

Research

Moving Home: Community Transition Supports
for People with Intellectual and Developmental
Disabilities



HCBS COMMUNITY TRANSITION SERVICES

Moving Home: Community Transition Supports for People with Intellectual and Developmental Disabilities

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Abstract

Background. In recognition of the important role housing plays in people's health and quality of life, Medicaid Home- and Community-Based Services (HCBS) programs are more frequently working to promote the housing security of Medicaid beneficiaries. One mechanism states use to promote housing security of people with intellectual and developmental disabilities (IDD) is to offer community transition services in their HCBS programs. Community transition services help with transition by assisting with securing housing and leases, obtaining basic furnishings, paying for utility setup, funding moving expenses, and making accessibility adaptations.

Objective. The aim of this study was to examine if and how states provided community transition services in their HCBS waiver programs for people with IDD.

Methods. We analyzed 107 fiscal year (FY) 2021 HCBS 1915(c) waivers for people with IDD from across the United States. We analyzed the service expenditures and utilization data for community transition services, including projected spending, projected number of users served, reimbursement rates, projected spending per participant, and annual service provision per participant.

Results. In FY2021, 49 waivers (45.8%) from 28 states provided community transition services to people with IDD. A total of \$7.21 million of spending was projected for community transition services for 2,405 people with IDD, with an average spending per person of \$2,303.

Conclusions. While community transition services can help promote the housing insecurity of people with IDD, there was wide variance in how these services were allocated to people with IDD in FY2021.

Keywords: People with intellectual and developmental disabilities; Medicaid Home- and Community-Based Services (HCBS); Community; Deinstitutionalization; Housing security

Abbreviations: Centers for Medicare and Medicaid Services (CMS); Fiscal year (FY); Home- and Community-Based Services (HCBS); Intellectual and developmental disabilities (IDD); Intermediate care facility (ICF); Long-Term Services and Supports (LTSS)

While institutionalization of people with intellectual and developmental disabilities (IDD) was once extremely common, today most people with IDD live in the community.^{1, 2} Medicaid Home- and Community-Based Services (HCBS) is a crucial mechanism to ensure people with IDD are able to live in the community. Medicaid HCBS are wrap-around, community-based Long-Term Services and Supports (LTSS) for people who might otherwise need institutional care. (Eligibility is close to the federal poverty line, requiring people to live with few assets.) Unlike acute health care, HCBS programs often include day and employment supports, respite and crisis services, assistive technology, transportation, and residential supports.

In recognition of the important role housing plays in people's health and quality of life, Medicaid HCBS programs are more frequently working to promote the housing security of Medicaid beneficiaries than previously.³⁻⁵ Due to federal regulations Medicaid, including HCBS, cannot cover the cost of room and board or rent; however, Medicaid programs do have a number of avenues at their disposal to facilitate housing security.^{3, 5, 6} One such mechanism states can use to promote housing security of people with IDD is to offer community transition services in their HCBS waiver programs.^{3, 5, 7} The Centers for Medicare and Medicaid Services (CMS)⁸ defines HCBS community transition services as:

non-recurring set-up expenses for individuals who are transitioning from an institutional or another provider-operated living arrangement to a living arrangement in a private residence where the person is directly responsible for his or her own living expenses. Allowable expenses are those necessary to enable a person to establish a basic household that do not constitute room and board and may include: (a) security deposits that are required to obtain a lease on an apartment or home; (b) essential household furnishings and moving expense

required to occupy and use a community domicile, including furniture, window coverings, food preparation items, and bed/bath linens; (c) set-up fees or deposits for utility or service access, including telephone, electricity, heating and water; (d) services necessary for the individual's health and safety such as pest eradication and one-time cleaning prior to occupancy; (e) moving expenses; (f) necessary home accessibility adaptations; and, (g) activities to assess need, arrange for and procure need resources. (p. 178)

This study's aim was to examine community transition services in HCBS for people with IDD. Our research question was: how did states provide community transition services to people with IDD in their HCBS waivers? To explore this question, we analyzed 107 fiscal year (FY) 2021 HCBS 1915(c) waivers for people with IDD from across the United States.

Methods

For this study, we obtained Medicaid HCBS 1915(c) waivers from the CMS Medicaid.gov website between December 2021 and January 2022. When doing so, we excluded HCBS waivers that were not 1915(c), did not exclusively serve people with IDD (developmental disability, intellectual disability, and/or autism), and did not include 2021 – while most states used the state FY (July 1, 2020 to June 30, 2021), others used the federal fiscal year (October 1, 2020 to September 30, 2021) or the calendar year (January 1, 2021 to December 31, 2021). This process resulted in the collection of 107 HCBS 1915(c) waivers for people with IDD from 44 states and the District of Columbia.

In waiver applications, CMS requires states to describe which services the waiver program will offer to participants. Then, for each service provided, states must also document how many people will receive the service, reimbursement rates for services, and projected spending for these services. We used this information to determine which waivers provided community transition services. We then aggregated and analyzed the service expenditures and utilization data for community transition services, including projected spending, projected number of users served, reimbursement rates, projected spending per participant, and annual service provision per participant using descriptive statistics.

Results

Our analysis of 107 HCBS IDD waivers revealed 49 waivers (45.8%) from 28 states provided 64 different community transition services.

Participants

In FY2021, 2,405 people with IDD were projected to receive community transition services, with the average service supporting 37.58 people with IDD (Table 1). The number of people receiving community transition services per service ranged from 1 (11 different services) to 450 (Ohio IO Waiver Amendment's [OH.0231.R05.08] "Community Transition Service"). The states that provided community transition services to the most people with IDD were Maryland (642 people), Ohio (450 people), and New Jersey (176 people), while the states that provided these services to the fewest people with IDD were Massachusetts (1 person), New Mexico (1 person) and Montana (2 people; Table 2).

Approximately 0.3% of all FY2021 HCBS IDD waiver unduplicated participants were projected to receive community transition services. Those states that provided community transition services to the smallest proportion of unduplicated participants were Massachusetts (0.005%), New Mexico (0.01%), and Montana (0.07%). Maryland (3.38%), Arkansas (2.57%), and Delaware (1.46%) provided community transition services to the largest proportion of unduplicated participants.

Total Spending

A total of \$7.21 million of spending was projected for community transition services for people with IDD. Total spending ranged from \$10.94 per service (Pennsylvania Person/Family Directed Support Waiver's [PA.0354.R04.10] "Housing Transition Services") to \$1.76 million per service (New Jersey Community Care Waiver's [NJ.0031.R06.00] "Community Transition

Services”), with an average of \$112,681 of spending per service. New Jersey (\$1.76 million), Maryland (\$1.23 million), and Georgia (\$1.20 million) projected spending the most for community transition services, while Massachusetts (\$514), New Mexico (\$787), and Utah (\$5,613) the least.

In total, 0.02% of FY2021 HCBS IDD waiver funding was projected for community transition services. The states that projected the smallest proportion of funding for community support services were Massachusetts (0.00003%), New Mexico (0.0002%), and Colorado (0.0001%), while the states with the largest proportion were Arkansas (0.20%), Georgia (0.14%), and New Jersey (0.11%).

Average Spending Per Person

Average annual spending per person with IDD for community transition services ranged from \$10.94 (PA.0354.R04.10’s “Housing Transition Services”) to \$20,000 (Georgia Comprehensive Supports Waiver Program’s [GA.0323.R04.02] “Transition Services and Supports”), with a mean of \$2,303 of spending per person with IDD (Figure 1). Georgia (\$20,000), New Jersey (\$10,000), and Kentucky (\$4,814) had the highest average spending per person for community transition services, while Alabama (\$400), Massachusetts (\$514), and Utah (\$624) had the lowest.

Reimbursement Rates

Community transition services were reimbursed by a range of different units, including paid by the hour ($n = 24$; 37.5%), day ($n = 1$; 1.6%), year ($n = 2$; 3.1%), and other (e.g., event, transition, each; $n = 37$; 57.8%). Hourly reimbursement rates for community transition supports ranged from \$12.52 an hour (Louisiana New Opportunities Waiver’s [LA.0401.R03.12] “Housing Stabilization Service” and “Housing Stabilization Transition Service”) to \$160.00 an

hour (Alabama HCBS Living at Home Waiver for Persons with Intellectual Disabilities' [AL.0391.R04.02] "Housing Stabilization Service"), with an average hourly reimbursement rate of \$51.81. One service, Utah Community Transitions Waiver's (UT.1666.R00.03) "Community Transition Service," reimbursed daily at \$703.32 a day for community transition supports. Two community transition support services reimbursed yearly, with Louisiana Children's Choice Waiver's (LA.0361.R04.10) "Housing Stabilization Transition services") reimbursing \$15.11 a year and New Jersey Community Care Waiver's (NJ.0031.R06.00) "Community Transition Services" \$10,000 a year. Forty services reimbursed by 'other' units, ranging from \$1.00 a unit (GA.0323.R04.02's "Transition Services and Supports" and New Mexico Developmental Disabilities Waiver Program's [NM.0173.R06.01] "Independent Living Transition (New)") to \$15,000 a unit (Nebraska Developmental Disabilities Day Services Waiver for Adults' [NE.0394.R03.10] "Transitional Services"), with an average of \$2,129 a unit.

Annual Service Provision

Among hourly community transition supports, participants were projected to receive an average of 17.78 hours of community transition services per year; this ranged from 0.25 hours (PA.0354.R04.10's "Housing Transition Services") to 100 hours (Pennsylvania Community Living Waiver's [PA.1486.R00.11] "Housing Transition and Tenancy Sustaining Service"). UT.1666.R00.03's "Community Transition Service" provided 1 day of service per person per year. Of those community transition services that were provided by year, participants were projected to receive an average of 3.00 times a year, ranging from 1 time a year (NJ.0031.R06.00's "Community Transition Services") to 4 times a year (LA.0361.R04.10's "Housing Stabilization Transition services"). Among community transition services provided by 'other' unit, participants were projected to receive between 1 unit (26 different services) and

20,000 units (GA.0323.R04.02's "Transition Services and Supports" service) of community transition services per year, with an average of 570.76 units.

Discussion

Transitioning from an institutional setting to a community-based setting, or from a congregate community-based setting to an individual community-based setting is a time of critical importance in people with IDD's lives. Not only does it represent a time of disruption and uncertainty in people with IDD's lives, how the household is established lays the foundation for people with IDD's long-term stability and security to ensure they are able to stay in that home. For these reasons, community transition services in HCBS aim to help people with IDD transition settings, including by securing housing and leases, obtaining basic furnishings, paying for utility setup, funding moving expenses, and making accessibility adaptations – all of which are necessary to help turn a house into a stable home for people with IDD.⁸

Our analysis of IDD HCBS suggests community transition services are relatively low cost, costing only a few thousand dollars per person on average, especially compared to institutional costs for people with IDD, which average at \$140,000 per person.⁹ In fact, the Center for Medicaid and CHIP Services¹⁰ encourages states to provide community transition services in their HCBS waivers because “providing housing-related activities and services facilitates community integration and is cost effective” (p. 1).

Despite being relatively low cost, community transition services were not widely implemented in IDD HCBS. While approximately half of IDD HCBS waivers offered community transition services in FY2021, only 2,405 people with IDD were projected to receive community transition services despite 860,000 people with IDD receiving HCBS in FY2021, 70,000 people with IDD living in ICF (as of 2018), and 200,000 people with IDD waiting for HCBS (as of 2018).^{9, 11} Moreover, in FY2021, only 0.02% of IDD HCBS funding was allocated

to community transition services. In fact, less was projected in FY2021 (\$7.2 million) for community transition services than in FY2014 (\$9.9 million [inflation adjusted]).⁷

We also found wide variance in use and allocation of community transition services across services, waivers, and states. While Georgia, New Jersey, and Maryland put more emphasis on supporting people with IDD with community transition services, Massachusetts, California, New Mexico, and Montana dedicated relatively little allocation for community transition services. For example, California projected providing community transition services to a total of 90 people with IDD in FY2021. During the same time period, the California Department of Developmental Services supported 375,000 people with IDD,¹² including 147,500 people with IDD on their HCBS waivers.¹¹ In addition, the following states had HCBS IDD waivers in FY2021 but did not offer community transition services to any people with IDD: Alaska, Connecticut, District of Columbia, Florida, Hawaii, Illinois, Iowa, Kansas, Maine, Michigan, Nevada, New Hampshire, Oregon, South Carolina, South Dakota, Tennessee, and West Virginia. While some of the states that did not offer community transition services to many or any people with IDD may not have public institutions for people with IDD (e.g., Alaska, Michigan, Oregon⁹), community transition services are designed so they can also be used to help people with IDD transition from community-based congregate settings, such as group homes, to individual and private residences. As such, people with IDD would continue to benefit from community transition services well beyond deinstitutionalization. This is especially true in 2021 during the COVID-19 pandemic when high infection and mortality rates in both institutional and community-based congregate settings indicated a need to increase the use of individualized settings.¹³⁻¹⁵ Moreover, the HCBS Settings Rule's emphasis on HCBS recipients' rights to autonomy, independence, choice in living setting, and the option to live in a private (individual)

residential unit,¹⁶ may also drive an increased need for community transition services as most people with IDD, including those who currently live in community-based group homes, want to live in their own homes and with family members.¹⁷

Implications

While community transition services are one of the main mechanisms to help promote housing security in HCBS, these services are designed to be one-time services and are vastly underfunded, as is HCBS more broadly.^{6,7} Therefore, we suggest the availability of community transition services in HCBS should be expanded so more people with IDD can benefit from these types of services. As people are likely to move more than once in their lives, for many people with IDD it would likely also be helpful if they could utilize these services more than one-time.

However, community transition services alone are not enough to ensure people with IDD are housing secure. Yet, Medicaid is prohibited from paying for room and board in community-based settings, despite the fact that room and board *can* be covered in institutional settings.^{3,5,6} Alison Barkoff¹⁸ the Principal Deputy Administrator and Acting Administrator and Assistant Secretary for Aging for the Administration for Community Living, referred to this discrepancy as the “second institutional bias in Medicaid.” Mathis¹⁹ proposes that if institutions are allowed to waive rules barring housing payments, there is no reason why other community-based Medicaid funding mechanisms should not also be allowed to do so – Mathis notes, “if one exclusion can be waived, so can the other” (p. 880). Until Medicaid HCBS – the most prevalent funding mechanism for LTSS for people with IDD¹ – are able to fund housing to the same degree that Medicaid-funded institutions can, housing insecurity will remain a critical problem for people with IDD. This institutional bias, especially when coupled with poverty requirements for

Medicaid, serves as a systemic barrier to people with IDD living in, and thriving in, their communities.

Limitations

When interpreting the findings from this study, a number of limitations should be noted. HCBS 1915(c) waiver applications are projections made to the federal government rather than utilization data; however, past research has found them to be accurate proxies of waiver utilization as they are designed based on previous years' utilization data.²⁰ In addition, six HCBS waivers from New York, Wisconsin, and Wyoming were excluded from this study because they combined recipient populations (i.e., people with IDD with other populations); as a result of combining populations, it is not possible to determine allocations for people with IDD from people with other disabilities and, therefore, these waivers had to be excluded from this study.

Conclusion

Housing security is crucial for people with IDD's health and quality of life.^{4, 5, 21, 22} Including community transition services in Medicaid HCBS can help promote the housing security of people with IDD. However, we found less than half of HCBS waivers offered community transition services to people with IDD in FY2021. Furthermore, among the waiver programs that did provide community transition services, there was wide variance in how the services were allocated. A suitable environment that is clean, adequately furnished, and accessible, such as those supported by community transition services, is necessary to ensure people with IDD are able to successfully transition to the community and/or an individual community-based setting.

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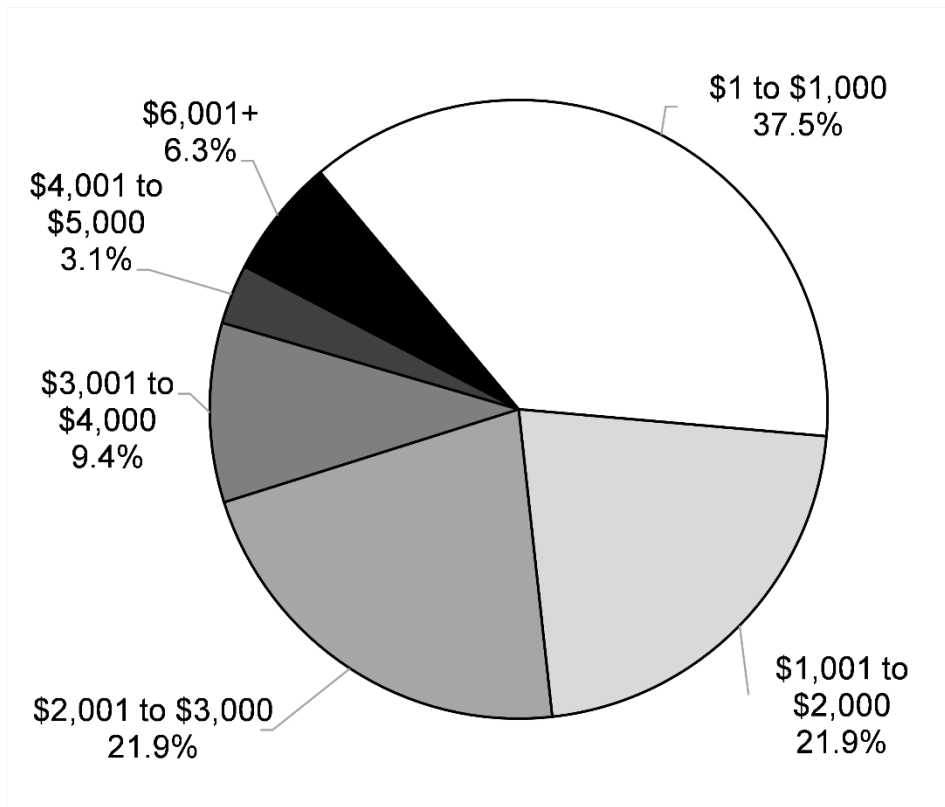


Figure 1. Average spending per participant on community transition services.

Table 1
Community Transition Services

Allocation	<i>M</i>	<i>SD</i>
Users	37.58	71.24
Total spending	\$112,681	\$293,683
Average spending per participant	\$2,303	\$3,267
Reimbursement rate		
Hourly	\$51.81	\$27.14
Daily	\$703.32	n/a
Year	\$5,007.56	\$7,060.00
Other	\$2,128.97	\$2,491.00
Annual service provision per user		
Hourly	17.78	23.12
Daily	1.00	n/a
Year	2.50	2.12
Other	570.76	3,285.60

Table 2
Community Transition Services By State

State	Users	% of unduplicated IDD HCBS users	Total Spending	% of total IDD HCBS spending	Average spending per person
Alabama	18	0.30%	\$7,200	0.002%	\$400
Alaska*	--	--	--	--	--
Arkansas	133	2.57%	\$454,428	0.20%	\$3,417
California	90	0.06%	\$66,241	0.001%	\$736
Colorado	12	0.08%	\$8,541	0.001%	\$712
Connecticut*	--	--	--	--	--
Delaware	40	1.46%	\$160,000	0.08%	\$4,000
District of Columbia*	--	--	--	--	--
Florida*	--	--	--	--	--
Georgia	60	0.43%	\$1,200,000	0.14%	\$20,000
Hawaii*	--	--	--	--	--
Idaho	11	0.16%	\$9,174	0.002%	\$834
Illinois*	--	--	--	--	--
Indiana	142	0.41%	\$355,000	0.04%	\$2,500
Iowa*	--	--	--	--	--
Kansas*	--	--	--	--	--
Kentucky	15	0.10%	\$72,215	0.008%	\$4,814
Louisiana	143	0.97%	\$115,648	0.02%	\$809
Maine*	--	--	--	--	--
Maryland	642	3.38%	\$1,225,515	0.10%	\$1,909
Massachusetts	1	0.005%	\$514	0.00003%	\$514
Michigan*	--	--	--	--	--
Minnesota	69	0.29%	\$114,863	0.006%	\$1,665
Mississippi	26	0.71%	\$20,800	0.01%	\$800
Missouri	35	0.19%	\$101,862	0.01%	\$2,910
Montana	2	0.07%	\$6,000	0.005%	\$3,000
Nebraska	22	0.40%	\$60,000	0.02%	\$2,727
Nevada*	--	--	--	--	--
New Hampshire*	--	--	--	--	--
New Jersey	176	1.29%	\$1,760,000	0.11%	\$10,000
New Mexico	1	0.01%	\$787	0.0002%	\$787
New York	51	0.05%	\$122,400	0.002%	\$2,400
North Dakota	15	0.23%	\$45,000	0.01%	\$3,000
Ohio	450	0.91%	\$900,000	0.04%	\$2,000
Oklahoma	11	0.17%	\$44,000	0.01%	\$4,000
Oregon*	--	--	--	--	--

Pennsylvania	46	0.10%	\$126,836	0.004%	\$2,757
South Carolina*	--	--	--	--	--
South Dakota*	--	--	--	--	--
Tennessee*	--	--	--	--	--
Texas	106	0.26%	\$124,892	0.01%	\$1,178
Utah	9	0.15%	\$5,613	0.002%	\$624
Virginia	26	0.16%	\$39,086	0.004%	\$1,503
Washington	53	0.22%	\$64,947	0.01%	\$1,225
West Virginia*	--	--	--	--	--

Note. * = State had IDD HCBS waiver in FY 2021 but did not provide community transition services. Wisconsin and Wyoming were excluded because they combined waiver populations. Arizona, North Carolina, Rhode Island, and Vermont do not have HCBS 1915(c) waivers for people with IDD.