

Research

Un/Paid Labor: Medicaid Home and Community Based Services Waivers that Pay Family As Personal Care Providers



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Un/paid labor: Medicaid Home and Community Based Services waivers that pay family as personal care providers

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Abstract

The United States long-term services and supports system is built on largely unpaid (informal) labor. There are a number of benefits to allowing family caregivers serve as paid personal care providers including better health and satisfaction outcomes, expanded workforces, and cost effectiveness. The purpose of this study was to examine how Medicaid HCBS Section 1915(c) waivers for people with intellectual and developmental disabilities allocate personal care services to pay family caregivers. Our analysis revealed about two-thirds of waivers in fiscal year (FY) 2014 allowed for family caregivers to potentially be paid for personal care services. This amounted to up to \$2.71 billion of projected spending, which is slightly more than half of all personal care service expenditures in FY 2014.

Keywords: *Personal care, caregiving, intellectual and developmental disabilities, Medicaid Home and Community Based Services*

Un/Paid Labor: Medicaid Home and Community Based Services**Waivers that Pay Family as Personal Care Providers**

The U.S. long-term care system is built largely upon unpaid (informal) voluntary labor; the economic value of which was estimated at \$199 billion to \$450 billion in 2009 (Gallanis & Gittler, 2012; Kunkel et al., 2003). Personal care services are often critical for facilitating community living over institutionalized living (Doty et al., 1996). Yet only 13% of people with intellectual and developmental disabilities (IDD) receive formal out of home residential supports (Braddock et al., 2015 based on Fujiura, 2012). Relatively few states provided personal care services through Medicaid prior to the 1980s (Doty et al., 1996). Personal care services are more common in Medicaid today, especially as provided in the Medicaid State Plan Personal Care Services benefit (Department of Labor, 2015; Kitchener, Ng, & Harrington, 2007; Ng, Harrington, Musumeci, & Reaves, 2014). Personal care services provided through Medicaid, including State Plans, are typically provided by home care agencies certified by the state as well as family care providers (Benjamin, 2001; Department of Labor, 2015; Lieber & Lockwood, 2013; Ng, Harrington, Musumeci, & Reaves, 2014). States vary in the extent family can be reimbursed through Medicaid, while some states allow only immediate family such as spouses and parents, others allow extended family (Benjamin, 2001; Department of Labor, 2014).

The largest funding stream for long-term services and supports (LTSS) for people with IDD is the Medicaid Home and Community Based Services (HCBS) 1915(c) waiver (Rizzolo, Friedman, Lulinski-Norris, & Braddock, 2013). By allowing some or all of the three main provisions of the Social Security Act to be ‘waived,’ HCBS waivers allow services to be delivered in integrated community-based settings, including private homes rather than segregated institutions (U.S. Department of Health and Human Services, 2000). Deinstitutionalization, the

benefits of community settings (including cost effectiveness), and the preferences of people with IDD have all contributed to the growth of HCBS waivers across the U.S. (Hemp, Braddock, & King, 2014; Lakin, Larson, & Kim, 2011; Mansell & Beadle-Brown, 2004). Thus, the purpose of this article is to examine how Medicaid HCBS Section 1915(c) waivers for people with IDD allocated personal care services, particularly to pay family members as providers. Fiscal year (FY) 2014 HCBS IDD waivers providing personal care services were analyzed to determine which waivers would allow paid family providers and how they did so; this included an examination of provision trends, funding and expenditure projections, and service utilization.

Background

An estimated 43.5 million people serve as unpaid (informal) caregivers to older adults, people with disabilities, and people with illnesses/diseases in the United States (U.S.) (National Alliance for Caregiving & AARP, 2015). On average these unpaid caregivers spend an estimated 24.4 hours per week providing care though this number increases to an average of 40.5 hours when the caregiver lives with the care recipient (National Alliance for Caregiving & AARP, 2015). The National Alliance for Caregiving and the AARP (2015) estimate that more than half of this caregiving time is spent on personal care activities including assistance with activities of daily living (ADLs) such as dressing, bathing, toileting, and feeding, and assistance with instrumental activities of daily living (IADLs) such as cooking, housekeeping, and shopping (Benjamin, 2001; Kaye & Harrington, 2015; Simon-Rusinowitz et al., 2005). Three million people in the community receive help with two or more ADLs and approximately 90% of people with care needs get help from friends and family (Kaye & Harrington, 2015).

Unpaid caregiving is associated with a large amount of physical and emotional caregiver stress (Gallanis & Gittler, 2012; Maes et al., 2003). In fact, the longer a family member provides

care the more likely they are to report poor health (National Alliance for Caregiving & AARP, 2015; San Antonio, Eckert, & Rusinowitz, 2006). Many caretakers find themselves juggling many responsibilities including raising children (Simon-Rusinowitz et al., 2005). This emotional and physical burden is also very much related to the stressors of specifically providing *unpaid* care (Gallanis & Gittler, 2012). Unpaid caregiving impacts workforce participation; although approximately three-quarters of caregivers are also formally employed, 66% of employed caregivers reported having gone to work late in the previous year, having left early, or having taken time off to do caregiving tasks (National Alliance for Caregiving & AARP, 2015; Silverstein & Parrott, 2001; Simon-Rusinowitz, Mahoney, & Benjamin, 1998). Caregivers also reported taking a leave of absence, reducing work hours, quitting jobs, turning down promotions, and taking early retirements because of their caregiving duties (Gallanis & Gittler, 2012; National Alliance for Caregiving & AARP, 2015; San Antonio et al., 2006). This can result in a financial burden, especially since it is estimated that almost half of caregivers have household incomes of less than \$50,000 a year, and because there are associated out-of-pocket expenses related to caregiving (Gallanis & Gittler, 2012; National Alliance for Caregiving & AARP, 2015; Silverstein & Parrott, 2001). Caregiving can also impact the long term financial well being of the caregiver because reduced formal employment results in fewer Social Security credits in addition to reduced retirement savings (Simon-Rusinowitz et al., 2005).

There are a number of benefits to allowing family caregivers to serve as paid service providers. Not only are agency providers commonly rotated and re-assigned, hindering relationship building, if agency providers are sick or do not show up, the consumer may be left without crucial services (Benjamin, 2001). Family providers, research has shown, are more reliable and flexible than agency workers (San Antonio et al., 2006). Family caregivers are also

likely to be more sensitive to the consumers' needs and it may cause less embarrassment when providing for intimate needs such as toileting (San Antonio et al., 2006). Another benefit of allowing paid family providers to provide care is increased consumer direction and choice for the individual with a disability (San Antonio et al., 2006; Simon-Rusinowitz et al., 2005). Agencies often must make decisions based on the best interests of the agency rather than the consumer; for example, scheduling bedtime is not necessarily based on what is best for the consumer (Benjamin, 2001). Without agencies serving as "intermediaries" consumers should have more choice and play a larger role in directing their own care (Doty, Kasper, & Litvak, 1996, p. 6; Benjamin, 2001).

Paying family caregivers also helps compensate for the shortage of employees in direct care services (Benjamin, 2001; Matthias & Benjamin, 2008; Simon-Rusinowitz et al., 2005). As Benjamin (2001) argues, "in a tight labor market recipients need maximum latitude to recruit help. Practically, family members represent a large pool of helpers for persons with disabilities" (p. 87). Of those paid family members in Benjamin's (2001) study, one in five paid family members were not caretakers prior to being paid, thus providing evidence for a potential expanded workforce pool.

Paid family providers may also be more cost effective than agency-based providers because a significant amount of agency funding goes towards overhead costs (Benjamin, 2001; Doty et al., 1996). Families are also more willing to receive low wages because they prefer it to unpaid labor (Benjamin, 2001). Paying family members to provide services also decreases the financial penalty of caregiving by making up for some of the negative financial impacts of unpaid caregiving such as limited workforce participation (Matthias & Benjamin, 2008; Simon-Rusinowitz et al., 1998). Another benefit of paying families for caregiving is its potential for

gender and class justice by “placing a monetary value on the labor of a primarily female, low-income workforce” (Simon-Rusinowitz et al., 1998, p. 71). States often reinvest these saved costs into providing more hours of service per consumer (Doty et al., 1996). Moreover, the primary effect of the new Final Rule, which extends the Fair Labor Standards Act (FLSA) protections including minimum wage and overtime pay to home care workers, will be the potential for shifting of funds from home care agencies to direct care workers (Department of Labor, 2015). In fact, if the Department of Labor’s (2015) suggested changes are followed, the Department of Labor suggests a projected “average annualized transfer of \$321.8 million” from home care agencies to direct care workers (p. 9).

Despite these benefits, progress in paying family caregivers has been hindered by a number of critiques. Paying family caregivers for their services goes against U.S. cultural norms about family responsibilities, work, and private and public spheres. Separating ‘care’ (i.e., work for love) from ‘work’ (i.e., work for money) is a U.S. based ideology (Kunkel, Applebaum, & Nelson, 2003). Moreover, some critics argue that family caretaking is a moral duty and paying family members would weaken this responsibility, and result in weakened family commitments (Benjamin, 2001; Kunkel et al., 2003; Matthias & Benjamin, 2008; Silverstein & Parrott, 2001). Others are critical because of the U.S. system of separation of government and family wherein caretaking is considered private and using public money to fund family providers is considered government entering the family sphere (Kunkel et al., 2003; Simon-Rusinowitz et al., 1998; Simon-Rusinowitz et al., 2005). Fraud and abuse by families is another common concern (Benjamin, 2001; Kunkel et al., 2003; Simon-Rusinowitz et al., 1998; Simon-Rusinowitz et al., 2005). Some believe paying families will expand costs because people will no longer be participating in unpaid labor (Benjamin, 2001; Kunkel et al., 2003; Simon-Rusinowitz et al.,

1998; Simon-Rusinowitz et al., 2005). A few critics are also concerned that paying family will complicate family relationships morphing them into one of employer-employee (Kaye & Harrington, 2015). Finally, another concern is that paying family caregivers could hinder the individual with IDD's opportunities for self-direction and decision-making; it is critical the individual with IDD choose the arrangement.

Research has found that these critiques of paying family members are largely unfounded. Paid family members provide quality care that produces better health and satisfaction outcomes than provider-funded care (Matthias & Benjamin, 2008; Simon-Rusinowitz et al., 2005). Paid family members have better relationships with the person receiving care (their family member) than agency workers typically do, which is especially important given the intimacy of the work (Matthias & Benjamin, 2008). Consumers report feeling more comfortable and secure with family providers and have increased overall care satisfaction (Kunkel et al., 2003; Simon-Rusinowitz et al., 2005). In addition to higher satisfaction, family providers produce positive health and safety outcomes as a result of increased communication and more in depth knowledge about the individual and their preferences (Benjamin, 2001; Kunkel et al., 2003; Matthias & Benjamin, 2008; Simon-Rusinowitz et al., 1998; Simon-Rusinowitz et al., 2005). For example, Kunkel et al. (2003) found those involved in a consumer-directed family provider program in Ohio were less likely to have bedsores, burns, or cuts when using family providers versus agency ones.

Concerns over fraud and abuse have also been largely disproven. The risk of fraud and abuse for family caregivers is less than with agency-based services (Benjamin, 2001; Kunkel et al., 2003; Matthias & Benjamin, 2008). Although family members typically provide more care than they are paid for, caregivers do not complain about not being compensated for all their work

because love, not money, was their primary motivation for caregiving (Kaye & Harrington, 2015; San Antonio et al., 2006; Simon-Rusinowitz et al., 1998). Paying family providers also helps caregivers balance caregiving and work by allowing them to work less or leave their jobs entirely (Simon-Rusinowitz et al., 2005). Caregivers have reported paid caregiving programs help support the family, make them feel their contributions are acknowledged, and help family relationships by reducing stress (Kunkel et al., 2003).

Methods

This study analyzed Medicaid Home and Community Based Services (HCBS) 1915(c) waivers because they are the most prevalent public funding stream for LTSS for people with IDD (Rizzolo et al., 2013). HCBS 1915(c) waiver applications were obtained through the Center for Medicare and Medicaid Services (CMS) Medicaid.gov web site over a 12-month period (June 2014 to June 2015). (See Figure 1 for a detailed tree of methods in addition to the following description.) All CMS waivers were then limited to 1915(c) waivers (as opposed to 1115 or 1915(b)), and were limited to those targeting people with IDD—either people with intellectual disability (ID), developmental disability (DD), autism, (ASD), and/or “mental retardation” (MR). Although the language “mental retardation” is outdated and should be replaced by intellectual disability, it remains in use in statutes and in the waiver application template thus was a necessary search term. No age limitations were imposed. The waiver year that most closely aligned with FY 2014 (July 1, 2013 and June 30, 2014) for each waiver application were used. Most of the time these were the state fiscal years however some states used the federal fiscal year of October 1, 2013 to September 30, 2014, while a few used the 2014 calendar year (January to December). ‘Fiscal year’ is used throughout this article for consistency. Waivers that were expired, terminated, withdrawn, disapproved, or pending were also excluded. Ultimately, FY

2014 data from 112 HCBS 1915(c) IDD waivers (45 states and the District of Columbia) were collected.

Waiver applications describe: CMS assurances and requirements; levels of care (LOC); waiver administration and operation; participant access and eligibility; available 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. Because of our interest in services that allow family/relatives to be paid we focused our attention on the “participant services: general service specification” sections, specifically where states were required to respond about the “provision of personal care or similar services by legally responsible individuals” and “state policies concerning payment for waiver services furnished by relatives/legal guardians.” If waivers allow the provision of personal care by a legally responsible individual, the state must then specify:

(a) the legally responsible individuals who may be paid to furnish such services and the services they may provide; (b) State policies that specify the circumstances when payment may be authorized for the provision of *extraordinary care* by a legally responsible individual and how the State ensures that the provision of services by a legally responsible individual is in the best interest of the participant; and, (c) the controls that are employed to ensure that payments are made only for services rendered. (Emphasis original.)

If the waiver allows payment of relatives/legal guardians for services, the state must specify:

the specific circumstances under which payment is made, the types of relatives/legal guardians to whom payment may be made, and the services for which payment may be made. Specify the controls that are employed to ensure that payments are made only for services rendered.

Ninety-four waivers allowed family/relatives to be paid providers through over 800 separate service lines. It should be noted that three waivers were excluded because although they said they allowed service provision by relatives/family, upon further examination they had no services in that fiscal year that allowed the services to be provided by family members. After this

data was compiled, the services were then organized categorically using Rizzolo et al.'s (2013) HCBS IDD waiver taxonomy. These services fell into 16 categories: personal care services (i.e., companion, homemaker, chore, personal attendant, supported living); residential habilitation; adult day health; community transition services; day habilitation; financial support services; care coordination; transportation; prevocational; supported employment; specialized medical equipment and assistive technology; health and professional services (i.e., clinical and therapeutic services, dental, nursing and home health); respite; family training and counseling (i.e., crisis, family training and counseling, family supports); individual goods and services; and, self-advocacy training. Because we were specifically interested in personal care services, the waiver specifications for personal care services in each of the waivers were further examined for trends. These personal care services that allowed family members to be paid were also analyzed to determine the projected number of users, average cost per unit, average hourly rate, and projected component cost.

Findings

Over 800 services available through ninety-four waivers allowed family to be potentially paid as providers. Out of these, 190 were personal care type services (74.5%, or 70 out of the 94 waivers). Waivers often expressed a willingness to pay family members as a way to strengthen the family unit and/or promote family-based environments. For example, the Tennessee HCBS Waiver for the MR and DD, and HCBS Waiver for Persons with MR waivers explained,

payment to family members is intended to promote a more family-oriented residential environment, allowing the person supported to stay in their own home. This promotes family involvement in the life of the person, with the intent to strengthen the person's family unit.

Not only did many waivers recognize family typically have the most experience and knowledge regarding their relative with IDD, they also explained that paying family was especially

beneficial for those people living in remote or underserved areas, and/or for individuals with IDD who need services during “hard-to-staff hours.” Despite these noted benefits, a few waivers paid family members as a last resort. For example, Virginia’s Individual and Family DD Support Waiver required “documentation that provides adequate justification that no other provider is available or suitable to provide care and that payment to a relative for services is the option of last resort.”

Waiver applications were required to specify which services may be provided by family, who could be paid to provide services, and how the waiver provided safeguards against fraud. However, waivers had a lot of flexibility in their responses and we observed a lot of variability in terms of the amount of detail and the length of these specifications. Furthermore, it should be noted that our description of themes only included instances when states purposely noted these items. It is unclear if the absence of an item meant the services were not provided or if the state merely omitted their response. For example, in this section seven waivers specified that the family provider must be 18 years old or older. Kansas HCBS-I/DD Waiver allowed providers to be 16 or older as long as the provider was not a sibling (18 and older for siblings). Although only a small number of waivers specified a minimum age requirement for paid family caregivers, it is assumed that the majority, if not all, of the other waivers require providers be 18 or older.

As part of the CMS requirements, states were required to specify whether the service may be provided by legally responsible persons, parents, relatives, and/or legal guardians; most often waivers allowed a combination of different family thus, the following figures are not mutually exclusive. Fifty-three of the 70 waivers that allowed paid family caregivers (75.71%) specified a parent or legal guardian could be a paid provider. Eighteen of the 70 waivers (25.71%) allowed siblings to be paid for providing these services, and 13 waivers (18.57%) allowed spouses to be

paid. Fifty-two waivers of the 70 waivers (74.29%) mentioned relatives could provide these services. Relatives were often defined as including blood/adoptive relatives and individuals related by marriage such as grandparents, aunts, uncles, and cousins. Five waivers went on to specify that relatives could not live in the same house while one waiver required the family live in the same house. Three waivers (4.29%) simply specified the provider must be a legally responsible individual – “any person who has a duty under State law to care for another person” – but did not have further specifications. It should be noted that most of these services also required the family provider to have appropriate skills to provide care.

Another trend among service specifications was that many waivers ($n = 30$ out of 70; 42.86%) specified family members could not be paid for services that could be considered their ‘typical’ responsibilities. For example, the Kentucky Supports for Community Living waiver specified,

in order for a legally responsible individual to provide paid services the services must be extraordinary, exceeding the range of activities that a legally responsible individual would ordinarily provide in the household on behalf of a person without a disability of the same age, and which are necessary to assure health and welfare of the person and avoid institutionalization

A few waivers allowed an exception to this rule if caretaking hindered participation in the labor market. For example, New Mexico Mi Via ICF/MR Renewal Waiver explained,

extraordinary circumstances include the inability of the legally responsible individual to find other qualified, suitable caregivers when the legally responsible individual would otherwise be absent from the home and, thus, must stay at home to ensure the participant’s health and safety.

In addition to already existing service caps, twenty-two waivers (31.43%) specified time limitations specifically for family providers. Twenty of these waivers mandated that family members may not be paid for more than 40 hours a week for services rendered. Meanwhile, Wyoming Child DD Waiver specified personal care services provided by family caregivers could

only be reimbursed up to a maximum of four hours per day per consumer. West Virginia MR/DD Waiver allowed eight to 12 hours of personal care by family providers per day explaining,

for participants eligible to receive public education services/home schooling/other education alternatives, participant-centered support services cannot exceed an average of 8 hours per day. The legal guardian of a participant who is not eligible for public education services/home schooling/other educational alternatives, is limited to an average of 12 hours per day of participant-centered support services.

It was not uncommon for waivers to include a number of other specifications. Nineteen waivers (27.14%) required the person selected as family caregiver be identified by the consumer with IDD. Not only does this promote consumer direction, it can also serve as an attempt to reduce fraud. A number of other waivers also detailed the required oversight of family providers. This was typically achieved by timesheets, unannounced visits by a supports coordinator or care management team, and supervision by appointed managers. It was also common for waivers to note that family could only provide these services when it was cost effective and these expenses may not exceed what would be paid to a typical provider agency.

Service Expenditures

In FY 2014 HCBS IDD 1915(c) waivers projected spending \$5.14 billion for personal care services (Friedman & Rizzolo, 2015). Out of the \$5.14 billion of projected spending for personal care services, \$2.71 billion (52.71%) was allocated for services that allowed potential family members to be paid providers. However, total projected spending for personal care services that allowed paid family caregivers varied widely by waiver, ranging from \$241.92 for the Missouri Children with DD (MOCDD) waiver's "personal assistant, group" service to \$422.69 million for Ohio IO Waiver Amendment's "homemaker/personal care - daily billing

unit.” On average, waivers allocated \$15 million on personal care services that allowed paid family providers.

Approximately 125,000 projected waiver participants had the potential to receive these personal care services in FY 2014. The average projected spending per participant receiving these services also varied widely. An average of \$16,610 was projected per participant for these services, with the majority (75.92%) projecting spending on average of less than \$20,000 per participant; 42.41% of services projected an average of less than \$6,000 per participant receiving these services.

States offered multiple personal care rates depending on the level of support needed or the types of services provided. The majority of personal care services that allowed paid family providers were paid using an hourly rate. The average hourly rate of those personal care services that paid family members was \$17.99 an hour; however, these rates ranged from a low of \$6.00 an hour in Wyoming (Child DD waiver) for “group companion services” to a high of \$54.32 an hour in South Dakota (South Dakota Family Support 360 waiver) for “companion care.” Figure 2 illustrates the variability in hourly rates across the waivers examined. Daily personal care rates for paid family caregivers ranged from \$30.00 a day for Maryland Community Pathways waiver’s “community supported living arrangement I and II retainer services” to \$459.56 a day for Nebraska Day Services for Adults with DD waiver, and Comprehensive DD for adults waivers’ “medical risk services”, with an average of \$147.98 a day (see Figure 3). New York NYS OPWDD Comprehensive Renewal waivers’ “live in caregiver” service reimbursed \$1,009.20 a month. Seven other services reimbursed per unit, most often this occurred for meals and chore services.

The average number of hours participants received in FY 2014 also varied. Participants averaged 733 hours per year when services were delivered in hourly increments, ranging from an average of 8 hours per participant per year for Missouri MOCDD waiver’s “personal assistant, group” to 6,041 hours per participant per year for West Virginia MR/DD waiver’s “participant-centered support – traditional;” see Figure 4. Daily-rate services averaged 255 days per participant per year, ranging from an average of 21 days per participant per year for Maryland’s Community Pathways waiver’s “community supported living arrangement I and II retainer services” to 365 days per participant per year for Nebraska’s Day Services waiver for adults with DD, their Comprehensive DD waiver for adults, and their HCBS Waiver for Children with DD and Their Families’ “medical risk services” and Louisiana New Opportunities and Residential Options waivers’ “companion care.” See Figure 5.

Discussion

Our analysis of FY 2014 HCBS 1915(c) waivers for people with IDD revealed that roughly two-thirds of the waivers examined allowed family members to potentially be paid as service providers for personal care services. This amounted to \$2.71 billion of projected spending in FY 2014, which is slightly more than half of all personal care service expenditures that year. Utilization of paid family providers was often justified because of the family’s knowledge and experience with their relative with IDD. They were also beneficial in rural and underserved areas where there is a shortage of providers, especially in instances where the individual needs specialized care. Waivers most commonly allowed parents and guardians to be the paid family provider; other relatives such as siblings, spouses, grandparents, aunts, uncles, and cousins were also allowed in numerous waivers to be paid providers. However, almost half

of the waivers examined specified that family members could only be paid in situations where services go above and beyond what would be considered their ‘typical’ responsibilities.

We found a wide amount of variability in funding levels for those services that allowed paid family providers, including total projected spending, hourly and daily rates, service hours, and spending per participant. For example, the average number of hours of personal care a participant received annually varied widely from 8 to 6,041 hours for hourly services, and 21 to 365 days for daily services. Similarly, hourly personal care rates ranged from \$6 to \$54, while daily rates ranged from \$30 to \$460. It is not uncommon for personal care work to pay rates at or slightly above minimum wage so it is likely these figures are simply representative of a poorly funded industry in general (Department of Labor, 2015; Matthias & Benjamin, 2008). Although the variance we found in terms of spending, rates, and hours is extreme it also appears to be a common theme among HCBS 1915(c) IDD waivers from our examination of other waiver services: family support services (Friedman & Rizzolo, 2014); dental services (Friedman, Rizzolo, & Schindler, 2014); mental/behavioral health services (Friedman, Lulinski, & Rizzolo, 2015); electronic monitoring services (Friedman & Rizzolo, under review-a); transportation services (Friedman & Rizzolo, under review-c); and supported employment services (Friedman & Rizzolo, under review-b). This variability is one of the hallmarks of the HCBS waiver – states have great leeway and flexibility to tailor services to the needs of individuals with IDD in their states.

The HCBS waiver application data used in the current study are based on projections of spending made to the federal government. Because it is based on previous years’ actual utilization, this data is a reasonably accurate proxy of IDD waiver services spending. Moreover, IDD waiver projection analyses, such as Rizzolo et al. (2013) have revealed results “congruent

with spending patterns identified by researchers at Mathematica who used 2008 Medicaid Statistical Information Systems claims data from 44 states and Washington, DC to determine trends in waiver expenditures across the states” (pp. 19-20). However, one of the drawbacks of using projected data is that we were only able to examine what states *would* allow as opposed to actual expenditures for paid family providers. Future studies should examine both how families are able to access information about waiver services that allow paid family caregivers and the process states use to pay family members. Family members could provide valuable information on effective methods for enrolling, training, and supporting family caregivers as well as collect information on the adequacy of rates and allowable hours. Future research should also would be examine the effectiveness of paying family as providers through HCBS waivers specifically in terms of increased personal outcomes, reduced family stressors, and reduction in service needs with implementation of a paid family caregiver model.

Our analysis found that less than one-third of the 70 FY 2014 IDD waivers that paid family members required waiver recipients to select which relative served as their paid provider. This is in spite of decades of research documenting the benefits of consumer direction (Benjamin, 2001; Crozier, Muenchberger, Colley, & Ehrlich, 2013; Heller, Arnold, McBride, & Factor, 2012). Personal care services can be very intimate, and directly impact a person’s quality of life. People with IDD should be able to choose the person that is being paid to assist them with their activities of daily living and who will likely spend a significant amount of time with them performing these tasks. In fact, the new CMS HCBS Final Rule calls for an increase in person centered planning and participant direction that includes goals and preferences identified by the individual with IDD; CMS suggest doing so will “contribute to the assurance of health and welfare” (Department of Health and Human Services, 2014, p. 3)

We are encouraged by the number of HCBS waivers for people with IDD that allow family members to be paid as personal care providers. The majority of people with IDD rely on unpaid family caregivers. Only 13% of people with IDD receive formal out of home LTSS (Braddock et al., 2015 based on Fujiura, 2012). While the majority of this care is provider-based we are seeing an increase in participant-directed services. Allowing family members to be paid to provide care and allowing individuals with IDD to choose family members as their care providers is another way people with IDD are increasing control over their services and supports.

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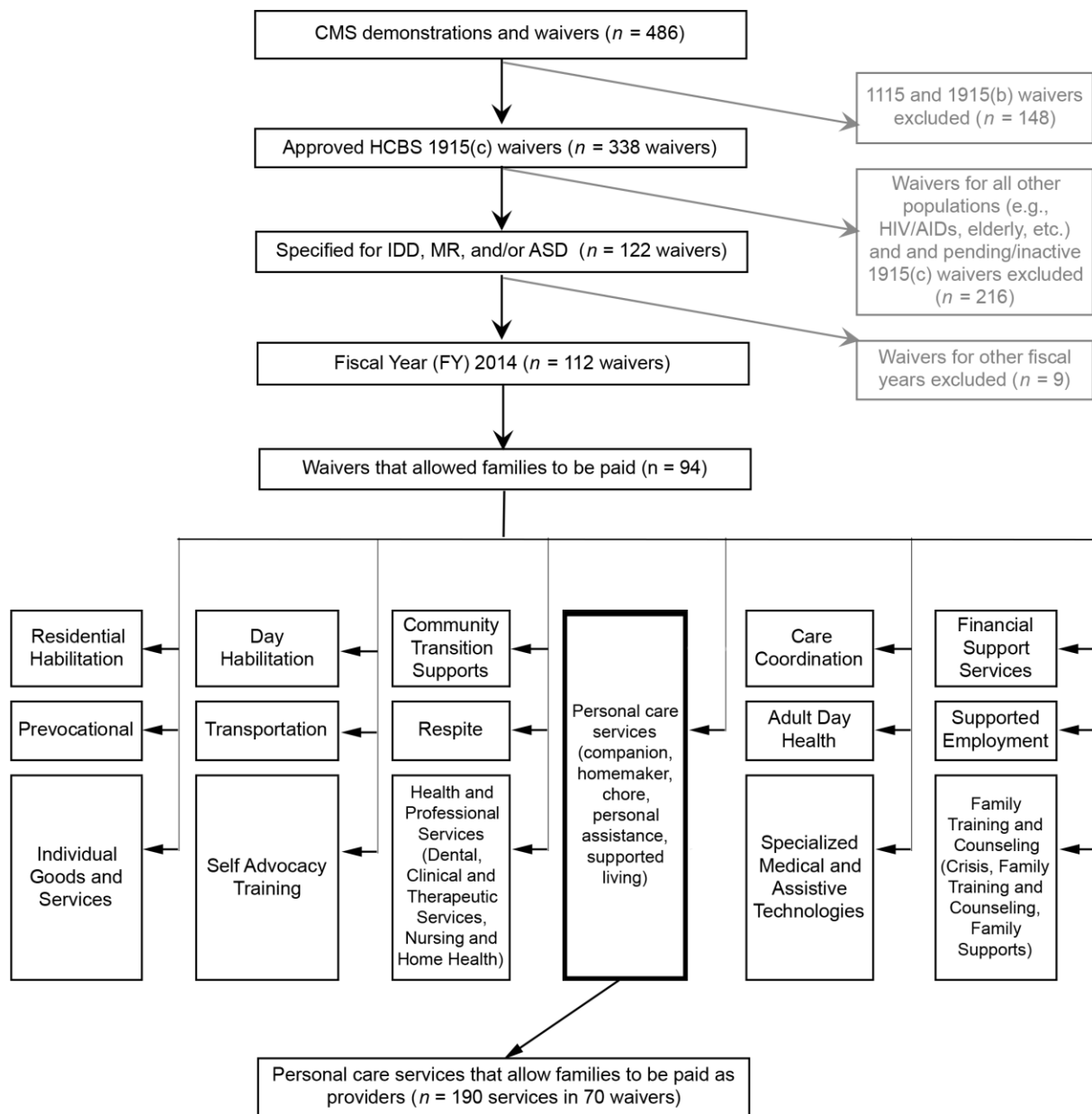


Figure 1. Process for identification of included HCBS 1915(c) IDD personal care services that will pay family as providers. CMS = Center for Medicare and Medicaid Services; HCBS = Home and Community Based Services; IDD = intellectual and developmental disabilities; MR = mental retardation; ASD = autism spectrum disorder; HIV/AIDs = human immunodeficiency virus/acquired immunodeficiency syndrome.

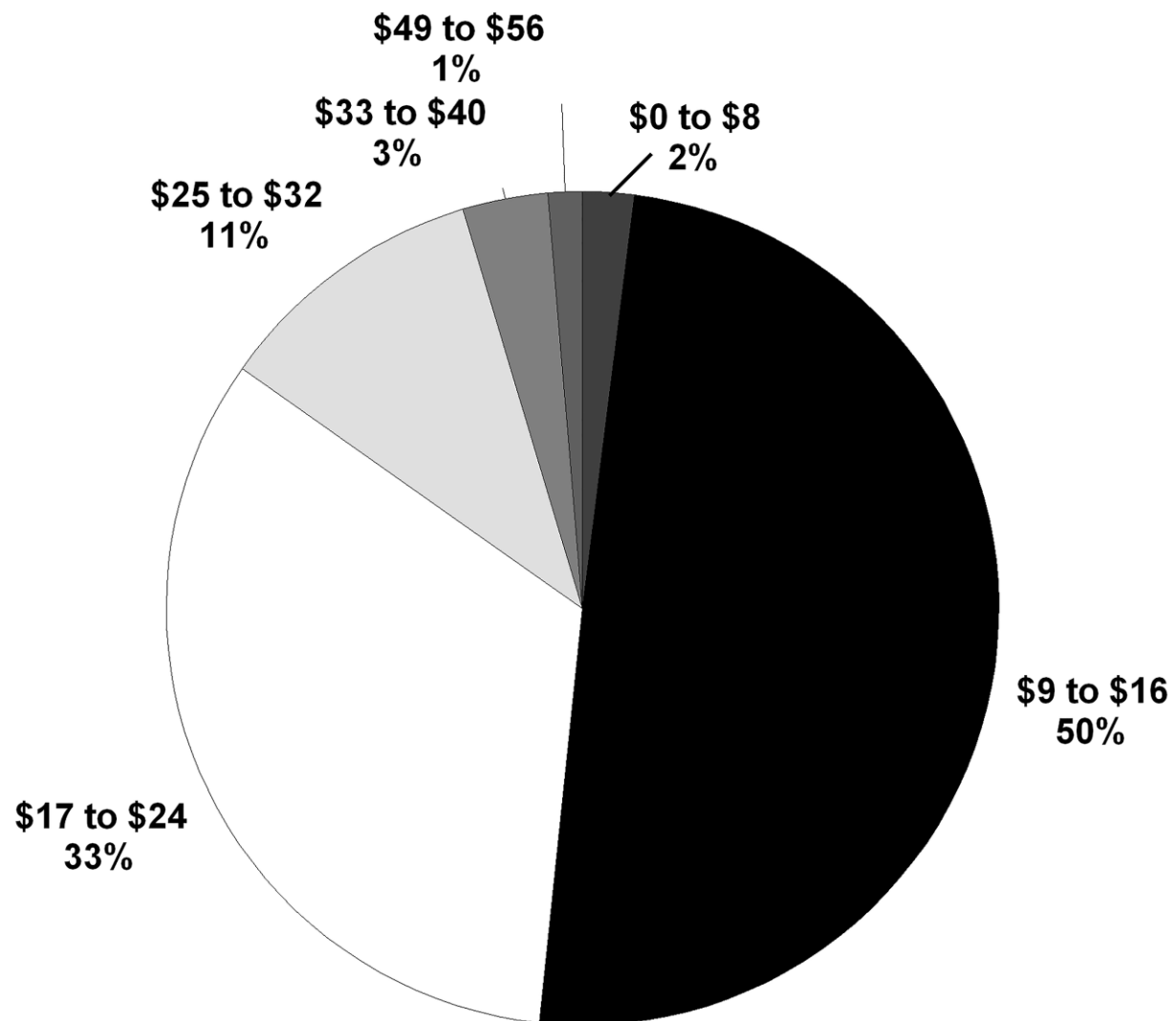


Figure 2. Projected hourly rates for personal care services that will pay family caregivers.

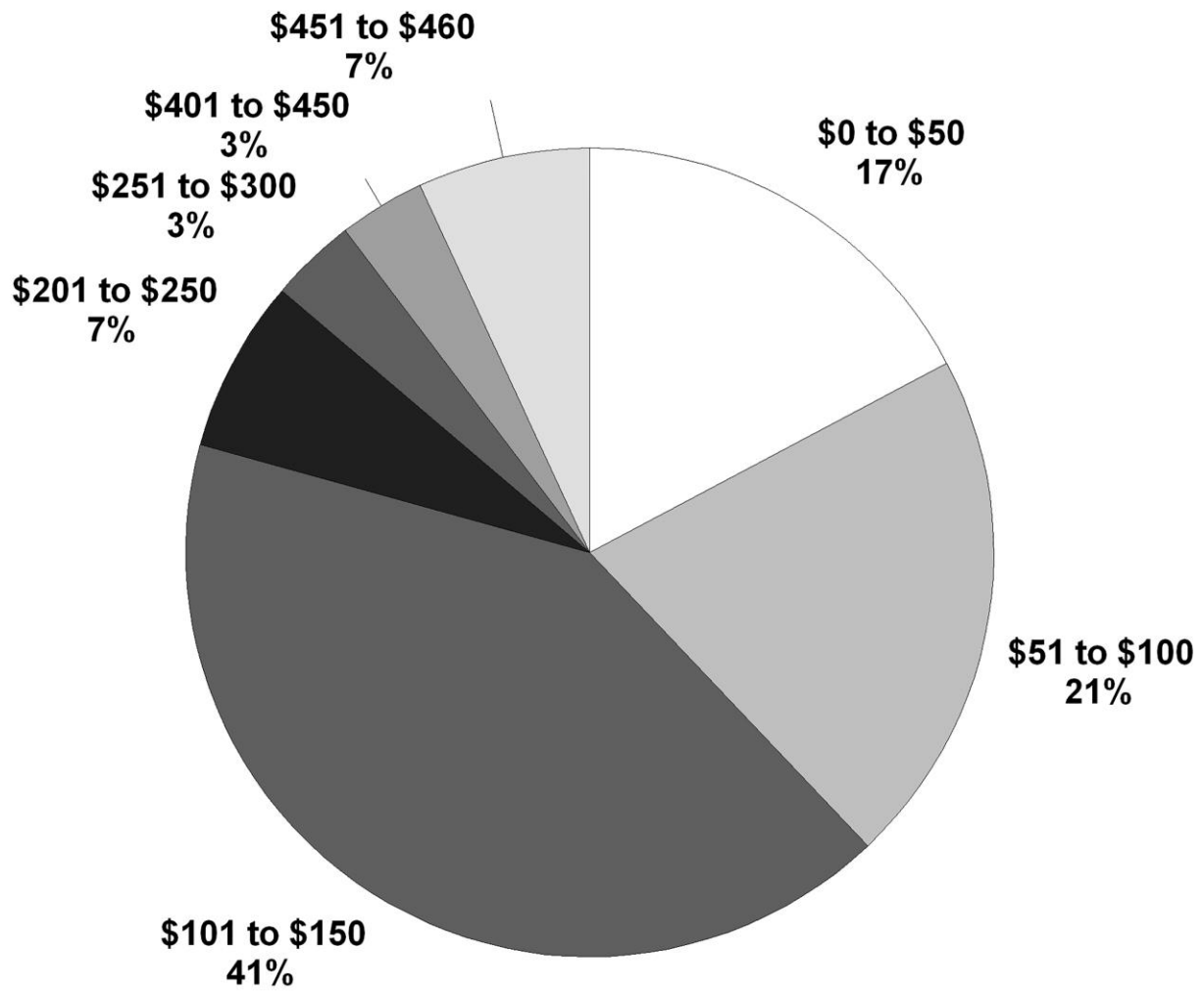


Figure 3. Projected daily rates for personal care services that will pay family caregivers.

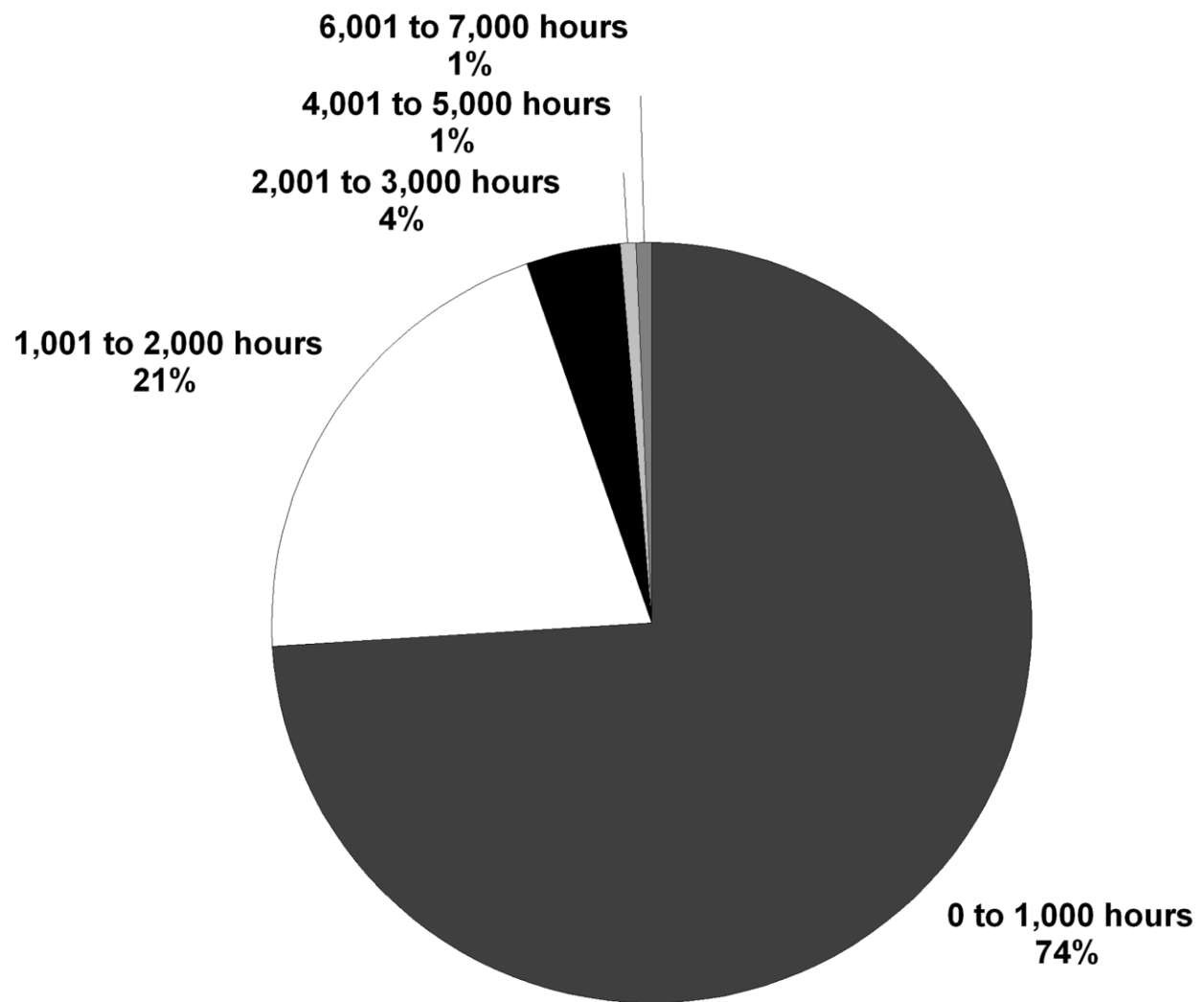


Figure 4. The number of hours of personal care services the average participant received in a year for hourly rate services that will pay family caregivers.

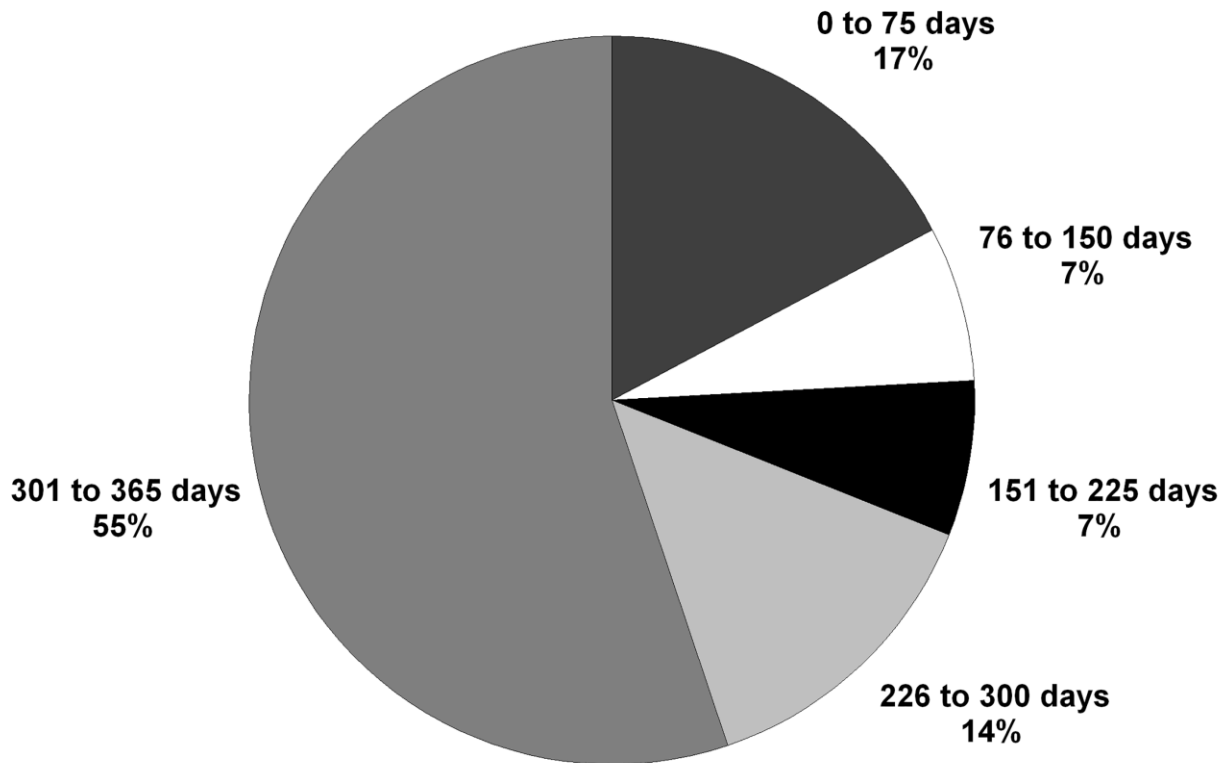


Figure 5. The number of days of personal care services the average participant received in a year for daily rate services that will pay family caregivers.