

Research

Mental/Behavioral Health Services: Medicaid Home and Community Based Services 1915(c) Waiver Allocation for People with Intellectual and Developmental Disabilities



Running head: MENTAL/BEHAVIORAL HEALTH SERVICES

**Mental/Behavioral Health Services: Medicaid Home and Community Based Services
1915(c) Waiver Allocation for People with Intellectual and Developmental Disabilities**

Carli Friedman, Amie Lulinski, & Mary C. Rizzolo

Corresponding Author:

Carli Friedman, PhD

Email: cfriedman@thecouncil.org

Acknowledgments:

This paper was sponsored in part by a grant from the Administration on Intellectual and Developmental Disabilities (90DN0296).

Reference:

Friedman, C., Lulinski, A., & Rizzolo, M. C. (2015). Mental/behavioral health services: Medicaid Home and Community-Based Services 1915 (c) waiver allocation for people with intellectual and developmental disabilities. *Intellectual and developmental disabilities*, 53(4), 257-270. <https://doi.org/10.1352/1934-9556-53.4.257>

Abstract

Research has indicated that people who have intellectual and developmental disabilities (IDD) appear to be more vulnerable to having a co-existing psychiatric diagnosis. This study examined Medicaid 1915(c) HCBS waiver applications for people with IDD to determine the mental/behavioral health services proposed. We found large variance exists across states in projected spending for services, spending per participant, annual hours of service per participant, and hourly reimbursement rates. Moreover, compared to overall funding we found a general lack of state commitment to mental/behavioral services. States must shore up the capacity of their HCBS 1915(c) waivers to support people with behavioral challenges in addition to IDD in order to assure that services continue to be delivered in the least restrictive environment appropriate.

Keywords: mental/behavioral health; dual diagnosis; intellectual and developmental disabilities; HCBS waivers

Mental/Behavioral Health Services: Medicaid Home and Community Based Services**1915(c) Waiver Allocation for People with Intellectual and Developmental Disabilities**

The Substance Abuse and Mental Health Services Administration (2012) reported that in 2012, an estimated 43.7 million United States adults (aged 18 or older) had experienced ‘any mental illness’ in the previous year; this represented 18.6% of all adults in the United States. The definition of ‘any mental illness’ used for the study was

currently or at any time in the past 12 months having had a diagnosable mental, behavioral, or emotional disorder (excluding developmental and substance use disorders) of sufficient duration to meet diagnostic criteria specified within the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV). (Substance Abuse and Mental Health Services Administration, 2012, p. 9)

The coexistence of intellectual disability along with a psychiatric disorder is referred to as dual diagnosis (National Association for the Dually Diagnosed, 2014). Estimates of the prevalence of psychiatric disability in individuals who also have intellectual and developmental disabilities (IDD) vary widely. In a literature review, Borthwick-Duffy (1994) reported prevalence from 10% to over 80%, while more recently, a systematic review by Einfeld, Ellis, and Emerson (2011) found dual diagnosis rates between 30-50% in children and adolescents with intellectual disability. Allott, Fancey, and Velligan (2013) reported that people who have IDD are three to five times more likely to have a psychiatric disability than the general population. Similarly, according to outcome measures data from the National Core Indicators¹, 34% of adults surveyed who have IDD and are receiving services have a co-occurring psychiatric diagnosis (National Association of State Directors of Developmental Disabilities Services &

¹ National Core Indicators is a program by the National Association of State Directors of Developmental Disability Services (NASDDDS) and the Human Services Research Institute (HSRI) that helps developmental disability agencies and systems measure their performance (National Core Indicators, 2015). This allows performance standards to be compared over time, across organizations, and across states (National Core Indicators, 2015). The goal is to use this data to strengthen policy, inform quality assurance, and compare performance norms (National Core Indicators, 2015).

Human Services Research Institute, 2012). Estimates likely vary as a result of differences in diagnostic tools, limited study samples, differences in settings across studies, and the overlapping and similar presentations of IDD, autism, and psychiatric symptoms (Buckles, Luckasson, & Keefe, 2013; Deb, Thomas, & Bright, 2001).

Although the official rate of dual diagnosis remains unclear, all estimates portray persons who have IDD as more vulnerable to having a diagnosis of psychiatric disability. This raises concern given that dual diagnosis can make successful community living challenging. People with IDD who have dual diagnosis or who present behavioral ‘challenges’ are more likely to be institutionalized and are often the last to get out of institutions (Charlot & Beasley, 2013; McIntyre, Blacher, & Baker, 2002). Additionally they have the least successful community transitions (Mansell, 2006; Wing, 1989) due in large part to community services and supports that are frequently inadequate to meet the needs of those with behavioral challenges. As a result of these compounding challenges, it is important to examine current services and supports which are intended to help maintain people with a dual diagnosis in community settings to better understand the current status of services and inform policy decisions.

Deinstitutionalization and Home and Community Based Services

Since reaching a peak in 1967 (U.S. Department of Health, Education, and Welfare, 1972), depopulation of institutional settings has occurred at an average rate of 5% nation-wide annually, resulting in the closure or in process closure of 174 public institutions in 43 states (Braddock et al., 2015). In addition to this trend toward census reduction, the 1999 *Olmstead* Decision issued by the United States Supreme Court (*Olmstead v. L.C.*, 1999), has also had a significant impact related to institutionalization. Then Assistant Attorney General Perez stated that “the *Olmstead* decision makes it clear that states have an obligation to provide services to

individuals with disabilities in the most integrated setting appropriate to their needs”

(“Testimony of Assistant Attorney General,” 2012, n.p.).

Over the past three decades, numerous studies have established that moving from institutional settings into smaller community-based ones lead to better outcomes for people who have IDD (Kim, Larson, & Lakin, 1999; Larson & Lakin, 1989; Larson & Lakin, 2012). Maladaptive behaviors (e.g., harm to self and/or others, property destruction) however, are often a common reason for failure of community-based residential settings after transition from an institutional setting (Causby & York, 1991; Intagliata & Willer, 1982; Lakin, Hill, Hauber, & Bruininks, 1983; Lulinski-Norris, Rizzolo, & Heller, 2012; Schalock, Harper, & Genung, 1981; Windle, Stewart, & Brown, 1961). For example, a study analyzing data for individuals transitioning from a state-operated institution in Illinois revealed 91% of individuals who returned to institutions did so because of behavioral issues (Lulinski, 2014). This suggests an inadequate community capacity to provide necessary intervention for situations in which an individual is experiencing a behavioral crisis.

Medicaid Home and Community Based Services (HCBS) 1915(c) waivers are one of the largest providers of long-term services and supports for people with IDD (Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013). Prior to the creation of the Medicaid HCBS waiver in 1981, many people with IDD who did not reside in the family home found themselves with few alternatives to segregated institutional settings. HCBS provides a number of community-based service options including: residential and day habilitation, prevocational and supported employment, family supports, transportation, dental, respite, assistive technology, and crisis services (Rizzolo et al., 2013). The HCBS waiver option allows service delivery in integrated community-based settings (including in private individual and family homes) as opposed to

segregated institutional settings due to permitting three main provisions of the Social Security Act to be ‘waived’ (U.S. Department of Health and Human Services, 2000). The use of HCBS waivers has grown significantly as a result of the benefits of community living, the cost effectiveness of these settings, and the preferences of people with IDD (Hemp, Braddock, & King, 2014; Lakin, Larson, & Kim, 2011; Mansell & Beadle-Brown, 2004).

Illustrating the shift in the provision of services from institutionally-based to community-based is allocation of funds, HCBS funding surpassed that of institutional funding in the year 2000. In FY 2013, a total of \$31.9 billion was spent on HCBS services as compared to \$13.0 billion on institutional settings (Braddock et al., 2015). Medicaid-funded programs provided 78%, or \$47.77 billion, of all IDD spending on long-term supports and services in the United States (Braddock et al., 2015). Additionally, the majority (66%) of Federal Medicaid spending in FY 2013 was allocated toward HCBS waiver services (Braddock et al., 2015).

Although Medicaid is the largest provider of mental health services in the United States, this Medicaid allows states great flexibility in how they will cover mental health services; as a result, services offered by states vary widely² (Mann & Hyde, 2013; The Henry J. Kaiser Family Foundation, 2012). A national analysis of trends in HCBS 1915(c) waiver applications services for people with IDD by Rizzolo et al. (2013) revealed that in FY 2010, a proposed \$24.6 million was allocated for crisis services, representing 0.01% of the total HCBS budget that year. Given the continuing trend of institutional depopulation in the United States in favor of community-based settings, a further analysis of categorical expenditures on mental health services is warranted.

² The Henry J. Kaiser Family Foundation (2012a, 2012b, 2012c, 2012d) serves as a good example of this variation. See The Henry J. Kaiser Family Foundation (2012a, 2012b, 2012c, 2012d) for tables of Medicaid mental health services provided in state plans across the country.

The purpose of this paper is to examine how mental/behavioral health services are allocated in Medicaid HCBS Section 1915(c) waivers for people with IDD. Such comparison across state HCBS Waiver applications is necessary due to the amount of variation across state waiver programs. As Peebles and Bohl (2014) observed, “researchers should use caution and consider looking into individual states’ waiver applications to learn more about what the state program covers, because each waiver is unique even when compared to waivers of the same type in different states” (p. E11). Fiscal year (FY) 2013 HCBS IDD waivers providing mental/behavioral health services were collected and compared to determine funding and expenditure projections as well as service utilization. In addition to examination of variation across states, analysis of services categories, hourly reimbursement rates, and annual hours of service per participant will be discussed. Finally, proposed FY 2013 mental/behavioral health spending was compared to FY 2012 expenditures to examine proposed changes in allocation.

Method

A number of Medicaid options (e.g., 1115 demonstrations, 1915(b) managed care, 1915(i) HCBS state plans, and 1915(k) Community First Choice) provide mental health services. For example, the Henry J. Kaiser Foundation has a number of tables that detail ways states provide mental health services in Medicaid state plans: psychologist services; public health and mental health clinics; mental health and substance abuse rehabilitation services; and, inpatient hospital and nursing facility services in institutions for mental diseases age 65 and older (The Henry J. Kaiser Foundation, 2012a, 2012b, 2012c, 2012d). However, this study analyzed Medicaid HCBS 1915(c) waivers because they are the most prevalent funding stream for people with IDD (Rizzolo et al., 2013). Methods for this study were similar to studies by Rizzolo et al. (2013) in which a national study of Medicaid HCBS 1915(c) waivers for people with IDD was

conducted, and Friedman, Rizzolo, and Schindler (2014), in which the authors examined dental services in Medicaid HCBS 1915(c) waivers for people with IDD.

HCBS 1915(c) waiver applications were obtained by reviewing all waiver applications available on the CMS Medicaid.gov website (see figure 1 for detailed tree of process in addition to the following description). While no age limitations were imposed, HCBS waiver applications needed to specify the inclusion of either “mental retardation” (MR)³, developmental disability (DD), or autism (ASD)—people with IDD. This data was collected over a 12-month period (June 2013 to June 2014). In addition to this technique, state developmental disability agency and division websites were reviewed. It should be noted that although we were aware of at least nine additional waiver programs operating in FY 2012 and six in FY 2013 we were not able to access detailed information about them.

Using these methods, FY 2013 data from 99 HCBS waivers (43 states and the District of Columbia) was collected. The waiver year that most closely aligned with FY 2013 (July 1, 2012 and June 30, 2013) for each waiver application were used. Much of the time these were the state fiscal years; however, other states used the federal fiscal year of October 1, 2012 to September 30, 2013. Still others used the 2013 calendar year (January – December). For consistency, the term fiscal year (FY) is used throughout this paper.

Each waiver application includes a brief summary description and describes: 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; participation direction of services; participant rights; participant safeguards; quality improvement strategies; financial accountability; and, cost-neutrality demonstrations. Data was

³ Although the term is considered outdated “mental retardation” remains in use in statute as well as a target group option in the waiver application template and thus necessitated its use as a search term.

collected from the FY 2013 waiver applications to determine, the types of services provided, the projected number of users, and the average projected cost of each service. CMS requires states to enter this information about their services to demonstrate cost neutrality (Rizzolo et al., 2013).

States also

project future waiver years' spending based on prior years' data with certain adjustments. Furthermore, states cap the number of persons who may be enrolled in the waiver, and many waivers cap the maximum cost per person so that they do not exceed the cost-neutrality limit. (Rizzolo et al., 2013, pp. 3-4)

The HCBS waiver application data used in the current study is based on projections of spending made to the federal government. However, we believe this data is a reasonably accurate proxy of IDD waiver services because states base proposed spending on previous years' actual utilization. Moreover, Rizzolo et al.'s (2013) analysis of IDD waiver projections revealed percentages "congruent with spending patterns identified by researchers at Mathematica (Irvin, 2011, September) who used 2008 Medicaid Statistical Information Systems (MSIS) claims data from 44 states and Washington, D.C., to determine trends in waiver expenditures across the states" (Rizzolo et al., 2013, pp. 19-20).

Additionally, all service definitions were analyzed to determine service patterns. The analysis of definitions aided the creation of a taxonomy of services similar to the one developed by and Thompson Reuters and Mathematica (Eiken, 2011) and Rizzolo et al.'s (2013) FY 2010 taxonomy that was specifically tailored to IDD waivers.

Once services were sorted into taxonomy categories, using service definitions we identified all services related to mental/behavioral health (e.g., behavior therapy, psychologist, crisis intervention professional). Although all taxonomy categories were examined for mental/behavioral services, these services ended up coming from only the "health and professional services" and "family training and counseling (crisis)" taxonomy categories.

Qualitative trends across the categories' definitions as well as any unique aspects are described further below. Once data was organized, data related to service expenditures was then quantitatively analyzed to determine projected spending, projected users targeted, and trends across services and waivers. To compare FY 2013 and FY 2012, the same process was completed with FY 2012 data gathered from 93 HCBS waivers (43 states and D.C.).

It should be noted that any mental/behavioral health provision that was provided within a bulk service, such as residential habilitation or in-home supports, were not included in this analysis. It would not have been possible for us to examine these services that provide some sort of support for challenging behavior because the funding is aggregated and is not differentiated for certain parts of the service. Including these items would have inaccurately inflated our results.

Findings

Service Definitions

In alignment with both the literature review and analysis, our qualitative analysis of service definitions revealed two major trends in mental/behavioral health services provided by HCBS Waivers. In general mental/behavioral health services tended to relate to behavioral/therapeutic services or crisis services. It should be noted that the line between these two trends is far from clear-cut and some of the behavioral/therapeutic services also contained crisis services.

Behavioral/therapeutic services are provided to individuals with emotional, behavioral, or mental health issues that result in functional impairments and may interfere with community living. These services commonly included behavior support plan (BSP), functional behavioral assessment (FBA) development, and/or psychological and adaptive behavior screening and

assessments. Another common aspect of behavioral/therapeutic services was counseling and development of therapeutic plans. This included therapy as well as environmental manipulation, behavioral intervention, or behavior technique implementation. It was also common for these services to include consultation with family members or support staff and training about BSP implementation to families, direct care workers, or staff.

Although they may differ slightly depending on the service, behavioral and therapeutic services often provide services with overlapping goals so are discussed in tandem. Behavior services typically emphasized the development of desirable adaptive behavior over the elimination or suppression of undesirable behavior; examples included Applied Behavior Analysis (ABA), relationship development intervention (RDI) and Floor Time. Examples of therapeutic service techniques included: individual counseling, biofeedback, cognitive behavioral therapy, family counseling, and substance abuse counseling and intervention.

A second trend was services designed to aid immediately in crisis situations. The services aimed at crisis often noted the goal was prevention of the individual being placed in a more restrictive institutionalized setting. In addition to general intervention these services often included making intervention treatment plans and assessing short term targets by analyzing psychological, social, ecological, other factors contributing to the crisis. They also typically included support, including self care and counseling and therapeutic services, and intensive supervision during the crisis.

Most definitions indicated that crisis related services could be provided in any setting – particularly the one in which the crisis was occurring. However, others, such as Massachusetts' Community Living Waiver and Massachusetts' Adult Residential Waiver, specified the crisis service should occur in a licensed respite facility or home of an individual family provider. Crisis

services also varied in terms of length of time the provision was allowed. For example, Maine's Home and Community Based Services for Adults with ID or Autistic Spectrum Disorder specified that these crisis services must not go past two weeks in length. North Carolina's Comprehensive Waiver and North Carolina's supports Waiver cannot exceed 14 calendar days. Yet other waivers, like Massachusetts' Community Living Waiver and Massachusetts' Adult Residential Waiver directly specified that there is no time limit imposed on the services because the goal is to stabilize the participant and then develop a new Individual Plan of Care at the proper pace.

Service Expenditures

Eighty out of 99 (80.8%) of the examined HCBS 1915(c) waivers provided some type of mental/behavioral health service in FY 2013 (see table 1). FY 2013 waivers providing mental health services projected \$327.78 million of spending (out of \$28.03 billion) for a total of 95,881 waiver participants (out of 685,000 unduplicated participants). This FY 2013 total of \$327.78 million in spending for mental health services amounts to only 1.17% percent of all projected HCBS waiver spending allocated for mental/behavioral health services. These proportions varied widely. Fourteen of the 80 (17.5%) waivers that provided mental/behavioral health services in FY 2013 projected spending less than .25% of their total projected budget for these services. Twelve (15%) waivers projected spending between .25% and .49%; 13 (16.3%) between .5% and .99%; 29 (36.3%) between 1% and 9.99%; 7 (8.8%) between 10% and 19.99%; two (2.5%) between 30% and 49.99%; and one (1.3%) between 90% and 99.99%; Finally, two of the waivers (2.5%) were specifically designed for mental health services; as such, 100% of these waiver were for mental/behavioral health supports.

Spending for individual mental health services ranged widely from \$18 for Indiana Family Supports Waiver’s psychological therapy – family (serving 1 participant) to \$109.8 million for California HCBS Waiver for Californians with Developmental Disabilities’ (CA0336.R03.00) behavioral intervention services (serving 16,428 participants), with the majority (88%) of projected spending per service below \$3 million.

On average these waivers projected an average spending of \$72.99 per hour for mental/behavioral health services, ranging from \$8.60 an hour for Indiana Community Integration and Habilitation Waiver’s Psychological Therapy – Group to \$1,400 an hour for South Carolina Pervasive Developmental Disorder waiver’s Early Intensive Behavioral Intervention Plan Implementation. Hourly rates are detailed further in figure 2.

As detailed in figure 3, the average projected spending per participant receiving these services varied largely in FY 2013. The majority of services (85.8%) projected spending less than \$8,000 on average per participant receiving these services; 29.4% of services projected less than \$1,000 of average spending per participant receiving these services.

The number of hours of service the average participant received in a year (FY 2013) also ranged widely, with an average of 93.52 hours per participant a year across the services. Indiana Community Integration and Habilitation Waiver and Indiana Family Supports Waiver’s “psychology therapy family” services both provided the smallest amount with an average 15 minutes of service per participant a year, while South Carolina Pervasive Developmental Disorder Waiver’s “line therapy,” “line therapy II,” “self-directed line therapy,” and “self-directed line therapy II” services⁴ provided the largest at 1,000 annual hours of service per

⁴ Line therapy in Indiana’s waivers is early intensive behavioral intervention treatment and behavioral support

average participant. As can be seen in figure 4, the majority of services (88.9%) provided less than 201 hours of annual service per average participant. In fact, 56.1% of services provided less than 30 hours of service a year to the average participant.

Examining FY 2012 mental/behavioral health services we found that ninety-six of the 104 (92.3%) examined waivers offered 208 types of mental/behavioral health services in FY 2012 and/or FY 2013. In FY 2012, \$190.34 million (out of \$20.97 billion), or .91% of projected HCBS spending, was allocated to mental health services. This is compared to \$327.78 million of spending for 65,219 participants in FY 2013. Thus, projected mental/behavioral health spending increased 26.5% (\$137.44 million) and participants increased 19.0% (30,662 participants) between FY 2012 and FY 2013.

Discussion

This study explored allocation of Medicaid HCBS 1915(c) waiver funding for mental/behavioral health services for people with IDD across the nation. Two major trends of mental/behavioral services were identified. Behavioral/therapeutic services often included development of behavior support plans and behavioral intervention, and therapy and counseling. Crisis services included immediate intervention, environmental analysis, supervision, counseling and/or therapeutic services, and support during the crisis. Most services could be provided in any setting – particularly the one in which the crisis was occurring. The goal was often to prevent the individual from being placed in a more restrictive institutionalized setting. FY 2013 waivers projected \$327.78 million to 95,881 waiver participants for mental health services. However, there appears to be a lack of commitment across states as 48.8% of waivers providing mental/behavioral health services in FY 2013 projected spending less than 1% of their total projected budget for these services.

One of our core findings was the extreme variance that exists across mental/behavioral health services. Spending for mental health services ranged greatly across the 99 waivers from \$18 to \$109.8 million. The average annual projected spending per participant receiving these services varied largely from \$18 to \$212,892 per participant. The number of hours of service the average participant received in a year also ranged widely from one-quarter of an hour to 1,000 hours. Moreover, these waivers projected hourly pay rates ranging from \$8.60 to \$1,400 an hour.

The low proportion of HCBS 1915(c) spending on mental/behavioral health services is a potential problem for those transitioning from institutional to community-based settings. Especially since a recent study by Lulinski (2014) found less than half (46%) of agencies providing residential services to former institutional residents in the state of Illinois indicated that they had access to a mental/behavioral health professional. Although there are no universally accepted standards about how many mental health service hours or how much spending per person is sufficient, Wang et al. (2005) suggest the following *minimally adequate* treatment guidelines (general, not IDD specific) “based on available evidence-based guidelines,” including from the American Psychological Association:

receiving either pharmacotherapy (≥ 2 months of an appropriate medication for the focal disorder plus >4 visits to any type of physician) or psychotherapy (≥ 8 visits with any HC [health care] or HS [human services] professional lasting an average of ≥ 30 minutes). The decision to require 4 or more physician visits for pharmacotherapy was based on the fact that 4 or more visits for medication evaluation, initiation, and monitoring are generally recommended during the acute and continuation phases of treatment in available guidelines...At least 8 sessions were required for minimally adequate psychotherapy based on the fact that clinical trials demonstrating effectiveness have generally included 8 psychotherapy visits or more...Treatment adequacy was defined separately for each 12-month disorder (ie, a respondent with comorbid disorders could be classified as receiving minimally adequate treatment for one disorder but not for another). (pp. 630-631)

Lulinski's (2014) finding that 91% of survey respondents indicated they had used police/911/Emergency Medical Services; this overreliance on these methods, along with the lack of agency access to mental/behavioral health services (Lulinski, 2014) highlights the inadequate availability of services suggested by our findings.

This study was limited by the lack of access to some waiver applications. We were aware of at least six other FY 2013 and nine other FY 2012 waiver applications that were not publicly available for examination. It is unknown what effect these waivers would have had on our results as it is possible that these waivers were also providing mental/behavioral health services. This must be considered when interpreting these findings. Another study limitation was that HCBS waiver spending was based on spending projections rather than actual expenditures. However, because the proposed figures are based on previous years' actual utilization, we believe they are a reasonably accurate proxy of services.

As the public institutional census continues to decline, it will become increasingly necessary to boost funding for treatment options for people with behavioral challenges, as they are often the last to be discharged from institutional settings (Mansell, 2006; Wing, 1989). Given the estimate that roughly one-third of persons with IDD have a co-occurring psychiatric disability, current spending on behavioral/mental health services seems insufficient. States must shore up the capacity of their HCBS 1915(c) waivers to support citizens who have behavioral challenges in addition to IDD in order to assure that services continue to be delivered in accordance with the Supreme Court's *Olmstead* Decision regarding individuals' right to receive services in the least restrictive environment appropriate. Additional analyses of current and expected service needs, community capacity to meet these needs, and the availability of

necessary funding are warranted to assure the needs of all people with IDD are met as mental/behavioral health services are crucial for successful community living.

References

- Allott, K. A., Francey, S. M., & Velligan, D. I. (2013). Improving Functional Outcome Using Compensatory Strategies in Comorbid Intellectual Disability and Psychosis: A Case Study. *American Journal of Psychiatric Rehabilitation, 16*(1), 50-65. doi: 10.1080/15487768.2013.762306
- Borthwick-Duffy, S.A. (1994). Epidemiology and prevalence of psychopathology in people with mental retardation. *Journal of Consulting and Clinical Psychology, 62*(1), 17-27.
- Braddock, D., Hemp, R., Rizzolo, M.C., Haffer, L., Tanis, E.S., & Wu, J. (2015). *The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession*. Washington, DC: The American Association on Intellectual and Developmental Disabilities.
- Buckles, J., Luckasson, R., & Keefe, E. (2013). A systematic review of the prevalence of psychiatric disorders in adults with intellectual disability, 2003–2010. *Journal of Mental Health Research in Intellectual Disabilities, 6*(3), 181-207.
- Causby, V. D., & York, R.O. (1991). Predictors of success in community placement of persons with mental retardation. *The British Journal of Mental Subnormality, 37, Part 1*(72), 25-34.
- Charlot, L., & Beasley, J. B. (2013). Intellectual disabilities and mental health: United States–based research. *Journal of Mental Health Research in Intellectual Disabilities, 6*(2), 74-105. doi: 10.1080/19315864.2012.715724

- Deb, S., Thomas, M., & Bright, C. (2001). Mental disorder in adults with intellectual disability: Prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *Journal of Intellectual Disability Research*, 45(6), 495-505.
- Eiken, S. (2011). *Revisiting the Name Game: A taxonomy of home and community-based services*. Paper presented at the National Home and Community-Based Services Conference, Washington, DC.
- Einfeld, S. L., Ellis, L. A., & Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *Journal of Intellectual and Developmental Disability*, 36(2), 137-143. doi: 10.1080/13668250.2011.572548
- Friedman, C., Rizzolo, M. C., & Schindler, A. (2014). Dental services: A nationwide study of Medicaid Home and Community-Based Services (HCBS) waiver service allocation. *Inclusion*, 2(1), 17-36.
- Hemp, R., Braddock, D., & King, M. (2014). Community-based Medicaid funding for people with intellectual and developmental disabilities. *National Conference of State Legislatures LegisBrief*, 22, 1-2.
- Intagliata, J., & Willer, B. (1982). Reinstitutionalization of mentally retarded persons successfully placed into family-care and group homes. *American Journal of Mental Deficiency*, 87(1), 34-39.
- Kim, S., Larson, S.A. & Lakin, K.C. (1999). Behavioral outcomes of deinstitutionalization for people with intellectual disabilities: A review of studies conducted between 1980 and 1999 Policy Research Brief (Vol. 10). Minneapolis: University of Minnesota, Institute on Community Integration.
- Lakin, K. C., Hill, B.K., Hauber, F.A., & Bruininks, R.H. (1983). New admissions and

- readmissions to a national sample of public residential facilities. *American Journal of Mental Deficiency*, 88(1), 13-20
- Lakin, K. C., Larson, S. A., & Kim, S. (2011). Behavioral outcomes of deinstitutionalization for people with intellectual and/or developmental disabilities: Third decennial review of U.S. studies, 1977-2010 *Policy Research Brief* (Vol. 21): Research and Training Center on Community Living, Institute on Community Integration, University of Minnesota.
- Larson, S. A., & Lakin, K. C. (1989). Deinstitutionalization of persons with mental retardation: Behavioral outcomes. *Journal of the Association for Persons with Severe Handicaps*, 14(4), 324-332.
- Larson, S.A., & Lakin, K.C. (2012). Behavioral outcomes of moving from institutional to community living for people with intellectual and developmental disabilities: US- studies from 1977 to 2010. *Research & Practice for Persons with Severe Disabilities*, 37(4), 235-246.
- Lulinski, A. (2014). *Community capacity to provide mental/behavioral health services to people with developmental disabilities*. (Unpublished doctoral dissertation). Chicago: University of Illinois at Chicago.
- Lulinski-Norris, A., Rizzolo, M.C. & Heller, T. (2012). *An analysis of movement from state operated developmental centers in Illinois*. Chicago: Institute on Disability and Human Development, University of Illinois at Chicago.
- Mann, C. (2013). Application of the Mental Health Parity and Addiction Equity Act to Medicaid MCOs, CHIP, and alternative benefit (benchmark) plans. Baltimore: Centers for Medicare & Medicaid Services.
- Mann, C., & Hyde, P. S. (2013). Coverage of behavioral health services for children, youth, and

- young adults with significant mental health conditions. Baltimore: Centers for Medicare & Medicaid Services.
- Mansell, J. (2006). Deinstitutionalisation and community living: progress, problems and priorities. *Journal of Intellectual and Developmental Disability, 31*(2), 65-76.
- Mansell, J., & Beadle-Brown, J. (2004). Person-centred planning or person-centred action? Policy and practice in intellectual disability services. *Journal of Applied Research in Intellectual Disabilities, 17*, 1-9.
- McIntyre, L. L., Blacher, J., & Baker, B. L. (2002). Behaviour/mental health problems in young adults with intellectual disability: the impact on families. *Journal of Intellectual Disability Research, 46*(3), 239-249. doi: 10.1046/j.1365-2788.2002.00371.x
- National Association for the Dually Diagnosed (2014). *Information on dual diagnosis*. Retrieved from <http://thenadd.org/resources/information-on-dual-diagnosis-2/>.
- National Association of State Directors of Developmental Disabilities Services & Human Services Research Institute. (2012). *National core indicators: Annual summary report 2011- 2012*. Alexandria, VA: National Association of State Directors of Developmental Disabilities Services & Human Services Research Institute.
- National Core Indicators. (2015). About National Core Indicators. Retrieved March 29, 2015, from <http://www.nationalcoreindicators.org/about/>
- Olmstead v. L.C.*, 119 S.Ct. 2176 (1999). (S.Ct. 1999).
- Peebles, V. & Bohl, A. (2014). The HCBS taxonomy: A new language for classifying home- and community-based services. *Medicare and Medicaid Research Review, 4*(3), E1-E17. doi: <http://dx.doi.org/10.5600/mmrr.004.03.b01>.
- 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

Schalock, R. L., Harper, R.S. & Genung, T. (1981). Community integration of mentally retarded adults: Community placement and program success. *American Journal of Mental Deficiency*, 85(5), 478-488.

Substance Abuse and Mental Health Services Administration (2013). *Results from the 2012 National Survey on Drug Use and Health: Mental Health Findings*, NSDUH Series H-47, HHS Publication No. (SMA) 13-4805. Rockville, MD: Substance Abuse and Mental Health Services Administration.

Testimony of Assistant Attorney General Thomas E. Perez on the ADA and Olmstead Enforcement, U.S. Senate (2012).

The Henry J. Kaiser Family Foundation. (2012a). Medicaid benefits: Inpatient hospital and nursing facility services in institutions for mental diseases, age 65 and older. Retrieved March 29, 2015, from <http://kff.org/medicaid/state-indicator/inpatient-hospital-nursing-facility-and-intermediate-care-facility-services-in-institutions-for-mental-diseases-age-65-and-older/>

The Henry J. Kaiser Family Foundation. (2012b). Medicaid benefits: Psychologist services. Retrieved March 29, 2015, from <http://kff.org/medicaid/state-indicator/psychologist-services/>

The Henry J. Kaiser Family Foundation. (2012c). Medicaid benefits: Public health and mental health clinics (clinic services by an organized facility or clinic not part of a hospital). Retrieved January 26, 2015, from <http://kff.org/medicaid/state-indicator/clinic-services->

by-an-organized-facility-or-clinic-not-part-of-a-hospital-public-health-and-mental-health-clinics/

The Henry J. Kaiser Family Foundation. (2012d). Medicaid benefits: Rehabilitation services – mental health and substance abuse. Retrieved March 29, 2015, from <http://kff.org/medicaid/state-indicator/rehabilitation-services-mental-health-and-substance-abuse/>

U.S. Department of Health, Education, and Welfare. (1972). *Mental retardation source book of the DHEW*. Washington, DC: U.S. Department of Health, Education, and Welfare.

U.S. Department of Health and Human Services. (2000). *Understanding Medicaid home and community services: A primer*. Washington, DC: U.S. Department of Health and Human Services.

Wang, P. S., Lane, M., Olfson, M., Pincus, H. A., Wells, K. B., & Kessler, R. C. (2005). Twelve-month use of mental health services in the United States: Results from the national comorbidity survey replication. *Archives of General Psychiatry*, 62(6), 629-640. doi: 10.1001/archpsyc.62.6.629

Windle, C. D., Stewart, E., & Brown, S. J. (1961). Reasons for community failure of released patients. *American Journal of Mental Deficiency*, 66(213-217).

Wing, L. (1989). *Hospital closure and the resettlement of residents: The case of Darenth Park Mental Handicap Hospital*. Aldershot, UK: Ashgate Publishing.

Table 1

HCBS mental/behavioral health services for people with IDD in FY 2013

State	Number of IDD Waivers Providing These Services	Services	Projected Spending
Alabama	2	Behavior Therapy 1 Prof Certified; Behavior Therapy 2 Professional; Behavior Therapy 3 Technician; Crisis Intervention	\$1,292,196
Arizona	1	Consultation; Crisis Intervention; Supplemental Support	\$368,757
California	1	Behavioral Intervention Services; Behavioral and Emotional Health; Crisis Support	\$114,789,061
Colorado	5	Behavioral Therapy (Lead and Senior Therapists, Line Staff); Behavioral Plan Development and Assessment; Behavioral Line Staff; Behavioral Services - Bx Plan Specialist; Behavioral Services - Senior and Lead; Behavioral Plan Development and Assessment	\$9,937,071
Connecticut	1	Behavioral Support Services (formerly Consultation)	\$1,018,560
Washington, DC	1	Behavioral Supports; Behavioral Supports Diagnostic Assessment; Bereavement Counseling	\$6,301,223
Delaware	1	Behavioral Consultative Services	\$1,447,027
Florida	2	Behavioral Analysis Assessment; Behavioral Services - Bachelors degree, Masters degree, and Doctorate degree; Behavior Assistant Services; Behavioral services	\$4,955,281
Georgia	2	Behavioral Supports Consultation	\$1,381,536
Idaho	2	Behavior Consultation/Crisis Management; Therapeutic Consultation; Emotional Support; Relationship Support; Crisis Intervention	\$1,155,685
Illinois	3	Behavior Intervention and Treatment; Behavior Intervention and Treatment; Behavioral Services - Psychotherapy - Individual and Group; Behavioral Services - Counseling - Individual and Group; Temporary Assistance (formerly called Crisis Services)	\$7,661,550
Indiana	2	Behavior Support Services - Level 1 and Level 2; Intensive Behavior Intervention - Level 1 and Level 2; Psychological Therapy - Family, Individual, and Group	\$30,319,332
Kansas	1	Consultative Clinical and Therapeutic Services (Autism Specialist)	\$233,056
Kentucky	1	Consultative Clinical and Therapeutic Services (Autism Specialist); Positive Behavioral Supports	\$2,036,470
Louisiana	2	Psychologist; Social Work; Applied Behavioral Analysis Based Therapy	\$371,867
Maryland	3	Behavioral Supports; Therapeutic Integration	\$6,264,957
Massachusetts	3	Behavioral Supports and Consultation - Senior Therapist and Provider Therapist; Behavioral Supports and Consultation; Stabilization	\$8,216,474
Maine	1	Counseling; Crisis Assessment; Crisis Intervention	\$1,474,015
Mississippi	1	Behavior Support/Intervention	\$2,496,900
Missouri	4	Senior Behavior Consultant; Behavior Intervention Specialist; Functional Behavioral Assessment	\$1,290,335
Montana	2	Board Certified Behavior Analyst; Psychological	\$774,487

		services; Program Design and Monitoring	
		Early Intensive Behavioral Intervention; Team	
Nebraska	3	Behavioral Consultation Services; Behavioral Risk Services	\$14,017,324
Nevada	1	Behavioral Consultation, Training and Intervention; Counseling	\$226,383
New Hampshire	1	Specialty Services; Crisis Response Services	\$3,342,328
New Mexico	1	Behavior Support Consultation; Skilled Therapy for Adults; Cognitive rehabilitation therapy	\$516,290
New York	2	Immediate Crisis Response Services; Intensive in-home Supports and Services; Crisis Avoidance and Management and Training; Intensive Behavioral Services	\$13,244,061
North Carolina	2	Behavior Consultant - Level 3 and Level 2; Crisis Services	\$1,704,405
North Dakota	2	Behavioral Consultation	\$114,538
Ohio	1	Social Work	\$122,292
Oklahoma	3	Psychological Services; Physician Services (provided by a Psychiatrist)	\$2,302,493
Oregon	3	Specialized Supports; Behavioral Consultant; Crisis / Diversion Services	\$4,170,390
Pennsylvania	3	Therapies - Counseling; Behavior Specialist Services-Ongoing Direct and Ongoing Consultative; FBA and BSP/CIP Development	\$12,239,058
South Carolina	3	EIBI Assessment; EIBI Plan Development/Training; EIBI Plan Implementation; EIBI Lead Therapy; EIBI Line Therapy; EIBI Self Directed Line Therapy; Line Therapy II; Behavior support services; Psychological Services	\$29,105,698
Tennessee	3	Behavior Analyst; Behavior Specialist	\$10,185,865
Texas	3	Behavioral Support; Social work	\$1,568,415
Utah	1	Behavior Consultation I; Behavior Consultation II; Behavior Consultation III	\$1,764,525
Virginia	2	Therapeutic Consultation; Crisis Stabilization; Crisis Supervision	\$653,871
Washington	1	Specialized Psychiatric Services; Sexual Deviancy Evaluation; Behavior Management and Consultation; Behavioral Health Crisis Stabilization Services-Specialized Psychiatric Services; Behavior Support and Consultation (Privately-Contracted and State-Operated); Crisis Diversion Bed Services (Privately-Contracted and State-Operated)	\$1,947,227
Wisconsin	3	Counseling and Therapeutic Services Consults and Hours; Counseling and Therapeutic Resources	\$9,566,599
West Virginia	1	Positive Behavior Support Professional; IPP Planning-Positive Behavior Support Professional; Therapeutic Consultant; IPP Planning-Therapeutic Consultant; Crisis Services	\$17,203,832

Note. For more detail about each particular service as well as projected participants contact the lead author.

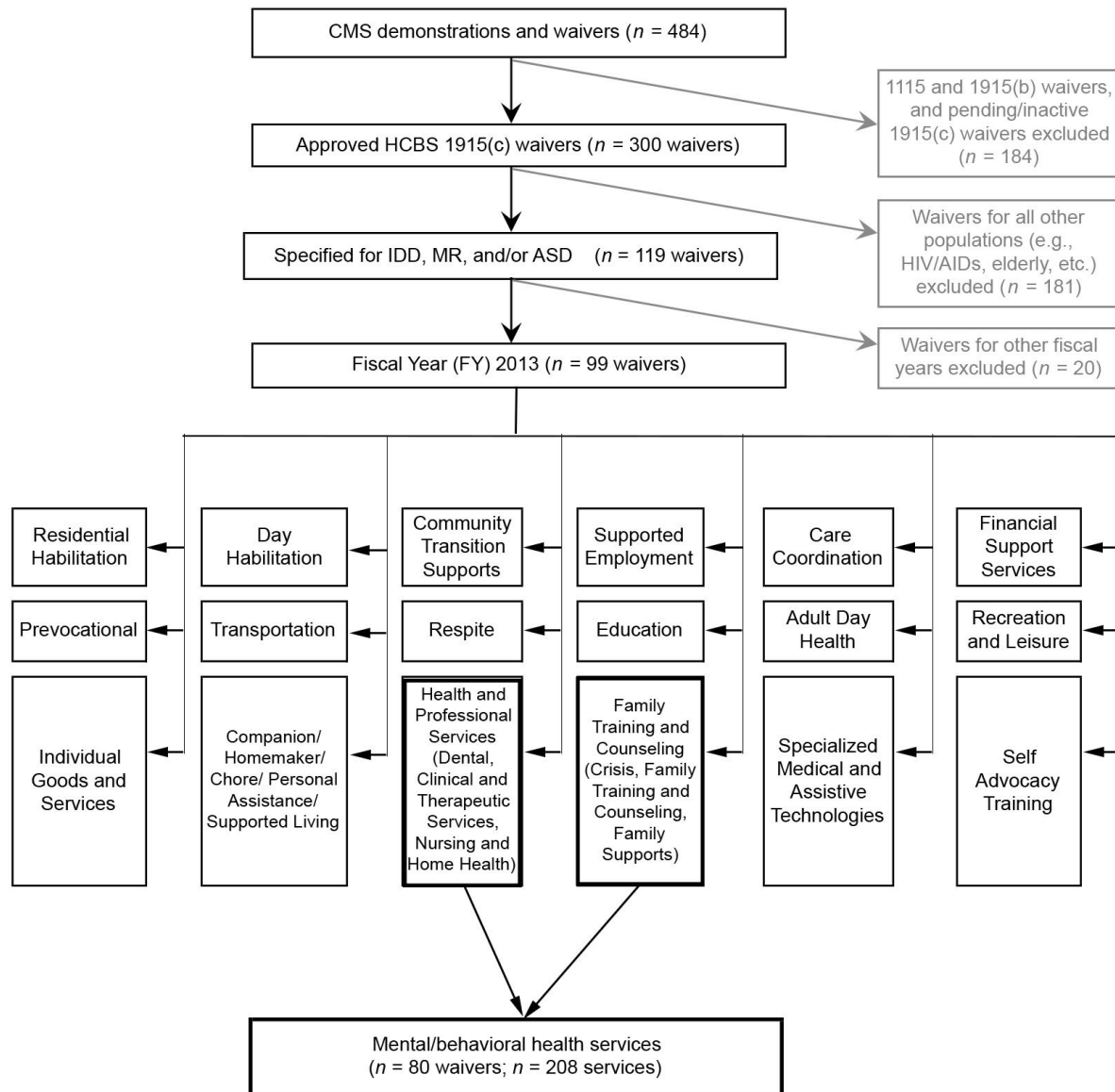


Figure 1. Process for identification of included HCBS 1915(c) IDD mental/behavioral health services. CMS = Center for Medicare & Medicaid Services; HCBS = Home and Community Based Services; IDD = intellectual and developmental disabilities; MR = mental retardation; ASD = autism spectrum disorder; HIV/AIDS = human immunodeficiency virus/acquired immunodeficiency syndrome.

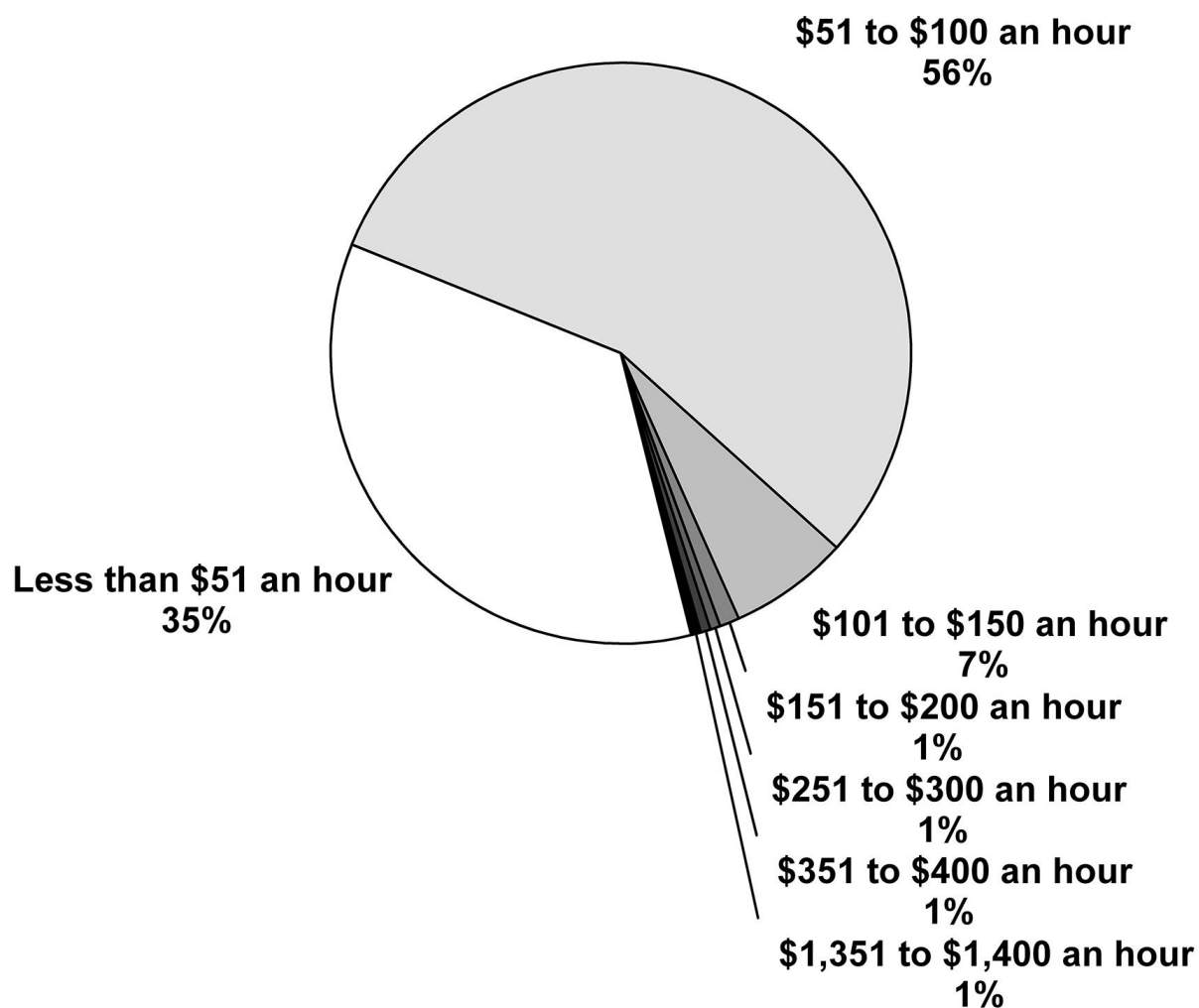


Figure 2. Hourly rates for mental/behavioral health services in fiscal year 2013.

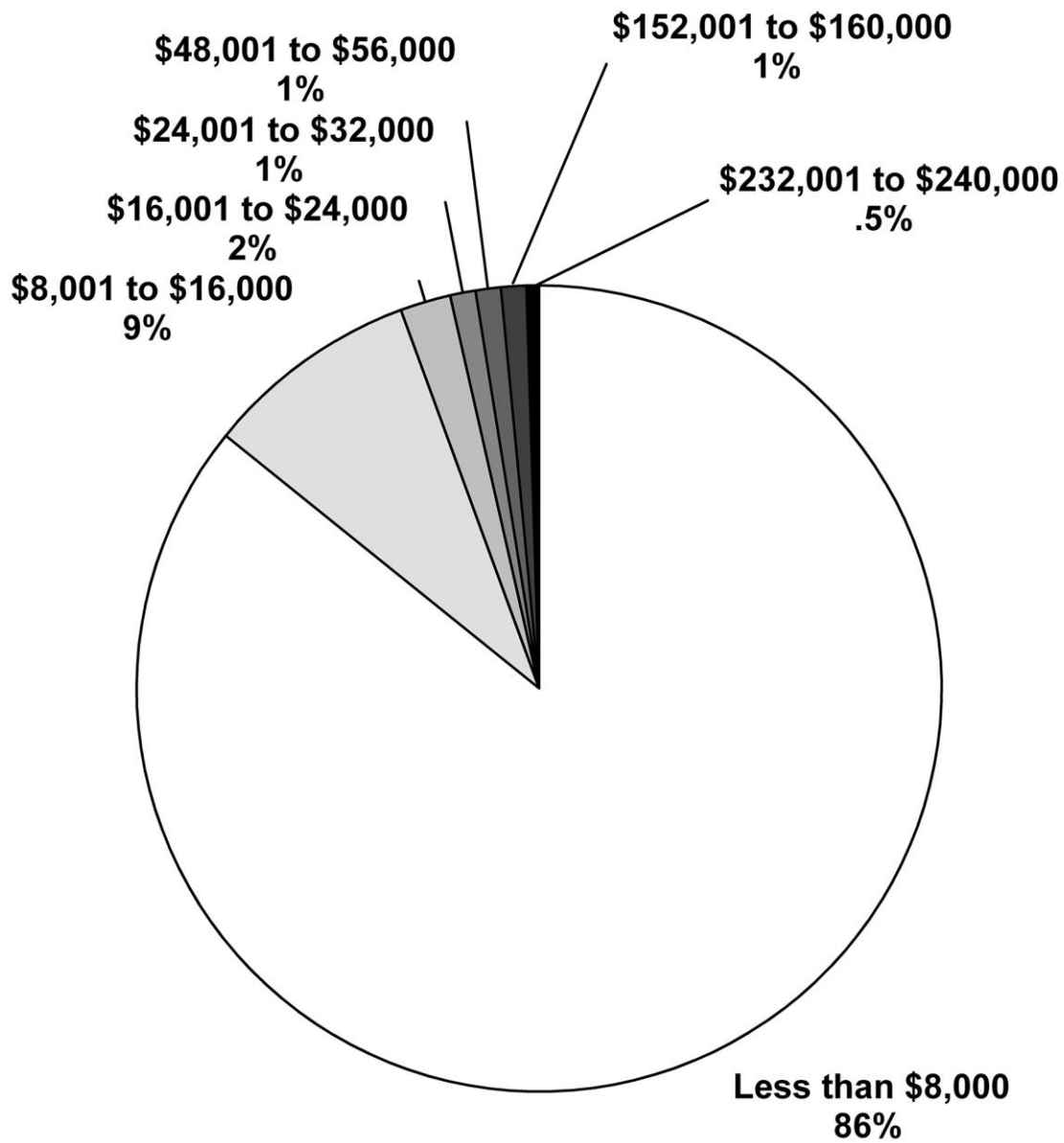


Figure 3. Average service spending per participant receiving these services in fiscal year 2013. This figure details how much of each service's projected spending is allocated per participant for the mental health services it provides.

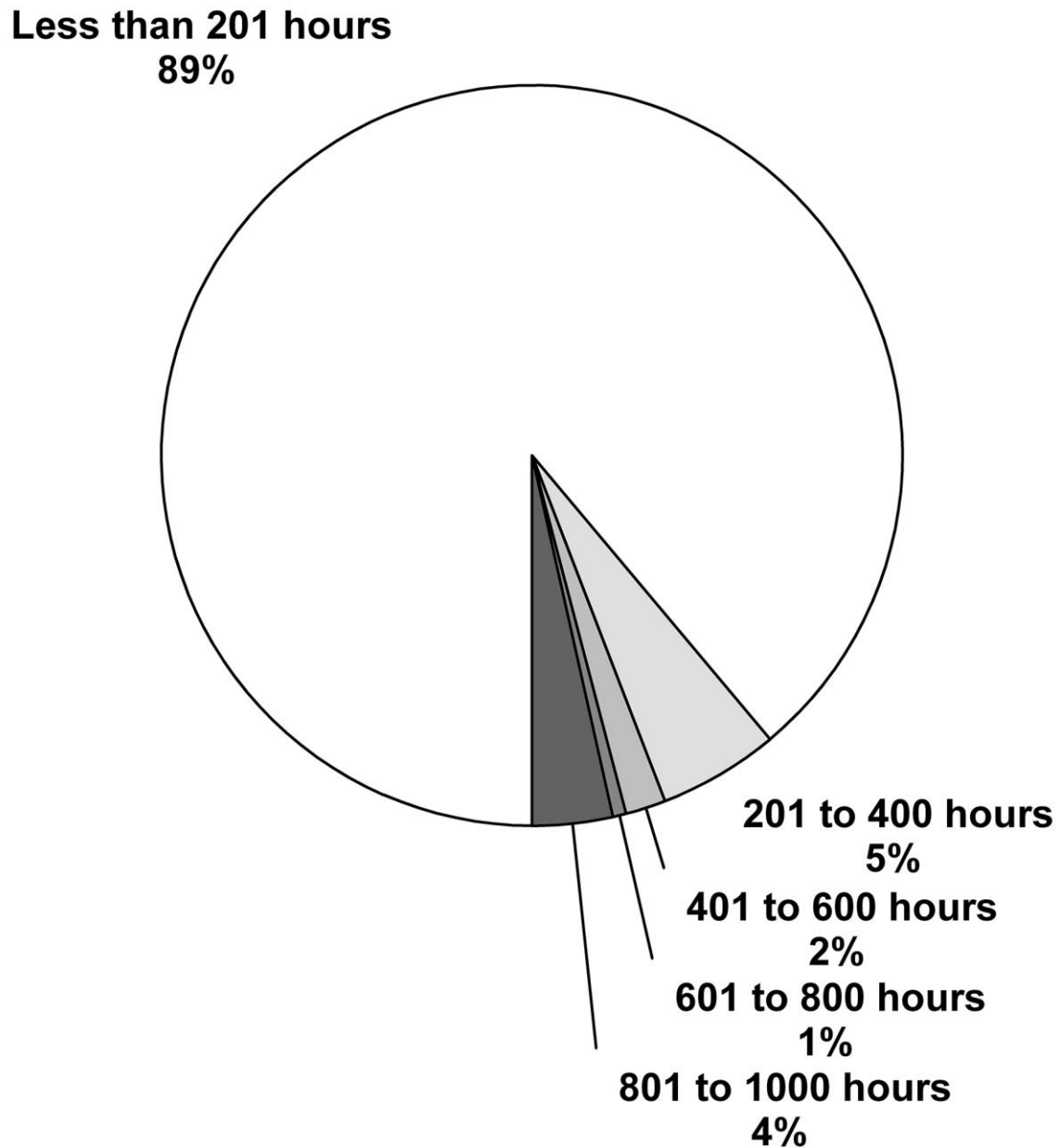


Figure 4. The number of hours of service the average participant received in a year (FY 2013).