

Research

Community Based Services for People with
Brain Injury: A National Analysis



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References:

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Abstract

Purpose: Where and how rehabilitation and long-term services and supports (LTSS) occur for individuals with brain injury (BI) has shifted dramatically over the last few decades. Medicaid Home and Community Based Services (HCBS) 1915(c) waivers allow states to offer LTSS that is tailored to the needs of underserved populations in the community rather than institutional settings.

Method: This study examined how states utilized waivers to provide for people with BI.

Results: Findings revealed only 15 states had waivers for people with BI in fiscal year 2016.

Conclusions: Of those waivers for people with BI, there were vast differences across states and services.

Keywords: brain injury; Medicaid Home and Community Based Services (HCBS) waivers; long term services and supports; community living; public policy

**Community Based Services for People
with Brain Injury: A National Analysis**

Over 5.3 million Americans are estimated to have long-term or life-long need for assistance and supports to perform basic daily tasks as a result of traumatic brain injury (TBI) (Coronado et al., 2012; Selassie et al., 2008). TBI occurs when an external mechanical force damages the brain resulting in loss of consciousness or post traumatic amnesia; it can also be determined by findings on physical or mental status examinations where mild, moderate or severe functional loss is found (Traumatic Brain Injury Model Systems National Data and Statistical Center, 2016). TBI can occur to any person, at any time, and in a various ways, but it often occurs catastrophically, such as in motor vehicle accidents, violence, or falls (Traumatic Brain Injury Model Systems National Data and Statistical Center, 2016) and casualties experienced by soldiers at war (Centers for Disease Control and Prevention et al., 2013). Emerging understanding of TBI exposes how repeat traumas brought on by sporting competition, such as football tackles and soccer head shots, can combine to produce similar loss in cognitive functioning, and ability to participate independently in activities of daily living (Faul, Xu, Wald, & Coronado, 2010).

Acute medical needs including orthopedic, neurologic and live-saving surgeries often accompany TBI. Major life-long residual deficits for people with TBI can include cognitive and physical impairments, often with co-existing deficits impacting behavioral, communicative, and sensory functioning making TBI long-term care complex (Pressman, 2007). These impairments can have the greatest impact on the person and family as they often manifest in difficulty with social relationships, working ability and employment, and activities of daily living (ADLs), such as household, community, and self-care tasks (Centers for Disease Control and Prevention, 2010;

Faul et al., 2010). These functional outcomes necessitate that individuals living with TBI require ongoing services and support networks delivered by providers with knowledge of cognitive, behavioral, and mental health needs of individuals living with TBI. Both research and advocates describe improved functional outcomes when treatment is delivered by specialty trained TBI providers from the earliest stages of medical intervention through acute rehabilitation, including cognitive and behavioral counseling post rehabilitation, and into long-term care (Cicerone et al., 2000; Sander et al., 2001; Maryland Traumatic Brain Injury Advisory Board, 2014).

Where and how specialized rehabilitation, post-rehabilitation, and long-term care services occur for individuals following TBI has shifted dramatically over the last few decades from primarily inpatient rehabilitation, to skilled nursing facility long-term care, and then to service provision in the community (Reynolds, Page, & Johnston, 2001). The move toward community based services is a result of a growing demand by consumers as well as federal rulings such as *Olmstead v. L.C.* (1999) giving individuals the right to receive services in the community rather than in institutional settings (Ng, Harrington, & Kitchener, 2010).

However, referral and receipt of rehabilitation and long-term care is dramatically different for a person with TBI depending on the funding source for receipt of services. Persons without insurance or receiving public assistance in the form of Medicaid are often still referred to a skilled nursing facility with a lack of specialty trained providers in the delivery of services to people with TBI (Pressman, 2007). This practice continues despite research documenting reduction in costs to the state when an individual can receive home and community based care (Hendrickson & Blume, 2008). Recognizing this disparity in specialty services, some states have developed trust funds for catastrophic events such as TBI in response to growing numbers of those who are under or uninsured (Degeneffe et al., 2008). However, in many states these trust

funds are slowly being replaced and funds are being shifted towards Medicaid TBI Home and Community Based Services (HCBS) waivers (Degeneffe et al., 2008; Milliren & Gordon, 1994; Reynolds et al., 2001).

Medicaid covers long term services and supports (LTSS) through institutional care or HCBS. Institutions providing long-term care include residential facilities that assume total care for the individual. There are three Medicaid HCBS programs where individuals with TBI receive care: Medicaid Home and Community Based Services (HCBS) 1915(c) waivers; home health; and personal care services. Home health and personal care services covered by Medicaid state plans cover all ages and diagnostic groups but vary in the services they provide from state to state (Harrington, Ng, & Kitchener, 2009; LeBlanc, Tonner, & Harrington, 2001). Many of these services are provided through states' Departments of Rehabilitation Services and have lower eligibility requirements than 1915(c) waiver programs. However, waiver programs - where they exist - hold the promise of tailoring service provision critical for an all-encompassing approach to the unique needs of the target population.

Medicaid HCBS 1915(c) waivers were created in 1981 under Section 1915(c) of the Social Security Act to provide services and supports to individuals in the community who would otherwise be at risk for institutionalization (LeBlanc, Tonner & Harrison, 2000). Waivers allow states the flexibility to develop and implement innovative services including nonmedical care, such as homemaker or adult day care, to best meet the needs of a target population in a home and/or community setting (United States Department of Health and Human Services, 2000). The Patient Protection and Affordable Care Act creation of the Balancing Incentive Program has enhanced matching funds to states specifically to allocate increases in the percentage of Medicaid LTSS for HCBS waivers (Wenzlow, Eiken, & Sredl, 2016). Flexible design and

additional funding provide an environment for states to design waivers around the distinct LTSS needs of populations that are at risk for institutionalization, such as individuals with TBI.

Coordinated community services for individuals with TBI also have the potential to save states significant money. States with streamlined and coordinated HCBS waiver programs for other target populations (e.g., people with intellectual and developmental disabilities) report less overall long-term care costs than those who mainly utilize institutional care (Braddock et al., 2015; Harrington, Ng, & Kitchener, 2011). However, little is known about how individuals with TBI access and use HCBS waivers. Past surveys on state TBI services include an analysis on the challenges of acquiring and implementing a state TBI waiver (Spearman et al., 2001), and a study exploring the impact of funding sources on the discharge disposition of individuals with TBI from acute care (Chan et al., 2001). Hendrickson and Blume (2008) surveyed Medicaid Brain Injury Programs across states to understand the process of waiver development, implementation, and cost of services for a state. These researchers reported that TBI waivers did provide cost savings for states but that waivers differ significantly across states.

Because of the benefits of HCBS waivers as well as community living, this study analyzed how states across the nation utilized HCBS 1915(c) waivers to provide LTSS for individuals with TBI in fiscal year (FY) 2016. Doing so is critical to better understand disparities in service provision and long-term functional outcomes for this community, especially as many states shift toward greater focus on community living for people with TBI, rather than institutional care.

Methods

Medicaid HCBS 1915(c) waivers were obtained from the Centers for Medicare and Medicaid (CMS) Medicaid.gov website between July 2016 and August 2016. (Figure 1 provides

a detailed tree of methodology.) First, all waivers that were not 1915(c) – 1115 and 1915(b) waivers – were excluded. Our next exclusion criteria required the HCBS waivers provide services for people with brain injury. States’ definitions of brain injury varied significantly - with some including and others excluding stroke or other non-traumatic diagnostic groups. This study includes all waivers that are designated to serve people with ‘brain injury;’ however, we distinguish between waivers designed specific for traumatic injury (TBI) versus non-traumatic diagnoses, or acquired brain injury (ABI) - such as stroke - for a more thorough analysis of waiver impact. When describing all waivers that might include TBI, ‘brain injury (BI)’ was used. Waivers for all other populations as well as waivers that were inactive or pending were then excluded. Next, waivers that did not include 2016 were excluded. Most often this was the state FY (July 1, 2015 to June 30, 2016). However, a few states used the federal FY (October 1, 2015 to September 30, 2016) while others used the 2016 calendar year (January 1, 2016 to December 31, 2016). The term FY is used for consistency. This process resulted in the collection of 17 HCBS 1915(c) waivers for people with brain injury.

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, 2015). We utilized this information to determine projected number of users, total projected spending, average spending per participant, and average length of stay.

As previous research has found large variance across HCBS waivers (Rizzolo et al., 2013; Friedman, 2017), we were also interested in exploring if one of the reasons for this

variance was because of the types of people with BI targeted by the waivers. For this reason, we used independent samples *t*-tests to determine if there were any differences across target age (both children and adults; only adults) and target population (including stroke; excluding stroke) in terms of projected spending, number of participants, average participant spending, and average length of stay. Bivariate linear regressions were also run between projected spending, number of participants, average participant spending, and average length of stay and the number of people with BI on the states' waiting list (Kaiser Family Foundation, 2014) to determine if there were significant relationships.

We also utilized waiver data to organize the services provided into a taxonomy (see figure 1) specific to BI services, similar to Rizzolo, Friedman, Lulinski-Norris, and Braddock's (2013) HCBS intellectual and developmental disabilities (IDD) waiver taxonomy. Doing so was necessary in order to determine what types of services were provided as well as service priorities across the waivers. It should be noted that two waivers (Florida's 'Traumatic Brain and Spinal Cord Injury Waiver' (FL0342R0303) and Mississippi's Traumatic Brain Injury/Spinal Cord Injury Waiver' (MS0366R0300)) combined target populations to include both people with brain injury and spinal cord injuries. The ability to combine target populations for HCBS 1915(c) waivers is a relatively new feature offered by CMS (Centers for Medicare and Medicaid Services, 2014). Because there is no way to differentiate allocation between the two groups, these two waivers were excluded from the analysis of allocation. We were able to analyze the types of services they provided however so these waivers are included in the analysis of service category frequency.

Results

Fifteen states provided services for people with BI through 17 HCBS 1915(c) waivers in FY 2016 (see table 1). Of the 17 waivers, 29.4% ($n = 5$) served both children and adults while 70.6% ($n = 12$) served only adults. 53.5% of the waivers ($n = 8$) served all people with TBI (excluding those with stroke), and 46.7% ($n = 7$) served all people with ABI (including those with stroke). The number of people on a states' waiting list for those states providing waivers ranged from zero to 1,250 ($M = 278.36$; $SD = 439.02$).

Although HCBS 1915(c) waivers permit home and community based services for individuals who meet institutional level of care, waiver programs must not exceed the average cost of institutional care. As such, federal regulations require states to identify an institutional comparison group for a waiver (LeBlanc et al., 2000). As a result there are two significant variables states have to determine spending for a given waiver: 1) the measurement of functional need; and, 2) the type of institution used for the comparison group in the level of care determination. For example, Kentucky Acquired Brain Injury Long Term Care Waiver's (KY0477R0100) level of care comparison group is a general nursing facility, rather than one that specializes in serving people with TBI. Table 2 details the comparison group used to determine level of care, the implications of which are noted in the discussion.

Total Unduplicated Participants

The total projected number of unduplicated participants to be served by HCBS BI waivers in FY 2016 was approximately 8,750. The number of unduplicated participants ranged per waiver from 40 (Nebraska's 'Traumatic Brain Injury' waiver (NE40199R0300)) to 4,905 (Illinois' 'HCBS Waiver for Persons with Brain Injury' (IL0329R0303)). The average waiver projected serving 583 participants with brain injury; the median was 270 participants.

An independent samples *t*-test failed to reveal a significant difference between the number of unduplicated participants served by BI waivers for both children and adults, and those only for adults (equal variances not assumed due to failed Levene's test ($p = .004$); $t(4.02) = 1.11$, $p = .33$). An independent samples *t*-test also failed to reveal significant differences between the number of unduplicated participants and target population type (equal variances not assumed due to failed Levene's test ($p = .042$); $t(6.08) = -1.28$, $p = .25$).

A linear regression to determine if there was a relationship between the number of people with BI on the state's waiting list and total unduplicated participants served was not significant ($F(1, 13) = .45$, $p = .51$, $R^2 = .036$).

Total Projected Spending

In FY 2016, a total of \$333.93 million was projected for HCBS waivers serving people with BI. Total projected spending ranged by waiver from \$1.53 million (Nebraska's NE40199R0300 waiver) to \$68.84 million (Illinois' IL0329R0303 waiver), with the average waiver projecting a total spending of \$22.26 million (median = \$21.15 million).

Spending per capita was used to determine a state's commitment to BI after controlling for the state's total population. (It should be noted the latest date available from the United States Census Bureau was from 2015 while our data is FY 2016. However, population data is not likely to shift that significantly so spending per capita should be relatively stable across the two timeframes. Moreover, it is still a useful mechanism for comparing across states.) The average HCBS BI spending per capita was \$6.14. See Table 1.

Fiscal effort was used to determine a state's commitment to BI 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 was calculated by dividing the state's total projected spending by the state's total personal income. 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.)

(It should be noted, as with population statistics, the most recent total personal income data available was FY 2015. However, we believe fiscal effort is still a useful metric to compare across states because it controls for some of the state's contextual differences.) A total of \$0.02 per \$1,000 of United States aggregate personal income was projected for HCBS BI waivers (see Table 1).

An independent samples *t*-test between waivers for both children and adults, and waivers for only adults did not reveal significant differences in total projected spending ($t(13) = .32, p = .75$). An independent samples *t*-test also failed to reveal significant differences between total spending and target population type ($t(13) = -1.12, p = .28$).

A linear regression to determine if there was a relationship between the number of people with TBI on the state's waiting list and total projected spending was not significant ($F(1, 13) = .36, p = .56, R^2 = .029$).

Average Spending per Participant

BI waivers projected spending \$68,893 on average per participant in a year. Average spending per participant in a year ranged from \$14,024 for Illinois' IL0329R0303 waiver to

\$144,630 for Massachusetts' 'Acquired Brain Injury with Residential Habilitation (ABI-RH) Waiver' (MA40701R0102). See Figure 2.

An independent samples *t*-test revealed significant differences in average spending per participant between waivers that provided for both children and adults, and waivers that only provided for adults (equal variances not assumed due to failed Levene's test ($p = .03$)); $t(12.93) = -3.42, p = .005$. Waivers for both children and adults ($M = \$32,751, SD = \$15,992$) on average projected spending less per participant in a year than those waivers that provided for only adults ($M = \$79,463, SD = \$36,737$). The 95% confidence interval for the difference in means was quite wide, ranging from $-\$76,200$ to $-\$17,224$. An independent samples *t*-test failed to reveal significant differences between average spending per participant and target population type ($t(13) = 1.10, p = .29$).

A linear regression between the number of people with BI on the state's waiting list and the waiver's average spending per participant was significant ($F(1, 13) = 14.27, p = .003, R^2 = .54$). The regression equation for predicting the average spending per participant is

$$\text{Average Spending Per Participant} = 64.27(\text{Number of People on Waiting List}) + \$43,433.27.$$

The number of people on the state waiting list was significant, $t = 3.78, p = .003$. According to the model, as the number of people on the waiting list goes up, so does the waiver's average spending per participant. For example, according to the model, a state that has zero people with BI on the waiting list is expected to spend an average of \$43,433 per participant on their BI waiver, 100 people \$49,860, 500 people \$75,568, and so on.

Average Length of Stay

Average length of stay is the average number of days participants are on the BI waiver each year. On average BI waivers had an average length of stay of 322 days in FY 2016 (median

= 324 days). This ranged from 260 days for Wyoming's 'Acquired Brain Injury Waiver' (WY0370R0300) to 365 days for West Virginia's 'Traumatic Brain Injury (TBI) Waiver' (WV0876R0100).

An independent samples *t*-test failed to reveal significant differences between the two types of waivers in regard to average length of stay ($t(13) = -.26, p = .80$). An independent samples *t*-test also failed to reveal significant differences between average length of stay and target population type ($t(13) = 1.33, p = .21$). A linear regression between the number of people with BI on the state's waiting list and average length of stay was not significant ($F(1, 13) = .14, p = .72, R^2 = .011$).

Comprehensive and Support Waivers

Comprehensive waivers are those that provide a wide range of supports including residential habilitation in licensed settings (Friedman, 2017). Support waivers are those that do not provide residential habilitation because they rely on unpaid natural supports (Friedman, 2017). In FY 2016, 73.3% of HCBS BI waivers ($n = 11$) were comprehensive waivers, while 26.7% ($n = 4$) were support waivers. Our analysis revealed the average cost of support waivers (\$27,991) was 36.4% of the average cost per person of comprehensive waivers (\$76,948). This difference was statistically significant based on an independent samples *t*-test (equal variances not assumed, $p = .017$), $t(12.79) = -4.07, p = .001$.

Service Taxonomy

Over 300 services from the FY 2016 BI waivers were reviewed and organized into a HCBS BI taxonomy. The taxonomy includes the following 16 service categories: adult day health; care coordination; clinical and therapeutic services; community transition supports; crisis; day habilitation; family training; nursing and home health; prevocational services; residential

habilitation; respite; specialized medical equipment and assistive technology; supported employment; supports to live in one's own home (companion, personal care, homemaker, supported living, meals, chore); transportation; and, financial support services.

Service category spending. The largest service category in FY 2016 according to projected spending was supports to live in one's own home (including the subcategories companion, personal care, homemaker, supported living, meals, chore), comprising 37.9% of FY 2016 projected spending (\$130.88 million) (Table 3). The HCBS Waiver technical guide (Disabled and Elderly Health Programs Group, 2015) defines companion as “non-medical care, supervision and socialization, provided to a functionally impaired adult... not entailing hands-on nursing care” (Disabled and Elderly Health Programs Group, 2015, pp. 170-171). Personal care is defined as “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... [and] may be provided on an episodic or on a continuing basis” (Disabled and Elderly Health Programs Group, 2015, p. 144). CMS defines homemaker 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...[is] unable to manage the home and care for him or herself or others in the home. (Disabled and Elderly Health Programs Group, 2015, p. 142)

CMS does not provide a direct definition for supported living; however, Rizzolo et al. (2013) compiled the following definition based on their FY 2010 analysis of HCBS waivers for people with IDD:

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... and the social and adaptive skills necessary to enable the individual to reside in a non-institutional setting. (p. 10)

Although the CMS technical guideline does not provide a direct definition of meals, we compiled the following definition based on the brain injury waiver definitions: meals are the preparation and delivery of meals for those unable to prepare food on their own. Often meals are provided to meet special dietary requirements and/or in the form of liquid nutritional supplements. Chore includes:

Services needed to maintain the home in a clean, sanitary and safe environment.

This service includes heavy household chores.... These services are provided only when neither the participant nor anyone else in the household is capable of performing or financially providing for them, and where no other relative, caregiver, landlord, community/volunteer agency, or third party payor is capable of or responsible for their provision. (Disabled and Elderly Health Programs Group, 2015, pp. 170-171)

The second largest category was residential habilitation, which comprised 31.7% of FY 2016 funding (\$109.73 million). The technical guide defines residential habilitation as: individually tailored supports that assist with the acquisition, retention, or improvement in skills related to living in the community. [For example,] these supports include... assistance with activities of daily living, community inclusion, transportation, [and] adult educational supports. [These services can] include

personal care and protective oversight and supervision. (Disabled and Elderly Health Programs Group, 2015, p. 145)

The third largest category according to service funding was day habilitation. \$44.69 million was projected for day habilitation services (12.9% of FY 2016 spending). Day habilitation is defined 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. [This can] be coordinated with any needed therapies in the individual's person-centered service plan, such as physical, occupational, or speech therapy. (Disabled and Elderly Health Programs Group, 2015, pp. 147-148)

These three service categories comprised more than three-quarters of all HCBS BI projected funding in FY 2016 (Figure 3). While clinical and therapeutic services comprised 9.1% of FY 2016, the rest of the service categories made up less than 2% of total projected spending, totaling less than \$29 million: prevocational, and care coordination (2% each); supported employment, specialized medical equipment and assistive technology, nursing and home health, and transportation (1% each); respite, community transition supports, adult day health, financial support services, crisis, and family training (less than 1% each).

Service category frequency. In addition to being the most prominently funded service, supports to live in one's own home was the most frequently provided service category with 94.1% of waivers ($n = 16$ waivers) providing these services in FY 2016. More than three-

quarters of waivers ($n = 14$ each; 82.4% each) also provided day habilitation, and specialized medical equipment and assistive technology. The following service categories were provided by at least half of the waivers: residential habilitation (70.6%; $n = 12$); clinical and therapeutic services (70.6%; $n = 12$); supported employment (64.7%; $n = 11$); care coordination (58.8%; $n = 10$); and, respite (58.8%; $n = 10$). The remainder of the services categories were provided by less than half of the waivers: transportation (47.1%; $n = 8$); community transition supports (41.2%; $n = 7$); adult day health (29.4%; $n = 5$); financial support services (29.4%; $n = 5$); nursing and home health (23.5%; $n = 4$); prevocational (17.7%; $n = 3$); crisis (11.8%; $n = 2$); and, family training (5.9%; $n = 1$). See Table 4.

Discussion

Estimates suggest there are 2.5 million emergency department visits presenting as new incidents of TBI across the United States annually (CDC, 2015). Research suggests TBI specific support services should include life-long individualized services with ongoing re-assessment to identify any progressive decline with built in structures to be responsive to the needs of the clients and families (Frasca, Tomaszczyk, McFadyen & Green, 2013). Accurate and thorough services for individuals with TBI are recommended to include cognitive, behavioral and mental, health service provision (Colantonio et al., 2015; Corrigan, Whiteneck, & Mellick, 2004). Evaluating a state's BI waiver program and how well it addresses the needs of the TBI population demands side-by-side state waiver comparisons.

According to our findings, approximately \$334 million was projected for BI waivers in FY 2016. While this may seem significant, for comparison, approximately \$26 billion was projected for IDD waivers in FY 2015 (Friedman, 2017). Furthermore, only a small fraction of people with TBI across the United States (approximately 8,750) appear to be benefiting from

HCBS BI waivers; in fact, only 15 states provide waivers specific to this population. The majority of those individuals with brain injuries that are traumatic (TBI) are not enrolled in HCBS waivers (Maryland Traumatic Brain Injury Advisory Board, 2014). In fact, it is estimated that 4,006 people with TBI are on waitlists that average approximately two years (Ng, Harrington, Musumeci & Reaves, 2015). Our findings revealed an inverse relationship between the average annual spending per participant and the number of people on the state waiting list. Although doing so is outside the bounds of our data, future research should explore if this relationship implies states with fewer people on waiting lists are spreading more money around or if there is another interaction at play. For example, in addition to the long waitlists, TBI families report that low BI waiver enrollment may also be due to narrow technical eligibility (Maryland Traumatic Brain Injury Advisory Board, 2014). Maryland families criticize their state BI waiver process for limiting enrollment to individuals transitioning from either a state operated chronic hospital, nursing facility, or state psychiatric hospital (Maryland Traumatic Brain Injury Advisory Board, 2014).

Of those states that did provide waivers specific to people with BI in FY 2016, our findings revealed vast differences in both scope and services across states. For example, average annual spending per participant ranged from \$14,024 to \$144,630. There are many challenges to understanding how the unique services and supports necessary for individuals with BI are accessed and used across states. Waivers use Medicaid eligibility and level of care as part of the criteria to qualify for receipt of services. Other diagnostic groups such as individuals with IDD or physical disability have more clear-cut comparisons to match the level of care criteria to determine the amount of services provided within a waiver. Because of the complex needs and

variability of long standing outcomes of those with a TBI, the cost neutrality of level of care is more difficult to determine (Hendrickson & Blume, 2008)

Another potential reason for these differences is that LTSS for individuals with TBI are often significantly different from the needs and supports of other clinical diagnoses with impairments of the brain. Although impairments such as cerebral vascular accidents or benign and malignant tumors may share some similar functional changes, these are acquired brain injuries (ABI) and have demographically and clinically different needs in acute, rehabilitation, and long-term care. Our findings present stark differences in the number of individuals served and the projected spending across states. However, when looking at the eligibility criteria of the two extreme examples – Nebraska (40) to Illinois (4,905) – Nebraska’s TBI waiver specifically excludes individuals with any non-traumatic, or acquired form of injury (ABI), such as stroke. Illinois’ Brain Injury waiver includes TBI and ABI such as: infection, stroke, malignant, or benign tumors, only excluding degenerative, congenital or neurological disorders related to aging. Illinois and other states that have broader eligibility criteria make it difficult to assess the service access and use of individuals with TBI within the state. This is problematic given the literature’s recommendation for streamlined and coordination of care across the continuum for individuals with TBI and their families (DePompei, Frye, DuFore & Hunt, 2001; Khan, Khan & Feyz, 2002). Many TBI associations call for TBI waiver eligibility to be based on neurobehavioral needs as well as those for physical disability as TBI sequelae can solely be neurobehavioral (Swift & Wilson, 2001).

Another potential reason BI specific waivers are only provided by 15 states is that individuals with TBI are covered by another state waiver, such as a waiver for people with physical disability. This is concerning given the specialized service needs of TBI, such as

vocational rehabilitation, behavioral therapy, or family crisis coverage, may not be included in a more generalized waiver for people with physical disabilities. If the functional components of TBI unique to this diagnosis are not considered during eligibility determination or when determining level of care TBI waivers may not differ from physical disability waivers in terms of how they support individuals with traumatic brain injury. This is especially troublesome as the name of the waiver may lead advocates and families of individuals with TBI to falsely believe the existing BI waivers will cover their unique needs (Jones, Dwyer, Bercovitz & Strahan, 2009).

Our findings also revealed the largest service categories in FY 2016 were supports to live in one's own home, residential habilitation, and day habilitation. Less than 10% of funding was projected for clinical and therapeutic services which is problematic given people with TBI may particularly need these services as a result of their impairments (Colantonio et al., 2015; Corrigan, Whiteneck, & Mellick, 2004). Moreover, very little funding was directed towards the services that help ensure people with TBI are integrated into the community rather than just placed there. For example, transportation is one of the largest needs for people with disabilities (Bernier & Seekins, 1999; Feeley, 2010; Stock, Davies, Hoelzel, & Mullen, 2013; White et al., 2010), yet transportation was provided by less than half of the waivers, and less than 1% of HCBS waiver spending was projected for these services.

Understanding the origin of a state BI waiver may provide insight into how and why some states have more thought out and streamlined provisions of community services and supports for the TBI population. In an interview with state Medicaid, researchers discovered that states with TBI specific waivers have been established because of aggressive lobbying of advocates, advocacy groups, or citizen and legislatively driven efforts (Hendrickson & Blume, 2008). Moreover, it would also be beneficial for future research to qualitatively explore if BI

waiver services are sufficiently supporting people with TBI; service provision alone is not necessarily a metric of quality or met needs.

When interpreting our findings one limitation should be noted; HCBS waivers are projections made to the federal government rather than actual utilization data. However, they have found to be reasonably accurate proxies as they are developed based on previous years' utilization data (Rizzolo et al., 2013). Moreover, an analysis of HCBS waivers for people with IDD by Rizzolo et al. (2013) found very similar projections to previous large scale analyses of actual utilization data by Braddock et al. (2015). However, changes in Medicaid funding can directly influence the ability of a state to maintain their current waiver program , and as a result the lives of those receiving services and supports.

The largest demographic group that experience TBI is working age men (Traumatic Brain Injury Model Systems National Data and Statistical Center, 2016). Many are under-insured (Pressman, 2007), and long-term needs are significant given the care needs over time (Fraas, Balz & Degrauw, 2007; Selassie et al., 2008). The demographics of TBI are also unique, as unlike individuals that are target populations for other waivers, such as those with IDD or older adults, those with TBI often do not have the necessary support systems (Penna et al., 2010). Moreover, many of the people with TBI that live at home are cared for by aging parents (Degeneffe, 2001), placing them at risk for institutionalization if support services are not well established.

The goal of the Medicaid HCBS 1915(c) program goes beyond simply shifting service provision to the community rather than an institutional setting. In fact, the new HCBS settings rule (CMS 2249-F/2296-F) shifts “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” (Centers for Medicare and Medicaid, 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” (Centers for Medicare and Medicaid, 2014, p. 2). As such, achieving the primary objectives of the HCBS waiver program requires understanding the impact a state waiver has on adequately serving a targeted population’s unique needs in order to optimize *meaningful* community participation. As people with TBI and professionals advocate for these changes, our findings should be utilized to understand states’ utilization of the BI waiver to determine areas of need and how to best promote community participation of people with TBI.

References

- Bernier, B., & Seekins, T. (1999). Rural transportation voucher program for people with disabilities: Three case studies. *Journal of Transportation and Statistics*, 2(1), 61-70.
- Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., & Wu, J. (2015). *State of the states in intellectual and developmental disabilities*. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Bureau of Economic Analysis. (2016). *Personal income and outlays* [Press release]. Retrieved from <http://www.bea.gov/newsreleases/national/pi/pinewsrelease.htm>
- Centers for Disease Control and Prevention (CDC). (2010). *Facts about concussion and brain injury: Where to Get Help*. Retrieved from www.cdc.gov/traumaticbraininjury/outcomes.html.
- Centers for Disease Control and Prevention. (2015). Report to Congress on Traumatic Brain Injury in the United States: Epidemiology and Rehabilitation. *National Center for Injury Prevention and Control; Division of Unintentional Injury Prevention*. Retrieved from https://www.cdc.gov/traumaticbraininjury/pdf/tbi_report_to_congress_epi_and_rehab-a.pdf.
- Centers for Disease Control and Prevention, the National Institutes of Health, the Department of Defense, and the Department of Veterans Affairs. (2013). *Report to Congress on traumatic brain injury in the United States: Understanding the public health problem among current and former military personnel*. Retrieved from https://www.cdc.gov/traumaticbraininjury/pdf/report_to_congress_on_traumatic_brain_injury_2013-a.pdf

- Centers for Medicare and Medicaid Services (CMS). (2014). *Fact sheet: Summary of key provisions of the 1915(c) Home and Community-Based Services (HCBS) waivers final rule* (CMS 2249-F/2296-F). Retrieved from <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/1915c-fact-sheet.pdf>
- Chan, L., Doctor, J., Temkin, N., MacLehose, R. F., Esselman, P., Bell, K., & Dikmen, S. (2001). Discharge disposition from acute care after traumatic brain injury: the effect of insurance type. *Archives of Physical Medicine and Rehabilitation*, 82(9), 1151-1154. doi.org/10.1053/apmr.2001.24892
- Cicerone, K. D., Dahlberg, C., Kalmar, K., Langenbahn, D. M., Malec, J. F., Bergquist, T. F.,... Herzog, J. (2000). Evidence-based cognitive rehabilitation: recommendations for clinical practice. *Archives of Physical Medicine and Rehabilitation*, 81(12), 1596-1615. doi.org/10.1053/apmr.2000.19240
- Colantonio, A., Hsueh, J., Petgrave, J., Hirdes, J. P., & Berg, K. (2015). A profile of patients with traumatic brain injury within home care, long-term care, complex continuing care, and institutional mental health settings in a publicly insured population. *Journal of Head Trauma Rehabilitation*, 30(6), E18-E29. doi.org/10.1097/HTR.0000000000000112
- Coronado, V. G., McGuire, L. C., Sarmiento, K., Bell, J., Lionbarger, M. R., Jones, C. D., ... Xu, L. (2012). Trends in traumatic brain injury in the US and the public health response: 1995–2009. *Journal of Safety Research*, 43(4), 299-307. doi.org/10.1016/j.jsr.2012.08.011

- Corrigan, J. D., Whiteneck, G., & Mellick, D. (2004). Perceived needs following traumatic brain injury. *The Journal of Head Trauma Rehabilitation, 19*(3), 205-216.
doi.org/10.1097/00001199-200405000-00002
- Degeneffe, C. E. (2001). Family caregiving and traumatic brain injury. *Health & Social Work, 26*(4), 257-268. doi.org/10.1093/hsw/26.4.257
- Degeneffe, C. E., Boot, D., Kuehne, J., Kuraishi, A., Maristela, F. D., Noyes, J., ...Will, H. (2008). Community-based interventions for persons with traumatic brain injury: A primer for rehabilitation counselors. *Journal of Applied Rehabilitation Counseling, 39*(1), 42-52.
- DePompei, R., Frye, D., DuFore, M., & Hunt, P. (2001). Traumatic brain injury collaborative planning group: a protocol for community intervention. *The Journal of Head Trauma Rehabilitation, 16*(3), 217-237. doi.org/10.1097/00001199-200106000-00002
- 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). *Application for a §1915(c) Home and Community-Based Waiver [Version 3.5]: Instructions, technical guide, and review criteria*. Retrieved from <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Downloads/Technical-Guidance.pdf>
- Faul, M., Xu, L., Wald, M. M., & Coronado, V. G. (2010). Traumatic brain injury in the United States. *Emergency Department Visits, Hospitalizations and Deaths, 2002-2006*. Atlanta, GA: Centers for Disease Control and Prevention.
- Feeley, C. (2010, January). *Evaluating the transportation needs and accessibility issues for adults on the autism spectrum in New Jersey*. Paper presented at the 89th annual meeting of the Transportation Research Board, Washington, DC. Retrieved from

<http://pressamp.trb.org/compendium/508/C3801FAE46D9.pdf>

- Fraas, M., Balz, M., & DeGrauw, W. (2007). Meeting the long-term needs of adults with acquired brain injury through community-based programming. *Brain Injury, 21*(12), 1267-1281. doi.org/10.1080/02699050701721794
- Friedman, C. (2017). A national analysis of Medicaid Home and Community Based Services waivers for people with intellectual and developmental disabilities: FY 2015. *Intellectual and Developmental Disabilities, 55*(5), 281-302. doi:10.1352/1934-9556-55.5.281
- Harrington, C., Ng, T., & Kitchener, M. (2011). Do Medicaid Home and Community Based Service waivers save money? *Home Health Care Services Quarterly, 30*(4), 198-213. doi.org/10.1080/01621424.2011.622249
- Hendrickson, L., & Blume, R. (2008). *Issue brief: a survey of Medicaid brain injury programs*. New Brunswick, NJ: Rutgers Center for State Health Policy.
- Khan, S., Khan, A., & Feyz, M. (2002). Decreased length of stay, cost savings and descriptive findings of enhanced patient care resulting from an integrated traumatic brain injury programme. *Brain Injury, 16*(6), 537-554. doi.org/10.1080/02699050110119862
- LeBlanc, A. J., Tonner, M. C., & Harrington, C. (2000). Medicaid 1915(c) Home and Community-Based Services Waivers across the States. *Health Care Financing Review, 22*(2), 159–174.
- LeBlanc, A. J., Tonner, C., & Harrington, C. (2001). State Medicaid programs offering personal care services. *Health Care Financing Review, 22*(4), 155-173.
- Maryland Traumatic Brain Injury Advisory Board. (2014). *2014 Annual Report of the Maryland Traumatic Brain Injury Advisory Board*. Retrieved from

<http://bha.dhmh.maryland.gov/Documents/TBI%20Advisory%20Board%20report%202014%20internet%20version.pdf>

Milliren, J. W., & Gordon, W. A. (1994). The development of an integrated rehabilitation system for persons with traumatic brain injury: The evolution of public policy in New York. *The Journal of Head Trauma Rehabilitation*, 9(2), 27-34. doi.org/10.1097/00001199-199406000-00005

Ng, T., Harrington, C., & Kitchener, M. (2010). Medicare and Medicaid in long-term care. *Health Affairs*, 29(1), 22-28. doi.org/10.1377/hlthaff.2009.0494

Ng, T., Harrington, C., Musumeci, M., & Reaves, E. L. (2015). *Medicaid Home and Community Based Services programs: 2012 data update*. Report prepared for the Kaiser Commission on Medicaid and the Uninsured. Washington, DC: Kaiser Commission on Medicaid and the Uninsured. December 2012. Retrieved from <http://www.kff.org/medicaid/upload/7720-06.pdf>

Olmstead v. L.C., 527 U.S. 581 (1999).

Penna, S., Novack, T. A., Carlson, N., Grote, M., Corrigan, J. D., & Hart, T. (2010). Residence following traumatic brain injury: A longitudinal study. *The Journal of Head Trauma Rehabilitation*, 25(1), 52-60. doi.org/10.1097/HTR.0b013e3181c29952

Pressman, H. T. (2007). Traumatic brain injury rehabilitation: case management and insurance-related issues. *Physical Medicine and Rehabilitation Clinics of North America*, 18(1), 165-174. doi.org/10.1016/j.pmr.2006.11.006

Reynolds, W. E., Page, S. J., & Johnston, M. V. (2001). Coordinated and adequately funded state streams for rehabilitation of newly injured persons with TBI. *The Journal of Head Trauma Rehabilitation*, 16(1), 34-46. doi.org/10.1097/00001199-200102000-00006

- Rizzolo, M. C., Friedman, C., Lulinski-Norris, A., & Braddock, D. (2013). Home and Community Based Services (HCBS) Waivers: A nationwide study of the states. *Intellectual and Developmental Disabilities, 51*(1), 1-21. doi:10.1352/1934-9556-51.01.001
- Sander, A. M., Roebuck, T. M., Struchen, M. A., Sherer, M., & High Jr, W. M. (2001). Long-term maintenance of gains obtained in post-acute rehabilitation by persons with traumatic brain injury. *The Journal of Head Trauma Rehabilitation, 16*(4), 356-373. doi.org/10.1097/00001199-200108000-00006
- Selassie, A. W., Zaloshnja, E., Langlois, J. A., Miller, T., Jones, P., & Steiner, C. (2008). Incidence of long-term disability following traumatic brain injury hospitalization, United States, 2003. *The Journal of Head Trauma Rehabilitation, 23*(2), 123-131. doi.org/10.1097/01.HTR.0000314531.30401.39
- Spearman, R. C., Stamm, B. H., Rosen, B. H., Kayala, D. E., Zillinger, M., Breese, P., & Wargo, L. M. (2001). The use of Medicaid waivers and their impact on services. *The Journal of Head Trauma Rehabilitation, 16*(1), 47-60. doi.org/10.1097/00001199-200102000-00007
- Stock, S. E., Davies, D. K., Hoelzel, L. A., & Mullen, R. J. (2013). Evaluation of a GPS-based system for supporting independent use of public transportation by adults with intellectual disability. *Inclusion, 1*(2), 133-144. [dx.doi.org/10.1352/2326-6988-01.02.133](https://doi.org/10.1352/2326-6988-01.02.133)
- Swift, T. L., & Wilson, S. L. (2001). Misconceptions about brain injury among the general public and non-expert health professionals: An exploratory study. *Brain Injury, 15*(2), 149-165.
- Traumatic Brain Injury Model Systems National Data and Statistical Center. (2016). *TBI Model Systems National Database Update*. Retrieved from <https://www.tbindsc.org>.

- United States Department of Health & Human Services. (2000). *A profile of Medicaid chartbook: 2000*. Retrieved from: <https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/TheChartSeries/downloads/2tchartbk.pdf>.
- United States General Accounting Office. (1998). *Traumatic Brain Injury: programs supporting long-term services in selected states* (GAO/HEHS-98-55). Washington (DC): U.S. Government Printing Office. Retrieved from <http://www.gao.gov/archive/1998/he98055.pdf>.
- Wenzlow, A., Eiken, S. & Sredl., K. (2016). *Improving the balance: The evolution of Medicaid expenditures for long-term services and supports (LTSS), FY, 1981-2014*. Retrieved from <https://www.medicaid.gov/medicaid/ltss/downloads/evolution-ltss-expenditures.pdf>.
- White, D. K., Jette, A. M., Felson, D. T., LaValley, M. P., Lewis, C. E., Torner, J. C., ... Keysor, J. J. (2010). Are features of the neighborhood environment associated with disability in older adults? *Disability and Rehabilitation*, 32(8), 639-645.
doi.org/10.3109/09638280903254547
- White, G. W., Simpson, J. L., Gonda, C., Ravesloot, C., & Coble, Z. (2010). Moving from independence to interdependence: A conceptual model for better understanding community participation of centers for independent living consumers. *Journal of Disability Policy Studies*, 20(4), 233-240. doi.org/10.1177/1044207309350561

Table 1
HCBS Waivers for People with Brain Injury (FY 2016)

State	Waiver	Age	Total projected spending	Total participants	Average spending per participant	Average length of stay	Spending per capita	Fiscal effort	Waiting list
Colorado	CO0288R0403	16+	\$24,555,404	421	\$58,326	309	\$4.50	\$0.09	10
Connecticut	CT0302R0304	18+	\$41,263,956	425	\$97,092	361	\$11.49	\$0.17	100
Florida	FL0342R0303	18+	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Illinois	IL0329R0303	0+	\$68,837,954	4,905	\$14,034	283	\$5.35	\$0.11	0
Indiana	IN4197R0301	0+	\$6,337,980	200	\$31,690	344	\$0.96	\$0.02	183
Kansas	KS4164R0501	16-64	\$21,153,229	723	\$29,258	292	\$7.27	\$0.16	0
Kentucky	KY0333R0301	18+	\$39,822,507	383	\$103,975	278	\$9.00	\$0.23	451
Kentucky	KY0477R0100	18+	\$22,055,222	400	\$55,138	335	\$4.98	\$0.13	451
Massachusetts	MA0359R0300	18+	\$9,786,407	100	\$97,864	345	\$1.44	\$0.02	1,250
Massachusetts	MA40701R0102	22+	\$46,426,363	321	\$144,630	321	\$6.83	\$0.11	1,250
Maryland	MD40198R0200	22+	\$9,749,623	112	\$87,050	322	\$1.62	\$0.03	37
Mississippi	MS0366R0300	0+	n/a	n/a	n/a	n/a	n/a	n/a	n/a
Nebraska	NE40199R0300	18-64	\$1,528,899	40	\$38,222	349	\$0.81	\$0.02	0
New Hampshire	NH4177R0400	22+	\$26,960,651	270	\$99,854	324	\$20.26	\$0.37	--
Utah	UT0292R0401	18+	\$4,489,077	130	\$34,531	337	\$1.50	\$0.04	86
West Virginia	WV0876R0100	3+	\$2,253,210	74	\$30,449	365	\$1.22	\$0.03	0
Wyoming	WY0370R0300	21-64	\$8,707,051	240	\$36,279	260	\$14.86	\$0.27	79

Note. Although they provide for people with brain injury, utilization data for Florida and Mississippi's waivers cannot be determined because they are combined with spinal cord injury and there is no way to differentiate spending between the two populations. For spending per capita and fiscal effort state population and personal income data were from fiscal year 2015, the latest year available; however, it is still useful to compare across states. There was no information about New Hampshire's waiting list.

Table 2
Waiver Comparison Groups

State	Waiver	Hospital	Specialized Nursing Facility	General Nursing Facility	Rehab Facility	ICF/IID
Colorado	CO0288R0403	X		X		
Connecticut	CT0302R0304	X	X			
Florida	FL0342R0303		X			
Illinois	IL0329R0303			X		
Indiana	IN4197R0301			X		X
Kansas	KS4164R0501				X	
Kentucky	KY0333R0301				X	
Kentucky	KY0477R0100			X		
Massachusetts	MA0359R0300			X		
Massachusetts	MA40701R0102				X	
Maryland	MD40198R0200	X	X			
Mississippi	MS0366R0300			X		
Nebraska	NE40199R0300			X		
New Hampshire	NH4177R0400			X		
Utah	UT0292R0401			X		
West Virginia	WV0876R0100			X		
Wyoming	WY0370R0300					X

Note. ICF/IID = Intermediate Care Facilities for Individuals with Intellectual Disabilities

Table 3
Spending by Category

Category	Total spending	%
Supports to live in one's own home (companion, personal care, homemaker, supported living, meals, chore)	\$130,877,579	37.9%
Residential habilitation	\$109,731,774	31.7%
Day habilitation	\$44,693,949	12.9%
Clinical and therapeutic services	\$31,559,486	9.1%
Prevocational	\$6,347,452	1.8%
Care coordination	\$5,176,907	1.5%
Supported employment	\$4,503,761	1.3%
Specialized medical equipment and assistive technology	\$3,549,188	1.0%
Nursing and home health	\$2,489,161	0.7%
Transportation	\$2,082,478	0.6%
Respite	\$1,155,322	0.3%
Community transition supports	\$1,112,192	0.3%
Adult day health	\$1,099,830	0.3%
Financial support services	\$741,542	0.2%
Crisis	\$568,956	0.2%
Family training	\$57,575	0.02%

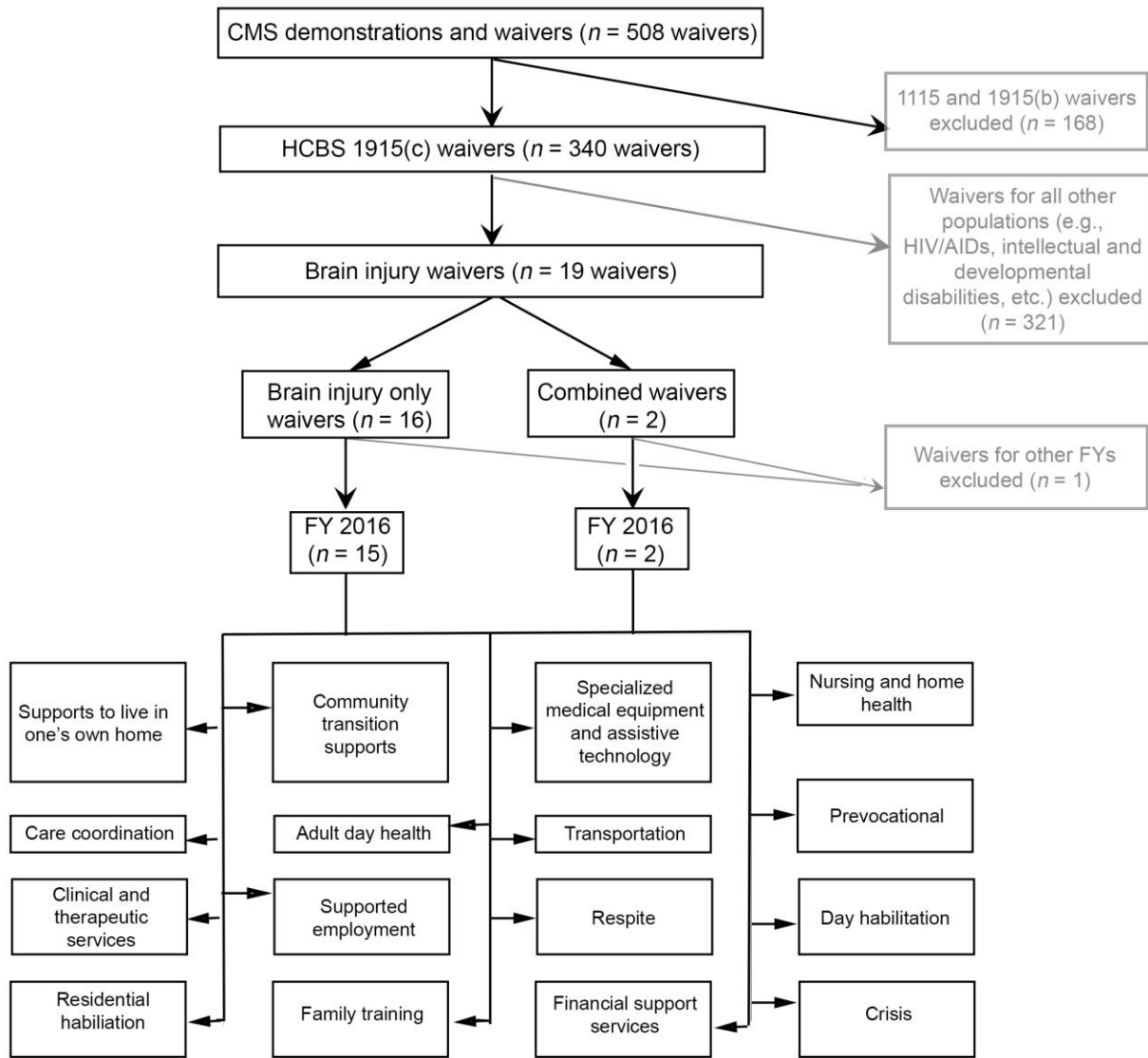


Figure 1. Methodology tree.

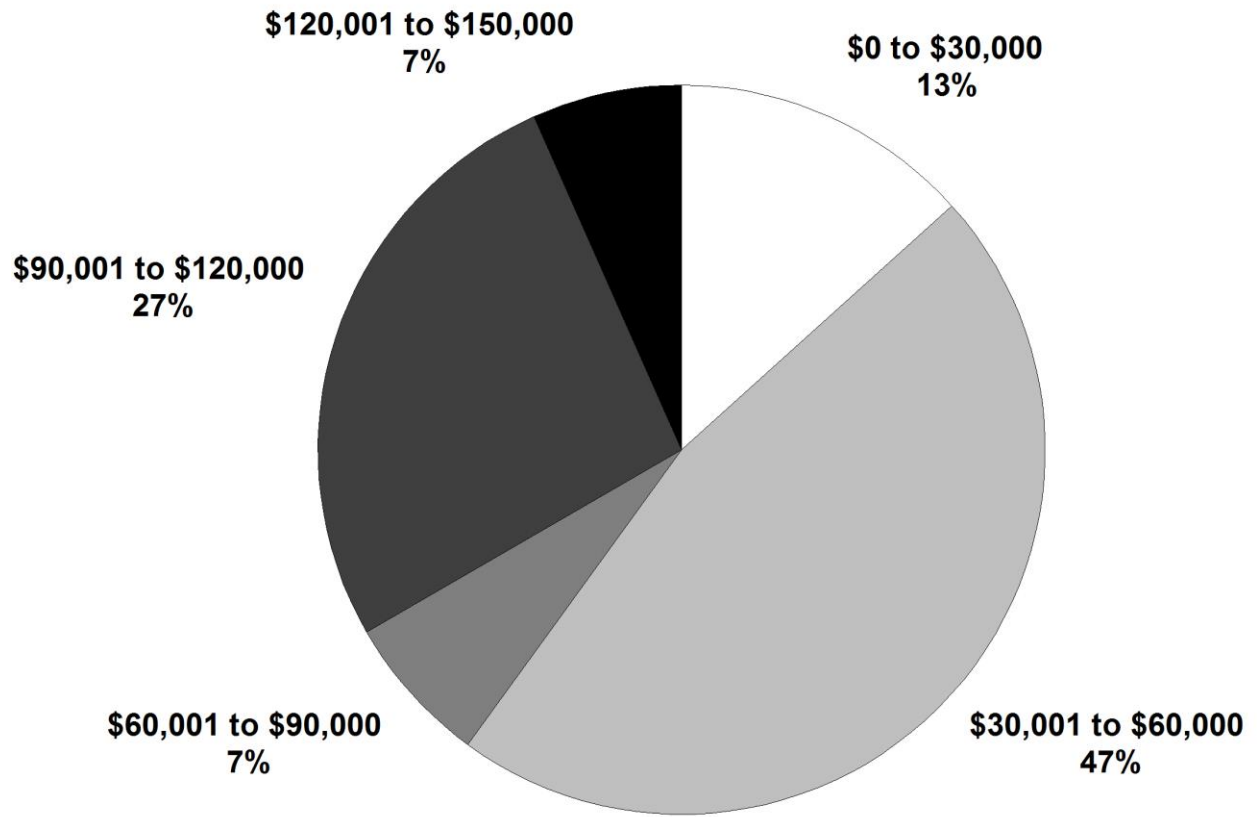


Figure 2. Average spending per participant.