Intellectual and Developmental Disabilities

Medicaid Home and Community Based Services Waivers for People with Intellectual and Developmental Disabilities

--Manuscript Draft--

Manuscript Number:	IDD-D-22-00016R1
Article Type:	Research
Keywords:	Intellectual and developmental disabilities; Medicaid Home- and Community-Based Services (HCBS); health policy; Community living; Long-Term Services and Supports (LTSS)
Corresponding Author:	Carli Friedman, PhD CQL | The Council on Quality and Leadership Towson, Maryland UNITED STATES
First Author:	Carli Friedman, PhD
Order of Authors:	Carli Friedman, PhD
Manuscript Region of Origin:	UNITED STATES
Abstract:	Medicaid Home and Community Based Services (HCBS) 1915(c) waivers are the most prominent funding mechanism for the long-term services and supports (LTSS) of people with intellectual and developmental disabilities (IDD). This study's aim was to conduct an in-depth national analysis of fiscal year (FY) 2021 HCBS 1915(c) waivers for people with IDD. In FY 2021, over $43.2 billion was projected for the HCBS of 861,038 people with IDD. An average of $47,315 was projected per person with IDD annually. The services that received the most funding were: residential habilitation; supports to live in one's own home; and day habilitation. HCBS is necessary so people with IDD can live and thrive in their communities.

Abstract

Medicaid Home and Community Based Services (HCBS) 1915(c) waivers are the most prominent funding mechanism for the long-term services and supports (LTSS) of people with intellectual and developmental disabilities (IDD). This study's aim was to conduct an in-depth national analysis of fiscal year (FY) 2021 HCBS 1915(c) waivers for people with IDD. In FY 2021, over $43.2 billion was projected for the HCBS of 861,038 people with IDD. An average of $47,315 was projected per person with IDD annually. The services that received the most funding were: residential habilitation; supports to live in one's own home; and day habilitation. HCBS is necessary so people with IDD can live and thrive in their communities.

Keywords: intellectual and developmental disabilities, Medicaid Home- and Community-Based Services (HCBS), health policy, community living; Long-Term Services and Supports (LTSS)

People with intellectual and developmental disabilities' (IDD's) health and quality of life is significantly impacted by the government services they receive (Burns, 2009). Medicaid has become "one of the most important components of the health care safety net" for people with disabilities in the United States (Frank et al., 2003, p. 101). Medicaid is also the nation's principal source for long-term services and supports (LTSS; Wachino et al., 2004). LTSS are community- or facility-based services for people who need support to care for themselves because of disability, age, or functional limitations, such as people with IDD.

Originally, comprehensive Medicaid LTSS were only available through institutional care, such as intermediate care facilities for individuals with intellectual disabilities (ICF/IID) or residential or skilled nursing facilities (Shirk, 2006). In 1981 the Omnibus Budget Reconciliation Act (OBRA) Section 2176 created Section 1915(c) of the Social Security Act authorizing Medicaid to provide Home- and Community-Based Services (HCBS). As a result, states are able to create and expand community LTSS tailored to populations that would typically require institutional care. To do so, HCBS waivers allow states the flexibility to determine not only who is eligible and how many people are served in their waiver program/s, but also what benefits their HCBS program/s will cover and the ways those benefits are provided (Wachino et al., 2004).

As a result of OBRA, the *Olmstead* Supreme Court decision (which ruled people with disabilities have a right to integration), the preferences of people with IDD, and the cost-effectiveness of community services, over the last few decades states have shown a significant decline in institutional Medicaid spending for people with IDD in favor of HCBS (Braddock et al., 2017; Centers for Medicare and Medicaid Services, 2020). In fact, Medicaid HCBS waivers

have become the largest funding stream for people with IDD; in fiscal year (FY) 2018, 79% of LTSS for people with IDD was for HCBS (Centers for Medicare and Medicaid Services, 2020).

Citation removed for review's (2017) national analysis of FY 2015 HCBS IDD waivers revealed $25.6 billion was projected for HCBS waivers for approximately 630,000 people with IDD through 111 waivers from 46 states and the District of Columbia. They found, in FY 2015, the majority of spending was projected for residential habilitation (42.3%), supports for people to live in their own home (20.5%) and day habilitation (16.5%; citation removed for review). However, Citation removed for review's (2017) findings also revealed vast differences across services, waivers, and states in terms of allocations and spending.

There have been a number of critical changes since FY 2015, both for people with IDD more broadly, and more specifically related to LTSS and HCBS. For example, states continue to align their programs and services with the HCBS Final Settings Rule (CMS 2249-F/2296-F) (Centers for Medicare and Medicaid Services, 2014). The HCBS Final Settings Rule was introduced in recognition that many people with IDD, even those who physically live in the community, are not meaningfully included in their communities (citation removed for review; Ligas Consent Decree Monitor, 2017). As such, the HCBS Settings Rule emphasizes meaningful, outcome-based community integration for people receiving HCBS Services, requiring states and providers to follow a number of guidelines to promote community integration. The original deadline for states to receive final approval for their transition plans was 2019, but it has since been pushed back twice, first to 2022 (Neale, 2017), and most recently to March 2023 (Lynch, 2020), in recognition that increased reform of states' HCBS programs was needed.

Another reason the HCBS Settings Rule deadline was extended was because of the COVID-19 pandemic (Lynch, 2020). People with IDD are not only contracting and dying of

COVID-19 at significantly greater rates (Landes, Turk, Formica, et al., 2020; Landes, Turk, & Wong, 2020), many IDD service providers are struggling because of a lack of resources and funding (Avalere Health, 2020; Lynch, 2020). Because of the number of deaths in nursing homes, institutions, and other congregate settings (e.g., group homes), the Centers for Medicare and Medicaid Services (CMS) notes there may be a shift in funding to prioritize people living in their own homes (Lynch, 2020). In addition, COVID-19 has also radically transformed HCBS service provision. For example, in addition to increased staffing shortages, many people with IDD are not able to attend their work or day programs (Shapiro, 2020). As such, there is an increased need for telecare, remote services and other technologies that, although not new, have not widely been used with people with IDD (citation removed for review). Compounding these issues is the fact that the majority of states have seen decreases in tax revenue and will need to make significant budget cuts to compensate (National Public Radio, 2020); this is particularly notable as during the Great Recession (2007-2009) there was a drop in the proportion of Medicaid spending for people with IDD (Braddock et al., 2015). Meanwhile, the American Rescue Plan Act of 2021 allowed states to receive enhanced funding to strengthen and expand their HCBS programs during the pandemic (Costello, 2021).

While these changes all represent challenges in HCBS since FY 2015, so too do they represent opportunities for states to improve HCBS service delivery. In fact, CMS observes, the flexibility granted to states by HCBS waivers, allow them to "develop and implement innovative" programs (Centers for Medicare and Medicaid Services, 2014, n.p.); it also allows states to "evaluate how the provision of Medicaid-funded HCBS fulfills larger public health priorities and advances the tenets of beneficiary autonomy and community integration" (Lynch, 2020, p. 2).

National-level state-specific analyses of HCBS 1915(c) waivers for people with IDD are crucial because of the recent CMS rule and regulation changes, the flexibility granted to states by HCBS, and the changing social, political, and economic landscapes. Therefore, the purpose of this study is to conduct an in-depth analysis of HCBS 1915(c) waivers for people with IDD in FY 2021. To do so, 107 Medicaid HCBS 1915(c) waivers for people with IDD from 44 states and the District of Columbia were examined to determine total projected spending, projected participants, average spending per participant, and average length of stay across states. In addition, over 3,850 services were organized into Citation removed for review's (2013) HCBS IDD waiver taxonomy to determine service priorities in FY 2021.

Methods

Medicaid HCBS 1915(c) waivers were obtained from the CMS Medicaid.gov website in December 2021 and January 2022. First, we excluded all HCBS waivers that were not 1915(c) waivers (e.g., 1115, 1915(b))); this resulted in 288 active 1915(c) waivers. Next, we excluded waivers that did not serve people with IDD – developmental disabilities (DD), intellectual disabilities (ID), and/or autism (ASD); this resulted in 167 waivers being excluded. (Waivers that combined target populations [e.g., IDD and physical disabilities; $n = 6$], were also excluded because it is impossible to differentiate between service provisions and expenditures for people with IDD and the other disability populations.) Finally, waivers that did not include 2021 were excluded from the analysis (14 waivers were removed). Most states used the state FY (July 1, 2020 to June 30, 2021), but others used the federal FY (October 1, 2020 to September 30, 2021), or the 2021 calendar year (January 1, 2021 to December 31, 2021); we use the term FY for consistency. 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 waivers, CMS requires states demonstrate how their programs will be cost-neutral compared to institutions; while doing so, states must demonstrate service information, including rates and provision, participant information, and spending allocations. We used this information to determine the services provided, the projected number of users, total projected spending (including spending per capita, fiscal effort, and a comparison of comprehensive and support waivers), the average annual service allocation per participant, and average length of stay per participant across the waivers and states. While doing so, we also used one-way analyses of variance (ANOVAs) to examine if there were significant differences between waivers for different target age groups (i.e., children only, adults only, and both children and adults) and different target populations (i.e., DD umbrella [including ID and ASD], ID only, and ASD only). Finally, waiver data about service provision was organized into citation removed for review's (2013) HCBS IDD waiver taxonomy. Doing so allowed us to examine how different service categories were prioritized.

Results

In FY 2021, 44 states and the District of Columbia provided services for people with IDD through 107 HCBS 1915(c) waivers (See Supplementary Table A: https://www.c-q-l.org/wp-content/uploads/2022/03/Supplementary_Tables_Medicaid_HCBS_IDD_FY21.pdf). Seventy-one of these IDD waivers (66.4%) served both adults and children, 13 waivers (12.1%) only children, and 23 waivers (21.5%) only adults. Eighty-two IDD waivers (76.6%) served people with DD (including ASD and ID), 14 waivers (13.1%) people with ID only, and 11 waivers (10.3%) people with ASD only.

Total Unduplicated Participants

The total number of unduplicated participants with IDD in FY 2021 was 861,038. Waivers provided services for 8,047 participants on average (*SD* = 17,428; median = 3,633). The number of people with IDD served by HCBS IDD waivers ranged from 15 people for Florida's Familial Dysautonomia Waiver (FL40205.R03.00) to 145,000 for California's HCBS Waiver for Californians with DD (CA.0336.R04.09). There were not significant differences between unduplicated participants based on waivers' target age groups or target populations.

Total Projected Spending

In total, HCBS IDD waivers projected $43.2 billion of spending in FY 2021. The average total projected spending in FY 2021 was $403.5 million (*SD* = $892.6 million), while the median total projected spending was $110.7 million. Total projected spending by IDD waiver ranged from $102,506 for Florida's FL40205.R03.00 waiver to $7.0 billion for New York's Comprehensive Renewal Waiver (NY.0238.R06.06). There were not significant differences between total projected spending for IDD waivers based on waivers' target age groups or target populations.

Spending Per Capita

Spending per capita was calculated by dividing the state's total projected HCBS IDD waiver spending (FY 2021) by the state's total population (FY 2021) from the United States Census Bureau (2021). The average HCBS IDD state spending per capita was $122.51 in FY 2021 (Table 1). Among the states, 28.9% (*n* = 13) had a projected spending per capita between $0 and $100, 44.4% (*n* = 20) between $101 and $200, 13.3% (*n* = 6) between $201 and $300, 11.1% (*n* = 5) between $301 and $400, and 2.2% (*n* = 1) of higher than $401. The District of Columbia ($407.86), North Dakota ($390.32), Maine ($364.97), New York ($352.70), and

Connecticut ($316.30) ranked highest in terms of spending per capita, while Oregon ($37.94), Texas ($42.69), Michigan ($46.38), Nevada ($52.70), and Florida ($55.60) ranked the lowest.

Fiscal Effort

Fiscal effort is a mechanism to examine a "state's commitment to IDD services after controlling for state wealth. Fiscal effort is theoretically based on the competitive struggle for government funding described… as the essence of politics" (Braddock et al., 2015, p. 14). Fiscal effort was calculated by dividing the state's total projected HCBS IDD waiver spending (FY 2021) by the state's total personal income (FY 2020; the latest year available) from the Bureau of Economic Analysis (2021). In FY 2021, a total of $2.20 per $1,000 of United States aggregate personal income was projected for HCBS IDD waivers. Across the 44 states and the District of Columbia, the average fiscal effort (per $1,000) was $2.81. Of the states, 11.1% (n = 5) had a fiscal effort between $0 and $1.00, 28.9% ($n$ = 13) between $1.01 and $2.00, 20.0% ($n$ = 9) between $2.01 and $3.00, 15.6% ($n$ = 7) between $3.01 and $4.00, 17.8% ($n$ = 8) between $4.01 and $5.00, and 6.7% ($n$ = 3) higher than $5.01. The states with the largest fiscal efforts in FY 2021 were Maine ($6.84), North Dakota ($6.42), Minnesota ($5.08), New York ($4.86), and West Virginia ($4.80). Meanwhile, Oregon ($0.67), Texas ($0.78), Michigan ($0.88), Nevada ($0.98), and Florida ($1.00) had the lowest fiscal efforts.

Comprehensive Waivers Versus Support Waivers

Comprehensive (or traditional) waivers are those waivers designed to provide people with IDD with a range of supports, including residential habilitation (in licensed settings). In contrast, support waivers rely on unpaid natural supports rather than residential habilitation. We were able to directly compare the comprehensive and support waivers of 9 states which served the same target populations and target ages; the states included: Illinois, Indiana, Missouri, Ohio,

Oklahoma, South Carolina, Tennessee, Texas, and Washington. Our analysis revealed the cost of IDD support waivers ($12,215) was 14.0% of the average cost per person of IDD comprehensive waivers ($87,088). This difference was statistically significant according to a paired samples *t*-test, $t(8) = 6.95$, $p < 0.001$.

Spending Per Participant

In FY 2021, the average estimated cost per participant for IDD waivers was $47,315 (*SD* = 39,237); the median cost per participant was $36,769. The average estimated cost per participant ranged from $690 for Washington's Individual and Family Services (WA.1186.R01.08) waiver to $163,565 for Tennessee's Comprehensive Aggregate Cap Waiver (TN357.R04.00). Among the waivers, 53.3% ($n = 57$) had an average spending per participant between $0 and $40,000, 29.0% ($n = 31$) between $40,001 and $80,000, 10.3% ($n = 11$) between $80,001 and $120,000, 5.6% ($n = 6$) between $120,001 and $160,000, and 1.9% ($n = 2$) higher than $160,000.

According to a one-way ANOVA, average spending per participant differed depending on waivers' target age groups, $F(2, 104) = 7.02$, $p = 0.001$, $\eta^2 = 0.12$. Post hoc analysis (Tukey's HSD) indicated more was spent on the average participant in IDD waivers for adults only (M = $59,206, SD = $46,239) than IDD waivers for children only (M = $12,563, SD = $10,166; $p = 0.001$). In addition, more was spent on average on participants served by IDD waivers for both adults and children (M = $49,826, SD = $36,938) than IDD waivers that were only for children (M = $12,563, SD = $10,166; $p = 0.004$). There was not a significant difference in terms of average spending per participant depending on IDD waivers' target populations.

Average Length of Stay

The average length of stay is the average number of days participants are on waivers each year. In FY 2021, the mean average length of stay across the IDD waivers was 331 days (*SD* = 33; median = 340). The average length of stay ranged from 151 days for Missouri's Division of DD Community Support Waiver (MO.0404.R03.02) to 365 days for Arkansas' Autism Waiver (AR.0936.R01.01).

According to a one-way ANOVA, average length of stay differed based on IDD waivers' target age groups, $F(2, 104) = 3.91$, $p = 0.02$, $\eta^2 = 0.07$. Post hoc analyses (Tukey's HSD) revealed IDD waivers for children only (M = 307.84, SD = 39.59) had a shorter average length of stay than IDD waivers for both children and adults (M = 334.94, SD = 30.58; $p = 0.018$). There was not a significant difference between the average length of stay based on target populations.

Service Taxonomy

Over 3,850 services from the 107 FY 2021 IDD waivers were organized into citation removed for review's (2013) HCBS IDD taxonomy. The taxonomy is comprised of the following service categories: adult day health; community transition supports; day habilitation; family services (subcategories: family training and counseling, family supports); financial support services; health and professional services (subcategories: crisis, dental, clinical and therapeutic services, nursing and home health); individual goods and services; prevocational; recreation and leisure; residential habilitation (facility-based); respite; self-advocacy training and mentorship; specialized medical and assistive technologies; support coordination; supported employment; supports to live in one's own home (e.g., companion, homemaker, chore, personal assistance, supported living); and, transportation.

Service Category Spending

According to projected spending, 46.7% of FY 2021 IDD projected spending ($20.2 billion) was allocated for residential habilitation, making it the largest service category (Table 2). The second largest service category in FY 2021, with 19.1% of spending ($8.2 billion), was supports to live in one's own home. The third largest service in FY 2021 was day habilitation, with 16.5% of total spending ($7.1 billion). These three services comprised approximately 82.3% of all HCBS IDD projected funding in FY 2021. The rest of the service categories each made up less than 4% of total projected spending (totaling less than $7.7 billion): health and professional services (4%); supported employment, respite, transportation, and support coordination (2% each); community transition supports, prevocational services, and family services (1% each); specialized medical equipment and assistive technology, financial support services, individual goods and services, adult day health, education, self-advocacy training and mentorship, and recreation and leisure (less than 1% each).

Frequency of Service Categories

While residential habilitation, supports to live in one's own home, and day habilitation were allocated the greatest spending in FY 2021, they were not the most frequently provided services (See Supplementary Table B: https://www.c-q-l.org/wp-content/uploads/2022/03/Supplementary_Tables_Medicaid_HCBS_IDD_FY21.pdf). In fact, despite comprising less than 4% of total projected spending each, 94% of waivers (n = 100) provided health and professional services and specialized medical equipment and assistive technology, making these two services the most frequently provided service categories. More than three-quarters of waivers also provided: respite (85.0%, n = 91); supported employment (84.1%, n = 90); supports in one's own home (77.6%, n = 83); and day habilitation (77.6%, n = 83). Between three-quarters and half of waivers provided: transportation (67.3%, n = 72);

community transition supports (63.6%, *n* = 68); residential habilitation (59.8%, *n* = 64), and support coordination (52.3%, *n* = 56). Between half to one-third of waivers provided: prevocational services (49.5%, *n* = 53), family training and counseling (48.6%, *n* = 52), and financial support services (40.2%, *n* = 43). The following service categories were provided by less than one-third of waivers: individual goods and services (29.0%, *n* = 31); adult day health (16.8%, *n* = 18); self-advocacy training and mentorship (14.0%, *n* = 16); education (4.7%, *n* = 5); and, recreation and leisure (1.9%, *n* = 2).

Discussion

According to CMS, "HCBS are a key feature of state efforts to offer a meaningful choice to beneficiaries on where to live and how to receive services" (Lynch, 2020, p. 2). Medicaid HCBS 1915(c) waivers are the largest funding mechanism for people with IDD (Braddock et al., 2017). As such, the aim of this study was to examine how states across the nation allocated HCBS for people with IDD in FY 2021. To do so, we analyzed 107 HCBS 1915(c) IDD waivers.

In FY 2021, over $43.2 billion was projected for HCBS for 861,038 unduplicated people with IDD. This amounted to a national spending of $141.25 per capita, and a fiscal effort of $2.20 per $1,000 of personal income. An average of $47,315 was projected to be spent annually per person with IDD for HCBS, which indicates that HCBS continues to be more cost effective for people with IDD than institutional care (Braddock et al., 2017). In fact, average HCBS spending per participant in FY 2021 was approximately one-third (34.4%) the average annual ICF/IID expenditures, which was $137,560 in FY 2018 (Larson et al., 2021). Less money was projected, on average, for waivers that served only children with IDD; waivers that only served children also had a shorter average length of stay.

Consistent with past analyses of HCBS IDD waivers (citations removed for review), there were also wide differences across waivers and states. For example, the average waiver spending per participant ranged by waiver from $690 to $163,565. In terms of differences across states, those states with the highest spending per capita and fiscal efforts allocated for HCBS IDD waivers in FY 2021 – comparisons which help control for state size and state wealth – included Maine, North Dakota, and the District of Columbia. The District of Columbia also had the highest average estimated cost per participant at $139,218 in FY 2021. In contrast, Texas had one of the lowest spending per capita and fiscal efforts in our study. Not only was Texas allocating a significantly smaller proportion of funding towards HCBS waivers for people with IDD compared to the rest of the nation in FY 2021, Texas also has one of the largest waiting lists for IDD services, with 323,434 people with IDD waiting for HCBS as of 2018 (The Henry J. Kaiser Family Foundation, n.d.). These state differences may, in part, be due to differences in how states provide HCBS and to whom. For example, a focus on support waivers, which rely on unpaid natural supports and therefore cost significantly less, would lead to states having less overall spending as well as spending less per person on average; so too could differences in the types of services categories provided in their waiver programs as some service lines are significantly more expensive to provide than others. If states are providing services for adults more frequently than children, this would also result in different expenditures as we found these waivers spend more per person.

Each state's ability to customize their waivers results in significant differences in HCBS programs across states, as well as across waivers within those states. The ability to design HCBS programs to meet the needs of specific populations is important, however, the lack of consistency across programs and states also leaves room for states to make relatively subjective choices

about how they prioritize HCBS and to whom, and, as such, may create and/or reinforce problematic service disparities. States must be mindful of these disparities when designing waiver programs, especially as research indicates both ableism and racism impact how states prioritize and fund HCBS (citations removed for review; Leitner et al., 2018). Moreover, given inconsistencies across states and waivers is one of the hallmarks of HCBS IDD waivers, it makes it even more important to continue to examine how services are provided, who services are provided to, and which services are prioritized.

Service Priorities

In FY 2021, the most funding was allocated for residential habilitation, supports to live in one's own home, and day habilitation. Services that support people with IDD to be able to physically live in their communities, such as residential habilitation and supports to live in one's own home, are critically important. Due to large numbers of infections and deaths in congregate settings (Landes, Turk, Formica, et al., 2020; Landes, Turk, & Wong, 2020), including both institutions and community-based settings such as group homes, the COVID-19 pandemic highlighted a need for more individualized housing for people with IDD. As such, we were surprised that, although predominantly funded, there was not a larger shift in funding towards supports to live in one's own home compared between FY 2021 and FY 2015 (Table 3). In fact, supports to live in one's home comprised a slightly smaller proportion of funding (-1.4%) in FY 2021 than FY 2015, whereas the proportion of funding for residential habilitation – facility-based supports, albeit community-based ones – increased by 4% in this time period. While this may, in part, be due to states not changing their waivers in response to the COVID-19 pandemic, when it extended the deadline for the HCBS Final Settings Rule, CMS did recommend states take advantage of the extra time to "give particular priority to those provisions of the [Settings] rule

regarding making available non-disability specific settings among the range of options available to individuals with disabilities" (Lynch, 2020, p. 2). As such, future research should examine if and how residential supports change when states and providers move beyond the crisis stage of the COVID-19 pandemic.

Beyond residential habilitation and supports to live in one's own home, there were relatively minimal changes across other service categories between FY 2015 and FY 2021. For example, given the HCBS Final Settings Rule's emphasis on individualized, person-centered settings, as well as CMS's recognition that "employment is a fundamental part of comprehensive HCBS systems" (p. 21), we anticipated a shift away from prevocational and day habilitation services towards supported employment. However, all three service categories experienced only small proportional changes in funding allocation from FY 2015 to FY 2021. Moreover, in FY 2021, significantly more funding was projected for day habilitation ($7.1 billion) than supported employment ($1.1 billion). States will need to continue to shift towards individualized, person-centered services to prepare for the HCBS Final Settings Rule compliance deadline (March 17, 2023), particularly as CMS has indicated the deadline will not be delayed any further (Lollar et al., 2021).

Limitations

When interpreting the findings from this study, a number of limitations should be noted. As mentioned in the methods section, six waivers were excluded from this study because they combined the following target populations with IDD: older adults, physical disability, other disability, brain injury, HIV/AIDs, medically fragile, technology dependent, mental illness, and/or serious emotional disturbance. These waivers included: New York's Children's Waiver (NY.4125.R05.09); Wisconsin's Family Care Renewal 2020 waiver (WI.0367.R04.00);

Wisconsin's Children's Long-Term Support Waiver Program (WI.0414.R03.02); Wisconsin's IRIS (Include, Respect, I Self-Direct) waiver (WI.0484.R03.00); Wyoming's Supports Waiver (WY.1060.R01.08); and Wyoming's Comprehensive Waiver (WY.1061.R01.08). As they combined populations, differentiations between allocation for people with IDD and people with other disabilities could not be made, and therefore they had to be excluded from this study. In addition, it should be noted that Medicaid HCBS Medicaid HCBS 1915(c) waivers are based on state projections to the federal government instead of utilization data. However, past research has found them to be an accurate proxy of utilization because of their basis on previous years' utilization data (citation removed for review).

Conclusion

Medicaid HCBS 1915(c) waivers provide people with IDD with the services they need to function and thrive, and do so in their homes and their communities. Examining HCBS is necessary not only to determine how states and waivers prioritize different service lines, but also to determine areas of need and provide guidance on how states can best capitalize on the limited funding available to them. Doing so provides vital information for the field on areas of strength and gaps in service delivery to inform the expansion of community-based services, which, ultimately, can help efforts to reform the health care and LTSS delivery system to maximize people with IDD's quality of life.

References

Avalere Health. (2020). *Impact of COVID-19 on organizations serving individuals with intellectual and developmental disabilities*. American Network of Community Options and Resources (ANCOR). https://www.ancor.org/sites/default/files/impact_of_covid-19_on_organizations_serving_individuals_with_idd.pdf

Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., & Wu, J. (2015). *The state of the states in intellectual and developmental disabilities: Emerging from the great recession* (10th ed.). The American Association on Intellectual and Developmental Disabilities.

Braddock, D., Hemp, R., Tanis, E. S., Wu, J., & Haffer, L. (2017). *The state of the states in intellectual and developmental disabilities: 2017* (11th ed.). The American Association on Intellectual and Developmental Disabilities.

Bureau of Economic Analysis. (2021). *SAINC1 Personal Income Summary: Personal income, population, per sapita personal income* https://apps.bea.gov/iTable/iTable.cfm?reqid=70&step=1&isuri=1&acrdn=8#reqid=70&step=1&isuri=1&7022=100&7040=-1&7023=8&7024=non-industry&7033=-1&7025=5&7026=xx&7001=8100&7027=2016&7028=1&7083=levels&7029=103&7090=70&7031=5

Burns, M. E. (2009). Medicaid managed care and health care access for adult beneficiaries with disabilities. *Health services research, 44*(5p1), 1521-1541. https://doi.org/10.1111/j.1475-6773.2009.00991.x

Centers for Medicare and Medicaid Services. (2014). *Medicaid Program; State Plan Home and Community-Based Services, 5-year period for waivers, provider payment reassignment,*

and Home and Community-Based Setting requirements for Community First Choice and Home and Community-Based Services (HCBS) waivers (CMS 2249-F/2296-F). Author.

Centers for Medicare and Medicaid Services. (2020). *Long-Term Services and Supports rebalancing toolkit*. Author. https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-toolkit.pdf

Costello, A. M. (2021). *SMD# 21-003 RE: implementation of American Rescue Plan Act of 2021 Section 9817: Additional support for Medicaid Home and Community-Based Services during the COVID-19 emergency*. Centers for Medicare and Medicaid Services. https://www.medicaid.gov/federal-policy-guidance/downloads/smd21003.pdf

Frank, R. G., Goldman, H. H., & Hogan, M. (2003). Medicaid and mental health: Be careful what you ask for. *Health Affairs, 22*(1), 101-113. https://doi.org/10.1377/hlthaff.22.1.101

Landes, S. D., Turk, M. A., Formica, M. K., McDonald, K. E., & Stevens, J. D. (2020). COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. *Disability and health journal, 13*(4), 100969. https://doi.org/10.1016/j.dhjo.2020.100969

Landes, S. D., Turk, M. A., & Wong, A. W. (2020). COVID-19 outcomes among people with intellectual and developmental disability in California: The importance of type of residence and skilled nursing care needs. *Disability and health journal, 14*(2), 101051. https://doi.org/10.1016/j.dhjo.2020.101051

Larson, S. A., van der Salm, B., Pettingell, S., Sowers, M., & Anderson, L. L. (2021). *Long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2018*. University of Minnesota Research and Training Center on

Community Living and Institute on Community Integration. https://ici-s.umn.edu/files/yFXkkmRteg/2018-risp-full-report?preferredLocale=en-US

Leitner, J. B., Hehman, E., & Snowden, L. R. (2018). States higher in racial bias spend less on disabled medicaid enrollees. *Social Science & Medicine, 208*, 150-157. https://doi.org/10.1016/j.socscimed.2018.01.013

Ligas Consent Decree Monitor. (2017). *Stanley Ligas, et al. v. Felicia Norwood, et al.: Fifth annual report of the Monitor*. Author.

Lollar, R., Harris, M., & Barkoff, A. (2021). *ACL/CMS promising practices series: The Home and Community-Based Services (HCBS) settings regulation: Where are we now and where are we going [Webinar]*. https://r20.rs6.net/tn.jsp?f=001cPjb_jk9ncxOjAYOzhbD_KcZVez40ql_os6yZUnGVNd0LW57exdRJcZ0YfcyneXgQGpCRhBdPce5-cIbKeD4UK5vtLMXbc3OEq8Zm2YboxfED4x_DKRjcFmwKSWcsLrdJiDKoHmhK2KRBlPos_KAAmoUW22xSiLMev7Ibomhz-FX52PqCvoJiGS46iuu6iOeexAefxEGAfFawbz4WBL9pYS42loSy0_NAidqkvCYJKUgkCm2HfTKn9cuZbJB3EBRAGv4iIdfvXwNZATwX4rxfA==&c=ToO8bRgBn_TLVFnqosqnb2fnVmjQ-RkiwMjr0SQb1gEtzRslethcVg==&ch=9BkDbEnEWV5KA2XHMODb_dN0orE-ogKi0cg0baBLgQPARuI69nkOYw==

Lynch, C. (2020). *Home and Community-Based Settings Regulation – implementation timeline extension and revised frequently asked questions (SMD #20-003).* https://www.medicaid.gov/Federal-Policy-Guidance/Downloads/smd20003.pdf

National Public Radio. (2020). *States are broke and many are eyeing massive cuts. Here's how yours is doing*. Author. https://www.npr.org/2020/08/03/893190275/states-are-broke-and-many-are-eyeing-massive-cuts-heres-how-yours-is-doing

Neale, B. (2017). *Extension of transition period for compliance with Home and Community-Based Settings criteria*. https://www.medicaid.gov/federal-policy-guidance/downloads/cib050917.pdf

Shapiro, J. (2020). *COVID-19 infections and deaths are higher among those with intellectual disabilities*. National Public Radio. https://www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disabili

Shirk, C. (2006). *Rebalancing long-term care: The role of the Medicaid HCBS waiver program*. National Health Policy Forum.

The Henry J. Kaiser Family Foundation. (n.d.). *Waiting list enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers*. https://www.kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D

United States Census Bureau. (2021). *Annual Estimates of the Resident Population for the United States, Regions, States, District of Columbia, and Puerto Rico: April 1, 2020 to July 1, 2021*. Author. Retrieved January 28, 2022 from https://www2.census.gov/programs-surveys/popest/tables/2020-2021/state/totals/NST-EST2021-POP.xlsx

Wachino, V., Schneider, A., & Rousseau, D. M. (2004). *Financing the Medicaid program: The many roles of federal and state matching funds*. Henry J. Kaiser Family Foundation.

Table 1
HCBS Waiver Provision by State

State	Total spending	Spending per capita	Fiscal effort (per $1,000)	Total unduplicated participants	Average estimated cost per participant
Alabama	$346,241,710	$68.70	$1.51	5,904	$58,645
Alaska	$206,612,033	$282.00	$4.45	2,869	$72,015
Arkansas	$223,891,286	$73.99	$1.56	5,173	$43,281
California	$4,601,432,567	$117.27	$1.67	147,500	$31,196
Colorado	$661,309,603	$113.78	$1.79	15,737	$42,023
Connecticut	$1,140,446,193	$316.30	$4.08	12,477	$91,404
Delaware	$197,185,440	$196.52	$3.56	2,734	$72,123
District of Columbia	$273,285,584	$407.86	$4.43	1,963	$139,218
Florida	$1,210,923,819	$55.60	$1.00	36,257	$33,398
Georgia	$875,073,074	$81.03	$1.58	13,808	$63,374
Hawaii	$147,899,664	$102.60	$1.79	2,980	$49,631
Idaho	$387,423,842	$203.81	$4.35	6,780	$57,142
Illinois	$1,464,365,383	$115.56	$1.85	24,784	$59,085
Indiana	$961,181,348	$141.23	$2.74	34,389	$27,950
Iowa	$517,230,940	$161.99	$3.06	14,345	$36,057
Kansas	$391,764,301	$133.50	$2.40	9,573	$40,924
Kentucky	$740,507,257	$164.21	$3.49	15,441	$47,957
Louisiana	$553,746,123	$119.75	$2.34	14,725	$37,606
Maine	$500,823,637	$364.97	$6.84	6,508	$76,955
Maryland	$1,174,798,827	$190.56	$2.90	18,990	$61,864
Massachusetts	$1,560,731,632	$223.45	$2.89	19,489	$80,083
Michigan	$466,181,255	$46.38	$0.88	8,787	$53,054
Minnesota	$1,783,598,249	$312.51	$5.08	23,956	$74,453
Mississippi	$175,064,944	$59.34	$1.40	3,650	$47,963
Missouri	$905,633,451	$146.82	$2.85	18,027	$50,238
Montana	$110,978,435	$100.50	$1.92	2,880	$38,534
Nebraska	$337,567,170	$171.90	$3.03	5,555	$60,768
Nevada	$165,692,688	$52.70	$0.98	2,842	$58,301
New Hampshire	$280,375,361	$201.86	$3.06	5,781	$48,499
New Jersey	$1,550,217,680	$167.28	$2.38	13,678	$113,337
New Mexico	$414,285,194	$195.80	$4.24	9,065	$45,702
New York	$6,996,132,905	$352.70	$4.86	96,573	$72,444
North Dakota	$302,474,082	$390.32	$6.42	6,476	$46,707
Ohio	$2,292,471,298	$194.61	$3.65	49,300	$46,500
Oklahoma	$373,073,537	$93.58	$1.88	6,300	$59,218
Oregon	$161,091,286	$37.94	$0.67	26,319	$6,121
Pennsylvania	$3,216,862,589	$248.14	$4.08	45,645	$70,476
South Carolina	$851,181,704	$163.98	$3.40	21,350	$39,868
South Dakota	$132,528,940	$148.01	$2.50	2,743	$48,315
Tennessee	$682,018,983	$97.78	$1.94	7,117	$95,830
Texas	$1,260,503,344	$42.69	$0.78	40,377	$31,218
Utah	$296,543,813	$88.84	$1.75	6,050	$49,016
Virginia	$1,089,161,382	$126.03	$2.05	15,971	$68,196
Washington	$804,242,477	$103.92	$1.56	24,206	$33,225
West Virginia	$385,635,608	$216.29	$4.80	5,964	$64,661

Table 2
HCBS Spending by Category

Service	Spending (in millions)	%
Residential habilitation	$20,160.6	46.70%
Supports to live in one's own home	$8,246.7	19.10%
Day habilitation	$7,102.6	16.45%
Health and professional services	$1,688.6	3.91%
Clinical and therapeutic services	*$1,147.2*	*2.66%*
Nursing and home health	*$386.4*	*0.89%*
Crisis	*$117.6*	*0.27%*
Dental	*$41.3*	*0.10%*
Supported employment	$1,050.1	2.43%
Respite	$1,045.9	2.42%
Transportation	$781.1	1.81%
Support coordination	$751.1	1.74%
Community transition supports	$575.3	1.33%
Prevocational	$591.9	1.37%
Family services	$443.5	1.02%
Family supports	*$433.3*	*1.00%*
Family training & counseling	*$10.2*	*0.02%*
Specialized medical equipment and assistive technology	$288.8	0.67%
Financial support services	$255.1	0.59%
Individual goods and services	$92.7	0.21%
Adult day health	$65.3	0.15%
Education	$24.44	0.06%
Self-advocacy training and mentorship	$2.46	0.006%
Recreation and leisure	$0.24	0.0006%

Table 3

Spending by Category: FY 2021 versus FY 2015

Service	FY 2015	FY 2021	Difference
Residential habilitation	42.30%	46.70%	4.40%
Supports to live in one's own home	20.49%	19.10%	-1.39%
Day habilitation	16.47%	16.45%	-0.02%
Health and professional services	4.42%	3.91%	-0.51%
Clinical and therapeutic services	*2.96%*	*2.66%*	*-0.30%*
Nursing and home health	*1.32%*	*0.89%*	*-0.43%*
Crisis	*0.12%*	*0.27%*	*0.15%*
Dental	*0.14%*	*0.10%*	*-0.04%*
Supported employment	2.62%	2.43%	-0.19%
Respite	2.31%	2.42%	0.11%
Transportation	2.12%	1.81%	-0.31%
Support coordination	2.42%	1.74%	-0.68%
Community transition supports	1.77%	1.33%	-0.44%
Prevocational	1.75%	1.37%	-0.38%
Family services	2.04%	1.02%	-1.02%
Family supports	*1.86%*	*1.00%*	*-0.86%*
Family training & counseling	*0.06%*	*0.02%*	*-0.04%*
Specialized medical equipment and assistive technology	0.82%	0.67%	-0.15%
Financial support services	0.19%	0.59%	0.40%
Individual goods and services	0.04%	0.21%	0.17%
Adult day health	0.23%	0.15%	-0.08%
Education	0.0017%	0.06%	0.05%
Self-advocacy training and mentorship	0.0060%	0.006%	-0.0003%
Recreation and leisure	0.0005%	0.0006%	0.0001%