

Community-Based Residential Alternatives for Persons with Intellectual and Developmental Disabilities: Current Practices, Trends and Issues

Suhui Li
Department of Health Policy
Milken Institute School of Public Health
The George Washington University

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This report is prepared by Suhui Li, an assistant professor at the Department of Health Policy in the George Washington University, Milken Institute School of Public Health. She is an applied health economist who specializes in quantitative analysis of public health policies. Before joining the GW, she has worked at Mathematica Policy Research and has earned a Ph.D. degree in Economics from Lehigh University.

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Executive Summary

Today, more than 6 million American adults (2.8% of population) with intellectual and other developmental disabilities (I/DD) rely on long-term services and supports (LTSS) from their communities. Persons with I/DD used to primarily live in public long-term care institutes, which were almost entirely segregated from society prior to the 1970s. As LTSS have evolved over time, they have become more concentrated on integrating people with disabilities into the community. As a result, an increasing amount of people with disability have transitioned to non-institutional care.

The trend in LTSS deinstitutionalization has been supported by the federal government through strong legislation, most notably the establishment of the Medicaid Home and Community-Based Services (HCBS) Waiver program. Currently, all state Medicaid programs receive HCBS funding to offer people LTSS outside of institutional settings. This initiative has spurred rapid growth in the number of community residential options designed to accommodate fewer persons, including group homes, small-size community based Intermediate Care Facilities, apartments, and host homes/foster care.

This report provides an overview of the community-based residential supports available for people with I/DD, reviews the cost-effectiveness of various residential alternatives, and discusses key challenges in providing I/DD services that the federal and state governments, as well as the private LTSS industry, continue to grapple with.

Current patterns and trends

Residential Settings. There is a rising trend in use of smaller residential settings. Nationwide, the average number of residents with I/DD in a residential setting declined steadily from 22.5 residents in 1977 to 2.3 in 2011. Living arrangements vary considerably by level of staff support, frequency of social activities, cost, and accommodations, etc. As of 2011, the most prominent type of residential setting is the family home, followed by congregate home/agency operated housing, and own home. The design of state HCBS waiver programs plays an important role in how people access different residential options.

Expenditures. The expansion of state HCBS programs has not only substituted for some intermediate care facilities for the intellectually disabled (ICF-ID) services, but has also increased service utilization for Medicaid enrollees who would otherwise not receive LTSS benefits. Though HCBS programs are less costly than institutional services on a per-participant basis, the growth of total LTSS costs for people with I/DD has not slowed with the development of HCBS programs. In many states, the growth of HCBS expenditures has offset the cost-savings from reduced ICF-ID expenditures. Further, the dramatic cross-state variation in the per-person HCBS expenditure calls for more research to determine whether HCBS programs have added better value for the money spent.

Cost-effectiveness. While evidence consistently supports the notion that institutional services have higher per person costs than smaller residential settings, little empirical research has

been conducted to compare the relative costs and outcomes between various community residential settings. Some studies suggest that the more individualized the services are—the more cost-effective the living arrangement may be. Overall, more research is needed to evaluate the settings and identify key aspects that influence cost and resident outcomes.

Challenges

Medicaid spending. Despite the growing utilization of waiver services for people with I/DD, the long-term financial sustainability of the current system is unclear. Between 2000 and 2011, total federal HCBS expenditures increased by almost three folds from \$9.66 billion to \$27.92 billion, outpacing the growth of total Medicaid expenditures. In 2011, the proportion of HCBS expenditures reached 7.02 percent of total Medicaid expenditures compared to 4.97 percent in 2000.

Waiting lists. On average, people with I/DD wait approximately 40 months on a wait list to receive waiver benefits, compared to other targeted groups that spend only 2 to 26 months waiting. Long wait lists highlight the substantial need for and access to I/DD residential services. However, given the tightened capacity of HCBS programs, further expansions do not seem feasible. States should focus efforts on reducing per person HCBS spending in order to serve more people within their current capacity.

Identifying the Best Residential Model. Experts have not yet determined the optimal residential model for producing best outcomes in the most cost-effective manner; nor is there a consensus, at the federal or state level, on the optimal residential settings for people with different levels of needs. Identifying the best residential setting is challenging given the ever-changing environment of I/DD diagnosis and the extreme state-to-state variation in funding and utilization of residential settings.

Quality measures. At the national level, there is currently no single quality measurement system implemented for care provided to persons with I/DD who live in community settings. The considerable variation in state HCBS programs, the lack of federal quality regulations, and the increased use of consumer-directed plans contributes to the barriers in defining and implementing HCBS quality standards on a national scale.

Industry viability. First, there is an extreme shortage of direct-support providers (DSPs) caring for people with I/DD in community residential settings. Providers have long struggled to recruit and retain their staff, primarily because the compensation (including wages and fringe benefits) of community support staff are consistently lower than that of institutional staff members. Second, as states move towards performance-based reimbursement approaches, the lack of risk-assessment tools tied to reimbursement adds to providers' financial risk. Third, some states have pursued a "one size fits all" approach to reduce the size of existing residences. Such policies may result in loss of properties from the service delivery system.

I. Introduction

Today, more than 6 million American adults (2.8% of population) with intellectual and other developmental disabilities (I/DD) rely on long-term services and supports (LTSS) from their communities.¹ Persons with I/DD used to primarily live in public long-term care institutes, which were almost entirely segregated from society prior to the 1970s. As LTSS have evolved over time, they have become more concentrated on integrating people with disabilities into the community. In the past three decades, there has been an upward trend in the utilization of home and community-based residential alternatives as states develop and expand their home and community-based services (HCBS). The total Medicaid HCBS expenditures on persons with I/DD have more than doubled from 10.9 billion in 2001 to 27.9 billion in 2011.² As the American population ages, the nation's demand for community-based residential services is likely to grow, creating uncertainty about the financial sustainability of state Medicaid programs in the near future.

On January 16th, 2014, The Centers for Medicare and Medicaid Services (CMS) issued a final rule regarding Medicaid HCBS regulation. The rule, as part of the Affordable Care Act (ACA), is intended to insure that HCBS program participants have full access to the benefits of community living and are able to receive services in the most integrated setting. Among other provisions, the rule outlines a more outcome-oriented definition of home and community-based settings, rather than based solely on a setting's location, geography, or physical characteristics. While the final rule has offered states more flexibility on how they expand HCBS programs, some states are instead moving toward a "one size fits all" approach that would abandon certain existing residential alternatives (e.g., group homes with 4 or more beds). As states seek to meet the home and community-based setting requirements according to the new rules, it is increasingly important to understand the costs and effectiveness of different residential settings for individuals with different needs, as well as the potential impacts of policies on HCBS providers.

This report provides an overview of the community-based residential supports available for people with I/DD, reviews the cost-effectiveness of various residential alternatives, and discusses key challenges in providing I/DD services that the federal and state governments, as well as the private LTSS industry, continue to grapple with.

II. Trends and Patterns of Residential Settings

A. Residential Size and Living Arrangements

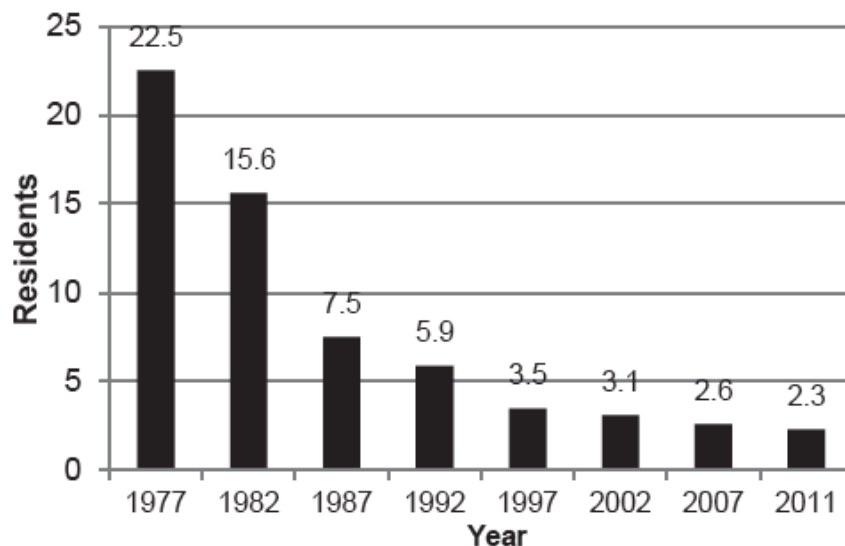
Moving LTSS from institutional to community-based settings has been an increasing trend since the 1970s, as states work to enhance the quality of services while control LTSS spending. The trend of deinstitutionalization has been supported by the federal government through the passage of the Americans with Disabilities Act of 1990, the Developmental Disabilities Assistance and Bill of Rights Act of 2000, and a series of other policies. In the mid-1980s, Medicaid, which had traditionally covered services almost exclusively in institutional settings, started to fund LTSS outside of institutions through what are know as Medicaid HCBS Waiver programs.

These efforts have led to greater availability of private-operated small, community homes, and massive closures of large state-operated residential facilities. A 2011 report found that between 1960 and 2011, 60 percent of prominent state-operated facilities for individuals with I/DD have closed, and more are predicted to shut. Eleven states have closed all of their large residential

settings that house 16 or more people with I/DD, and only three states have 10 or more state-operated facilities still serving more than 16 residents.³

On the other hand, there is a rising trend in the use of smaller residential settings. Today, there are nearly 200,000 residential settings housing people with I/DD, and the average size of an I/DD setting is rapidly decreasing.⁴ In 1977, the majority of people with I/DD lived in large, state-operated institutions, and only 40,400 individuals lived in a setting with 15 or fewer residents. In 2005, this figure exploded to over 344,100 individuals, with nearly all growth being concentrated in settings of six or fewer people.⁵ Nationwide, the average number of residents with I/DD in a residential setting declined steadily from 22.5 in 1977 to 2.3 in 2011 (Figure 1). Ninety percent of individuals with I/DD now live in a setting with 15 or fewer people, 75 percent of which reside in settings of six or fewer residents and 49 percent in settings of three or fewer residents.⁶ This shift from large institutions to small residential facilities is present in varying degrees across the country. In Delaware and Maryland, above 92 percent of people with I/DD live in settings of six or fewer, compared to only 60 percent of residents in Virginia.⁷

Figure 1.
Average Number of Residents with I/DD Per Residential Setting, 1977 - 2011



Source: Larson et al, 2013.⁸

There is also tremendous variation in living arrangements for individuals with I/DD. Settings differ based on the level of staff support, frequency of social activities, cost, and accommodations, to name a few. Individuals are often placed in settings based on the degree of need and support sought. In 2010, 631,436 individuals lived in a home with their family, 126,998 lived in a home they leased or owned, 44,457 lived with a host or foster care family, and 290,010 lived in congregate care or another setting. Family support housing is one of the fastest growing models today, in large part due to Medicaid HCBS waivers that allow families to obtain reimbursements from state funds. Of the HCBS recipients living in a residential facility, 51 percent live in a home shared with a family member.⁹ As witnessed in the past, large state institutions continue to care for a majority of residents with severe or profound I/DD.¹⁰

B. The Impacts of HCBS Waivers on Access to Residential Support

The Medicaid HCBS waiver program was designed to help states finance non-institutional services for Medicaid-eligible people who are at risk of being placed in a long-term care facility such as a nursing home or large intermediate care facilities for the intellectually disabled (ICF-IDs) housing 16 or more people. Since the enactment of the program in 1981, all states have received authorization to provide home and community based services as an alternative to institutional care.¹¹ In 1982, there were only 1,381 HCBS waiver recipients, and by 2011, there were an estimated 616,491.¹² Despite the remarkable growth in overall utilization of HCBS waivers, states vary drastically in their adoption. In 2008, the nation average for HCBS utilization was 172.7 per 100,000 residents, yet five states had more than doubled the national average and five states had less than half the national average.¹³

Waiver programs are typically designed to target a specific population, based on group or geographic factors, and eligibility is determined by state requirements. Because waivers grant states the flexibility to be innovative in their designs under broad federal requirements, there is a wide range of variation in state HCBS waivers, creating substantial inequities in access to HCBS amenities across states. Some states have very few criteria for participation and allow thousands of Medicaid beneficiaries to enroll, while other states set conditions for waivers permitting their use only in settings where the number of residents with I/DD is capped.¹⁴ Waiver utilization is also heavily dictated by state investment in the HCBS program.

In addition to variation in eligibility, waiver programs also differ in type, number of participants, cost, and services. In 2009, the National Council on Disability reported that 48 states plus the District of Columbia offered over 125 HCBS waiver programs for persons with I/DD.¹⁵ Though waivers have become more accessible, individuals still only have access to the supports available in their state, and payments for HCBS programs diverge considerably across the country.¹⁶ A 2010 report by CMS found that the relative size of HCBS programs fluctuated largely across states. HCBS expenditures accounted for anywhere between 13 to 59 percent of a state's long-term care spending, and states that allotted a high percentage of long-term care spending to HCBS programs tended to serve a larger proportion of elderly and nonelderly participants with disabilities, more long-term care users, and were more likely to offer state plans.¹⁷

III. Cost-Effectiveness of Residential Settings: Regarding Size and Type

Along with the nationwide objection of large institutions, it is widely believed that “diseconomy of scale” is present in long-term residential care, meaning that the efficiency declines when the facility becomes too large. Indeed, evidence consistently supports the notion that institutional services have higher per person costs than smaller residential settings. On average, institutions cost 5 to 27 percent more than community-based homes, and yet participant outcomes tend to be poorer in institutional settings.¹⁸ Equally concerning is the fact that as an institutional population decreases in size, the cost per person of operating the institution increases. One study found that the annual cost for residence in an institution more than doubled between 2005 and 2007.¹⁹ A 2009 study echoed these findings, estimating that the average annual cost per person with I/DD in an institutional setting was \$115,830 compared to \$96,010 in a community residence. The study found that those in a community setting benefitted from improved community integration and additional hours of staff support, at a lower cost.²⁰

While it is clear that community-based residential settings are a more cost effective option than institutions, little research has been done in this area to definitively state what residential setting is the most cost-effective. A 2010 study found that although HCBS appears to be less costly than community ICFs-ID (with 4-15 residents), comparing the costs of HCBS and ICF-ID settings is difficult due to differences in financing approaches.²¹ Researchers point out that ICFs-ID expenditure may be explained by artificially inflated institutional costs resulting from deinstitutionalization. On the other hand, HCBS expenditure may be underestimated because “day program” costs are more likely to be covered by educational agencies and HCBS recipients rely more on non-paid informal care.

There is mixed evidence regarding the outcome differences between community residential sizes. A number of observational and synthetic studies found no “economy of scale” in smaller settings, concluding that there is little association between residential size and residents’ quality of life when resident’s ability level is controlled for.^{22 23 24} More recently however, researchers at the University of Minnesota analyzed self-reported lifestyle quality in six states and found that residents of smaller settings, especially 1-2 person homes, are more likely to report liking where they live and having more freedom for personal and support-related choice.^{25 26} Others report that a four to six resident threshold exists, where settings with more than four residents start to witness diminishing returns on outcomes.²⁷ No consistent size-related outcome data has been reported thus far, though some settings have been able to measure resident improvement on a case-by-case basis.

Studies of outcome differences between residential types demonstrate that each residential setting has its own strengths and disadvantages. Researchers consistently found that residents of semi-independent households experience better outcomes in some, but not all measures, than those living in group homes with full-time staffing.^{28 29} For example, one study shows that semi-independent living residents had better outcomes for choice and community activities.³⁰ On the other hand, another study showed that people living in host family and family home (most of who have semi-independent living) are most likely to forego preventive health exams and procedures.³¹ This evidence suggests that type of living arrangement can affect an individual’s access to health services, in addition to their daily living activities.

Researchers also found that supported living, which involves living independently in one’s own or rented home, provides residents greater control of choices compared with other residential settings.³² However, supported living is also more expensive than semi-independent and group-home living.³³ Thus, the relative cost-effectiveness of independent living is not clear. Such setting may be beneficial to people with mild to moderate I/DD, but not for those with severe or profound I/DD.

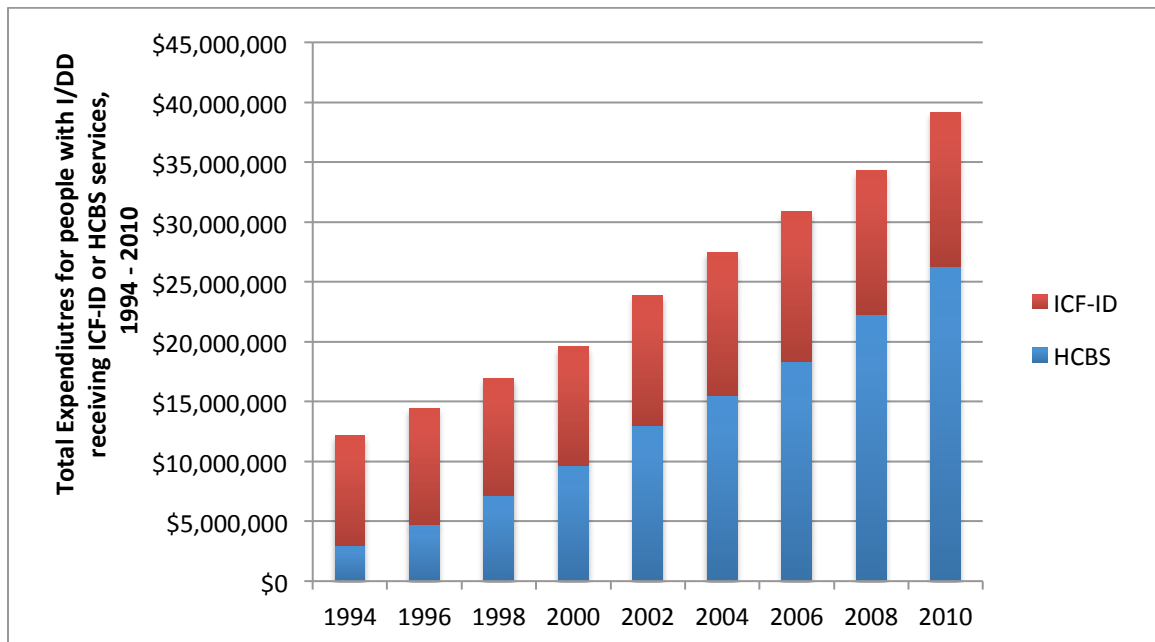
Overall, the literature does not provide clear evidence that any residential size or type is more preferable than others. Existing studies show conflicting evidence on the benefits and drawbacks of different residential settings. More research is needed to evaluate the settings and identify key aspects that influence cost and resident outcomes. In addition, currently few people with I/DD make decisions about where and with whom to live, especially those with more severe intellectual disability.³⁴ Therefore, at least in the short run, policy makers should focus on providing people with more choice of arrangement, rather than arbitrarily limiting certain types of residential settings.

IV. The Costs of Community Residential Services under HCBS Waiver Programs

The total number of HCBS recipients has increased steadily over time, with the growth varying significantly by state. Between 2001 and 2011, the number of Medicaid HCBS waiver recipients with I/DD rose by 88 percent from 327,941 to 616,491. Accordingly, the total HCBS expenditures for persons with I/DD reached \$27.9 billion, an increase of 156 percent from \$10.9 billion in 2001. In contrast, the number of residents in ICF-IDs declined gradually, slowing the growth of total ICF-ID expenditures.³⁵

The expansion of state HCBS programs has not only substituted for some ICF-ID services, but has also increased service utilization for Medicaid enrollees who would otherwise do not receive LTSS benefits. Despite the evidence that HCBS programs are less costly than institutional services on a per-participant basis,^{36 37} the growth of total LTSS costs for people with I/DD has not slowed down with the development of state HCBS programs (Figure 2). In many states, the growth of HCBS expenditures has offset the cost savings from reduced ICF-ID expenditures.

Figure 2.
Total Expenditures for people with I/DD receiving ICF-ID or HCBS services, 1994 – 2010

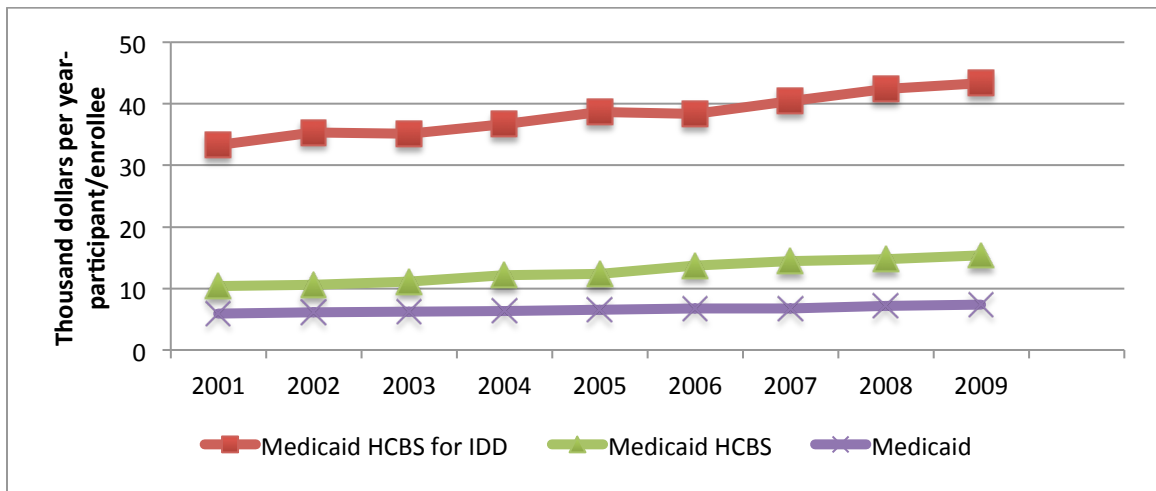


Source: Analysis of data from Larson et al., 2013³⁸

As the size and total expenditures of HCBS programs rise, it is important to examine the trend of expenditures per recipient. Figure 3 shows that between 2001 and 2009, national average HCBS expenditures per recipient with I/DD climbed steadily by 36 percent from \$33,310 to \$45,290 per year. This growth outpaced the 27 percent increase in Medicaid spending per enrollee during the same period.³⁹ Such finding indicates that the average spending per person with I/DD grew more rapidly than the average spending of other HCBS target populations as well as non-HCBS Medicaid enrollees.

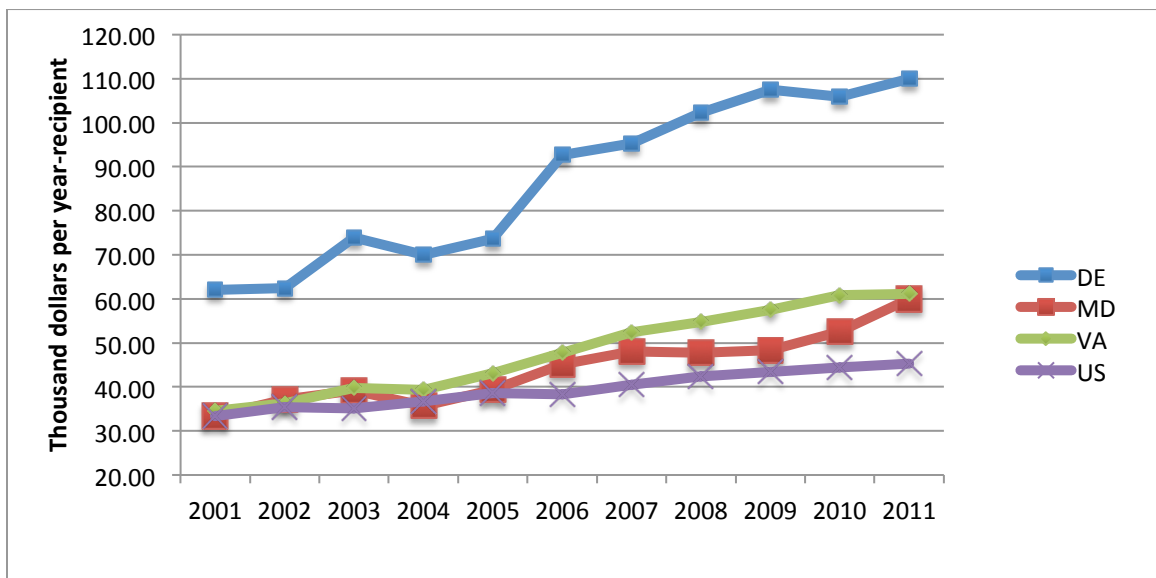
Wide variation exists in the level and growth of per-resident HCBS spending across states. The annual HCBS expenditure per-resident with I/DD in 2011 was as low as \$19,399 in Mississippi, and as high as \$109,900 in Delaware.⁴⁰ Since 2000, per-resident expenditures in Delaware have been double the national average (Figure 4). In Maryland and Virginia, the per-resident expenditures remained relatively low in the early 2000s, but have since exceeded the national average with more rapid growth in recent years. Such variation calls for more research to determine whether HCBS programs have added better value for the money spent.

Figure 3.
Medicaid Spending Per Enrollee, Per HCBS Participant, and Per HCBS Participant with I/DD, 2001-2009



Source: Analysis of data from Larson et al., 2013⁴¹; Urban Institute, 2012⁴²; Kaiser, 2012⁴³.

Figure 4.
Expenditures Per Year-Recipient with I/DD in the U.S. and Selected States, 2001-2011



Source: Analysis of data from Larson et al., 2013⁴⁴

The cross-state variation in HCBS costs correlates with demographic factors, case-mix of participants, and state HCBS policies. In general, states with higher per person HCBS expenditures tend to have larger populations aged 85 or older, higher personal income per capita,⁴⁵ and use relatively more formal versus informal care.⁴⁶ On average, participants with a higher level of intellectual disability, who need more frequent medical care, who have limited mobility or vision, and who are diagnosed with autism have more staffing needs and thus higher expenditures.⁴⁷ Comparisons across types of residential settings suggest that even after adjusting for the level of need, residents living in their own home cost significantly more than those living in group homes, host families, or family homes.⁴⁸ While no study has examined the association of state average HCBS expenditure and the composition of residential types, it is reasonable to believe based on current evidence that HCBS programs with higher percentages of persons with I/DD living in their own homes tend to have higher average expenditures.

State cost containment policies may also have an impact on average HCBS expenditures, the most profound being Medicaid eligibility standards and reimbursement methods. In addition to providing Medicaid coverage to people who meet the applicable financial standards, states may choose to expand Medicaid eligibility to the medically needy (those who “spend down” to Medicaid eligibility levels because of medical expenses). In 2011, medically needy were covered in 33 states with home health programs and 19 states with personal care programs.⁴⁹ States that have higher eligibility criteria for the medically needy and that use relatively more generous reimbursement methods for the Medicaid home health program (which usually also have more generous HCBS payment rates) have higher HCBS spending per participant.⁵⁰

V. Challenges of the Current System

A. Unsustainable Medicaid Spending on LTSS for People with I/DD

Despite the growing utilization of waiver services for people with I/DD, the long-term financial sustainability of the current system is unclear. Home and community-based services for persons with I/DD account for a considerable and disproportionate share of total Medicaid HCBS expenditures. In 2009, 42 percent of HCBS participants were persons with I/DD, and they consumed 72 percent of total HCBS expenditures.⁵¹

Between 2000 and 2011, the total federal HCBS expenditures by increased almost three fold from \$9.66 billion to \$27.92 billion, outpacing the growth total Medicaid expenditures.⁵² In 2011, the proportion of HCBS expenditures reached 7.02 percent of total Medicaid expenditures compared to 4.97 percent in 2000 (Figure 5). The continuing trend of transitioning from institutional to less costly, community-based settings has not slowed the total expenditure of long-term care for people with I/DD. The combined ICF-ID and HCBS expenditures continue to grow at a steady rate, accounting for roughly 10 percent of total Medicaid expenditures. As previously noted, the growth of total HCBS expenditures is attributed to increases in both utilization and per-resident cost of HCBS services. Further, even though the size of institutional populations is decreasing, states still have to invest in their ICF-ID facilities and maintain an appropriate staffing ratio, while also expanding funding for HCBS programs. This can create financial challenges in realizing savings and often leads states to significantly downsize staffing or close institutions.

Figure 5.
Expenditures of ICF-ID and HCBS Programs for Persons with I/DD as a Proportion of Total Federal Medicaid Expenditures, 2000-2011



Source: Analysis of data from Larson et al., 2013⁵³

B. Growing Demand and Long Waiting Lists

Between 1991 and 2002, the demand for I/DD residential services grew by nearly 37 percent, and left 60,000 individuals on a waitlist for placement in a residential setting. Service utilization increased by almost 20 percent and lack of access to services spurred a national crisis.⁵⁴ In 2007, the number of U.S. households with one or more people living with a disability increased to one-third,⁵⁵ and there are now over seven million individuals in the U.S. with an I/DD.⁵⁶ U.S. Department of Health and Human Service's Office of Disability, Aging and Long-Term Care Policy estimates that the direct support professional (DSP) workforce will need to grow by 37 percent by 2020 in order to account for this growing demand. Officials attribute the high demand to five pressing factors:

1. A growing population;
2. Increased prevalence of I/DD;
3. Increasing life expectancy of individuals with I/DD
4. The aging of family caregiver; and
5. A national commitment to expanding services for people with I/DD.⁵⁷

This commitment is becoming more apparent as the number of publically funded beneficiaries with I/DD escalates, and the pool of non-institutional services expands.⁵⁸

The increasing number of eligible people that need residential services but that cannot obtain support reflects the widening gap in need for and access to I/DD residential services. Faced with the growing burden of financing waiver programs for people with I/DD, many states have had to contain costs by putting more eligible people in need of services on waiting lists. In 2011, 41 states reported that 73,106 individuals with I/DD were on waiting lists.⁵⁹ The number of people with I/DD was significantly greater than that of other targeted groups (i.e., aged or disabled), making up of 62 percent of all Medicaid eligible beneficiaries on waiver wait lists. This proportion

was much lower in 2004 (45%).⁶⁰ On average, people with I/DD wait approximately 40 months on a wait list to receive waiver benefits, compared to other targeted groups that spend only 2 to 26 months waiting.⁶¹

In 2011, it was estimated that states would need to expand their residential service capacity by 16.6 percent in order to meet the needs of every person with I/DD on waiting lists. The percentage of unmet need in DE, MD, and VA was estimated to be 8.1, 43.8, and 52.1 percent, respectively.⁶² Given the constrained capacity of HCBS programs, further expansions seem unfeasible. Instead, states should focus on reducing per person HCBS spending as a way to serve more people under the current capacity.

C. Challenges in Identifying the Best Residential Model

Experts have not yet determined the optimal residential model for producing best outcomes in the most cost-effective manner. Identifying the best residential setting is challenging given the ever-changing environment of I/DD diagnosis and the extreme state-to-state variation in funding and utilization of residential settings.

First, it is nearly impossible to group persons with I/DD into categories of needed care and residence, and to do so would be making vast generalizations. Every individual with an I/DD is unique and requires varying levels of support. Adults with I/DD differ not only in residential placement, but also in personal characteristics, such as age, level of I/DD, and mobility.⁶³ An individual with moderate I/DD may find success in developing functional skills in a semi-independent living setting, while the same setting may instigate feelings of loneliness for another individual with a similar degree of I/DD. It can be exceedingly challenging to compare residential models when personal characteristics fall across such a wide-spectrum, especially when states radically differ in the proportion of residents with a behavior or developmental condition.⁶⁴

Another challenge in pinpointing the ideal model is the extent to which residential settings differ in type, staffing, scope of practice, and mission. There are numerous residential settings for people with I/DD across the country, and they decisively vary in levels of support in order to meet the needs and preferences of their populations. Supported living arrangements strive to provide individualized services to enhance community integration, while group homes aim to provide intensive supervision for the protection of residents with severe I/DD.⁶⁵ As noted above, though both offer settings for individuals with I/DD, they have distinct goals that are not easily compared on one measure. Differences in size are then influenced by service type or staffing commitments, and hardly any studies have been able to tease out the impact of such factors on cost and outcomes.⁶⁶

By nature, there are a number of confounding factors that cloud residential model comparisons. The workforce aiding people with I/DD has long suffered from staff recruitment problems. In a climate of high turnover, low pay, and lack of training, staff competence and retention present a major barrier in ensuring quality services in residential settings.⁶⁷ While some states have made great strides in improving workforce conditions and indirectly bettering residential models, other states struggle to find the right balance to accommodate the growing demand for I/DD services. Workforce issues therefore interfere in evaluating optimal settings, as some facilities may bear a heavier burden in stabilizing staff requirements. Another influencing factor is the role of quality and evaluation. Community services and supports are held to different quality performance benchmarks, and there is no standardization for assessing residential settings across a consistent set of criteria.⁶⁸ For this reason, very little is known about the quality of life in

many settings, particularly for those residing in federal housing,⁶⁹ and it is difficult to appraise models that meet one set of standards, but fail on others.

Overwhelmingly, the biggest challenge in identifying the best residential model is the lack of research that currently exists in the field. There is little research to support one setting over another and only conflicting evidence persists. Though much has been published on the transition from institutional to smaller, community-based settings, there is insufficient literature on the impact of community residential size and living arrangement on resident health outcomes.⁷⁰

D. Challenges in Adopting National Standard Quality Measures

Having a set of consistent, valid, and reliable outcome measures is critical to ensuring quality improvement. From a provider's perspective, adopting and using such measures allows them to monitor their services and make timely improvements on specific quality dimensions. From a state Medicaid HCBS program's perspective, information about provider quality helps them to identify high-performance providers for contracting purposes, and to evaluate the impacts of changes in state policies such as eligibility criteria and HCBS reimbursement methods. Given the dramatic geographic variation in HCBS expenditures, a uniform outcome measures system comparing the quality and cost-effectiveness of HCBS programs across states is greatly needed.

Currently, no single measurement system is implemented nationwide. The National Core Indicators (NCI) is perhaps the most widely used performance and outcome measurement tool for developmental disability care in the US, currently adopted by 38 states and the District of Columbia. Collaboratively developed by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI), the NCI provides a wide array of quality indicators concerning five domains: service planning inclusion, employment, choice, health, and safety. Participating agencies follow NCI data collection protocols to gather information about the performance of HCBS for people with I/DD, which is then used to inform LTSS policies and quality assurance activities. A 2013 report found that some states have adopted other survey tools such as the Participant Experience Survey (PES) for HCBS elderly and disabled beneficiaries, Wisconsin's "Personal Experience Outcomes Integrated Interview and Evaluation System (PEONIES)," and Personal Outcome Measures developed by the Council on Quality and Leadership (CQL).⁷¹

Synthetic research suggests that there is a significant lack of information on HCBS quality. The majority of quality research is focused on the comparison of institutional versus non-institutional care,^{72 73} while considerably less knowledge is available on actual outcome and performance standards across different community-based settings and HCBS programs. In an effort to assess the quality of Medicaid HCBS programs nationwide, the Agency for Healthcare Research and Quality (AHRQ) recently conducted a comprehensive environmental scan of potential HCBS measures relating to the domains of client functioning, client satisfaction, and program performance. Within these domains, 21 measures were identified as relevant, meaningful aspects of HCBS quality services. However, the Agency concluded that none of the existing measurement systems comprehensively addressed all 21 quality dimensions. For specific populations like people with intellectual disabilities, very few tested and reliable measures are available.⁷⁴

Several other studies suggest that the development and standardization of outcome measures for HCBS is far behind those of hospital and nursing home settings.^{75 76} Scientifically validated health outcome measures, such as patient's weight, blood pressure, and cholesterol level, are being used nationwide in acute care. However, given the nature of LTSS, outcome measures for

HCBS need to go beyond biometric clinical indicators and cover other domains such as community engagement, cultural competence, and client satisfaction. Unfortunately, only a few measures have been developed that apply to individuals transitioning from clinical to community-based settings; and even fewer are designed specifically for persons with I/DD who live in community settings.

There are a number of barriers to defining and implementing HCBS quality standards on a national scale. As noted above, states design and run their own residential programs, offer diverse services, invest unevenly in institutional versus non-institutional settings, and set HCBS eligibility requirements based on their own criteria.⁷⁷ Consequently, HCBS programs vary in their participants' level of needs, service packages, and mixes of formal and informal supports, making cross-state comparisons difficult. In addition, community-based services are often furnished among widely dispersed locations arranging from person's home to clinics and schools. When services are rendered by multiple providers, which is not uncommon, it can be extremely challenging to gather data on quality and attribute quality to any single component of the service.⁷⁸ These obstacles are tough to overcome and make it hard to identify where success is occurring and why.

Furthermore, current federal regulation does not provide sufficient incentive for states to collect HCBS quality information. Except for an annual report on enrollment and cost summary, CMS does not require any reporting on the quality of waiver programs.⁷⁹ The only time that CMS reviews performance is when states apply for re-authorization of the waiver, which occurs only every three or five years. In comparison, nursing homes subject to both federal and state scrutiny are mandated to report quality information through the federal database, Minimum Data Set (MDS), which uses uniform survey tools across all states. To strengthen HCBS quality monitoring, the federal government should reinstate requirements on regular quality reporting by states.

The rise of consumer-directed plans in recent years has presented another challenge in quality measurement. The 2014 CMS final rule on HCBS waivers requires that states must offer the choice of person-centered planning, which allows individuals, rather than health care agencies, to manage their benefit funds and arrange their supportive services.⁸⁰ While such plans may achieve high satisfaction among some beneficiaries for highly individualized options⁸¹, they also tend to dampen quality monitoring for the exact same reason.

The ACA provides new opportunities to align HCBS quality measurements across states. The State Balancing Incentive Payments (BIP) program was created by CMS to help states to undertake specific reforms to increase nursing home diversion and access to HCBS between 2012 and 2015. Aiming to improve quality measures and oversight through this program, CMS requires participating states to collect data on core quality measures that are linked to population-specific health outcomes, beneficiary and caregiver experience with providers, and satisfaction with services.⁸² With an increased emphasis on data reporting and performance evaluation by the federal government, more robust quality information can be expected in the future.

E. The Long-Term Viability of the Industry

Challenges around the growing service costs, widening demand gaps, and lack of reliable risk adjustment tools also threaten the long-term viability of the provider industry. Perhaps the most pressing challenge that community residential service providers face is the shortage of direct-support providers (DSPs) caring for people with I/DD. Virtually all Medicaid community residential services are provided by private-operated agencies. Private providers have long struggled to recruit and retain their staff, primarily because the compensation (including wages and fringe benefits) of community support staff is consistently lower than that of institutional staff members.⁸³ In 2009,

the average hourly wage was \$10.14 for private-operated providers (virtually all providing community-based services), compared to \$15.53 for state-operated providers.⁸⁴ For the same reason, private providers are more likely to seek professional opportunities where they can recoup their investment in training. These workers tend to circulate into higher-paid jobs at state-run institutional facilities once they have been fully trained at community-based settings.

A 2006 report to Congress by the Office of the Assistant Secretary for Planning and Evaluation (ASPE) highlighted the looming direct-support workforce crisis. It was estimated that the demand for full-time workers assisting people with I/DD would grow by 37 percent to 1.2 million by 2020, while the number of workers providing such support was expected to grow by only 7 percent.⁸⁵ Between 2000 and 2007, the national average turnover rate was 50 percent in residential services and 65 percent in in-home services.⁸⁶ Studies have consistently found considerably higher turnover rates in community-based services relative to institutional services, again citing the vast discrepancies in compensation.^{87 88} High turnover rates impose major fiscal burdens on providers as they contribute to increased costs in staff recruitment, training, and overtime pay.

Both federal and state governments have endorsed considerable efforts to address the DSP shortage problem. A recent example is the 2013 Department of Labor ruling to apply the Fair Labor Standards Act to domestic service. This policy extends the minimum wage and overtime provisions to nearly two million home health and personal care workers.⁸⁹ In the past decade, the unionization of direct-support workers in the private sector has also experienced growing influence, although this is somewhat controversial among private providers, advocacy groups, and policy makers.⁹⁰ Union supporters claim that DSPs currently are undervalued; unionization would effectively increase wages and benefits, leading to lower turnover and vacancy rates. On the other hand, opponents argue that unionization would jeopardize many private home health agencies, who already operate on tight budgets and simply cannot afford to offer workers higher wages.⁹¹ Such conundrum has been reported in a case study of unionization among south Florida nursing homes, where a manager said “We are very pro-worker, but when a union comes in they can’t do anything about the wage base or benefit base. ... I do believe that most union reps are sincere and see it as a service, [but] they promise what they can’t deliver. ... These people have very hard jobs, [but] the government has not done a good job to keep up reimbursement rates to keep wages up.”⁹² Concerns from both sides are real, and any policy favoring one side over the other is likely to cause further distortion in the DSP labor market. Therefore, unionization efforts should be paralleled with policies that support increased funding for DSP compensations.

Another barrier to the development of the community-based service industry is the lack of risk-assessment tools that are tied to reimbursement. Medicaid LTSS is undergoing a significant transition from a fee-for-service (FFS) payment approach, which rewards a higher volume of services, to performance-based alternative approaches. Increasingly more states are looking to adopt managed care arrangements for their Medicaid LTSS participants, including people with I/DD. Unlike traditional Medicaid services that use a FFS payment, managed care organizations (MCOs) often use some form of capitated payment, in which providers are paid a fixed amount per client over a certain period of time (e.g., a month), regardless of the volume of services that they actually provide. However, it has been reported that MCOs may lack the experience and capacity to adequately adjust capitated payment rates for differences in clients’ level of needs,⁹³ which add to providers’ financial risk. For example, a recent study of New York licensed MCOs for people with I/DD concluded that the long-term financial viability of MCO plans depends critically on the risk-assessment of the payment structure and premium rates.⁹⁴

Last but not least, current state HCBS policies favoring smaller residential settings may force many residential providers to remodel or divest their properties, which have several cost implications. As discussed above, currently 75 percent of people with I/DD already reside in settings of six or fewer persons. In addition, the CMS' new regulation has pushed for more outcome-oriented definition of HCBS residential setting, rather than based solely on a setting's location, geography, or physical characteristics. Nevertheless, with the general notion that "smaller is better", some states continue to reduce the size of existing residences through financing mechanisms. Because the majority of these providers are not-for-profit and rely heavily on federal and state funding, many of them would have no choice but to divest their real estate. There are concerns that such transition will increase providers' cost of operation due to higher rents paid to third-party property owners, and that the state and federal governments will eventually have to pay for substantial expenses associated with renovations of existing residences. Given that empirical evidence reaches no consensus on what constitutes the optimal number of people in a residence, states that aim to control HCBS costs may find it feasible to create broader opportunities by expanding the variety of residential options for people with I/DD rather than limiting residential models.

VI. Conclusion

Moving LTSS from institutional to community-based settings has been an increasing trend since the 1970s, as federal and state governments work to improve the quality of services while control LTSS spending. As a result of deinstitutionalization, the average number of residents with I/DD in a residential setting declined steadily from 22.5 in 1977 to 2.3 in 2011. Today, 75 percent of people with I/DD already reside in settings of six or fewer persons. Nevertheless, the general notion that "smaller is better" has led some states to continue to reduce the size of existing residences. These policies are not well supported by empirical evidence on the economies of scale of smaller residences. Existing research has shown that no single residential model achieves optimal outcomes for all persons with LTSS needs. In addition, such policies are likely to threaten the viability of the provider industry as private providers are forced to downsize or divest their properties. Under the dual goals of improving quality and saving costs, state policy makers should make efforts to ensure broader residential options for people with I/DD rather than arbitrarily limiting certain residential models.

Community-based care is less costly than institutional care on a per-person base. However, because of growth of total utilization and per-resident cost of community supports, the expansion of state HCBS programs has not slowed the total expenditure of long-term care for people with I/DD. In many states, the growth of HCBS expenditures has even offset the cost savings from reduced institutional expenditures. This creates financial uncertainty for the provision of Medicaid community-based LTSS in the long run.

Aside from budget constraints, states also face the pressure to address the gap in access to LTSS. On average, people with I/DD wait approximately 40 months to receive waiver benefits. An important barrier to narrowing such gap is that community residential providers are faced with increased shortage in direct-support workforce resulting from the discrepancies in compensation between staff working in community versus institutional settings. Increasingly, states seek to shift from FFS payment approach to more performance-based approaches as a way to reduce resource waste. However, there are a number of barriers to defining and implementing HCBS quality standards on a national scale. The lack of HCBS quality information makes it difficult to compare

provider quality within and across states. As the ACA provides new opportunities to align HCBS quality measurements, more robust quality information can be expected in the future.

Glossary of Terms

ACA	Affordable Care Act
AHRQ	Agency for Healthcare Research and Quality
ASPE	Assistant Secretary for Planning and Evaluation
BIP	State Balancing Incentive Payments
CMS	Center for Medicare and Medicaid Services
CQL	Council on Quality and Leadership
DSP	Direct-support providers
FFS	Fee-for-service
HCBS	Medicaid Home and Community-based services
HSRI	Human Services Research Institute
I/DD	Intellectual and other developmental disabilities
LTSS	long-term services and supports
MCO	Managed care organization
MDS	Minimum Data Set
NASDDDS	National Association of State Directors of Developmental Disability Services
NCI	National Core Indicators
PEONIES	Personal Experience Outcomes Integrated Interview and Evaluation System
PES	Participant Experience Survey

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