Research

Community Based Dietician Services for People with Intellectual and Developmental Disabilities

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Abstract

Background. People with intellectual and developmental disabilities (IDD) experience significantly poorer health outcomes and a shorter life expectancy when compared to the general population. People with IDD are also more likely to become over weight or develop obesity because of poor nutrition and lack of education. Due to the health disparities that people with IDD experience and the high prevalence of developing obesity it is important that preventive health measures, such as cost-effective nutrition interventions and services, are readily available.

Specific Aims. The aim of this study is to explore how Medicaid Home and Community Based Services (HCBS) 1915(c) waivers – the largest providers of long term services and supports for people with IDD – across the United States provided dietician services for people with IDD.

Method. This study analyzed fiscal year (FY) 2015 HCBS waivers for people with IDD from across the United States (n = 111) to determine how dietary services were provided, particularly focusing on service utilization and expenditures, including unduplicated participants, total projected spending, average spending per participant, reimbursement rates, and average annual service provision per participant. Services' definitions were also analyzed for trends.

Findings. We found that dietician services were not widely provided in HCBS waivers – less than 1% of the approximately 630,000 people with IDD supported by HCBS waivers in FY 2015 were projected to receive dietician services. Moreover, despite being useful for health promotion, .01% of FY 2015 funding ($26.5 billion) was projected for dietician services. There was also a lack of consistency across states and services

Discussion. People with IDD who do not receive support services are less likely to engage in health services or health promotion activities and more likely to develop secondary conditions; for this reason, it is imperative that states utilize HCBS waivers to provide dietician services.

Community Based Dietician Services for People with Intellectual and Developmental Disabilities

People with intellectual and developmental disabilities (IDD) experience significantly poorer health outcomes and a shorter life expectancy when compared to the general population (Krahn, Hammond, & Turner, 2006; Ouellette-Kuntz, 2005; Taggart & Cousins, 2014). In fact, a recently conducted systematic review reported that people with IDD are more likely to die 20 years younger than the general population, with causes of death being commonly preventable (O'Leary, Cooper, & Hughes-McCormack, 2017). Health disparities such as environmental conditions, social circumstances, genetics, and access to health care play a key role in how people with IDD experience health (Krahn et al., 2006). Some of the major health risks which are commonly reported for people with IDD include cardiovascular disease, type 2 diabetes, hypertension, osteoporosis, depression, overweight, and obesity (Haveman et al., 2010; Rimmer & Yamaki, 2006; Taggart & Cousins, 2014; Yamaki, 2005). In the United States, the prevalence of an individual with IDD being overweight or obese is similar or higher when compared to the general population (Centers for Disease Control and Prevention, 2017; De Winter et al., 2012; Hsieh, Rimmer, & Heller, 2014; Yamaki, 2005;). A four-year longitudinal study by Hsieh et al. (2014) examining obesity and associated factors for adults with IDD, found that people with IDD had a higher prevalence of developing obesity (38%) compared to the general population (28%). The longitudinal study also found that being female, having Down syndrome, engaging in less physical activity, drinking greater amounts of soda, and taking medication that causes weigh gain result in an increased risk of developing obesity (Hsieh et al., 2014).

Health consequences that are commonly associated with being overweight and obese include: coronary health disease, type 2 diabetes, high blood pressure, stroke, liver and

gallbladder disease, respiratory problems, and certain types of cancers, such as breast and colon cancer (Centers for Disease Control and Prevention, 2017). Genetics, environment, and behavior can all play in a role in a person being overweight or developing obesity. People with IDD commonly have nutritional concerns, such as metabolic disorders, medication-nutrient interactions, and poor feeding skills, and may require total or partial dependence on enteral or parenteral nutrition, thus requiring nutritional intervention (Griffiths et al., 2018; Van Riper, 2010;). The environment also plays a role in the type of diet an individual may have. External factors such as availability, cost, accessibility, media attention, and cultural/religious practices influence the food choices made by an individual (Conner & Armitage, 2002; O'Kane, 2016; Rodriguez-Arauz, Ramirez-Esparza, & Smith-Castro, 2016). According to research, people with IDD who live in less restrictive environments, such as their own homes or group homes, have a significantly higher prevalence of becoming overweight or obese, reinforcing the environment as an influential determinant of obesity for people with IDD (Hsieh et al., 2014; Rimmer & Yamaki, 2006; Yamaki, 2005).

Yamaki (2005) suggest three potential reasons as to why people with IDD living in less restricted environments may be more likely to become over weight or develop obesity: (1) people with IDD are typically from low socioeconomic status and thus less likely to be able to afford healthy food options; (2) people with IDD who have transitioned into a less restrictive living environment are not used to the reduced supervision of their choices and thus tend to choose to eat high fat foods; and/or (3) people with IDD may not be aware of the health risks associated with being overweight or obese.

People with IDD have been commonly reported have poor nutrition due to limited knowledge about nutrition, diets that are high in fats with minimal fresh fruits and vegetables,

low incomes, and limited food preparation skills. Although there is limited research about how people with IDD choose the food they eat, people with IDD generally have little to no involvement in food shopping, meal planning, or meal preparation (Sisirak & Marks, 2014). For example, people with IDD living in group homes typically do not have a choice in what they are eating as they are typically not involved in grocery shopping, meal planning or meal preparation due to organization rules and safety policies (Rodgers, 1998; *citation removed for review*). Furthermore, time restraints for menu planning and food preparation commonly leads to prepackage foods that are high in calories and fat being served (Nestle et al., 1998; *citation removed for review*).

Due to the lack of knowledge people with IDD have about healthy lifestyle choices, such as diet, there is a greater demand placed on external influences and services to facilitate healthy conscious decisions for people with IDD (Rimmer & Yamaki, 2006). Medicaid Home and Community Based Services (HCBS) 1915(c) waivers are the perfect vehicle to examine nutrition and dietary service provision for people with IDD as they are the largest provider of long term services and supports (LTSS) for people with IDD in the United States (Braddock et al., 2017; *citation removed for review*). HCBS waivers were developed as an alternative to service provision in segregated settings. HCBS waivers allow states to provide community-based LTSS developed for underserved populations, such as people with IDD, by 'waiving' key provisions of the Social Security Act: state-wideness, comparability, and income and resource rules (U.S. Department of Health and Human Services, 2000). HCBS waivers have become the largest provider of LTSS for people with IDD because of the cost effectiveness of community living, the improved outcomes associated with waivers, and the preferences of people with IDD (Braddock

et al., 2017; Hemp, Braddock, & King, 2014; Lakin, Larson, & Kim, 2011; Larson & Lakin, 1989; Mansell & Beadle-Brown, 2004).

Due to the health disparities that people with IDD experience and the high prevalence of developing obesity it is important that preventive health measures, such as cost-effective nutrition interventions and services, are readily available. The aim of this study was to explore how Medicaid HCBS 1915(c) waivers across the United States provide dietician services for people with IDD. This study analyzed fiscal year (FY) 2015 HCBS waivers for people with IDD to determine how dietary services were provided, particularly focusing on service utilization and expenditures. Service definitions were also examined to determine trends across HCBS dietician services for people with IDD.

Methods

This study was exempt from institutional review board (IRB) review because it is publicly available existing data thereby not meeting the criteria for human subjects research. Medicaid HCBS 1915(c) waivers were obtained from the Centers for Medicare and Medicaid (CMS) website over a period of approximately 11 months (May 2015 to April 2016). (Figure 1 provides a detailed methodology tree.) We first excluded waivers that were not 1915(c) (i.e., 1115 demonstration waivers, and 1915(b) managed waivers were excluded as they are not common funding mechanisms for people with IDD) by filtering by waiver type. Next, all waivers that were inactive or pending, as well as waivers that did not serve people with IDD (i.e., intellectual disability, developmental disability, and/or autism spectrum disorder) were excluded. Our next exclusion criteria required waivers be for 2015. While most often waivers used the state FY (July 1, 2014 to June 30, 2015), a few waivers used the 2015 calendar year (January 1, 2015 to December 31, 2015) or the federal FY (October 1, 2014 to September 30, 2015). We use the

term FY for consistency. Through this process we collected 111 Medicaid HCBS 1915(c) waivers for people with IDD from 46 states and the District of Columbia.

[Figure 1 about here]

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, Center for Medicaid and State Operations, Centers for Medicare and Medicaid Services, & Department of Health and Human Services, 2015). This information was utilized to organize services into a waiver taxonomy (see *citation removed for review*) in order to examine dietician services in more depth. Cost-neutrality demonstration data was then analyzed to determine allocation of dietician services. This included determining the number of unduplicated participants, total projected spending, average spending per participant, reimbursement rates, and average annual service provision per participant. Services' definitions were also analyzed for trends using content analysis (Patton, 2002).

It should be noted that four services provided dietician services embedded within another service (i.e., specialized consultative services; counseling and therapeutic services). Since we were unable to differentiate between utilization and expenditures between dietician and other services provided within these four services they were excluded from the quantitative allocation analysis.

Findings

Service Definitions

Dietician services for people with IDD were provided by 29 waivers from 17 states and the District of Columbia through 33 services in FY 2015. Dietician services for people with IDD provided by HCBS waivers typically included assessment, intervention, and counseling. Thirty services (88.2%) specifically mentioned the inclusion of nutritional assessment as part of their service. For example, North Carolina Comprehensive Waiver's 'Specialized Consultative Services' included, "observing the participant prior to the development/revision of the Person Centered Plan to assess and determine treatment needs and the effectiveness of current interventions/support techniques."

Thirty-four dietician services (100%) included the development of special dietary plans, and interventions. For example, Texas Home Living Program waiver's 'Dietary' service mentioned,

> The Dietary service component assists individuals in meeting their basic and/or special therapeutic nutritional needs. Medically oriented nutritional services are especially important to ensure and maintain the health of persons on modified diets required by a disability and those requiring enteral or parenteral nutrition regimens. The dietary service component consists of assessment and treatment by licensed dietitians... Services include: … development of therapeutic treatment plans; direct therapeutic intervention; and participating on the interdisciplinary team, when appropriate.

Twenty-seven services (79.4%) provided counseling for participants and their caregivers as part of dietician services. For example, Pennsylvania OBRA Waiver's 'Nutritional Counseling' explained,

> Nutritional Consultation assists the participant and/or their paid and unpaid caregivers in developing a diet and planning meals that meet the participant's nutritional needs, while avoiding any problem foods that have been identified by a physician…The purpose of Nutritional Consultation services is to improve the ability of participants, paid and/or unpaid caregivers and providers to carry out nutritional interventions.

Uniquely, both of Connecticut's waivers (Comprehensive Supports Waiver and Individual and Family Support Waiver) included "recommendations for adaptive equipment for eating" within their 'Nutrition' services. It should also be noted one service, Washington Children's Intensive In-Home Behavioral Support waiver's 'Specialized Nutrition,' combined its dietician services with specially prepared food. It was the only waiver to provide food within its dietician services.

Service Allocation

HCBS waivers projected providing dietician services to approximately 5,500 people with IDD in FY 2015. Each service projected providing dietician services to 182 participants on average (median = 20). This ranged from 1 participant for Montana Home and Community-Based Waiver for Individuals with Developmental Disabilities' 'Nutritionist' service to 913 participants for District of Columbia's Persons with Intellectual and Developmental Disabilities Renewal Waiver's 'Nutritional Counseling' service.

In FY 2015, HCBS waivers projected spending $3.3 million on dietician services for people with IDD. This ranged from $141 (Louisiana New Opportunities Waiver's 'Nutrition/Dietary Services') to $780,605 (Oklahoma Community Waiver's 'Nutrition Services')

per service, with the average service projecting a total spending of $110,889 (median = $12,064). Table 1 details total projected spending by state and spending per capita.

[Table 1 about here]

On average HCBS IDD waivers projected spending $613.22 per participant annually on dietician services. This ranged from $70.56 (Louisiana New Opportunities Waiver's 'Nutrition/Dietary Services') to $1,955.10 (Pennsylvania OBRA Waiver's 'Nutritional Counseling'), with a median of $533.75. Figure 2 details average annual spending per participant by service.

[Figure 2 about here]

Dietician services were reimbursed by hour (n = 21) and by session (n = 9). The average hourly rate was $57.48 per hour. However, hourly rates ranged widely from $25.00 (Missouri Autism Waiver, DD Comprehensive Waiver, and Division of DD Community Support Waiver's 'Dietician' services) to $106.16 (Oklahoma In-Home Supports Waiver for Adults' 'Nutrition Services') per hour; see figure 3. The average session rate was $160.15 per session. 22.2% of session rate services (n = 2) paid a reimbursement rate between $0 and $75, 33.3% ($n$ = 3) between $76 and $150, 33.3% ($n$ = 3) between $226 and $300, and 11.1% ($n$ = 3) between $301 and $375.

[Figure 3 about here]

Of hourly rate services, the average participant was projected to receive 13 hours of dietician services per year. This ranged from 2 hours (Louisiana New Opportunities Waiver's 'Nutrition/Dietary Services') to 37 hours (Pennsylvania OBRA Waiver's 'Nutritional Counseling' service) per year; see figure 4. On average session rate services projected providing the average participant with 5 sessions of dietician services per year. Three session rate services

(33.3%) provided 1 session per participant per year, 1 service (11.1%) provided 3 sessions per participant per year, 2 services (22.2%) provided 4 sessions per participant per year, 1 service (11.1%) provided 5 sessions per participant per year, 1 service (11.1%) provided 6 sessions per participant per year, and 1 service (11.1%) provided 23 sessions per participant per year.

[Figure 4 about here]

Discussion

Lack of dietary knowledge plays a role in the poor nutrition people with IDD experience (Rimmer & Yamaki, 2006; Sisirak & Marks, 2014). As people with IDD are at risk for having poorer health outcomes, including for developing obesity and poor nutrition, the purpose of this study was to examine how the largest provider of LTSS across the United States, Medicaid HCBS waivers, provided dietician services for people with IDD. In doing so we found that dietician services were not widely provided in HCBS waivers, as evidenced by the fact that only about a quarter of waivers (29 out of 111) provided dietician services, and only 5,500 people with IDD out of the 630,000 people with IDD supported by HCBS waivers in FY 2015 (less than 1%) were projected to receive dietician services (*citation removed for review*). Moreover, despite being useful for health promotion, only .01% of FY 2015 HCBS funding ($3.3 million out of $26.5 billion) was projected for dietician services (*citation removed for review*).

According to the service definitions analyzed for this study, those states that provided dietician services in their waivers did so to develop treatment plans, interventions, and perhaps most importantly, counseling for people with IDD and their caregivers. However, there was a lack of consistency across states and services. For example, the number of participants receiving dietician services ranged from 1 participant to approximately 900 participants. Spending per person also ranged significantly from approximately $70 to approximately $2,000 per person

annually. Similarly, there were large differences across reimbursement rates, ranging from $25 to $107 per hour for hourly rate services. While this variance is a hallmark of the HCBS waiver (*citations removed for review*), the lack of standardization, particularly across reimbursement rates and annual service provision per participant may be problematic given the increased need people with IDD have for nutrition services.

Our findings demonstrate dietetic services are underutilized across the United States in one of the largest funding mechanisms for people with IDD, which is troubling given that people with IDD are more likely to develop obesity or be overweight when compared to the general population (Centers for Disease Control and Prevention, 2017; De Winter et al., 2012; Hsieh et al., 2014; Yamaki, 2005). Given that less than 1% of people with IDD on HCBS waivers (approximately 5,500) were projected to receive dietetic services suggests the need for services to be expanded throughout the country. As a result, states should examine means to expand dietetic services in HCBS waivers to address the health needs of people with IDD through proper nutritional support services. Furthermore, findings showed that even those individuals who did receive dietetic services in waivers were provided with limited services, with the average participant estimated to receive 13 hours or 5 sessions of dietetic services annually. As a result of the lack of consistent HCBS dietetic services, one questions the potential such services even have to improve the health of people with IDD. The underutilization of dietician services in waivers provides an opportunity for research to help determine from a multi-level system analysis how to most effectively develop and utilize dietetic services that are meaningful to meeting the needs of people with IDD, cost-effective, and more likely to be implemented and sustained long-term.

Although we recommend states expand their dietician services, we also recognize in this financial landscape states may have limited ability to significantly increase Medicaid service provision. Yet, there are a number of low-cost options regarding how nutrition and dietician services may be utilized to ensure people with IDD are receiving proper dietary supports. Community organizations can utilize participatory action methods, such as photovoice (which involves individuals with IDD taking pictures of a certain topic and discussing those photos either individually or as a group) or action planning (which involves individuals with IDD and members of their community organization developing a plan that would be best suited to meet their needs) as a means to gain a better understanding of the health and diet needs of the people with IDD they support. For example, they can use these methods to determine what having a healthy diet means to people with IDD, what supports people with IDD feel they need to maintain a healthy diet, and what barriers people with IDD identify to maintaining a healthy diet.

As research has also shown the environment plays a role in the dietary habits adopted by an individual (Conner & Armitage, 2002; O'Kane, 2016; Rodriguez-Arauz et al., 2016), person-centered education can also be utilized to inform people with IDD, their support people, and family about nutrition, and the effects it has on an individual's health and overall wellbeing. Education can also be provided to staff to improve staff competencies in health and nutrition so that they are better able to support people with IDD and their nutritional needs. Providing organizational training for both staff and people with IDD in how to prepare and cook food safety can also increase people with IDD and staff's knowledge and interest in nutrition (O'Leary et al., 2018; *citation removed for review*). Nutritional counseling can also focus on the individual's attitude, self-efficacy, and autonomy to maintaining a healthy diet. Organizations that work with people with IDD can also support dietary needs by examining how their policies,

resources, and practices may be influencing the dietary habits of people with IDD (O'Leary et al., 2018; *citation removed for review*). In doing so, organizations can implement a cultural shift within their agency that recognizes and values the importance of a healthy diet, not only for people with IDD but for their staff members as well. Thus, increasing the likelihood of long term sustainability of people with IDD practicing healthy eating. As part of this cultural shift, organizations can also revise organizational policies to ensure they allow people with IDD to be involved in choosing what foods they eat and being able to prepare their own meals. Doing so may ensure long term implementation and sustainability of nutritional initiatives.

To our knowledge there have not been any other studies that have investigated expenditure on dietician services for people with IDD conducted within the United State or internationally. Although the Medicaid HCBS 1915(c) waivers are unique to the United States, the current study can be used to spark much needed investigation in how other countries are funding and providing dietician services for people with IDD as this area is under examined.

When interpreting the findings of our study a number of limitations should be noted. Medicaid HCBS 1915(c) waivers are projections made to the federal government, rather than actual utilization data. However, they are a reasonably accurate proxy as waivers are based on previous years' utilization data. Moreover, *Citation removed for review's* FY 2010 IDD waiver analysis revealed similar findings to expenditure analyses by Braddock et al. (2015) and Irvin (2011).

People with IDD who transition into the community do not always have the knowledge or skills needed to make dietary decisions on their own – it is an unmet health care need. People with IDD living in the community need to have access to health care professionals, such as dietitians, to ensure that they receive proper care to prevent manageable health concerns from

developing into potentially life-threating conditions (Krahn et al., 2006). Dietary services should focus on preventative health to ensure that people with IDD are able to maintain a healthy lifestyle, thus potentially decreasing their risk of developing obesity and other secondary chronic health conditions that are related to poor dietary habits. People with IDD who do not receive support services are less likely to engage in health services or health promotion activities and more likely to develop secondary conditions (Emerson, 2011); for this reason, it is imperative that states utilize HCBS waivers to provide dietician services.

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Table 1

Projected Dietician Service Spending by State

State	Total projected spending	Spending per capita	Rank
Connecticut	$8,383	$0.002	10
District of Columbia	$548,941	$0.82	1
Florida	$181,418	$0.01	7
Louisiana	$2,733	$0.001	14
Missouri	$252,555	$0.04	6
Montana	$230	$0.0002	16
Nevada	$258,983	$0.09	4
New Mexico	$14,003	$0.01	9
Ohio	$6,799	$0.001	13
Oklahoma	$1,098,985	$0.28	2
Pennsylvania	$15,641	$0.001	11
Tennessee	$798,792	$0.12	3
Texas	$9,176	$0.0003	15
Washington	$6,903	$0.001	12
West Virginia	$118,938	$0.06	5
Wyoming	$4,184	$0.01	8

Note. Rank is spending per capita from highest to lowest.

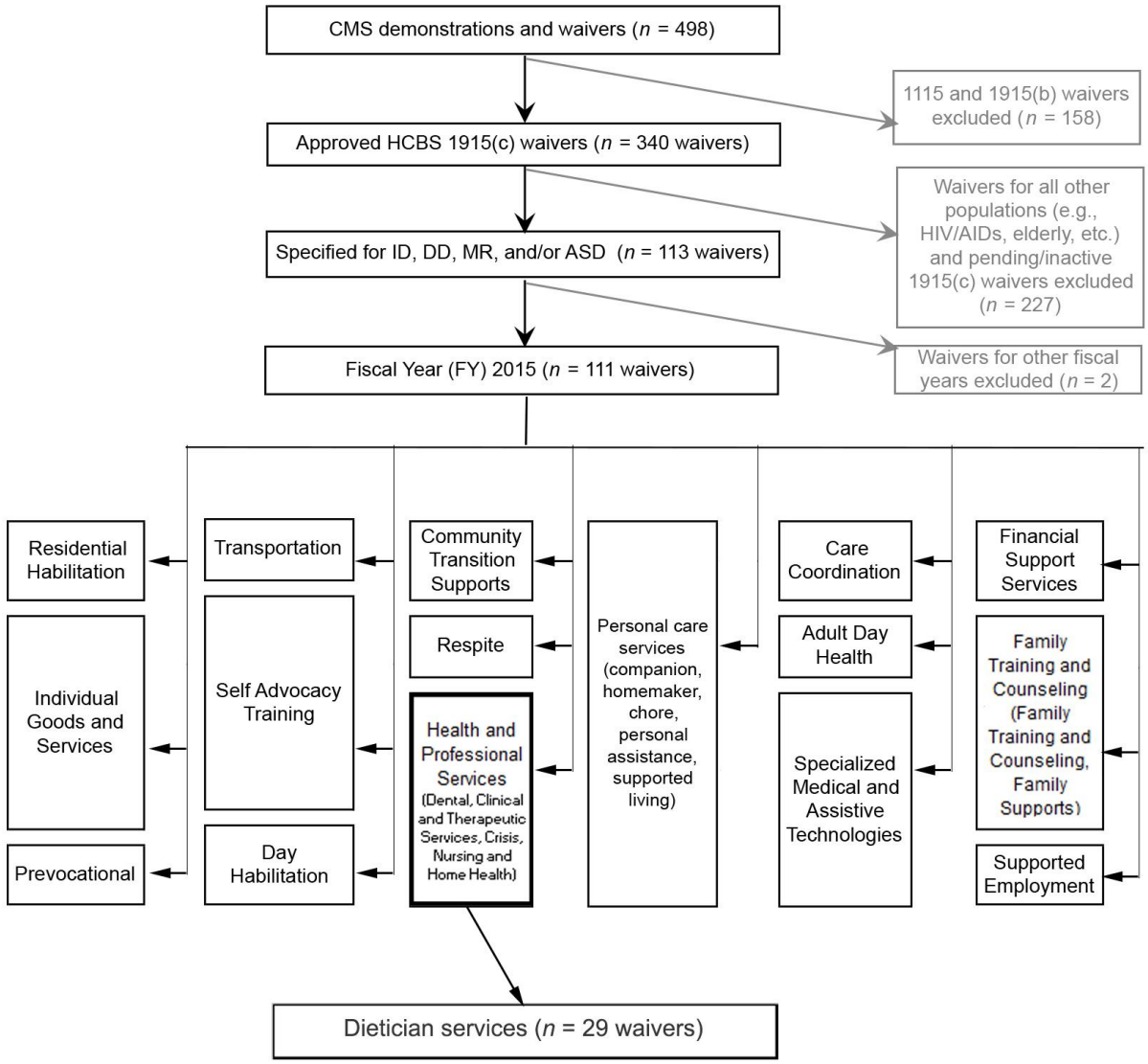

Figure 1. Methodology tree.

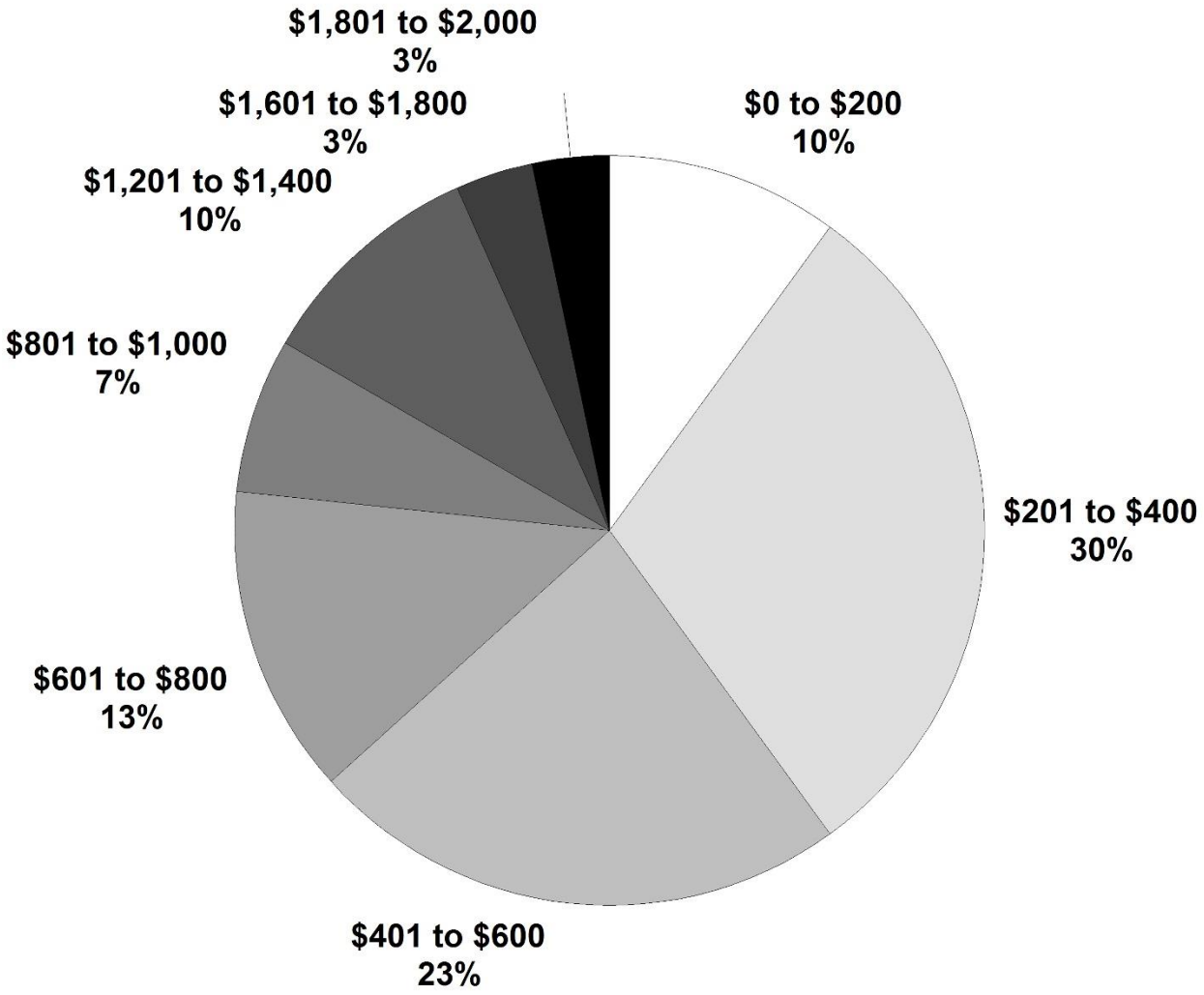

Figure 2. Average spending per participant by service.

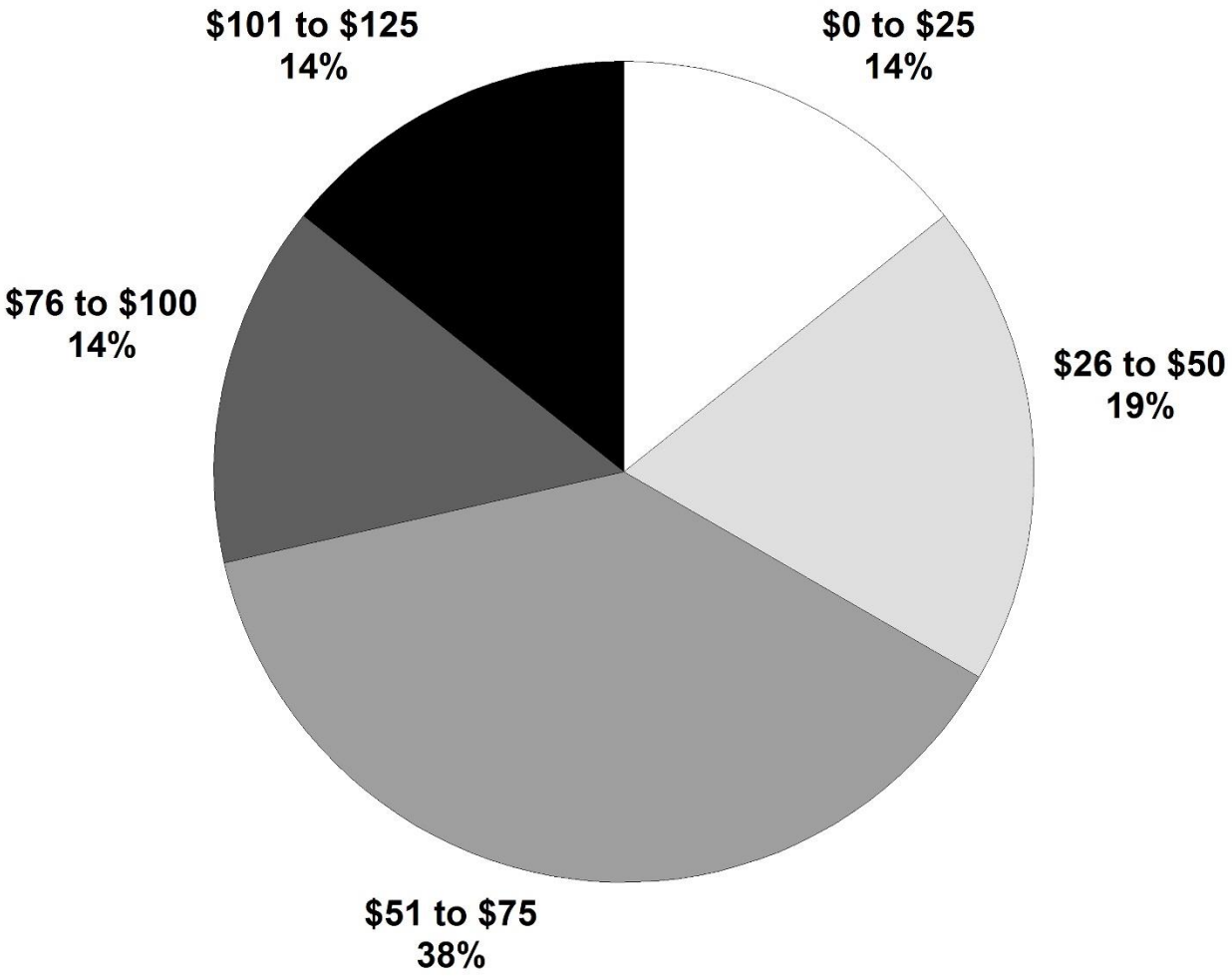

Figure 3. Reimbursement rates for hourly rate services.

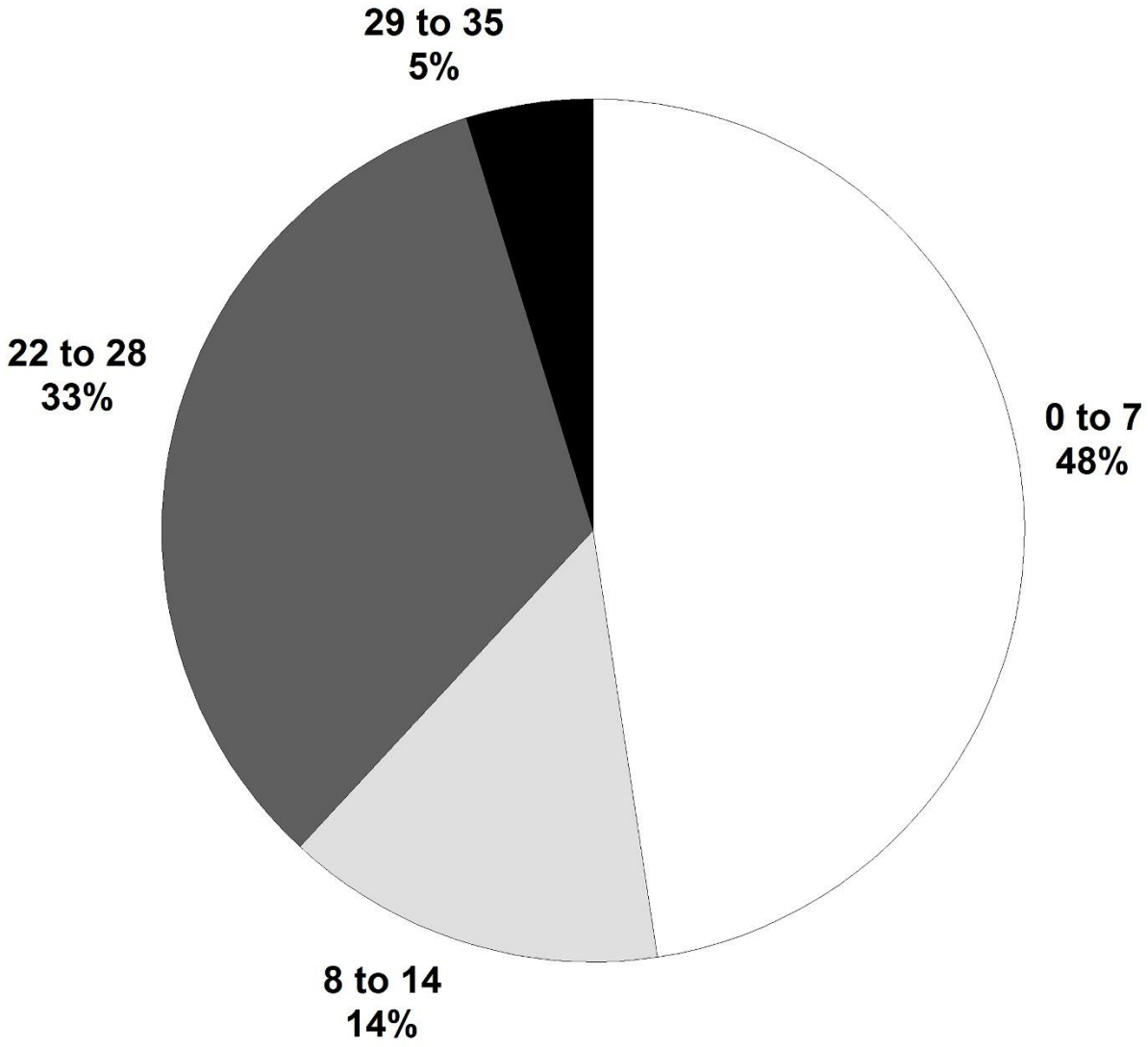

Figure 4. Average annual service provision for hourly rate services.