Isreal, England & Wales were single instances). In four of the total 44 reports the number of study participants was “unknown.” The remaining studies in this portion of the review reported subject numbers ranging from n=10 to n= 12, 236.

Study	Themes/ Topics Addressed	Location (Country)	Brief Description	Number of Subjects or Study Participants	Target Population
1. Gardner & Carran, 2005	Personal outcomes, residential type	United States	Independent living had a significantly greater percentage of outcomes than other arrangements (natural family, foster family, supported living, supervised living). Supervised living was significantly lower than the others. In general, comparisons indicate a lower level of outcome attainment in larger settings than in moderate-sized settings.	3,630	Intellectual and Developmental Disabilities (IDD)
2. Kim & Dymond, 2012	Community participation, level of assistance, and type of residence	United States	Residents with severe disabilities who lived in supported apartments showed more independence in performing domestic, safety skills, more participation in community activities compared with people in group homes. Regardless of residence type, individuals with severe disabilities do not engage frequently in most community activities. People who need more assistance tend to live in more restrictive and traditional living environments such as group homes.	280 residential specialists	IDD
3. Stancliffe, Abery, & Smith, 2000	Personal control and the ecology of community living settings	United States	Individuals supported by semi-independent living exercised more personal control than did those in HCBS waiver-funded supported living services, who, in turn, enjoyed more personal control than did community ICF residents.	74	IDD

<b>Study</b>	<b>Themes/ Topics Addressed</b>	<b>Location (Country)</b>	<b>Brief Description</b>	<b>Number of Subjects or Study Participants</b>	<b>Target Population</b>
4. Stancliffe, Hayden, Larson, & Lakin, 2002	Adaptive and challenging behaviors of post-institution adults	United States	Relative to institutional levels, adaptive behavior declined for those who moved to ICFs but was unchanged for those moving to HCBS. Higher adaptive behavior scores were for individuals with shorter periods of institutionalization, lived in smaller sized community residences, and experienced larger increase in community participation.	148	IDD
5. Stancliffe, Lakin, Taub, Chiri, & Byun, 2009	Satisfaction and sense of well-being, in ICF/IIDs and HCBS	United States	Self-reported satisfaction and sense of well- being. Loneliness was greatest problem. Few differences between HCBS and institutions. Findings document benefits of support provided in very small settings, with choices of where and with whom to live, and for people living with family.	1,885	IDD
6. Stancliffe, Lakin, Doljanac, Byun, Taub, & Chiri, 2007	Loneliness and living arrangements	United States	Self-reported loneliness in relation to residence size, social contact, personal characteristics, and social climate. Residents of larger settings (7-15 people) reported more loneliness. More social contact and liking where one lives were associated with less loneliness. Social climate variables (e.g., being afraid at home or in community) were strongly associated with greater loneliness.	1,002	IDD
7. Tichá, Lakin, Larson, Stancliffe, Taub, Engler, Bershady, & Moseley, 2012	Everyday choice and support-related choice based on National Core Indicators	United States	Among adults with intellectual and developmental disabilities across 19 states, people residing in settings of 16 or more had less everyday choice than people in other residential settings. People residing in their own homes had more support-related everyday choices. The individual's state of residence was notably predictive of the	8,892	IDD

Study	Themes/ Topics Addressed	Location (Country)	Brief Description	Number of Subjects or Study Participants	Target Population
8. Stancliffe, Lakin, Larson, Engler, Taub, & Fortune, 2011	Choice of living arrangements, based on National Core Indicators	United States	support-related choice. Individuals living in own home or agency- operated apartment were more likely to choose where and with whom to live than individuals in nursing homes, institutions, or group homes. However, few individuals with severe or profound intellectual disability chose where and with whom to live regardless of where they lived.	6,778	IDD
9. Lakin, Doljanac, Byun, Stancliffe, Taub, & Chiri, 2008	Choice-making among HCBS and ICF/IID residents, based on National Core Indicators	United States	Everyday choice in daily life and support- related choice was considerably higher on average for HCBS than ICF. But after controlling for level of disability, medical care needs, mobility, behavior and psychiatric conditions, and self-reporting, choice was more strongly associated with not living in congregate settings, whether HCBS or ICF. Marked difference in choice between states also.	2,398	IDD
10. Stancliffe, Lakin, Larson, Engler, Taub, Fortune, & Bershinsky, 2012	Demographic characteristics, health conditions, and residential service use	United States	Adults with Down syndrome were less likely to live in institutions or their own home, but more likely to live with a family member. A smaller percent of people with Down syndrome were overweight in institutions; a higher percentage in agency apartments, own home, and family homes (however authors state that this finding may be confounded by other variables).	1,199	Down syndrome and a comparative sample of people with IDD but not Down syndrome
11. Heller, Miller, & Hsieh, 2002	Impact of environmental characteristics on well-being	United States	Residents who moved to community-based settings had higher levels of adaptive behavior and community integration than those who remained in nursing homes. Facility size was not associated with resident	186	IDD



Study	Themes/ Topics Addressed	Location (Country)	Brief Description	Number of Subjects or Study Participants	Target Population
			outcomes. Facility type was no longer significant when specific environ features were included. Hence, it was not size or type of facility per se but specific aspects of smaller, community-based residences (e.g., opportunity for autonomy and physical attractiveness) that are likely associated with well-being.		
12. Woolf, Woolf, & Oakland, 2010	Adaptive behavior and relationship to community independence	United States	People living independently displayed the highest adaptive behavior, followed by those living in community, group, and residential treatment settings. The development of adaptive behavior is likely linked to greater autonomy at work and home.	272	IDD
13. Stancliffe & Lakin, 2006	Minority status and consumer outcomes	United States	Ethnic group membership had very limited or no association with consumer outcomes. Where significant ethnic group differences were found, they were small, and there was no consistent pattern of a particular ethnic group doing better.	4,591	IDD
14. Feinstein, Levine, Lemanowicz, Sedlak, Klein, & Hagner, 2006	Homeownership and outcomes	United States	Study compared homeowners with those who were waiting to purchase a home and others who had been unsuccessful in purchasing a home. In comparison to the other groups, homeowners had more choice and control of their residence and over their lives in general. Homeowners also reported more community participation, although this difference was not statistically significant.	129	IDD
15. Bershadsky, Taub, Engler, Moseley, Lakin, Stancliffe, Larson,	Place of residence and preventive health care,	United States	People living with their families, and (to a somewhat lesser degree) those living in their own homes, are consistently less likely to receive preventive health care.	11,569	IDD

<b>Study</b>	<b>Themes/ Topics Addressed</b>	<b>Location (Country)</b>	<b>Brief Description</b>	<b>Number of Subjects or Study Participants</b>	<b>Target Population</b>
Tichá, Bailey, & Bradley, 2012	based on National Core Indicators				
16. Stancliffe, Lakin, Larson, Engler, Bershadsky, Taub, Fortune, & Tichá, 2011	Overweight and obesity, from National Core Indicators	United States	Highest prevalence of obesity was individuals living in their own home and the lowest was among institutional residence. Both host/foster home and group home had significantly lower prevalence than agency apartment, own home, and family home. Family home was significantly lower than own home, and own home and agency apartment did not differ.	8,911	IDD
17. Neely-Barnes, Marcenko, & Weber, 2008	Choice and quality of life	United States	Smaller living arrangements are associated with experiencing more protection of rights. Both greater choice and smaller living arrangements are associated with increased quality of life. People with less severe intellectual disability lived in smaller settings. No association was found between choice and living arrangement.	224	Mild IDD
18. Hsieh, Heller, & Freels, 2009	Residential characteristics and mortality	United States	Homes with less than 15 residents had a higher mean of environmental diversity and community integration than homes with more than 15 residents. Findings indicated that higher environmental diversity and community integration were associated with lower mortality.	330	IDD
19. National Core Indicators (NCI) data brief, 2011	People with self-direction	United States	People who self-direct were more likely to live in their own home or a relative's home and less likely to live in a group home or an institution than people who were not self-directing.	10,722	IDD
20. Hartley,	Life of men and	United	Strongest predictor of outcomes in adult life	328	IDD

<b>Study</b>	<b>Themes/ Topics Addressed</b>	<b>Location (Country)</b>	<b>Brief Description</b>	<b>Number of Subjects or Study Participants</b>	<b>Target Population</b>
Seltzer, Raspa, Olmstead, Bishop, & Bailey, 2011	women with Fragile X syndrome	States	may be the presence of an autism spectrum disorder. Men and women living independently had higher functional skills and a smaller number of co-occurring mental health conditions than those in group homes. For women, there was also a significant difference by residential setting in education and ability to interact appropriately, with those living independently having more education and greater ability to interact. Socioeconomic status is not a critical factor in living arrangements.		
21. Bonham, Basehart, Schalock, Marchand, Kirchner, & Rumenap, 2004	Consumer-based QOL assessment	United States	Type of residential placement for those not living with family did not show any significant correlation with QOL. Transportation was a major factor related to QOL.	923	IDD
22. Nonnemacher & Bambara, 2011	Self-advocates' perspectives on their self-determination support needs	United States	Based on self-advocates' responses, congregate and family living settings posed the most restrictions to expression of self-determination. For example, staff members control often pre-empted opportunities to decide where to work and where to live and with whom, or control of their money.	10	IDD
23. Nord, Kang, Tichá, Hamre, Kay, & Moseley, 2014	Residential size and individual outcomes, across all National Core Indicators-related	United States	Across all outcome areas, smaller settings, on average, produce better quality of life outcomes. People living in their own homes, family homes, host family homes, or in small agency residences rank consistently better in achieving positive outcomes than those living in moderate and large agency residences and institutions. At the same time, variability	Unknown	IDD

<b>Study</b>	<b>Themes/ Topics Addressed</b>	<b>Location (Country)</b>	<b>Brief Description</b>	<b>Number of Subjects or Study Participants</b>	<b>Target Population</b>
	research		exists, particularly with regard to health outcomes.		
24 National Core Indicators, 2011-2012	Annual summary report	United States	Residence type: parents' or relative's home (33%), independent home or apartment (14%), community-based residence (37%), specialized facility (5%), other (11%). Only 7% were identified as using self-direction. Varied by state (from 0% to 18%). People living in parents' home were most likely to self-direct, followed by people living in own home. Many people reported not having input in major life decisions. People living with parents or in own homes were less likely to have received exams and health care tests than people living in community residences or institutions.	12,236	IDD
25. Head & Conroy, 2005	Outcomes of self-determination	United States	Participants in SD perceive themselves as having more choice, less professional domination and higher overall quality in their lives.	70	IDD
26. Bigby, C., Knox, M., Beadle-Brown, J., Clement, T., Mansell., J, 2012	Models of community living, importance of size and type	Australia	Small scale community living models are a necessary but insufficient condition for good quality of life outcomes. Evidence strongly indicates better quality of life outcomes in smaller settings and where ordinary housing is dispersed in the community rather than clustered. Advantages of models that separate the provision of housing from support services compared to linking them are less clear.		IDD
27. Mansell & Beadle-Brown, 2009	Dispersed or clustered housing for	United Kingdom	Review of 19 studies. Results show that dispersed housing is superior to cluster housing on the majority of quality indicators.	2,500	IDD

Study	Themes/ Topics Addressed	Location (Country)	Brief Description	Number of Subjects or Study Participants	Target Population
	adults with intellectual disabilities: a systematic review		Exception: village communities for people with less severe disability have some benefits. Cluster housing is usually less expensive than dispersed housing because it provides fewer staff hours per person. There is no evidence that cluster housing can deliver the same quality of life as dispersed housing at a lower cost.		
28. Tichá, Hewitt, Nord, & Larson, 2013	System and individual outcomes and their predictors	United States	Great disparities exist between states in the quantity and quality of community supports. Type of living arrangement was a significant predictor in seven studies of these outcomes: every day and support-related choice; preventative health care; choice of living arrangement; obesity and being overweight; and expenditures. Individuals living in their own homes were significantly more likely to make everyday choices than individuals living in other settings.	Unknown	IDD
29. Stancliffe, 2001	Predictors of choice and self-determination	United States	Consistent evidence that differences in living arrangements are related to choice and SD. There is mounting evidence that smaller, more individualized, independent living arrangements are associated with greater choice and self-determination.	Unknown	IDD
30. Kozma, Mansell, & Beadle-Brown, 2009	Outcomes in different residential settings	United Kingdom	Review of 68 studies. Small-scale community settings were found to offer more community involvement than larger settings. Semi-independent or supported living provided more community integration, choice, and self-determination than traditional services. Community-based services did not, guarantee better outcomes. Crucial in	Unknown	IDD

Study	Themes/ Topics Addressed	Location (Country)	Brief Description	Number of Subjects or Study Participants	Target Population
			promoting choice were staff practices, empowerment, individual characteristics, such as adaptive skills and level of disability. Three domains where community services might not do better are: challenging behavior, psychotropic medication, and mortality. Better outcomes for community-based services compared to congregate settings are not necessarily good enough.		
31. LeRoy, Walsh, Kulik, & Rooney, 2004	Life experiences of older women with IDD, mostly in group homes	United States and Ireland	High staff turnover. Having to travel to places and at times for the convenience of staff. Loss of privacy and personal property in group home. Mean age 60	29	IDD
32. Stancliffe, 2005	Semi-independent living and group homes in Australia	Australia	Study found that adults with IDD and low to moderate support needs living semi-independently achieved equivalent or better lifestyle outcomes at substantially lower staff cost—as compared with peers in group homes.	90	IDD
33. Stancliffe & Keane, 2000	Outcomes and costs of community living; comparison of group homes and semi-independent living	Australia	Most outcomes did not differ significantly by setting. Where significant differences were found, those living semi-independently had better outcomes. There were no outcomes with significantly better results for group home residents. Per-person expenditure was substantially higher for group home residents. The lower level of staffing provided in semi-independent living was not associated with poorer outcomes.	54 (27 pairs)	IDD
34. Felce, Perry, Romea,	Outcomes and costs of	England and	Group homes residents had better outcomes in money management and some health	70 (35 pairs)	IDD

<b>Study</b>	<b>Themes/ Topics Addressed</b>	<b>Location (Country)</b>	<b>Brief Description</b>	<b>Number of Subjects or Study Participants</b>	<b>Target Population</b>
Robertson, Meek, Emerson, & Knapp, 2008	community living: semi-independent living and fully staffed group homes	Wales	indicators. Semi-independent residents had better outcomes for choice and community activities undertaken without staff support. Costs for semi-independent living were less.		
35. Perry & Felce, 2005	Factors associated with outcome in group homes (all small, from 1-5 people; average 3.3)	Wales	Adaptive behavior was a powerful influence on outcomes. Level of staff attention was also a significant factor predicting outcomes. Size was not found to be a significant predictor of any outcome.	154	IDD
36. Chou, Lin, Pu, Lee, & Chang, 2008	Outcomes and costs of residential services	Taiwan	Comparisons between institutions (50 or more beds), group/community living (less than 50 beds), and community living (6 or fewer beds). Small homes: significantly better outcomes than other two models. Small homes and group/community homes did not differ significantly on choice variable. Majority of people across three models had very little opportunity to make choices. People in small homes had relatively greater choice (but no group/community homes difference), better quality of life, more extensive community inclusion, more frequent family contact, greater satisfaction with accommodation, and were happier with their housemates.	248	IDD
37. Felce, Lowe, & Jones, 2002	Association between provision characteristics	Wales	There were no significant differences in outcome between statutory, voluntary, and private section provision after differences in ability were taken into account. Smaller	97	IDD

Study	Themes/ Topics Addressed	Location (Country)	Brief Description	Number of Subjects or Study Participants	Target Population
	and resident outcomes; average no. per setting – 3.3; range: 2 to 6		residence size was associated with lower resident engagement in activity, and was not a predictive factor in the explanation of other resident outcomes. This finding may be explained by the narrow range of sizes in this study. Quality of life is strongly associated with people's abilities, and that in turn tends to be associated with absence of challenging behavior.		
38. Felce, Lowe, & Jones, 2002	Staff activity in supported housing services	Wales	Larger residence size was correlated with lower typical staff-to-resident ratios during late afternoon/evening, more qualified staff, and staff doing more household tasks. However, in regression analyses, size of residence did not predict how much time staff spent attending to residents or the extent of attention or assistance residents received.	97	IDD
39, Duvdevany, Ben-Zur, & Ambar, 2002	Self- determination, living arrangement, and lifestyle satisfaction	Israel	Focused on differences between people who live in a community residence and those living in parents' home. Self-determination is found to be lower among group home residents than among parental home residents. Lifestyle satisfaction was higher among group home residents. This related to the availability of social life and leisure activities, as well as accessibility to community services and work opportunities.	80	IDD
40. Robertson, Emerson, Pinkney, Caesar, Felce, Meek, Carr, Lowe, Knapp, & Hallam,	Quality and costs of community- based supports for people with challenging	United Kingdom	Comparing people in congregate care (over 50% have challenging behaviors) and noncongregate (50% or fewer have challenging behavior). All houses have 2-6 residents. Congregate settings have higher staffing ratios and better quality internal	25 matched pairs	IDD



Study	Themes/ Topics Addressed	Location (Country)	Brief Description	Number of Subjects or Study Participants	Target Population
2004	behavior		working practices for person centered planning, assessment and teaching, activity planning, and staff support of residents. However, these inputs do not appear to translate to improved outcomes for residents, with the exception of slightly more staff contact observed in the form of general social interaction.		
41. Emerson, Robertson, Gregory, Hatton, Kessissoglou, Hallam, Knapp, Jarbrink, Walsh, & Netten, 2000	Quality and costs of community-based supports, village communities and residential campuses	United Kingdom	Residential campuses were not preferable over village communities and dispersed housing schemes on any indicator of quality. Apparent distinct pattern of benefits associated with dispersed housing (choice, size of social networks, social integration, and recreation/leisure) and village communities (size of social networks, reduced risk of exposure to verbal abuse and crime, greater number of scheduled day activities). Residential campuses offer a significantly poorer quality of care & life than dispersed housing. Also, scored across a range of measures of resource and non-resource inputs (staffing ratios, size, homelikeness, institutional climate), village communities offer a significantly poorer quality of care than dispersed housing.	500	IDD
42. Perry & Felce, 2002	Outcomes across provider sectors (health and local authorities, voluntary, and private	United Kingdom	Focus on homes serving 6 or fewer people. Outcomes did not appear to vary as a function of type of service provider. Rather, they are significantly inversely correlated with the ability of residents.	154	IDD

<b>Study</b>	<b>Themes/ Topics Addressed</b>	<b>Location (Country)</b>	<b>Brief Description</b>	<b>Number of Subjects or Study Participants</b>	<b>Target Population</b>
43. Robertson, Emerson, Gregory, Hatton, Kessissoglou, Hallam, & Linehan, 2001	providers) Social networks	United Kingdom	Study included people in residential campuses, village communities, and community-based supports. People supported in smaller community-based settings had larger and more inclusive social networks.	500	IDD
44. Emercon, Robertson, Gregory, Hatton, Kessissoglou, Hallam, Jarbrink, Knapp, Netten, & Walsh, 2001	Quality and costs of supported living and group homes	United Kingdom	For similar costs, supported living may offer distinct benefits in the areas of choice and community participation, as well as higher staffing ratios. Negative outcomes associated with supported living included internal implementation of habilitative procedures, regularity of day activities, and victimization and risk.	270	IDD

**Appendix B. Mental Health Studies Chart:** The research literature review in the chart below presents information from 32 mental health studies. Among themes/topics are: residence type and/or size, choice, environment, staffing, cost, adaptive behavior, and others. While one study location was listed as unknown, one study each occurred in Canada, and Israel, there were two studies in British Columbia and Australia. The majority of participants were adults with mental illnesses residing in the United States (n=26 of the total 32 mental health reports addressing community outcomes).

Study	Themes/Topics Addressed	Location	Brief Description	Number of Subjects or Study Participants	Target Population	Intervention(s)
1. Barr et al. 2013	Residence Type, Staffing	United Kingdom	Comparison of "step-down" community housing services for women vs. inpatient care; baseline, 6 month, 12 month follow-up done	37 total (9 experimental , 28 control)	Women with psychiatric illnesses detained in services with an offending profile or at serious risk of offending	A high support "step-down" community housing vs. secure inpatient/prison
2. Burt 2012	Staffing	United States	Compared two types of program locations. Los Angeles/L.A. Hope site provided enhanced intensity homelessness and employment support services, compared to regular intensity homelessness and employment support services; propensity score matching; outcomes assessed at 13 months.	471 (56 L.A .Hope, 415 other programs)	Homeless adults with mental illnesses	LA Hope similar to Housing First
3. Chalmers-McLaughlin 2011	Costs	United States	Random selection: formerly homeless people with mental illnesses, receiving scattered site vouchers; examined service, jail, emergency records for 2 years before & after housing; system cost analysis 6 months before housing plus 6-month intervals after was housing obtained	263	Individuals with mental illnesses who were formerly homeless	Permanent Supported Housing
4. Clark & Rich 2003	Staffing, Level of disability	United States	Pre-Post comparison at 6 & 12 months between housing program and case management, severity	152	Homeless adults with serious mental illnesses	Comprehensive Housing Services

Study	Themes/Topics Addressed	Location	Brief Description  level	Number of Subjects or Study Participants	Target Population	Intervention(s)
5. De Heer-Wunderink et al., 2012	Residence size, Residence type	Netherlands	Survey of community housing residents, compared supported independent living vs residential care; housing type as independent variable in statistical model; randomly selected available participant diaries	255 (154 supported housing, 101 residential center)	Individuals with severe mental illnesses	Supported Housing vs. Residential Care
6. Grant & Westhues 2010	Health, Staffing	Canada	Followed people moving into 2 supported housing programs over 12 months (data collection at baseline, 6 months, and 12 months).	27	Consumer-survivors (mental health) entering housing program in Canada	Supported housing (one higher support, one lower support program)
7. Gulcer et al., 2003	Residence size, Costs	United States	Same core study as Tsemberis et al., 2004, looking at different outcomes; outcomes assessed at 24 months;	225 total (126 control, 99 Housing First)	Adults with psychiatric disabilities living on streets (chronic homelessness)	Pathways to Housing/Housing First vs Continuum of care
8. Lambert et al., 2000	Residence type, Choice, Environmental	Australia	Random survey: housing needs and preferences of mental health center /service consumers compared to a general population housing needs survey; respondents were in a hospital, community housing program, or community mental health service program	101 (surveys completed)	Clients of a mental health service	None
9. Lipton et al., 2000	Residence size, Residence type, Environmental, Staffing	United States	Tracked all individuals entering housing in 5 year period with follow-up all in supported housing	2,937	Adults with mental illnesses	Supportive Housing (of varying intensity)

Study	Themes/Topics Addressed	Location	Brief Description	Number of Subjects or Study Participants	Target Population	Intervention(s)
10. Mares et al., 2004	Residence type, Staffing, Level of disability	United States	Tracked entrants in VA supported housing programs over 7 year period; compared people in residential treatment 6 months prior to program entry to people without residential treatment in time period prior to entry.	655	Veterans with serious mental illnesses	Supportive Housing
11. Martinez & Burt 2006	Residence size	United States	Pre-Post comparison of service use 2 years before and 2 years after program entry. Used a waitlist control analysis for subgroup analysis.	236	Homeless adults with co-occurring mental illnesses, substance use or HIV/AIDS	Permanent Supported Housing
12. McCoy et al., 2003	Residence type	United States	Retrospective assessment of 18 month outcomes	38	People with dual diagnosis, history of homelessness, recurring hospitalization	Residential integrated treatment
13. McHugo et al., 2004	Staffing	United States	Randomly assigned individuals to single provider for services and housing or parallel service delivery (community housing, provider services) structures, followed for 18 months	121 total (61 integrated, 60 parallel)	Adults with serious mental illnesses at risk of homelessness	Integrated Housing and Services vs. Traditional Housing and Community Services
14. Nath et al., 2012	Health, Staffing	United States	Randomized sample, cross-sectional study; individuals receiving Supported Independent Housing in 4 groups based on frequency of support services; looked at access to medical services	252	Adults with an Axis I diagnosis in supported independent housing, at least 6 months sober	Supported Independent Housing (scatter site)
15. Padgett et al., 2011	Residence size, Residence type	United States	Conducted 3 in-depth qualitative interviews with people in two housing programs at 0, 6, and 12 months after program entry. Coded interviews: dichotomous variables & used regression analysis.	75 total (27 Housing First, 48 Treatment First)	Individuals with mental illnesses and substance use history	Housing First vs Treatment First

Study	Themes/Topics Addressed	Location	Brief Description	Number of Subjects or Study Participants	Target Population	Intervention(s)
16. Patterson et al., 2013	Residence size, Residence type, Environmental, Level of disability	Vancouver British Columbia	Compared Housing First to treatment as usual at 6 and 12 months, stratified by need then random assignment to condition. Assessed quality of life. Same core study as Patterson, Moniruzzaman, and Somers, 2013.	497	Homeless adults with mental illnesses	Housing First
17. Sacks et al., 2003	Residence size	United States	Compared people receiving therapeutic community-oriented supported housing to those not receiving supports from entry to 24 months post entry (at 0, 12, 24 months)	115 total (81 in supported housing, 34 not)	Homeless individuals with mental illnesses & chemical abuse who were referred	Supportive Housing; people completed a residential therapeutic community program
18. Schutt & Goldfinger 2009	Level of disability	United States	Random assignment to supported housing or group home programs, looked at housing loss at 18 and 36 months	118 (55 supported housing, 63 group home)	Individuals with severe mental illnesses in homeless shelters	Supportive Housing vs. Group Home
19. Shern et al., 2000	Residence size	United States	Random assignment to a psychiatric rehabilitation intervention or treatment as usual; outcomes assessed at baseline and every 6 months for 24 months; assessed average change from baseline to 24 months	168 total (91 experimental, 77 usual treatment)	Individuals with severe and persistent mental illnesses living on the streets of NYC	Choices program (intensive case management e.g., respite housing, no direct transition to community apartments housing beyond respite)
20. Siegel et al., 2006	Residence size, Choice, Residence type	United States	Compared people receiving supported housing to others in "community" residences. Propensity scoring used. Data collected at baseline (3.5 weeks after housing), 6 months, and 12 months.	139 total (67 supported housing, 72 Community)	People with serious mental illnesses and a history of homelessness	Supported Housing (scattered site) vs. Community (people in congregate, settings)
21. Siskind et al., 2013	Environmental, Costs	Australia	Compared people receiving Transitional Housing Team services to controls; 1 year follow-up	252 (113 Transitional, 139 controls)	People with severe mental illnesses, tenuous housing	Transitional Housing Team program

Study	Themes/Topics Addressed	Location	Brief Description	Number of Subjects or Study Participants	Target Population	Intervention(s)
22. Stefancic & Tsemberis 2007	Residence size, Residence type, Costs	United States	Randomly assigned people—Housing First interventions or treatment as usual; compared housing status between groups at 20 months	260 total (209 Housing First, 51 control)	Adults with serious mental illnesses and strong history of shelter use	Housing First vs treatment as usual
23. Townley & Kloos 2011	Residence size, Residence type, Environmental	United States	Examined factors associated with sense of community, (supported housing type (individual apartment vs. congregate) regression model	402	Individuals with severe mental illnesses in supported housing program	Supported Housing
24. Tsai & Rosenheck 2012	Choice	United States	11-city multisite study focused provided supported housing, primary care, mental health services; follow-up at 3, 6, and 12 months; used choice variables in regression model predicting outcomes	534	Adults who were chronically homeless	Supported Housing and Housing First
25. Tsai et al., 2010	Choice, Residence type, Environmental	United States	Qualitative interviews with clients of Thresholds discussing their housing, desires for housing	40 (20 Supervised Housing, 20 Independent Housing)	Individuals with dual diagnoses	Supervised Housing and Independent Housing
26. Tsemberis & Eisenberg 2000	Residence size, Choice	United States	Compared those in Pathways to Housing (Housing First ) to traditional linear housing programs	1842 total (242 in Housing first vs 1600 Comparison)	Individuals with mental illnesses that are homeless	Pathways to Housing vs. traditional linear residential treatment
27. Tsemberis et al., 2004	Residence size, Choice	United States	Random assignment to interventions as usual (continuum of care models), outcomes assessed every 6 months for 24 months	206 total:87 experimental +119 control	Individuals with dual diagnoses and chronic homelessness	Pathways to Housing vs. traditional linear/continuum of care residential treatment
28. Warren & Bell 2000	Residence size, Choice, Residence type	(unknown)	Conducted qualitative interviews with clients of a mental health service discussing their housing, desires for housing	10	Clients of a mental health service	None

Study	Themes/Topics Addressed	Location	Brief Description	Number of Subjects or Study Participants	Target Population	Intervention(s)
29. Weiner et al., 2010	Residence type	Israel	Compared group home to supportive housing (permanent supported housing)	97 total 40 Supportive, 57 Group Home)	Individuals with serious mental illnesses	supportive housing vs. group home
30. Wright & Kloos 2007	Adaptive behavior, Environmental	United States	One time administration of survey; explores whether perceived characteristics of a dwelling, immediate neighborhood, or broader surrounding area have different relationships with domains of well-being	249	Individuals with serious mental illnesses in programs (by community mental health centers	Supported Housing
31. Yanos et al., 2004	Residence size, Choice, Residence type, Staffing	United States	Qualitative Analysis of responses: subset of Metraux et al., 2003 participants, comparing independent housing with care staff apartments, regardless of condition assignment. (independent apartment vs. other residence type)	80 total (46 experimental , 34 control)	Adults with mental illnesses	Pathways to Housing (Housing First ) vs. traditional linear/ continuum of care (overall study)
32. Yanos et al., 2012	Residence type	United States	Compared community integration among those in supported housing to others (without mental health history) living in the community	124 total (60 supported housing, 64 community)	Mental health consumers living in supported housing in Bronx, NY	Supported Housing



## **Appendix C. Supplemental Information: Selected Terminology and Descriptions**

This appendix provides information on these nine topics: (1) Adaptive Behavior; (2) Autonomy, (3) HCBS State Plan, (4) HCBS Residency Choice, (5) Intermediate Care Facilities, (6) Mental Health Terms, and (7) Permanent Supportive Housing, as follows:

### **1. Adaptive Behavior – An Operational Definition for Consideration**

According to the American Association of Intellectual and Developmental Disabilities, an intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18. Adaptive behavior refers to the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives. Conceptual skills include language and literacy; money, time, and number concepts; and self-direction. Social skills refers to interpersonal functioning, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized. Practical skills refer to those concerned with activities of daily living (personal care), occupational aptitude, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

Source: The American Association of Intellectual and Developmental Disabilities

**2. Autonomy** – Within the context of HCBS, the term autonomy refers to independence or freedom to make choices. Autonomy for individuals with mental health disabilities is the same as for those without, though historically the autonomy of individuals with mental health disabilities has often been limited (see, for example, the response of the courts to such limits with the *Olmstead* decision). In the context of the mental health system, autonomy encompasses but is not limited to the right to choose to take part in services, set goals and steps for achieving goals, where to live, with whom to socialize, and so forth.

Source: Carole E. Siegel, et al., "Outcomes in Supported Housing"

[http://usich.gov/usich\\_resources/research/tenant\\_outcomes\\_in\\_supported\\_housing\\_and\\_community\\_residences\\_in\\_new\\_york](http://usich.gov/usich_resources/research/tenant_outcomes_in_supported_housing_and_community_residences_in_new_york)

### **3. HCBS State Plan and Community Choice Information**

**Section 1915(i)** HCBS as a State Plan Option permits states to offer a variety of services to eligible individuals who meet State-defined criteria based on need and who typically receive a combination of medical services (i.e. dental services, skilled nursing services) and long-term services (respite, case management, supported employment, and environmental modifications). Originally enacted in 2005 through the Deficit Reduction Act (effective January 1, 2007), this option was subsequently amended through the Affordable Care Act.

**Section 1915(j)** Self Directed Personal Assistance Services was enacted in 2005 as a part of the Deficit Reduction Act. The provision allows states to offer self-directed personal assistance services (PAS), including personal care, and related services furnished under the Medicaid State Plan and/or section 1915(c) waivers that the State already has in place.

**Section 1915(k)** The "Community First Choice Option" permits States to provide home and community-based attendant services to Medicaid enrollees with disabilities under their State Plan. This option became available on October 1, 2011 and provides a 6 percent increase in Federal matching payments to States for related expenditures under this option.

The HCBS rule provides additional requirements related to privacy, lease and/or residency agreements, visitor policies, access to food, and choice of whether and with whom to share a room that apply when an individual receives services in a provider-owned or -operated setting. Any changes must be documented and must address a need in the individual's plan of care. Review timelines must be included so that restrictions do not carry on in perpetuity without a basis in need. Additional provisions are that the setting:

- Is integrated in, and supports full access of individuals receiving Medicaid HCBS to, the greater community, including opportunities to seek employment and to 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;
- Is selected by the individual from among setting options, including non-disability specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the individual’s needs, preferences, and, for residential settings, the resources available for room and board;
- Ensures an individual’s rights of privacy, dignity and respect, and freedom from coercion and restraint;
- Optimizes but does not regiment individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact; and
- Facilitates individual choice regarding services and supports, and who provides them.

Source: 42 U.S.C. § 1396n(i); 42 U.S.C. § 1396n(j); 42 U.S.C. § 1396n(k)

#### **4. HCBS Residency Choice and Privacy Information**

To ensure lasting compliance with the HCBS regulation, states should document performance through valid and reliable measures of system performance, such as the National Core Indicators (NCI), to assist in gauging ongoing regulatory compliance. The core indicators are standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern including employment, rights, service planning, community inclusion, choice, and health and safety. As detailed in the May 2014 publication “NCI Performance Indicators: Evidence for New HCBS Requirements and Revised HCBS Assurances,” the NCI can

provide data and information on state adherence to HCBS rules, particularly as they relate to the type of home in which individuals live and the experience of individuals served through HCBS programs. Related information is included in joint project of NASDDDS and the Human Services Institute (HSRI) a September 2014 document-- How State ID/DD Systems Can Use National Core Indicators to Assess Congruence with New CMS HCBS Settings Requirements.

Source: For details see information online at; <http://www.nasddds.org/resource-library/quality/national-core-indicators/nci-performance-indicators-evidence-for-new-hcbs-requirements-and-revised-hcbs-assurances/>; and <http://www.hcbs.org/sites/nasud/files/How%20States%20Can%20Use%20Data%20from%20NCI.pdf>

## **5. Intermediate Care Facilities for Individuals with Intellectual Disabilities**

For decades, federal law and regulations have used the term "intermediate care facilities for the mentally retarded." People with intellectual disabilities now have the benefit of a federal law removing use of the latter term in federal programs. HHS/CMS explains: Based on changes made in Rosa's Law in 2010, Intermediate Care Facilities for Individuals with Mental Retardation (ICF/MR) will now reflect nationwide changes and be referred to as Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID).

Source; <http://www.cms.gov/Regulations-and-Guidance/Legislation/CFCsAndCoPs/Intermediate-Care-Facilities-for-Individuals-with-Intellectual-Disabilities-ICF-IID.html>

## **6. Mental Health Terms**

The terminology adopted by NCD is explained in the agency's 2008 report on inclusive living for people with psychiatric disabilities. This report incorporates information from traditional academic literature and from organizations of people with psychiatric disabilities and their publications. There are a number of terms commonly used to refer to the population described in this paper: "people labeled with psychiatric disabilities,"

"people with mental illnesses," "mental health consumers," "psychiatric survivors," and a number of others. Sometimes diagnoses are included, as in "schizophrenics," "people with bipolar disorder," and so forth. In this paper, NCD has determined that the terminology used in its 2008 report, "people labeled with psychiatric disabilities," best captures the identity and experiences of this population. However, because such a wide diversity of terms are used in the field—including those used by people with psychiatric disabilities themselves—the NCD paper on Inclusive Living will include a variety of terminology used by people quoted herein. The exceptions are editing choices such as removing terms considered detrimental to the community, to NCD's mission, and to ensuring the use of "people first" language.

Source: National Council on Disability, "Inclusive Livable Communities for People with Psychiatric Disabilities" (2008)

<http://www.ncd.gov/publications/2008/03172008#Terminology>

## **7. Permanent Supportive Housing**

Permanent Supportive Housing is an evidence-based approach to ending homelessness, providing people who are experiencing homelessness with housing as quickly as possible—and then providing support services as needed. This intervention provides case management and wrap-around care to consumers to assist them with their transition from homelessness and progression through the different stages of recovery.

Source: Homelessness Resources Center, Permanent Supportive Housing Kit,

<http://homeless.samhsa.gov/channel/permanent-supportive-housing-510.aspx>

## **8. Sense of Community, Social Connections, Social Inclusion**

Though these constructs may be similar to one another, they differ in important ways. In their 2011 research Townley and Kloos (cited in the Community Outcomes Research section of this NCD report) used a measure of "sense of community" that addressed not only social connections, but also mutual concern and community values. Other researchers, such as De Heer-Wunderink and colleagues' 2012 research in the

Netherlands, measured a construct called “social inclusion” among 255 residents of psychiatric community housing programs, using the counts of activities with other people, as identified in service user diaries. According to this report, the people with severe mental illnesses who were living independently and their peers whose MH services were linked to the provision of housing had different perspectives on “social inclusion.” People living independently indicated feeling more “socially included” in activities and because of visits by friends and associates, than their peers with housing tied to MH service. While the “social inclusion” concept is similar to the “social connections” element of Townley and Kloos, the DeHeer-Wunderink’s “social inclusion” does not address the “mutual concern” or “community values” found in the Townley and Kloos research – and so is a much narrower gauge than the more far-reaching “sense of community.”

Source: C. De Heer-Wunderink, E. Visser, S. Sytema, and D. Wiersma “Social inclusion of people with severe mental illness living in community housing programs” (Psychiatric Services 2012 Nov; 63(11) pp. 1102-7)  
<http://www.ncbi.nlm.nih.gov/pubmed/22948812>

## **9. Using National Core Indicators to Assist Implementation of HCBS Requirements (see end note 33)**

NCI is a voluntary effort by public developmental disabilities agencies to measure and track performance (self-assessment). According to the collaboration of relevant entities (participating states, the Human Services Research Institute, and the National Association of State Directors of Developmental Disabilities Services), in 2012, the majority of people with IDD lived in either a community-based residence (which includes group home and agency-operated apartment-type setting) (38 percent) or with a parent or relative (34 percent). Smaller percentages lived independently in a home or apartment (14 percent), in a specialized facility (5 percent), or in other arrangements (11 percent).

Source: National Core Indicators, “Annual Summary Report 2011-2012,” (2012).  
Update available at <http://www.nationalcoreindicators.org/resources/reports/2014/>

## VII. ENDNOTES

---

<sup>1</sup> [Olmstead v. L.C.](#), 527 U.S. 581 (1999).

<sup>2</sup> Cindy Mann, Director, U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services, “Information Bulletin: Final Rule 1915(i) State Plan Home and Community Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, Setting Requirements for Community First Choice, and 1915(c) Home and Community-Based Services Waivers,” (2014), accessed February 2015, <http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-01-10-14.pdf>.

<sup>3</sup> “Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.*,” U.S. Department of Justice, Civil Rights Division, accessed February 2015, [http://www.ada.gov/olmstead/q&a\\_olmstead.htm](http://www.ada.gov/olmstead/q&a_olmstead.htm).

<sup>4</sup> *Olmstead v. L. C.*, 527 U.S. 581 (1999).

<sup>5</sup> *Ibid.*

<sup>6</sup> 42 U.S.C. §§ 1396 – 1396v (1965).

<sup>7</sup> The term “Mental Health Disabilities” derived from a review of the literature for this paper. NCD has used the term “people with psychiatric disabilities” in prior publications as described in Appendix C.

<sup>8</sup> 42 C.F.R. §§ 430-431; 42 C.F.R. §§ 435-436; 42 C.F.R. §§ 440-441; 42 C.F.R. §447

<sup>9</sup> The HCBS regulations in no way impact institutional service models available under Medicaid, such as Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID), nursing facilities and hospitals. Settings not meeting HCBS requirements may fit within those rubrics for Federal Financial Participation.

<sup>10</sup> U.S. Department of Justice, “Enforcement of the Integration Mandate.”

<sup>11</sup> Max Barrows *et al.*, The Autistic Self Advocacy Network, “Keeping the Promise: Self Advocates Defining the Meaning of Community Living” (2011), February 2015, <http://autisticadvocacy.org/wp-content/uploads/2012/02/KeepingthePromise-SelfAdvocatesDefiningtheMeaningofCommunity.pdf>

<sup>12</sup> National Council on Disability (NCD), “Medicaid Managed Care for People with Disabilities: Policy and Implementation Considerations for State and Federal Policymakers” (2013), February 2015, <http://www.ncd.gov/publications/2013/20130315/>

<sup>13</sup> *Ibid.*

<sup>14</sup> Douglas Biklen, “The Least Restrictive Environment: Its Application to Education,” *Child and Youth Services* 5, no. 1-2 (1982): 121-144, doi: 10.1300/J024v05n01\_08

---

<sup>15</sup> Steven J. Taylor, "The Continuum and Current Controversies in the USA," *Journal of Intellectual and Developmental Disability* 26, no. 1 (2001): 15-33, doi: 10.1080/13668250020032741.

<sup>16</sup> Steven Taylor, Douglas Biklen, and James Knoll, eds., "Community Integration for Persons with Severe Disabilities," (New York, NY: Teachers College Press, 1987).

<sup>17</sup> Note that the 1971 case was the seminal case in achieving drastic deinstitutionalization of previously committed patients. *Wyatt v. Stickney*, 325 F.Supp. 781 (M.D. Ala. 1971), 334 F.Supp 1341 (M.D. Ala. 1971), 344 F.Supp. 373 (M.D. Ala. 1972), Sub Nom *Wyatt v. Aderholt*, 503 F.2d 1305 (5th Cir. 1974).

<sup>18</sup> Taylor, S., Biklen, D. & Knoll, J. (1987). "Community Integration."

<sup>19</sup> Developmentally Disabled Assistance and Bill of Rights Act of 1975, P.L. 94-103 (October 4, 1975).

<sup>20</sup> *Pennhurst State School and Hospital v. Halderman*, 451 U.S. 1 (1981).

<sup>21</sup> Taylor, "The Continuum and Current Controversies."

<sup>22</sup> 42 U.S.C. §1396n.

<sup>23</sup> Americans with Disabilities Act of 1990, P.L. 101-336 (July 26, 1990).

<sup>24</sup> *Ibid.*

<sup>25</sup> Charles R. Moseley, National Association of State Directors of Developmental Disabilities Services, "The ADA, Olmstead, and Medicaid: Implications for People with Intellectual and Developmental Disabilities" (2013), accessed February 2015, [http://www.nasddds.org/uploads/documents/ADA\\_Olmstead\\_and\\_Medicaid.pdf](http://www.nasddds.org/uploads/documents/ADA_Olmstead_and_Medicaid.pdf).

<sup>26</sup> *Olmstead v. L. C.*, 527 U.S. 581 (1999).

<sup>27</sup> *Ibid.* 600-01, 607; Moseley, "ADA, Olmstead, and Medicaid."

<sup>28</sup> 28 C.F.R. § 35.130(b)(1).

<sup>29</sup> *Olmstead Enforcement Update: Using the ADA to Promote Community Integration: Hearing Before the Help, Education, Labor and Pensions Committee, United States Senate*, 112<sup>th</sup> Cong. (2012) (statement of Thomas E. Perez, Assistant Attorney General, Civil Rights Division, U.S. Department of Justice).

<sup>30</sup> "President Obama Commemorates Anniversary of Olmstead and Announces New Initiatives to Assist Americans with Disabilities," The White House, [http://www.whitehouse.gov/the\\_press\\_office/President-Obama-Commemorates-](http://www.whitehouse.gov/the_press_office/President-Obama-Commemorates-)



---

[Anniversary-of-Olmstead-and-Announces-New-Initiatives-to-Assist-Americans-with-Disabilities](#) (accessed August 2014).

<sup>31</sup> Information and Technical Assistance on the Americans with Disabilities Act “Olmstead: Community Integration for Everyone,” accessed February 2015, <http://www.ada.gov/index.html>.

<sup>32</sup> The Omnibus Budget and Reconciliation Act of 1981, P.L. 97-35 (August 13, 1981).

<sup>33</sup> In FY 2011, Arizona, Rhode Island and Vermont did not operate 1915(c) programs. They provided alternatives to institutional services through Section 1115 demonstration programs. Since 2011, additional states have moved HCBS programs into 1115 demonstrations.

<sup>34</sup> Steve Eiken *et al.*, Mathematica Policy Research, “Medicaid Expenditures for Section 1915(c) Waiver Programs in FFY 2011” (2013), accessed February 2015, <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/downloads/1915-c-expenditures-report.pdf>.

<sup>35</sup> 42 U.S.C. § 1396n(i); 42 U.S.C. § 1396n(j); 42 U.S.C. § 1396n(i)

<sup>36</sup> 42 U.S.C. § 1315; See also: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/Section-1115-Demonstrations.html>.

<sup>37</sup> U.S. Department of Health and Human Services, 42 CFR Parts 430, 431, et al., Final Rule, accessed February 2015, <http://www.gpo.gov/fdsys/pkg/FR-2014-01-16/html/2014-00487.htm>.

<sup>38</sup> Ibid.

<sup>39</sup> Moseley, “ADA, Olmstead, and Medicaid”.

<sup>40</sup> “Overview,” National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Association of University Centers on Disability (AUCD) Evidence Based Policy Initiative, accessed August 2014, <http://www.evidence-basedpolicy.org/overview/>; Charles Moseley *et al.*, “Using research evidence to inform public policy decisions,” *Intellectual and Developmental Disabilities* 51 no. 5 (2013):412–422.

<sup>41</sup> National Core Indicators, “NCI Performance Indicators: Evidence for New HCBS Requirements and Revised HCBS Assurances” (2014), accessed February 2015, [http://www.nasddd.org/uploads/documents/HCBS\\_Reqmts\\_and\\_CMS\\_Assurances\\_Crosswalk\\_with\\_NCI\\_May\\_2014.pdf](http://www.nasddd.org/uploads/documents/HCBS_Reqmts_and_CMS_Assurances_Crosswalk_with_NCI_May_2014.pdf).

<sup>42</sup> Tamar Heller, Alison B. Miller, and Kelly Hsieh, “Eight-year follow-up of the impact of environmental characteristics on well-being of adults with developmental disabilities,” *Mental Retardation* 40, no. 5(2002): 366-378; Paul Lerman, Dawn Hall Apgar, and

---

Tameeka Jordan, "Longitudinal changes in adaptive behaviors of movers and stayers: Findings from a controlled research design," *Mental Retardation* 43, no.1 (2005): 25-42.

<sup>43</sup> K. Charlie Lakin *et al.*, "Choice-making among Medicaid HCBS and ICF/MR recipients in six states," *American Journal of Mental Retardation* 113 no. 5 (2008): 325-342.

<sup>44</sup> Similar to the HHS/CMS preference, NCD uses the accepted term "individuals with intellectual disability" (ID), accessed February 2015, <http://medicaid.gov/medicaid-chip-program-information/by-topics/delivery-systems/institutional-care/intermediate-care-facilities-for-individuals-with-mental-retardation-icfmr.html>.

<sup>45</sup>The Fourth International Conference on Grey Literature, Washington, DC, October 1999.

<sup>46</sup> Owen Williams, University of Minnesota Crockston Library, "Gray Literature" (2014), accessed February 2015, [http://www1.crk.umn.edu/library/researchresources/CRK\\_CONTENT\\_119693.html](http://www1.crk.umn.edu/library/researchresources/CRK_CONTENT_119693.html).

<sup>47</sup> Sheryl Larson *et al.*, University of Minnesota, College of Education and Human Development, Institute on Community Integration/UCEDD, Research and Training Center on Community Living, National Residential Information Systems Project (RISP), "Residential Services for Persons with Intellectual or Developmental Disabilities: Status and Trends through 2011," (2013), accessed February 2015, <http://rtc.umn.edu/risp/docs/risp2011.pdf>.

<sup>48</sup> Roger J. Stancliffe *et al.*, "Loneliness and Living Arrangements," *Intellectual and Developmental Disabilities* 45, no. 6 (2007): 380–390.

<sup>49</sup> Roger J. Stancliffe, Brian H. Abery, and J. Smith, "Personal control and the ecology of community living settings: Beyond living-unit size and type," *American Journal of Mental Retardation* 105, no. 6 (2000): 431-54, 445, 447; Roger J. Stancliffe *et al.*, "Longitudinal study on the adaptive and challenging behaviors of deinstitutionalized adults with mental retardation," *American Journal of Mental Retardation* 107 no. 4 (2002): 302-320.

<sup>50</sup> James Gardner and Deborah Carran, "Attainment of personal outcomes by people with developmental disabilities," *Mental Retardation* 43 no. 3 (2005): 157-174.

<sup>51</sup> Geoffrey Nelson, "Housing for people with serious mental illness: Approaches, evidence, and transformative change," *Journal of Sociology and Social Welfare* 37 no. 4 (2010): 123-146.

<sup>52</sup> Sam Tsemberis and R.F. Eisenberg, "Pathways to Housing: Supported housing for street-dwelling homeless individuals with psychiatric disabilities," *Psychiatric Services* 51 no. 4 (2000): 487-493, doi:10.1176/appi.ps.51.4.487.

- 
- <sup>53</sup> National Council on Disability, "Inclusive Livable Communities for People with Psychiatric Disabilities," (2008), accessed February 2015, <http://www.ncd.gov/publications/2008/03172008>
- <sup>54</sup> Permanent Supportive Housing as described in Appendix C is a project of the U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration.
- <sup>55</sup> H. Stephen Leff *et al.*, "Does one size fit all? What we can and can't learn from a meta-analysis of housing models for persons with mental illness" *Psychiatric Services* 60 (2009): 473-482.
- <sup>56</sup> Renáta Tichá, *et al.*, "System and individual outcomes in services and support for people with IDD and their predictors," *Intellectual and Developmental Disabilities* 51 no. 5 (2013): 298-315.
- <sup>57</sup> Renáta Tichá, *et al.*, "Correlates of everyday choice and support-related choice for 8,892 randomly sampled adults with intellectual and developmental disabilities in 19 states," *Intellectual and Developmental Disabilities* 50 no.6 (2012): 486-504.
- <sup>58</sup> Derek Nord *et al.*, University of Minnesota, Research and Training Center on Community Living, Policy Research Brief 24(3), "Residential size and individual outcomes: An assessment of existing National Core Indicators research," (2014), accessed February 2015, <http://rtc.umn.edu/prb/242/>.
- <sup>59</sup> Ibid.
- <sup>60</sup> Frank R. Lipton *et al.*, "Tenure in supportive housing for homeless persons with severe mental illness," *Psychiatric Services* 51 no. 4 (2000): 479-486, doi:10.1176/appi.ps.51.4.479.
- <sup>61</sup> Tsemberis and Eisenberg, "Pathways to Housing."
- <sup>62</sup> Stefancic and Tsemberis, "Housing for shelter dwellers."
- <sup>63</sup> Sam Tsemberis, Leyla Gulcur, and Maria Nakae "Housing First , Consumer Choice, and Harm Reduction for Homeless Individuals with a Dual Diagnosis," *American Journal of Public Health* 94 no. 4 (2004): 651-656, doi: 10.2105/AJPH.94.4.651.
- <sup>64</sup> Deborah K. Padgett *et al.*, "Substance use outcomes among homeless clients with serious mental illness: Comparing Housing First with Treatment First Programs," *Community Mental Health Journal*, 47 no. 2 (2011): 227-232, doi: 10.1007/s10597-009-9283-7.
- <sup>65</sup> Leyla Gulcer *et al.*, "Housing, hospitalization and cost outcomes for homeless individuals with psychiatric disabilities participating in continuum of care and Housing

---

First programs,” *Journal of Community & Applied Social Psychology*, 13 no. 2 (2003): 171-186, doi:10.1002/casp.723.

<sup>66</sup> Carole E. Siegel et al., “Tenant Outcomes in Supported Housing and Community Residences in New York City,” *Psychiatric Services* 57 no. 7 (2006): 982-991, doi:10.1176/appi.ps.57.7.982.

<sup>67</sup> Philip T. Yanos, Ana Stefancic, and Sam Tsemberis, “Objective Community Integration of Mental Health Consumers Living in Supported Housing and of Others in the Community,” *Psychiatric Services* 63 no. 5 (2012): 438-444, doi:10.1176/appi.ps.201100397.

<sup>68</sup> Greg Townley, and Bret Kloos, “Examining the Psychological Sense of Community for Individuals with Serious Mental Illness Residing in Supported Housing Environments,” *Community Mental Health Journal* 47 no. 4 (2011): 436-446, doi: 10.1007/s10597-010-9338-9.

<sup>69</sup> Razelle Warren and Pamela Bell, “An Exploratory Investigation into the Housing Preferences of Consumers of Mental Health Services,” *Australian & New Zealand Journal of Mental Health Nursing* 9 no. 4 (2000): 195-202, doi:10.1046/j.1440-0979.2000.00172.x.

<sup>70</sup> Michelle L. Patterson, Akm Moniruzzaman, and Julian M. Somers, “Community Participation and Belonging Among Formerly Homeless Adults with Mental Illness after 12 Months of Housing First in Vancouver, British Columbia: A Randomized Controlled Trial,” *Community Mental Health Journal* 50 no. 5 (2013): 604-611, doi:10.1007/s10597-013-9672-9.

<sup>71</sup> Ibid.

<sup>72</sup> Charlotte De Heer-Wunderink et al., “Social Inclusion of People with Severe Mental Illness Living in Community Housing Programs,” *Psychiatric Services* 63 no. 11(2012): 1102-07, doi:10.1176/appi.ps.201100538.

<sup>73</sup> Townley, and Kloos, “Psychological Sense of Community;” De Heer-Wunderink et al., “Social Inclusion.”

<sup>74</sup> Additional description is presented in Appendix C. “Definition of Intellectual Disability” American Association of Intellectual and Developmental Disabilities, accessed February 2015, <http://aaid.org/intellectual-disability/definition#.VATNKqMXP3U>.

<sup>75</sup> Stancliffe, Abery, and Smith, “Ecology of Community Living”; Stancliffe *et al.*, “Behaviors of Deinstitutionalized Adults;” Stancliffe, R.J., Hayden, M.F., Larson, S.A., & Lakin, K.C. (2002). Longitudinal study on the adaptive and challenging behaviors of deinstitutionalized adults with mental retardation. *AJMR*, 107(4), 302-320.

<sup>76</sup> Heller, Miller, and Hsieh, “Impact of Environmental Characteristics.”

---

<sup>77</sup> Steve Woolf, Christine Woolf, and Thomas Oakland, "Adaptive behavior among adults with intellectual disabilities and its relationship to community independence," *Intellectual and Developmental Disabilities* 48 no. 3 (2010): 209-215.

<sup>78</sup> Patricia Ann Wright and Bret Kloos "Housing Environment and Mental Health Outcomes: A Levels of Analysis Perspective," *Journal of Environmental Psychology*, 27 no. 1 (2007): 79-89, doi:10.1016/j.jenvp.2006.12.001.

<sup>79</sup> Ibid.

<sup>80</sup> Stancliffe *et al.*, "Loneliness and Living Arrangements."

<sup>81</sup> Roger J. Stancliffe *et al.*, "Satisfaction and sense of well-being among Medicaid ICF/MR and HCBS recipients in six states," *Intellectual and Developmental Disabilities* 47 no. 2 (2009): 63-83.

<sup>82</sup> Ibid.

<sup>83</sup> Roger J. Stancliffe *et al.*, "Overweight and Obesity Among Adults with Intellectual Disabilities who use ID/DD Services in 20 U.S. States," *American Journal of Intellectual and Developmental Disabilities*, 116 no. 6 (2011): 401-418.

<sup>84</sup> Stancliffe *et al.*, "Adults with Intellectual and Developmental Disabilities."

<sup>85</sup> Sara Bressi Nath *et al.*, "Predictors of Health Services Utilization Among Persons with Psychiatric Disabilities Engaged in Supported Independent Housing," *Psychiatric Rehabilitation Journal* 35 no. 4 (2012): 315-323, doi:10.2975/35.4.2012.315.323.

<sup>86</sup> Jill Grant and Anne Westhues, "Choice and Outcome in Mental Health Supported Housing," *Psychiatric Rehabilitation Journal* 33 no. 3 (2010), doi:10.2975/33.3.2010.232.235.

<sup>87</sup> K. Charlie Lakin *et al.*, "Factors Associated with Expenditures for Medicaid HCBS and ICF/MR Services for Persons with Intellectual and Developmental Disabilities," *Intellectual and Developmental Disabilities* 46 no. 3 (2008): 200-214.

<sup>88</sup> Ibid.

<sup>89</sup> Lakin *et al.*, "Factors Associated with Expenditures for Medicaid HCBS and ICF"...

<sup>90</sup> Tichá *et al.*, "Choice for Adults with IDD."

<sup>91</sup> Ibid.

<sup>92</sup> K. Charlie Lakin *et al.*, "Factors associated with Expenditures."

<sup>93</sup> Stancliffe *et al.*, "Satisfaction among Medicaid Recipients."

- 
- <sup>94</sup> Stancliffe *et al.*, “Adults with Intellectual and Developmental Disabilities.”
- <sup>95</sup> Ibid; Ilana Duvdevany, Hasida Ben-Zur, and A. Ambar, “Self-determination and Mental Retardation: Is there an association with Living Arrangement and Lifestyle Satisfaction?” *Mental Retardation* 40 no. 5 (2002):379-89.
- <sup>96</sup> National Council on Disability, “Inclusive Livable Communities for People with Psychiatric Disabilities and Creating Livable Communities,” (2008), accessed February 2015, <http://www.ncd.gov/publications/2008/03172008>; “Creating Livable Communities,” (2006), accessed February 2015, <http://www.ncd.gov/publications/2006/Oct312006>; “Livable Communities for Adults with Disabilities,”(2004), accessed February 2015, <http://www.ncd.gov/publications/2004/12022004>.
- <sup>97</sup> Ibid.
- <sup>98</sup> Carole E. Siegel *et al.*, “Outcomes in supported housing.”
- <sup>99</sup> Ibid.
- <sup>100</sup> Tsemberis, Gulcur, and Nakae, “Housing First, Consumer Choice.”
- <sup>101</sup> Philip T. Yanos, Susan M. Barrow, & Sam Tsemberis, “Community Integration in the Early Phase of Housing among Homeless Persons Diagnosed with Severe Mental Illness: Successes and Challenges,” *Community Mental Health Journal* 40 no. 2 (2004): 133-150, doi:10.1023/B:COMH.0000022733.12858.cb.
- <sup>102</sup> Jack Tsai and Robert A. Rosenheck, “Consumer Choice over Living Environment, Case Management, and Mental Health Treatment in Supported Housing and its Relation to Outcomes,” *Journal of Health Care for the Poor and Underserved* 23 no.4 (2012): 1671-1677.
- <sup>103</sup> Tsemberis and Eisenberg, “Pathways to Housing.”
- <sup>104</sup> National Core Indicators, “Annual Summary Report 2011-2012,” (2012), accessed February 2015, [http://www.nationalcoreindicators.org/upload/core-indicators/ANNUAL\\_SUMMARY\\_REPORT\\_FINAL\\_2011-12.pdf](http://www.nationalcoreindicators.org/upload/core-indicators/ANNUAL_SUMMARY_REPORT_FINAL_2011-12.pdf).
- <sup>105</sup> K. Charlie Lakin *et al.*, “Factors associated with Expenditures.”
- <sup>106</sup> Stancliffe, Abery, and Smith, “Ecology of Community Living.”
- <sup>107</sup> Ibid.
- <sup>108</sup> Stancliffe *et al.*, “Adults with Intellectual and Developmental Disabilities.”
- <sup>109</sup> Gardner and Carran, “Attainment of Personal Outcomes.”

---

<sup>110</sup> Ibid.

<sup>111</sup> David Felce *et al.*, "Outcomes and Costs of Community Living: Semi-independent Living and Fully Staffed Group Homes," *American Journal on Mental Retardation* 113 no. 2 (2008): 87-101.

<sup>112</sup> David Felce *et al.*, "Outcomes and Costs of Community Living."

<sup>113</sup> Ibid. 98-99.

<sup>114</sup> Stancliffe *et al.*, "Ecology of Community Living."

<sup>115</sup> Ibid.

<sup>116</sup> Celia S. Feinstein *et al.*, "Homeownership Initiatives and Outcomes for People with Disabilities," *Journal of the Community Development Society* 37 no. 3 (2006): 1-7.

<sup>117</sup> Lipton *et al.*, "Tenure in Supportive Housing." Stefancic and Tsemberis, "Housing for Shelter Dwellers."

<sup>118</sup> Padgett *et al.*, "Substance Use Outcomes." Siegel *et al.*, "Outcomes in Supported Housing."

<sup>119</sup> U.S. Department of Housing and Urban Development. *Housing Choice Vouchers*, accessed February 2015, [http://portal.hud.gov/hudportal/HUD?src=/topics/housing\\_choice\\_voucher\\_program\\_section\\_8](http://portal.hud.gov/hudportal/HUD?src=/topics/housing_choice_voucher_program_section_8).

<sup>120</sup> Alvin S. Mares, Wesley J. Kaspro, and Robert A. Rosenheck, "Outcomes of Supported Housing for Homeless Veterans with Psychiatric and Substance Abuse Problems," *Mental Health Services Research* 6 no. 4 (2004): 199-211, doi:10.1023/B:MHSR.0000044746.47589.06.

<sup>121</sup> Townley, and Kloos, "Psychological Sense of Community."

<sup>122</sup> Yanos, Barrow, and Tsemberis, "Community Integration in Early Phase."

<sup>123</sup> Yanos, Stefancic, and Tsemberis, "Objective Community Integration."

<sup>124</sup> Jack Tsai *et al.*, "Housing Preferences and Choices among Adults with Mental Illness and Substance Use Disorders: A qualitative study," *Community Mental Health Journal* 46 no. 4 (2010): 381-388, doi: 10.1007/s10597-009-9268-6.

<sup>125</sup> Ibid.

<sup>126</sup> Warren and Bell, "Investigation into Housing Preferences."

<sup>127</sup> Patterson, Moniruzzaman, and Somers, "Community Participation and Belonging."

- 
- <sup>128</sup> Gordon Lambert *et al.*, "Housing Needs of Consumers of Mental Health Services in Rural New South Wales, Australia," *International Journal of Social Psychiatry* 46 no. 1 (2000): 57-66, doi: 10.1177/002076400004600107.
- <sup>129</sup> Wally Barr *et al.*, "How Effective is High-Support Community-Based Step-Down Housing for Women in Secure Mental Health Care?" *Journal of Psychiatric and Mental Health Nursing* 20 no. 1(2013): 41-49, doi:10.1111/j.1365-2850.2012.01886.x.
- <sup>130</sup> De Heer-Wunderink *et al.*, "Social Inclusion."
- <sup>131</sup> Patterson, Moniruzzaman, and Somers, "Community Participation and Belonging."
- <sup>132</sup> Adi Weiner *et al.*, "Housing Model for Persons with Serious Mental Illness moderates the Relation between Loneliness and Quality of Life," *Community Mental Health Journal* 46 no. 4(2010): 389-397, doi: 10.1007/s10597-009-9279-3.
- <sup>133</sup> Ibid.
- <sup>134</sup> Heller, Miller, Hsieh "Impact of Environmental Characteristics."
- <sup>135</sup> Jonathan Perry and David Felce, "Factors Associated with Outcome in Community Group Homes," *American Journal of Mental Retardation* 110 no. 2 (2005): 121-135.
- <sup>136</sup> Gardner and Carran, "Attainment of Personal Outcomes."
- <sup>137</sup> Lipton *et al.*, "Tenure in Supportive Housing."
- <sup>138</sup> Tsai *et al.*, "Housing Preferences and Choices."
- <sup>139</sup> Wright and Kloos, "Housing Environment and Outcomes."
- <sup>140</sup> Townley and Kloos, "Psychological Sense of Community."
- <sup>141</sup> David Felce *et al.*, "Outcomes of Community Living."
- <sup>142</sup> Janet Robertson *et al.*, "Quality and Costs of Community-Based Residential Supports for People with Mental Retardation and Challenging Behavior," *American Journal of Mental Retardation* 109 (2004): 332-344.
- <sup>143</sup> Stancliffe, *et al.*, "Personal Control" (2000).
- <sup>144</sup> Stefancic and Tsemberis, "Housing for Shelter Dwellers."
- <sup>145</sup> Ibid.
- <sup>146</sup> Gulcur *et al.*, "Housing, Hospitalization and Cost."



- 
- <sup>147</sup> Thomas Chalmers-McLaughlin, "Using Common Themes: Cost-effectiveness of Permanent Supported Housing for People with Mental Illness," *Research on Social Work Practice* 21 no. 4 (2011): 404-411, doi: 10.1177/1049731510387307.
- <sup>148</sup> Stefancic and Tsemberis, "Housing for Shelter Dwellers."
- <sup>149</sup> Dan Siskind *et al.*, "A Retrospective Quasi-Experimental Study of a Transitional Housing Program for Patients with Severe and Persistent Mental Illness," *Community Mental Health Journal* 50 no. 5(2014):538-547, doi:10.1007/s10597-013-9654-y.
- <sup>150</sup> Perry and Felce, "Factors Associated with Outcome."
- <sup>151</sup> Heller, Miller, and Hsieh, "Impact of environmental characteristics."
- <sup>152</sup> Stancliffe *et al.*, "Loneliness and Living Arrangements."
- <sup>153</sup> Felce *et al.*, "Outcomes of Community Living."
- <sup>154</sup> Lipton *et al.*, "Tenure in Supportive Housing."
- <sup>155</sup> Ibid.
- <sup>156</sup> Yanos, Barrow, Tsemberis, "Community Integration in the Early Phase."
- <sup>157</sup> Mares, Kaspro and Rosenheck, "Outcomes of Supported Housing."
- <sup>158</sup> Martha R. Burt, "Impact of Housing and Work Supports on Outcomes for Chronically Homeless Adults with Mental Illness: LA's HOPE," *Psychiatric Services* 63 no. 3 (2012): 209-215, doi:10.1176/appi.ps.201100100.
- <sup>159</sup> Colleen Clark and Alexander R. Rich, "Outcomes of Homeless Adults with Mental Illness in a Housing Program and in Case Management only," *Psychiatric Services* 54 no. 1 (2003): 78-83, doi:10.1176/appi.ps.54.1.78.
- <sup>160</sup> Nath *et al.*, "Predictors of Health Services."
- <sup>161</sup> Gregory J. McHugo *et al.*, "A Randomized Controlled Trial of Integrated Versus Parallel Housing Services for Homeless Adults with Severe Mental Illness," *Schizophrenia Bulletin* 30 no. 4 (2004): 969-982.
- <sup>162</sup> Wally Barr *et al.*, "How effective?"
- <sup>163</sup> Grant and Westhues, "Choice and outcomes."
- <sup>164</sup> Duvdevany, Ben-Zur, and Ambar, "Self-determination."
- <sup>165</sup> Gardner and Carran, "Attainment of personal outcomes."

- 
- <sup>166</sup> Stancliffe *et al.*, “Adults with Intellectual and Developmental Disabilities.”
- <sup>167</sup> *Ibid.*
- <sup>168</sup> Rah Kyung Kim and Stacy K. Dymond, “A National Study of Community Living: Impact by Type of Residence and Hours of In-Home Support,” *Research and Practice for Persons with Severe Disabilities* 37 (2012): 116-129.
- <sup>169</sup> Lakin *et al.*, “Choice-making.”
- <sup>170</sup> Tichá *et al.*, “Correlates of everyday choice.”
- <sup>171</sup> H. Stephen Leff *et al.*, “Does one size fit?”; Stefancic and Tsemberis, “Housing for Shelter Dwellers.”
- <sup>172</sup> Clark and Rich, “Outcomes of Homeless Adults.”
- <sup>173</sup> *Ibid.*
- <sup>174</sup> Russell K. Schutt and Stephen M. Goldfinger, “Fundamental Causes of Housing Loss among Persons Diagnosed with Serious and Persistent Mental Illness: A theoretically guided test,” *Asian Journal of Psychiatry* 2 no. 4 (2009): 132-138, doi:10.1016/j.ajp.2009.10.006.
- <sup>175</sup> Mares, Kaspro, and Rosenheck, “Outcomes of Supported Housing.”
- <sup>176</sup> *Ibid.*
- <sup>177</sup> Patterson, Moniruzzaman, and Somers, “Community participation and belonging.”
- <sup>178</sup> National Alliance to End Homelessness, “What is Housing First Solutions Brief” (2006), accessed February 2015, <http://www.endhomelessness.org/library/entry/what-is-housing-first>.
- <sup>179</sup> Lakin *et al.*, “Choice-making.”
- <sup>180</sup> Tichá *et al.* “Correlates of everyday choice.”
- <sup>181</sup> *Ibid.*
- <sup>182</sup> Stancliffe *et al.*, “Satisfaction among Medicaid recipients.”
- <sup>183</sup> Samuel R. Bagenstos, *Law and the Contradictions of the Disability Rights Movement*. (New Haven, CT: Yale University Press, 2009).
- <sup>184</sup> Moseley, “ADA, Olmstead, and Medicaid.”

---

<sup>185</sup> “Olmstead Enforcement: Investigation of the Commonwealth of Virginia’s Compliance with the Americans with Disabilities Act and of Central Virginia Training Center,” United States Department of Justice, Letter of Findings, Commonwealth of Virginia (2011), accessed February 2015, [http://www.ada.gov/olmstead/documents/virginia\\_findings.pdf](http://www.ada.gov/olmstead/documents/virginia_findings.pdf).

<sup>186</sup> Ibid. 5, Endnote 3.

<sup>187</sup> *United States Department of Justice v. Delaware*, Settlement Agreement, July 15, 2011.

<sup>188</sup> U.S. Department of Health and Human Services Centers for Medicare & Medicaid Services, State Medicaid Director Letter, Guidance on Olmstead (2000), accessed February 2015, <http://downloads.cms.gov/cmsgov/archived-downloads/SMDL/downloads/smd011400c.pdf>.

<sup>189</sup> Centers for Medicare & Medicaid Services, State Medicaid Director Letter, July 25, 2000, accessed February 2015, <http://www.medicaid.gov/Federal-Policy-Guidance/downloads/smd072500a.pdf>.

<sup>190</sup> Preamble to the final rule, Federal Register, Vol. 79, January 16, 2014.

<sup>191</sup> 42 CFR 441.201(c)(4).

<sup>192</sup> 42 U.S.C. § 1396.

<sup>193</sup> National Council on Disability (NCD), “Inclusive Livable Communities for Individuals with Psychiatric Disabilities,”

<sup>194</sup> Barrows *et al.*, “Keeping the Promise.”

<sup>195</sup> Ibid.

<sup>196</sup> Ibid.