Research

A National Analysis of Medicaid Home and Community Based Services Waivers for People with Intellectual and Developmental Disabilities: FY 2015

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Intellectual and Developmental Disabilities

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Abstract

Medicaid Home and Community Based Services (HCBS) 1915(c) waivers are the largest source of funding for the long term services and supports of people with intellectual and developmental disabilities (IDD). National-level analyses of HCBS IDD waivers are crucial because of the large variance across states, the recent CMS rule and regulation changes (CMS 2249-F/2296-F), and the ever changing economic and political landscape. Therefore, the aim of this study was to examine state waiver priorities for people with IDD. In FY 2015, 111 waivers projected spending $25.6 billion for approximately 630,000 people with IDD. The services with the most funding were residential habilitation, supports to live in one's own home, and day habilitation. However, our analysis revealed large discrepancies across states and services.

Keywords: intellectual and developmental disabilities; Medicaid Home and Community Based Services 1915(c) waivers; public policy; community living

A National Analysis of Medicaid Home and Community Based Services Waivers for People with Intellectual and Developmental Disabilities: FY 2015

The majority of government spending (federal, state, and local) for people with IDD is by Medicaid (Braddock et al., 2015). Of the $47.77 billion funded through Medicaid programs for people with IDD in 2013, 66% was allocated specifically for Medicaid Home and Community Based Services (HCBS) 1915(c) waivers (Braddock et al., 2015). Developed in 1981 as an alternative to intermediate care facilities for individuals with intellectual disabilities (ICF/IIDs), HCBS waivers allow states to create community-based service programs particularly tailored to populations that would typically require institutional care, such as people with IDD. To do so, HCBS waivers allow states the flexibility to determine target groups, services furnished, participant direction, provider qualifications, health and welfare strategies, and cost-effective delivery (Disabled and Elderly Health Programs Group, Center for Medicaid and State Operations, Centers for Medicare and Medicaid Services, & Department of Health and Human Services, 2015).

Surpassing ICF/IID funding in 2000, HCBS waivers are now the largest funding source for the long term services and supports (LTSS) of people with intellectual and developmental disabilities (IDD) (Braddock et al., 2015). Rizzolo, Friedman, Lulinski-Norris, and Braddock (2013) in depth national analysis of FY 2010 HCBS IDD waivers revealed $23.5 billion was projected for HCBS waivers for approximately 515,000 people with IDD through 88 waivers from 41 states and the District of Columbia. Rizzolo et al. (2013) also developed an HCBS IDD waiver taxonomy to categorize services to better understand waiver priorities. They found in FY 2010 the majority of spending was projected for residential habilitation (53%), day habilitation

(19%), and supports for people to live in their own or family home (companion, homemaker, chore, personal assistance, supported living) services (11%) (Rizzolo et al., 2013).

Rizzolo et al.'s (2013) findings revealed vast differences across states and services in terms of total projected spending, unduplicated participants, spending per participant, and average length of stay. This wide variance lead Rizzolo et al. (2013) to conclude "with the increased utilization of the HCBS Waivers to support individuals with IDD, there is a great need to better understand the variability of services provided through this funding" (p. 19).

There have been a number of critical changes since FY 2010. The fiscal landscape differs significantly, especially in wake of recovery from the 2007-2009's Great Recession (National Bureau of Economic Research, 2012). Between 2008 and 2009 more people were relying on Medicaid because of unemployment, resulting in a drop in the proportion of total federal Medicaid spending going towards people with IDD (Braddock et al., 2015). Since then inflation has changed significantly from 2009 from -6.4% to 2.6% in FY 2014 (Braddock et al., 2015). In wake of recovery from the Great Recession, between 2011 and 2013 states allocation toward community supports and institutional care increased (Braddock et al., 2015). However, states continue to lean on families and fail to provide family support to a large proportion of families caring for people with IDD (Braddock et al., 2015).

Since FY 2010 there has also been a number of rule and regulation changes from the Centers for Medicare and Medicaid Services (CMS). Perhaps the most significant new regulation is the new CMS HCBS 1915(c) final settings rule (CMS 2249-F/2296-F) which was implemented in 2014, but was first raised in the end of FY 2009 (CMS, 2014; Medicaid Program, 2014). Significantly, the final rule shifted "away from defining home and community-based settings by 'what they are not,' and toward defining them by the nature and quality of

participants' experiences" (CMS, 2014, p. 2). In doing so, the rule "establish[ed] a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting's location, geography, or physical characteristics" (CMS, 2014, p. 2).

The final rule also emphasizes person centered planning, requiring LTSS be directed by individuals' preferences and goals (Medicaid Program, 2014). The rule's focus on person centered planning draws particular attention to community participation, employment, education, and healthcare, the impact of which could shift how states need to provide their services (CMS, 2014; Medicaid Program, 2014). For example, under the new rule states may find they need to move away from segregated day services in order to meet person-centered planning and community participation requirements.

The final rule also allows states the flexibility to create 1915(c) waivers for combined target groups (Medicaid Program, 2014). For example, a state may now create a waiver that serves both people with physical disabilities and older adults (65+). The ability to serve multiple target populations could impact what types of services are provided for the new combined groups. Another important change implemented with the new final rule was the requirement that state HCBS programs have thorough transition plans that pay particular attention to setting compliance to ensure all settings truly fall under home and community-based settings (Medicaid Program, 2014).

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 improved fiscal landscape. Therefore, the aim of this study was to provide an update to Rizzolo et al. (2013) – to examine projected spending allocations and state priorities for LTSS for people with IDD in FY 2015. In doing so 111 Medicaid HCBS 1915(c) waivers for

people with IDD from 46 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. Over 2,850 services were also organized into an updated HCBS IDD waiver taxonomy mirroring Rizzolo et al.'s (2013) to determine which services were the most frequently provided as well as which services received the most funding in FY 2015.

Methods

Medicaid Home and Community Based Services (HCBS) 1915(c) waivers were obtained from the Centers for Medicare and Medicaid Services (CMS) Medicaid.gov website over a period of approximately 11 months (May 2015 to April 2016). (Figure 1 presents a detailed tree of methodology.) First, all HCBS waivers that were not 1915(c) – 1115 and 1915(b) waivers – were excluded. Our next exclusion criteria required waivers serve people with IDD – developmental disabilities (DD), intellectual disabilities (ID), autism (ASD), and/or mental retardation (MR). (Although the term mental retardation is considered outdated and pejorative it continues to be used by some HCBS 1915(c) waivers thus was a necessary search term. See Friedman (2016).) Waivers for all other populations as well as pending or inactive 1915(c) waivers were excluded. Waivers that combined target groups (e.g., intellectual and physical disabilities) (n = 4), which is a new feature permitted under a relatively new CMS rule (Home and Community Based Services Waivers (CMS-2296-F), 2011), were also excluded during this stage because service provisions and expenditures between people with IDD and other target groups cannot be differentiated. Next, waivers that did not include 2015 were excluded from the analysis. While most often this was the state fiscal year (FY) (July 1, 2014 to June 30, 2015), a few states used the federal FY (October 1, 2014 to September 30, 2015), while others used the 2015 calendar year (January 1, 2015 to December 31, 2015). We use the term FY for

consistency. This process resulted in the collection of 111 HCBS 1915(c) waivers for people with IDD from 46 states and the District of Columbia.

CMS requires waivers to describe: CMS assurances and requirements; levels of care; waiver administration and operation; participant access and eligibility; participant services, including limitations and restrictions; service planning and delivery; participant direction of services; participant rights; participant safeguards; quality improvement strategies; financial accountability; and cost-neutrality demonstrations (Disabled and Elderly Health Programs Group et al., 2015). Using this information waivers were analyzed to determine the services provided, the projected number of users, total projected spending, and the average annual service allocation per participant. We also examined waivers in order to compare comprehensive and support waivers (Rizzolo et al., 2013) funding using an independent samples *t*-test. We also utilized one-way analyses of variance (ANOVAs) in order to determine if there were significant differences between waivers for different target age groups (children, adults, and both children and adults) and different target populations (DD umbrella (including ID and ASD), ID only, and ASD only) in terms of projected spending, average participant spending, and average length of stay.

Waiver data was next utilized to organize the HCBS waivers into a taxonomy (see figure 1) mirroring Rizzolo et al.'s (2013) FY 2010 HCBS IDD waiver taxonomy, which was developed based on an analysis of over 1,300 HCBS IDD waiver services. This was necessary to determine what types of services waivers were providing as well as waiver spending by category.

Findings

Fiscal Year 2015 Waivers

In FY 2015 46 states and the District of Columbia provided services for people with IDD through 111 HCBS 1915(c) waivers. Sixty-four of these waivers (58%) served both adults and

children, 27 waivers (24%) only children, and 20 waivers (18%) only adults. Eighty-three waivers (75%) served people with DD (including ASD and ID), 17 waivers (15%) people with ID specifically, and 11 waivers (10%) people with ASD specifically. See Table 1.

Total unduplicated participants. The total number of estimated unduplicated participants with IDD in FY 2015 was 629,694. The number of people with IDD served by the HCBS waiver varied widely by waiver, ranging from 15 people for Florida's Familial Dysautonomia Waiver (FL40205.R02.00) to 110,000 for California's HCBS waiver for Californians with DD (CA336.R03.00). On average waivers estimated providing for 5,673 participants (median = 2,500).

A one-way ANOVA revealed significant differences between waivers' target age groups (children; adult; both) and unduplicated participants, $F(2, 108) = 4.45$, $p = .014$. Post hoc comparisons using Tukey's HSD revealed significant differences between the waivers for both children and adults (M = 8,279, SD = 14,411) and waivers for children (M = 967, SD = 1,593) ($p = .014$), indicating there were more participants on waivers for both children and adults than waivers for children. There was not a significant difference between unduplicated participants for waivers for different target populations (DD umbrella (including ID and ASD), ID only, ASD only).

Total projected spending. In total HCBS IDD waivers projected $25.6 billion of spending in FY 2015. However, this ranged from $28,793 for Connecticut's Early Childhood Autism Waiver (CT1040.R00.00) to $2.8 billion for California's CA336.R03.00 waiver. The average total projected spending in FY 2015 was $230.3 million, while the median total projected spending was $79.8 million.

The average HCBS IDD spending per capita was $111.42 in FY 2015. The District of Columbia ($276.86), Maine ($253.09), North Dakota ($245.14), Connecticut ($240.58), and Alaska ($221.42) ranked highest in terms of HCBS IDD spending per capita while Mississippi ($26.67), Wisconsin ($17.49), South Carolina ($11.65), Arkansas ($1.67) and New York ($1.49) ranked the lowest; see figure 2. Approximately three-quarters of the states that provided HCBS waivers in FY 2015 projected spending less than $150.00 per capita in FY 2015 (see figure 3).

Fiscal effort was used as a tool to determine "state's commitment to I/DD services after controlling for state wealth. Fiscal effort is theoretically based on the competitive struggle for government funding described by Key (1949) and Wildavsky (1974) as the essence of politics" (Braddock et al., 2015, p. 14). Fiscal effort is calculated by dividing the state's total projected HCBS IDD waiver spending (FY 2015) by the state's total personal income (FY 2015). Total personal income is

> the income received by, or on behalf of, all persons from all sources: from participation as laborers in production, from owning a home or business, from the ownership of financial assets, and from government and business in the form of transfers. It includes income from domestic sources as well as the rest of world. It does not include realized or unrealized capital gains or losses. (Bureau of Economic Analysis, 2016, n.p.)

In FY 2015, a total of $1.66 per $1,000 of United States aggregate personal income was projected for HCBS IDD waivers. Across the 46 states and the District of Columbia providing waivers the average fiscal effort was $2.34. The states with the largest fiscal efforts in FY 2015 were Maine ($6.01), West Virginia ($5.23), North Dakota ($4.51), Minnesota ($4.24), and New Mexico ($3.96). Meanwhile, Mississippi ($0.75), Wisconsin ($0.38), South Carolina ($0.31),

Arkansas ($0.04), and New York ($0.03) had the lowest fiscal efforts (figure 4). The majority of states providing HCBS IDD waivers had a fiscal effort below $3.00 per $1,000 of aggregate personal income (see figure 5).

There were significant differences in total projected spending depending on the waivers' target age groups – children, adults, or both – based on a one-way ANOVA, $F(2, 108) = 7.37$, $p = .001$. Post hoc comparisons using Tukey's HSD test revealed there was a significant difference between the waivers for children (M = $15.05 million, *SD* = $20.01 million) and waivers for both children and adults (M = $341.32 million, *SD* = $478.33 million), with the children's waivers spending significantly less money (*p*. = .001). There was not a significant difference between the children and adults waivers, or the adult waivers and the waivers for both children and adults. There were also not significant differences in total projected spending depending on waivers' target populations (DD (including ID and ASD), ID, and ASD).

Total spending: Comprehensive versus support waivers. Comprehensive (or traditional) waivers are those waivers which provide a range of supports including residential habilitation while support waivers rely on unpaid natural supports rather than residential supports in licensed settings. We were able to directly compare the comprehensive and support waivers of 11 states which served the same target populations: Alabama, Georgia, Illinois, Indiana, Massachusetts, Maine, Montana, North Carolina, Ohio, Oklahoma, and Texas. Our analysis revealed the cost of support waivers was 26% of the average cost per person of comprehensive waivers ($14,779 versus $65,120). The difference between comprehensive and support waivers was statistically significant based on an independent samples *t*-test, $t(20) = -5.15$, $p < .001$.

Spending per participant. In FY 2015 the average estimated cost per participant ranged from $576 for Connecticut's CT1040.R00.00 waiver to $146,502 for Tennessee's

Comprehensive Aggregate Cap Waiver (TN357.R03.00) (see table 1). The average estimated cost per participant in FY 2015 was $39,989; the median cost per participant was $31,919. The majority of waivers projected less than $40,000 per participant on average (figure 6).

A one-way ANOVA revealed significant differences in terms of spending per participant depending on the waivers' target age groups (children; adult; both), $F(2, 108) = 6.27$, $p = .003$. Post hoc comparisons using Tukey's HSD revealed significant differences between the waivers for children (M = $23,297, SD = $18,742) and adult waivers (M = $53,382, SD = $43,328) groups ($p = .003$), indicating more was spent on the average participant in adult waivers than waivers for children. There was also a significant difference between the children's waivers (M = $23,297, SD = $18,742) and the waivers for both children and adults (M = $42,845, SD = $29,630) groups ($p = .017$), indicating more was spent on average on participants served by waivers for adults and children than waivers that were strictly for children. There was not a significant difference between the adult waivers, and waivers for both children and adults.

According to a one-way ANOVA there were significant differences in terms of average spending per participant depending on waivers' target groups (DD (including ASD and ID), ID, and ASD), $F(2, 108) = 3.58$, $p = .031$. Tukey's HSD post hoc comparisons revealed significant differences between waivers for people with ID (M = $53,705, SD = $44,760) and ASD (M = $21,561, SD = $12,833) ($p = .023$), with ID waivers projecting more spending per participant on average. There were no other significant differences.

Average length of stay. The average length of stay is the average number of days participants are on waivers each year. In FY 2015, the average length of stay ranged from 186 days for Pennsylvania's Medicaid Waiver for Infants, Toddlers and Families (PA0324.R03.00)

to 365 days for Arkansas' Autism Waiver (AR936.00.00), and Florida's FL40205.R02.00 waiver. The mean average length of stay across the waivers was 330 days.

An one-way ANOVA comparing the target age groups (children; adults; both) and the average length of stay was significant, $F(2, 108) = 9.24$, $p < .001$. A post hoc Tukey's HSD revealed significant differences between the average length of stay of children's waivers ($M = 306.85$, $SD = 52.87$) and adult waivers ($M = 337.40$, $SD = 18.97$) ($p = .005$), with adult waivers having a longer average length of stay. There were also significant differences between waivers serving both children and adults ($M = 337.72$, $SD = 23.13$) and waivers for children ($M = 306.85$, $SD = 52.87$) ($p < .001$), with children's waivers having a shorter average length of stay.

There were also significant differences between the average length of stay of the target populations (DD (including ASD and ID), ID, and ASD) according to a one-way ANOVA, $F(2, 108) = 5.65$, $p = .005$. According to the post hoc Tukey's HSD the average length of stay of DD waivers (including ID and ASD) ($M = 332.00$, $SD = 29.58$) differed significantly from ASD waivers ($M = 299.55$, $SD = 66.92$) ($p = .013$), with participants on ASD waivers having a shorter length of stay on average. Moreover, there were significant differences between the average length of stay of ASD waivers ($M = 299.55$, $SD = 66.92$) and ID waivers ($M = 340.94$, $SD = 14.78$) ($p = .006$), with ASD waivers having a shorter length of stay on average.

Service Taxonomy

Over 2,850 services from the 111 FY 2015 waivers were reviewed and sorted into themes according to an updated version of *Citation for review*'s FY 2010 HCBS IDD taxonomy: residential habilitation; individual goods and services; prevocational; transportation; self-advocacy training; day habilitation; community transition supports; respite; health and professional services (crisis, dental, clinical and therapeutic services, nursing and home health);

supports to live in one's own home (companion, homemaker, chore, personal assistance, supported living); care coordination; adult day health; specialized medical and assistive technologies; financial support services; family training and counseling (family training and counseling, family supports); recreation and leisure; and, supported employment.

Service category spending. According to projected spending, the largest service category in FY 2015 was residential habilitation, comprising 42% of FY 2015 projected spending ($10.8 billion). The HCBS Waiver technical guide (Disabled and Elderly Health Programs Group et al., 2015) defines residential habilitation as:

> Residential habilitation means individually tailored supports that assist with the acquisition, retention, or improvement in skills related to living in the community. These supports include adaptive skill development, assistance with activities of daily living, community inclusion, transportation, adult educational supports, social and leisure skill development, that assist the participant to reside in the most integrated setting appropriate to his/her needs. (p. 145)

In this instance, residential habilitation was limited to supports provided in facilities rather than in participant's homes or non-facility settings (personal assistance/supported living).

Supports to live in one's own home or a family home – personal care, companion, homemaker, chore, and supported living – were the second largest service category in FY 2015, totaling $5.2 billion of projected spending (20% of FY 2015 spending). The CMS definition for personal care is as follows:

> A range of assistance to enable waiver participants to accomplish tasks that they would normally do for themselves if they did not have a disability. This assistance may take the form of hands-on assistance (actually performing a task for the

> person) or cuing to prompt the participant to perform a task. (Disabled and Elderly Health Programs Group et al., 2015, p. 144)

Homemaker is defined as:

> Services that consist of the performance of general household tasks (e.g., meal preparation and routine household care) provided by a qualified homemaker, when the individual regularly responsible for these activities is temporarily absent or unable to manage the home and care for him or herself or others in the home. (Disabled and Elderly Health Programs Group et al., 2015, p. 142).

Companion is:

> Non-medical care, supervision and socialization, provided to a functionally impaired adult. Companions may assist or supervise the participant with such tasks as meal preparation, laundry and shopping…Providers may also perform light housekeeping tasks that are incidental to the care and supervision of the participant. (Disabled and Elderly Health Programs Group et al., 2015, pp. 170-171)

CMS defines chore as:

> Services needed to maintain the home in a clean, sanitary and safe environment. This service includes heavy household chores such as washing floors, windows and walls, tacking down loose rugs and tiles, moving heavy items of furniture in order to provide safe access and egress. (Disabled and Elderly Health Programs Group et al., 2015, pp. 170-171)

Although CMS does not provide a direct definition for supported living, Rizzolo et al. (2013) compiled the following definition of supported living based on their FY 2010 analysis:

> This service is designed to provide support to participants who may have limited natural supports and have an assessed need for assistance with acquisition, retention, or improvement in skills related to activities of daily living, such as personal grooming and cleanliness, bed making and household chores, eating and the preparation of food, and the social and adaptive skills necessary to enable the individual to reside in a non-institutional setting. (p. 10)

The third largest service in FY 2015 was day habilitation. Approximately 16% of total spending ($4.2 billion) was projected for day habilitation services, which the HCBS waiver technical guide defines as:

> Provision of regularly scheduled activities in a non-residential setting, separate from the participant's private residence or other residential living arrangement, such as assistance with acquisition, retention, or improvement in self-help, socialization and adaptive skills that enhance social development and develop skills in performing activities of daily living and community living. Activities and environments are designed to foster the acquisition of skills, building positive social behavior and interpersonal competence, greater independence and personal choice. (Disabled and Elderly Health Programs Group et al., 2015, pp. 147-148)

These three services comprised approximately 80% of all HCBS IDD projected funding in FY 2015. The rest of the services each made up less than 4% of total projected spending, totaling less than $5.3 billion: health and professional services (4%); supported employment (3%); care coordination, respite, transportation, family services, community transition supports, and prevocational services (2% each); specialized medical equipment and assistive technology (1%); adult day health, financial support services, individual goods and services, self advocacy

training, and education, and recreation and leisure (less than 1%). Table 2 details FY 2015 spending across these categories.

Frequency of service categories. Despite making up less than 4% of total projected spending in FY 2015, 95% of waivers (*n* = 105) provided health and professional services, making it the most frequently provided service category; see table 3. More than three-quarters of waivers also provided: specialized medical equipment and assistive technology (*n* = 100); respite (*n* = 92); supports in one's own home (companion, homemaker, personal care, supported living, chore) (*n* = 85); day habilitation (*n* = 83); and, supported employment (*n* = 83). Less than three-quarters of waivers provided transportation (*n* = 66), residential habilitation (*n* = 63), and care coordination (*n* = 58). Less than half of waivers provided community transition supports (*n* = 50), prevocational services (*n* = 47), and family training and counseling (*n* = 47). The following service categories were provided by less than one-third of waivers: financial support services (*n* = 35); individual goods and services (*n* = 30); adult day health (*n* = 19); self advocacy training (*n* = 8); education (*n* = 2); and, recreation and leisure (*n* = 1).

Discussion

In FY 2015, 111 HCBS 1915(c) waivers provided over 2,850 services to approximately 630,000 people with IDD. Over $25.6 billion was projected for HCBS waivers, with a national spending per capita of $111.42, and a fiscal effort of $1.66. On average waivers projected spending $39,989 per participant in a year. The services with the most funding in FY 2015 were residential habilitation, supports to live in one's own home (personal care, companion, homemaker, chore, and supported living), and day habilitation.

There were a number of differences across waivers depending on target populations and ages. Although there were not significant differences in terms of total projected spending,

waivers for people with ID projected spending more on the average participant in a year than waivers for people with ASD. Participants on ASD waivers had a shorter length of stay on average than participants on DD waivers (including ID and ASD) and ID waivers. Meanwhile, waivers for both children and adults had higher total projected spending and average spending per participant than waivers for children. Participants on children's waivers also had a shorter average length of stay than those on waivers for adults, or both children and adults

This national-level analysis was necessary to compare across states and determine inconsistencies and variance, especially in wake of the changed political and economic landscape since Rizzolo et al.'s (2013) examination of FY 2010 waivers. In our FY 2015 analysis there was also large variance across states and waivers in terms of unduplicated participants, total projected spending, average spending per participant, and average length of stay. For example, the average spending per participant ranged from $576 to $146,502. As we have found, the flexibility granted to states in designing and customizing HCBS 1915(c) waivers by CMS creates large discrepancies across states. While these large differences may in part relate to contextual differences (e.g., location, landscape, population makeup, state priorities, etc.) in each of these states, the lack of standardization may also produce problematic service disparities. This may be especially problematic given there are already long waiting lists for services. In 2013, approximately 233,000 people with IDD across the nation were waiting for Medicaid LTSS (Larson et al., 2016). One of the states with the most people with IDD waiting for Medicaid LTSS in 2013, Illinois (n = 22,999) (Larson et al., 2016), also had one of the lowest spending per capita and fiscal efforts in our study (FY 2015 ranked 39 and 40 respectively). These disparities emphasize the need for continued national level analyses across states.

Compared to Rizzolo et al.'s (2013) FY 2010 findings, our analysis revealed overall waiver growth in FY 2015; this finding parallels the economic changes that have occurred in wake of recovery from the Great Recession. Total projected spending grew almost 5% from $23 billion to $26 billion. The number of total unduplicated participants increased by over 115,000 participants. However, waivers were projecting spending less on average annually per participant. Despite FY 2015 waiver growth, there were a number of changes at the state level between the two fiscal years in terms of spending. For example, New York's waiver funding for people with IDD changed the most dramatically between FY 2010 and FY 2016, dropping 99%. This is largely accounted for by New York's termination of two IDD waivers (Care at Home IV and VI waivers), and a missing FY 2015 waiver (OPWDD waiver) which was not available on CMS, perhaps because of a redesign between FY 2014 and FY 2016. Conversely, states like Washington, New Mexico, Nebraska, and Connecticut expanded their waiver funding, with each waiver's total projected spending increasing by over 75%. Such expansion both at the state and national level suggest, even as some states utilize 1115 demonstration waivers (Braddock et al., 2015), HCBS waivers continue to be an important and predominantly utilized system for LTSS of people with IDD.

Compared to Rizzolo et al.'s (2013) FY 2010 analysis we also found a number of states dramatically changed how much they projected spending per participant in FY 2015. For example, the average annual amount projected in Tennessee grew 68% between FY 2010 ($14,989) and FY 2015 ($77,384). Meanwhile, the largest reduction came from Oregon, which dramatically reduced average projected spending per participant 61% from $24,618 in FY 2010 to $5,921 in FY 2015. These shifts suggest a move towards support waivers over comprehensive waivers for Oregon and the opposite for Tennessee. While support waivers can significantly

reduce costs, by design they also rely on unpaid supports, which can be problematic given the increased burden already placed on family members (Rizzolo et al., 2013*;* Rizzolo, Hemp, & Braddock, 2006). Our findings revealed less spending was projected for family training and counseling services in FY 2015 than in Rizzolo et al.'s (2013) FY 2010 analysis. This is especially problematic because of the positive outcomes for people with IDD produced by family supports, and because HCBS waivers were one of the largest providers of family supports in 2013 (Braddock et al., 2015). These shifts among states, as well as the large discrepancies across states, point to a need for future research to examine state-level factors that contribute to the variability found in this study.

Our FY 2015 analysis also revealed differences from Rizzolo et al.'s (2013) FY 2010 examination of service categories. In terms of funding, community transition supports, adult day health, individual goods and services, and health and professional services had the largest growth by FY 2015. Conversely, funding for the already small service categories recreation and leisure, and education both dropped more than 25% in FY 2015. Prevocational services saw the third largest drop in spending between FY 2010 and FY 2015.

Although funding for residential habilitation remained relatively stable between Rizzolo et al. (2013) and our analysis, residential habilitation comprised a smaller proportion of total funding relative to other services in FY 2015. At the same time, supports for living in ones' own home comprised a larger proportion of overall service funding in FY 2015. Although residential habilitation is still the largest spending category, these trends suggest a potential shift in funding away from facility based supports (e.g., provider agency, group home, foster care) to supports provided in people with IDD's homes and other nonfacility-based settings. However, from our data we cannot determine if these shifts mark a preference by waivers for these individual

settings or simply a reflection of a larger shift in the preferences of people with IDD; future research should examine these changes in more detail.

When interpreting our findings two limitations should be noted. First, four waivers were unavailable for FY 2015: New Mexico's Mi Via-ICF/MR waiver; New York's OPWDD Comprehensive waiver; Utah's Autism waiver; and, Washington's Individual and Family Services waiver. Several attempts were made to obtain these waivers, both through CMS and state IDD agencies, but ultimately we were not able to acquire them. The second limitation of our study is that Medicaid HCBS 1915(c) waivers are based on state projections to the federal government instead of utilization data. However, HCBS 1915(c) waivers are a reasonably accurate proxy of utilization because of their basis on previous years' utilization data (Rizzolo et al., 2013). Moreover, Rizzolo et al.'s (2013) analysis found waiver projections similar to previous expenditure analyses by Braddock et al. (2015) and Irvin (2011).

While the Great Recession had a sizable impact on Medicaid IDD spending (Braddock et al., 2015; Rizzolo et al., 2013), it appears from our findings HCBS 1915(c) IDD waivers are steadily recovering. There are still large differences and discrepancies across states and waivers, especially in terms of funding and annual provisions per participant. As states reevaluate and rebuild their IDD Medicaid programs, especially in response to the changes required by the new final rule (CMS 2249-F/2296-F) (Medicaid Program, 2014), states should use our findings to determine areas of need, as well as how to best capitalize on the limited funding available to them.

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Figure 1. Methodology tree.

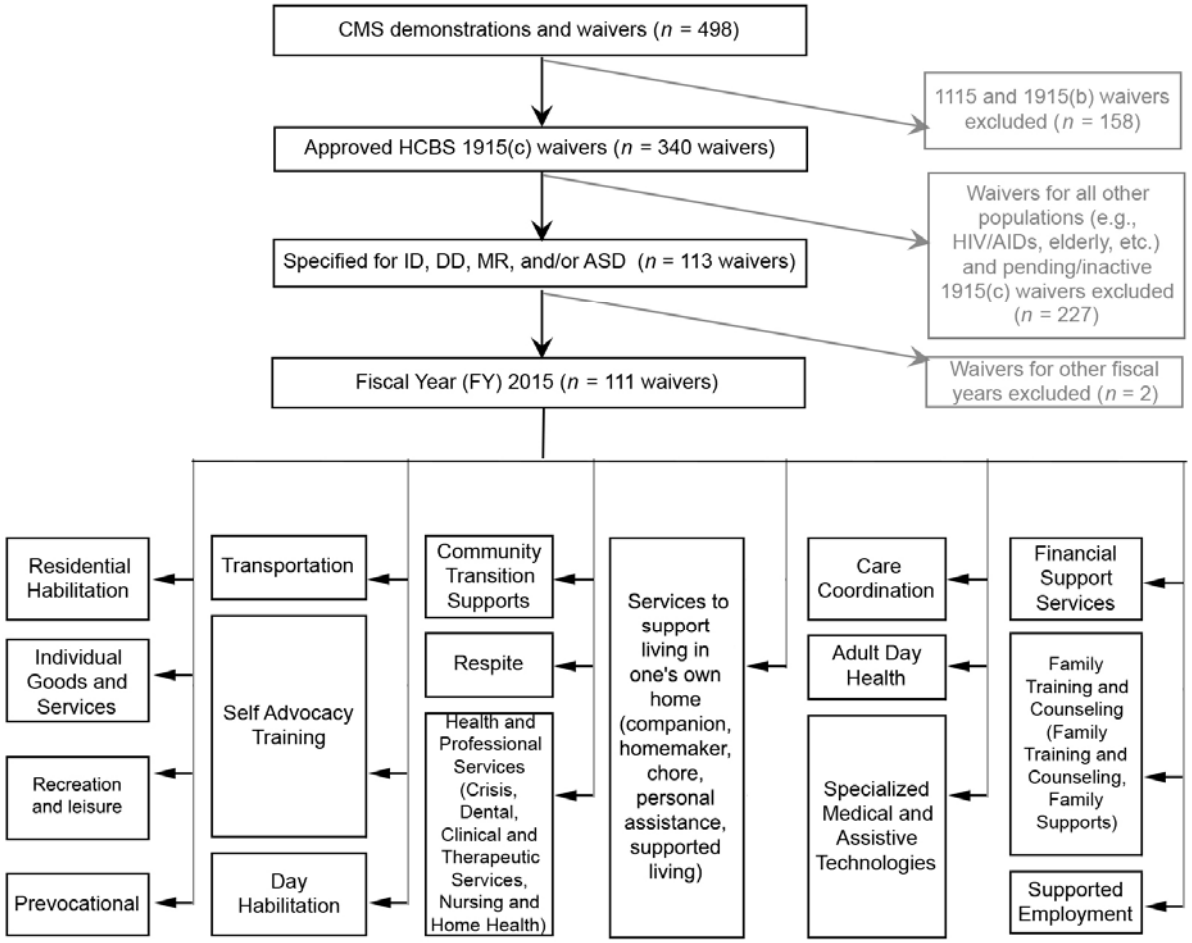

Figure 2. State spending per capita on HCBS IDD waivers (FY 2015).

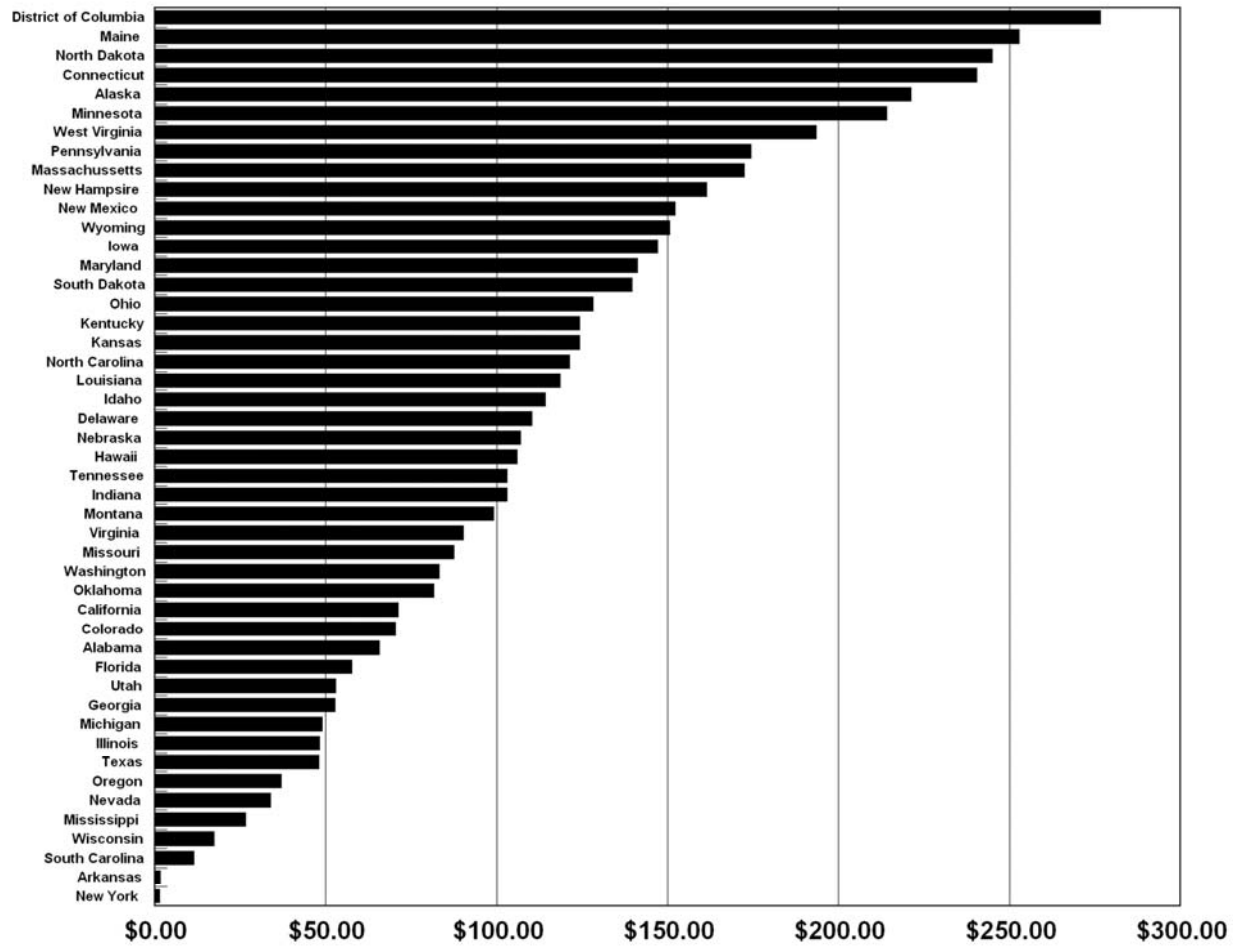

Figure 3. Spending per capita variance across HCBS IDD waivers (FY 2015).

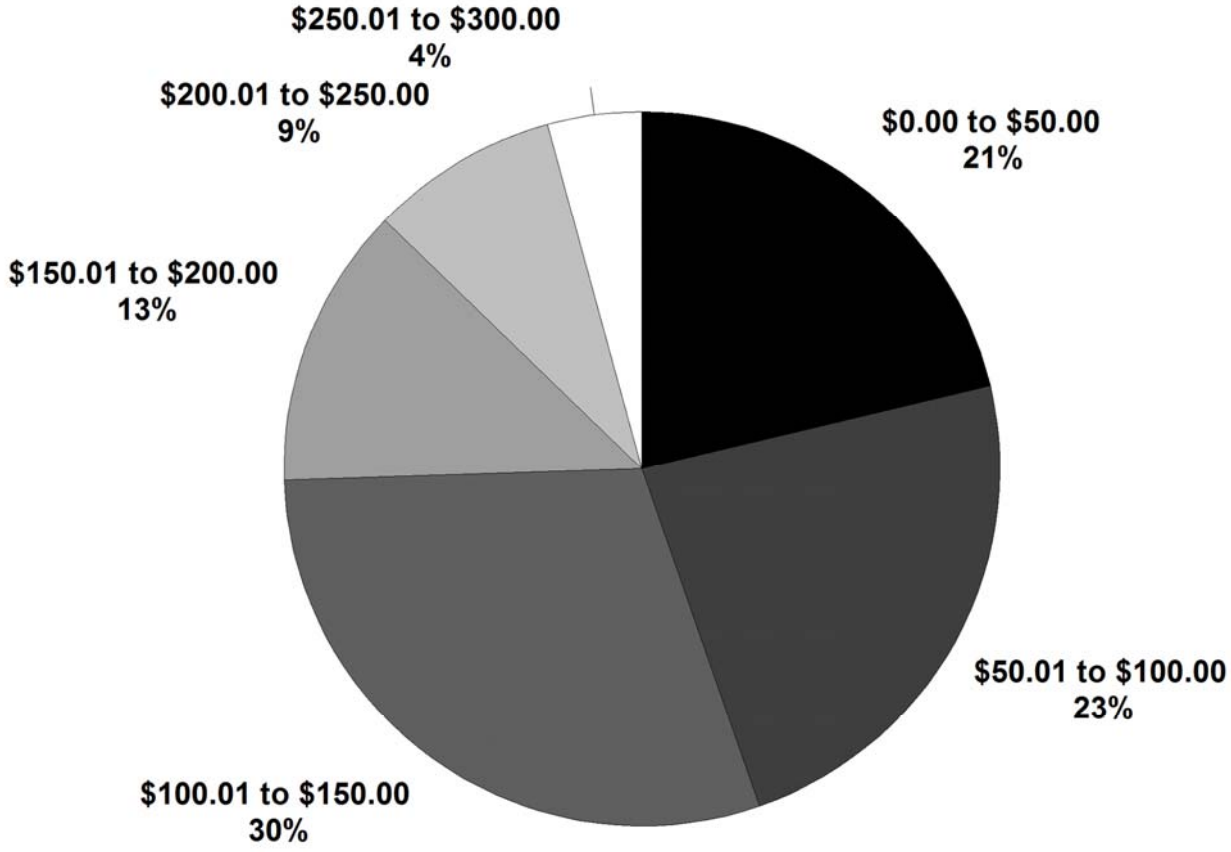

Figure 4. State fiscal effort on HCBS IDD waivers (FY 2015).

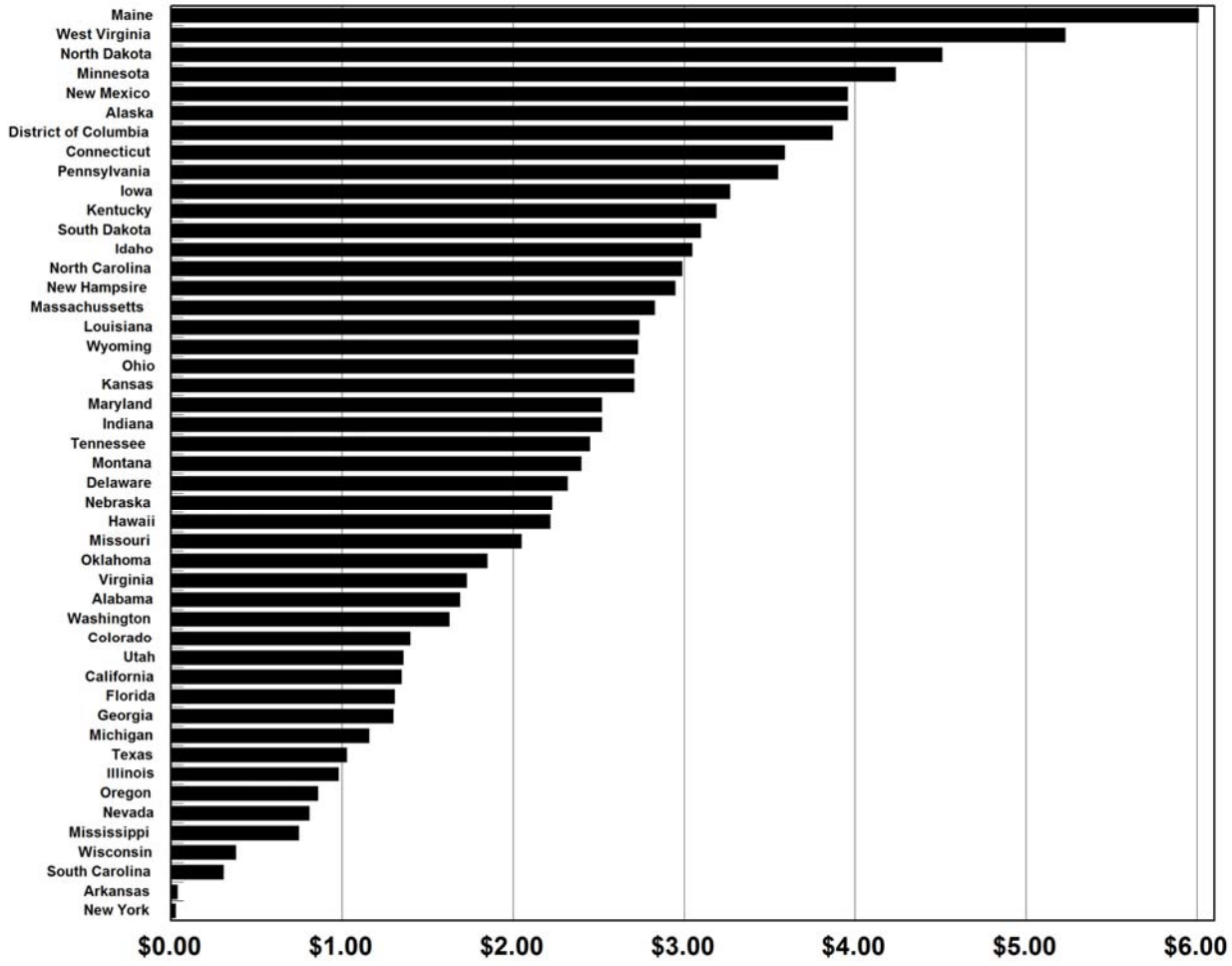

Figure 5. Fiscal effort variance across HCBS IDD waivers (FY 2015).

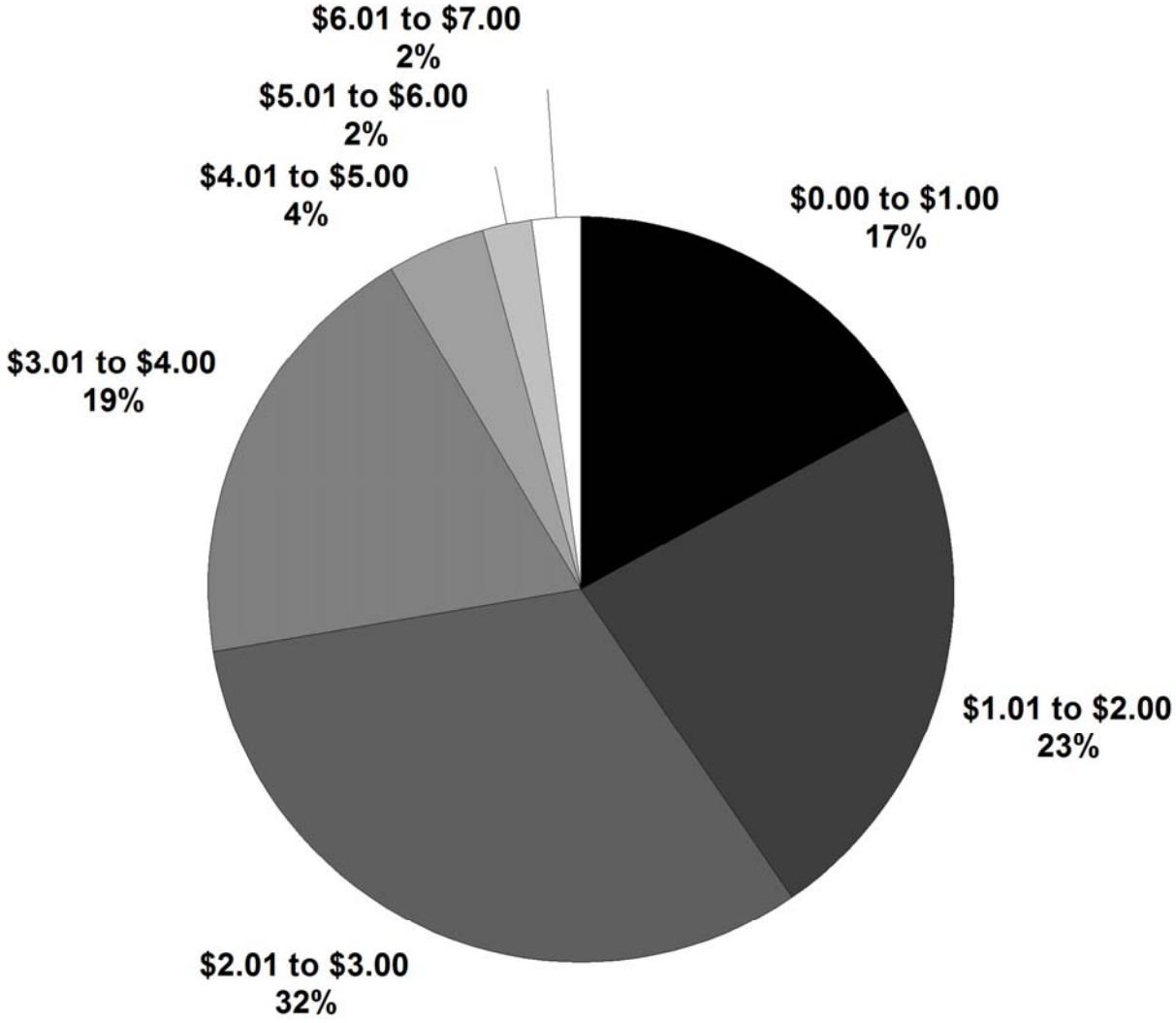

Figure 6. Average annual spending per participant (FY 2015).

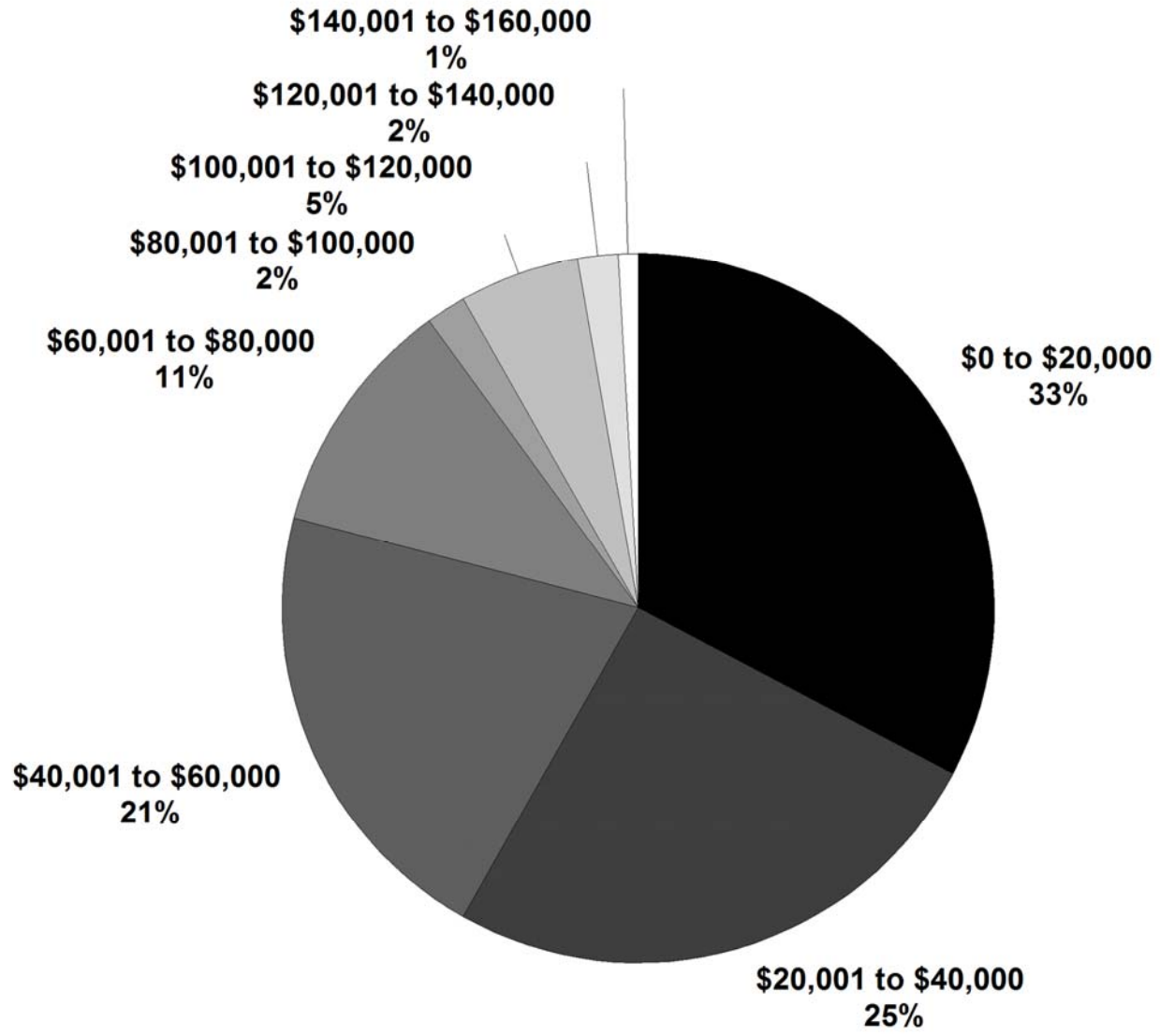

Table 1

FY 2015 Home and Community Based Services Waivers for People with Intellectual and Developmental Disabilities

State	Waiver number	Target population	Target age	2015 Estimated grand total	Total estimated unduplicated participants	Average estimated cost per participant	Average length of stay on the waiver
Alabama	AL0001.R7.00	ID	child & adult	$310,526,554	5,260	$59,035	353
Alabama	AL391.R02.01	ID	child & adult	$8,920,042	569	$15,677	348
Alaska	AK260.R04.04	ASD, DD, ID	child & adult	$163,503,363	2,206	$74,118	340
Arkansas	AR936.00.00	ASD	child	$4,978,940	150	$33,193	365
California	CA336.R03.00	ASD, DD, ID	child & adult	$2,792,277,988	110,000	$25,384	336
Colorado	CO.305.R04.00	DD	child	$5,494,124	122	$45,034	268
Colorado	CO434.R02.00	ASD	child	$1,416,010	144	$9,833	191
Colorado	CO0007.R07.00	DD	adult	$311,241,876	4,818	$64,600	350
Colorado	CO293.R04.00	DD	adult	$56,766,531	4,451	$12,754	340
Colorado	CO4180.R04.00	DD	child	$15,730,407	1,204	$13,065	323
Connecticut	CT437.R02.01	DD, ID	DD adult, ID child	$730,795,826	5,300	$137,886	349
Connecticut	CT426.R02.01	DD, ID	DD adult, ID child	$111,428,300	4,275	$26,065	352
Connecticut	CT881.R00.02	DD, ID	DD adult, ID child	$18,956,323	1,000	$18,956	352
Connecticut	CT993.R00.00	ASD	child & adult	$2,670,607	122	$22,364	359
Connecticut	CT1040.R00.00	ASD	child	$28,793	50	$576	344
District of Columbia	DC307.R03.01	DD, ID	adult	$186,115,988	1,692	$109,998	357
Delaware	DE009.R07.00	ASD, ID	child & adult	$104,447,777	1,100	$94,953	350
Florida	FL867.R01.00	ASD, DD, ID	child & adult	$1,168,625,827	32,400	$36,069	350
Florida	FL40205.R02.00	DD (familial dysautonomia)	child & adult	$376,718	15	$25,115	365
Georgia	GA323.R03.02	DD, ID	child & adult	$450,431,370	8,350	$53,303	324
Georgia	GA175.R05.01	DD, ID	child & adult	$88,818,446	7,793	$11,397	292
Hawaii	HI0013.R06.00	DD, ID	child & adult	$151,859,951	3,328	$45,631	354
Idaho	ID0076.R05.03	ASD, DD, ID	adult	$145,215,919	3,935	$36,904	345
Idaho	ID859.R01.00	ASD, DD, ID	child	$27,570,042	2,277	$12,108	325
Idaho	ID887.R01.00	ASD, DD, ID	child	$16,508,217	771	$21,411	344

Illinois	IL473.R01.03	ASD, DD, ID	child	$24,172,880	295	$81,942	310
Illinois	IL464.R01.02	ASD, DD, ID	child	$19,730,618	1,440	$13,702	335
Illinois	IL350.R03.00	ASD, DD, ID	adult	$578,208,600	19,000	$30,432	335
Indiana	IN0387R0204	ASD, DD, ID	child & adult	$115,490,000	11,964	$9,653	299
Indiana	IN378.R03.01	ASD, DD, ID	child & adult	$567,195,491	9,244	$61,358	343
Iowa	IA242.R05.01	ID	child & adult	$459,846,272	14,203	$32,377	339
Kansas	KS224.05.00	ASD, DD, ID	child & adult	$360,733,460	9,358	$38,548	347
Kansas	KS476.R01.02	ASD	child	$1,606,251	150	$10,708	335
Kentucky	KY314.R03.04	DD, ID	child & adult	$340,631,786	4,701	$72,459	336
Kentucky	KY475.R01.00	DD, ID	child & adult	$210,280,972	10,000	$21,028	301
Louisiana	LA401.R02.02	ASD, DD, ID	child & adult	$513,123,670	9,100	$56,387	356
Louisiana	LA361.R03.00	ASD, DD, ID	child	$15,209,892	1,700	$8,947	294
Louisiana	LA453.R02.01	ASD, DD, ID	adult	$17,391,436	2,500	$6,957	310
Louisiana	LA472.R01.00	ASD, DD, ID	child & adult	$8,633,063	325	$26,563	356
Maryland	MD0023.R06.00	DD, ID	child & adult	$817,334,054	15,450	$52,902	350
Maryland	MD339.R03.00	ASD	child	$31,680,305	1,100	$28,800	357
Massachusetts	MA40207.R01.02	ASD	child	$4,792,237	325	$14,745	292
Massachusetts	MA828.R01.00	ID	adult	$57,904,724	2,893	$20,015	332
Massachusetts	MA826.R01.00	ID	adult	$88,294,399	2,197	$40,189	329
Massachusetts	MA827.R01.00	ID	adult	$1,022,423,271	8,970	$113,983	352
Maine	ME159.R05.02	ASD, ID	adult	$308,529,438	2,955	$104,409	357
Maine	ME467.R01.00	ASD, ID	adult	$27,910,158	1,480	$18,858	343
Michigan	MI4119.r05.00	ASD, DD, ID	child	$13,047,209	464	$28,119	344
Michigan	MI0167.R05.01	DD	child & adult	$473,648,904	8,268	$57,287	350
Minnesota	MN0061.R06.01	DD, ID	child & adult	$1,175,987,007	17,053	$68,961	351
Mississippi	MS282.R04.01	ASD, DD, ID	child & adult	$79,798,684	2,500	$31,919	361
Missouri	MO698.R01.00	ASD	child	$2,929,559	175	$16,740	339
Missouri	MO4185.R04.00	DD, ID	child	$2,314,463	366	$6,324	341
Missouri	MO40190.R03.03	DD	adult	$26,008,414	245	$106,157	345
Missouri	MO178.R05.03	DD, ID	child & adult	$459,628,765	8,610	$53,383	350
Missouri	MO404.R02.03	DD, ID	child & adult	$23,438,986	2,091	$11,209	328
Missouri	MO841.R01.02	ASD, DD, ID	child & adult	$19,427,288	3,125	$6,217	296
Montana	MT208.R05.01	DD, ID	child & adult	$99,530,041	2,750	$36,193	340
Montana	MT1037.R00.01	DD, ID	child & adult	$463,182	30	$15,439	345
Montana	MT667.R01.01	ASD	child	$2,549,058	110	$23,173	183
North Dakota	ND842.R00.00	ASD	child	$2,167,219	47	$46,111	242

North Dakota	ND0037.R07.01	DD, ID	child & adult	$183,384,475	5,260	$34,864	310
Nebraska	NE394.R02.00	ASD, DD, ID	adult	$30,274,975	1,625	$18,631	329
Nebraska	NE396.R02.00	ASD, DD, ID	adult	$149,982,687	4,180	$35,881	341
Nebraska	NE4154.R05.01	DD, ID	child	$22,864,206	475	$48,135	341
Nevada	NV125.R06.00	ID	child & adult	$98,209,170	2,033	$48,308	338
New Hampshire	NH53.R05.00	ASD, DD, ID	child & adult	$207,076,183	4,306	$48,090	290
New Hampshire	NH397.R02.00	ASD, DD, ID	child	$7,951,090	455	$17,475	281
New Mexico	NM173.R05.03	ASD, DD, ID	child & adult	$317,881,142	4,229	$75,167	347
New York	NY470.R01.00	ASD, DD, ID	child	$29,444,483	676	$43,557	267
North Carolina	NC662.R01.00	ASD, DD, ID	child & adult	$566,869,152	10,325	$54,903	356
North Carolina	NC663.R01.00	ASD, DD, ID	child & adult	$15,807,795	1,150	$13,746	356
North Carolina	NC423.R02.01	DD, ID	child & adult	$636,892,187	12,488	$51,000	343
Ohio	OH383.R02.03	ASD, DD, ID	child & adult	$71,033,150	3,200	$22,198	343
Ohio	OH380.R02.03	DD, ID	child & adult	$170,231,034	15,400	$11,054	335
Ohio	OH877.R00.00	DD, ID	child & adult	$49,979,314	2,000	$24,990	257
Ohio	OH231.R4.01	DD, ID	child & adult	$1,199,526,086	19,000	$63,133	330
Oklahoma	OK351.R03.02	ID	child	$2,659,106	307	$8,662	324
Oklahoma	OK343.R03.02	ID	adult	$27,071,941	1,617	$16,742	343
Oklahoma	OK179.R05.02	ID	child & adult	$199,286,784	3,154	$63,185	350
Oklahoma	OK399.R02.02	ID	adult	$90,909,848	693	$131,183	360
Oregon	OR117.R05.03	DD, ID	child & adult	$102,914,484	14,750	$6,977	340
Oregon	OR375.R03.00	DD, ID	adult	$46,010,655	7,805	$5,895	340
Oregon	OR40194.R03.00	DD, ID	child	$699,553	143	$4,892	340
Pennsylvania	PA593.R01.04	ASD	adult	$16,825,145	544	$30,929	288
Pennsylvania	PA354.R03.04	ID	child & adult	$245,948,431	13,300	$18,492	300
Pennsylvania	PA147.R05.04	ID	child & adult	$1,870,374,212	18,067	$103,524	342
Pennsylvania	PA235.R04.05	DD	adult	$73,248,864	1,694	$43,240	300
Pennsylvania	PA0324.R03.00	DD, ID	child	$29,147,331	6,762	$4,310	183
South Carolina	SC676.R01.01	ID	child & adult	$57,016,420	4,250	$13,416	331
South Dakota	SD44.R07.01	DD, ID	child & adult	$115,883,345	2,765	$41,911	345
South Dakota	SD338.R03.00	DD, ID	child & adult	$4,014,822	1,017	$3,948	340
Tennessee	TN427.R02.01	DD, ID	DD child, ID child & adult	$39,012,355	1,802	$21,649	349
Tennessee	TN357.R03.00	ID	child & adult	$281,722,656	1,923	$146,502	358
Tennessee	TN128.R05.00	DD, ID	DD child, ID child & adult	$360,014,339	5,072	$70,981	356

Texas	TX110.R06.06	DD, ID	child & adult	$1,026,095,974	24,398	$42,057	335
Texas	TX281.R04.02	DD	child & adult	$9,275,930	218	$42,550	294
Texas	TX221.R05.00	DD	child & adult	$225,626,485	5,250	$42,976	345
Texas	TX403.R02.03	DD, ID	child & adult	$61,122,250	8,017	$7,624	260
Utah	UT158.R05.04	ASD, DD, ID	child & adult	$159,087,367	4,600	$34,584	349
Virginia	VA358.R03.03	ASD, DD	child & adult	$28,319,275	1,074	$26,368	348
Virginia	VA430.R02.00	ID	child & adult	$4,399,874	300	$14,666	352
Virginia	VA372.R03.02	ID	child & adult	$725,365,908	10,822	$67,027	345
Washington	WA40669.R01.03	DD	child	$5,246,601	104	$50,448	347
Washington	WA411.R02.04	DD	adult	$54,905,238	458	$119,880	352
Washington	WA0410.R02.06	DD	child & adult	$376,012,243	4,738	$79,361	346
Washington	WA0409.R02.06	DD	child & adult	$161,502,657	8,113	$19,907	349
Wisconsin	WI414.R02.01	ASD, DD, ID	child	$100,920,337	5,450	$18,517	340
Wyoming	WY253.R04.02	DD, ID	child	$15,429,569	835	$18,479	330
Wyoming	WY1061.R00.00	DD, ID	child & adult	$88,415,074	1,700	$52,009	351
West Virginia	WV133.R05.01	DD, ID	child & adult	$357,225,912	4,634	$77,088	352

Note. ID = intellectual disability; DD = developmental disabilities; ASD = autism spectrum disorder.

Table 2

Spending by Category (FY 2015)

Service	Total proposed spending (in millions)	%
Residential habilitation	$10,815.6	42.30%
Companion, homemaker, personal assistant, supported living	$5,239.6	20.49%
Day habilitation	$4,210.0	16.47%
Health and professional services	$1,130.9	4.42%
Clinical and therapeutic services	$758.0	2.96%
Nursing and home health	$336.6	1.32%
Dental	$36.3	0.14%
Crisis	$30.6	0.12%
Supported employment	$669.3	2.62%
Care coordination	$618.7	2.42%
Respite	$589.6	2.31%
Transportation	$541.2	2.12%
Family services	$520.3	2.04%
Family supports	$475.6	1.86%
Family training & counseling	$14.1	0.06%
Community transition supports	$451.7	1.77%
Prevocational	$448.6	1.75%
Specialized medical equipment and assistive technology	$210.1	0.82%
Adult day health	$59.6	0.23%
Financial support services	$48.0	0.19%
Individual goods and services	$10.6	0.042%
Self advocacy training	$1.57	0.006%
Education	$0.43	0.0017%
Recreation and leisure	$0.14	0.0005%

Table 3

Services by Waiver

	0001	391	260	936	336	305	434	0007	293	4180	437	426	881	993	1040	307	009	867	40205	323
Services	AL	AL	AK	AR	CA	CO	CO	CO	CO	CO	CT	CT	CT	CT	CT	DC	DE	FL	FL	GA
Residential habilitation	x		x		x	x		x			x	x		x		x	x	x		x
Companion, homemaker, personal assistant, supported living	x	x	x		x				x	x	x	x		x		x	x	x		x
Adult day health											x	x	x							
Community transition supports	x	x			x	x		x	x	x				x	x	x			x	x
Day habilitation	x	x	x		x			x	x	x	x	x	x			x	x	x		
Financial support services					x						x	x	x							x
Care coordination			x								x	x	x	x				x	x	x
Transportation	x	x	x		x			x	x		x	x	x	x				x		x
Prevocational	x	x			x			x	x		x	x					x			x
Supported employment	x	x	x		x			x	x		x	x	x	x		x	x			x
Specialized medical equipment and assistive technology	x	x	x		x			x	x	x	x	x	x	x		x		x	x	x
Health and professional services	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Respite	x	x	x		x	x			x	x	x	x	x	x		x		x	x	x
Family services										x	x	x				x				x
Individual goods and services	x	x									x	x	x	x						x
Education																				
Self advocacy training									x		x	x	x							
Recreation and leisure										x										

175	0013	0076	859	887	473	464	350	0387	378	242	224	476	314	475	401	361	453	472	0023	339	40207	828	826	827
GA	HI	ID	ID	ID	IL	IL	IL	IN	IN	IA	KS	KS	KY	KY	LA	LA	LA	LA	MD	MD	MA	MA	MA	MA
		x			x		x		x	x	x		x	x	x	x	x	x	x	x				x
x	x	x	x			x	x	x	x	x	x		x	x	x		x	x	x		x	x	x	x
	x	x					x	x	x	x				x										
x		x							x		x		x	x	x			x	x		x			x
			x	x			x	x	x	x	x	x	x	x	x		x	x	x		x	x	x	x
x		x	x							x	x		x						x					
x						x	x	x	x				x	x		x	x	x		x				
x	x	x	x				x	x	x	x			x	x				x	x			x	x	x
x	x							x	x	x					x		x	x						
x	x	x					x	x	x	x	x		x	x	x		x	x	x			x	x	x
x	x	x	x		x	x	x	x	x	x	x		x	x	x	x	x	x	x	x	x	x	x	x
x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x	x	x
x	x	x	x	x		x		x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
x			x	x		x	x	x	x			x			x	x			x	x	x	x	x	x
x										x			x	x					x		x	x	x	x
																						x	x	x

159	467	4119	0167	0061	282	698	4185	40190	178	404	841	208	1037	667	842	0037	394	396	4154	125
ME	ME	MI	MI	MN	MS	MO	MO	MO	MO	MO	MO	MT	MT	MT	ND	ND	NE	NE	NE	NV
x			x	x	x				x		x	x				x	x	x	x	
x	x	x		x	x	x	x	x	x	x	x	x	x			x	x	x	x	x
				x								x				x				
				x	x	x	x		x	x	x	x								
x	x		x	x	x		x		x	x	x	x		x	x	x	x	x	x	x
		x				x	x		x	x	x	x	x							
			x	x	x	x	x		x	x	x	x		x	x					x
x	x	x		x		x	x		x	x	x	x	x	x		x				x
x	x		x	x	x												x	x	x	x
x	x		x	x	x				x	x	x	x	x				x	x	x	x
x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	
x		x	x		x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
	x	x	x	x	x	x	x		x	x		x	x	x	x		x	x	x	
		x	x	x								x				x				
			x									x	x	x						

53	397	173	470	662	663	423	383	380	877	231	351	343	179	399	117	375	40194	593	354	147	235	0324	676	44
NH	NH	NM	NY	NC	NC	NC	OH	OH	OH	OH	OK	OK	OK	OR	OR	OR	OR	PA	PA	PA	PA	PA	SC	SD
x		x		x		x				x			x	x				x		x	x			x
	x	x		x	x	x	x	x	x	x		x	x	x					x	x	x		x	
				x	x		x						x	x									x	
x		x	x	x		x							x					x			x		x	
x		x	x	x	x	x		x	x	x	x	x	x	x	x			x	x	x	x	x	x	x
		x				x			x							x			x	x				
x		x	x							x					x	x	x	x	x	x	x		x	x
		x		x	x		x	x	x	x		x	x	x					x	x	x		x	
			x					x	x	x		x	x	x		x			x	x	x		x	x
x		x	x	x	x	x		x	x	x		x	x	x	x	x		x	x	x	x		x	x
x	x	x	x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x	x		x	x
x	x	x	x	x	x	x	x		x	x	x	x	x	x	x	x	x	x	x	x	x		x	x
x	x	x	x	x	x	x	x	x	x	x	x	x	x	x				x	x	x	x		x	
	x		x	x	x	x			x		x	x	x	x	x	x	x	x						
				x	x	x			x		x	x					x							
																			x	x				

338	427	357	128	110	281	221	403	158	358	430	372	40669	411	0410	0409	414	253	1061	133
SD	TN	TN	TN	TX	TX	TX	TX	UT	VA	VA	VA	WA	WA	WA	WA	WI	WY	WY	WV
	x	x	x	x	x	x		x			x			x	x	x	x	x	
x	x	x	x	x	x	x		x	x		x	x	x	x	x	x	x	x	x
				x	x		x	x	x		x		x	x	x	x			
	x	x	x	x	x		x	x	x	x	x					x	x	x	x
				x	x	x	x	x								x	x	x	x
x		x	x	x	x	x	x	x	x		x					x	x	x	x
	x	x	x					x				x	x	x	x	x		x	x
						x			x	x	x		x	x	x			x	
x	x	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x	x	x
x	x	x	x	x	x	x	x	x	x		x	x	x	x	x	x	x	x	x
x	x	x	x	x	x	x	x	x	x		x	x	x	x	x	x	x	x	x
x	x	x	x	x	x	x	x	x	x		x	x		x	x	x	x	x	x
								x	x			x	x	x	x		x		
																	x	x	x
																x			