

Services that Support Families in Medicaid Home and Community Based Services (HCBS) Waivers

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Introduction

Deinstitutionalization and the benefits of community integration for people with intellectual/developmental disabilities (I/DD) has led to significant increases in community living (Kim, Larson, & Lakin, 2001; Mansell & Brown, 2004). Although this is cost effective for states families tend to incur additional out of pocket costs (Caldwell, 2006). In alignment with this trend, Lewis and Johnson as cited by Rizzolo, Hemp and Braddock (2006) have commented on the shift in “financial burden from taxpayers to the families themselves” (p. 85).

Services that support families in both coping with caregiving stress and in increasing strengths emerged because of the challenges families were facing with increases in community living (Rizzolo, Hemp, & Braddock, 2006). These services also aimed to prevent people with I/DD from having to return to out-of-home residential settings. Although family support services for family members of people I/DD emerged in the early 1980s (Agosta & Bradley, 1985; Fujiura, Garza, & Braddock, 1990; Rizzolo, Hemp, & Braddock, 2006; Turnbull & Turnbull, 2000) state and national funding has not yet met risen to match the increased needs.

In Fiscal Year (FY) 2011, \$4.0 billion was spent by the states to support approximately 468,000 individuals with I/DD living in the family home (Braddock et al., 2013). Almost 80% of this funding came from Medicaid Home and Community Based Services (HCBS) Waivers (Braddock et al., 2013). We analyzed 95 HCBS Waivers to determine what services and supports states were providing through their HCBS Waivers that specifically target family caregivers and assessed the states’ level of commitment to funding these services.

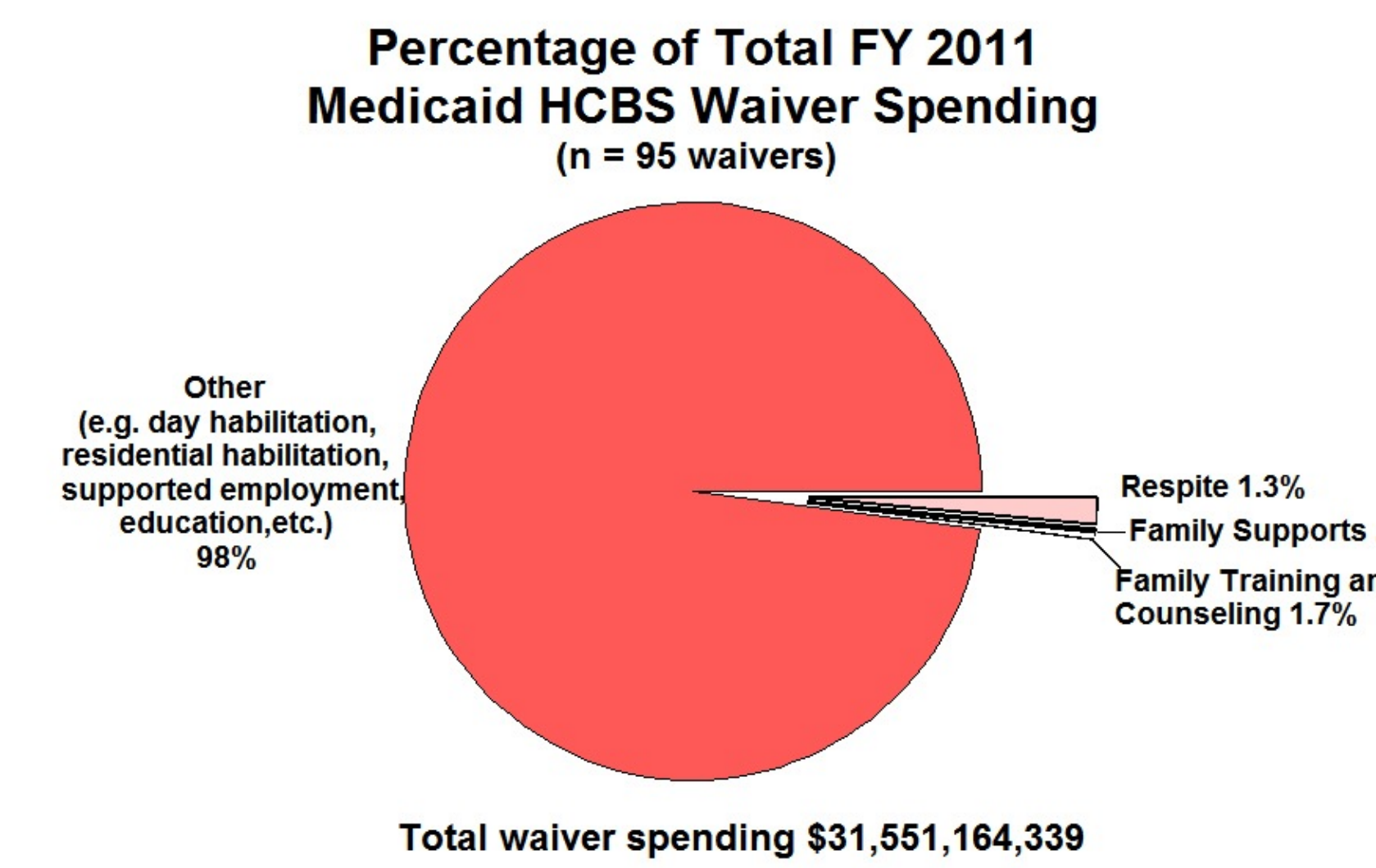
Method

Methods for this study were similar to a national study of HCBS Medicaid Waivers for people with I/DD by Rizzolo, Friedman, Lulinski-Norris, and Braddock (2013). HCBS Waiver data was obtained by reviewing all Medicaid Waiver applications that were available on the CMS Medicaid.gov website over a period of 37 Months (May 2010 to May 2013). In addition to a review of these Waivers on the CMS website, state developmental disability agencies and division websites were reviewed and agency staff were contacted when a known waiver was unavailable online. To be included in this study, HCBS Waiver applications needed to specify the target group served by the Waiver was people with I/DD. Ultimately, we were able to collect FY 2011 data from 95 HCBS Waivers (43 states and D.C.). Data was collected from the FY 2011 Waiver applications to determine, if applicable, the services provided that supported families, the projected number of users, the average unit of service per user, and the average cost of each unit of service. Additionally, the definitions of services supporting families that were provided in the 95 Waivers were analyzed to determine patterns across them.

Findings

Service categories and definitions

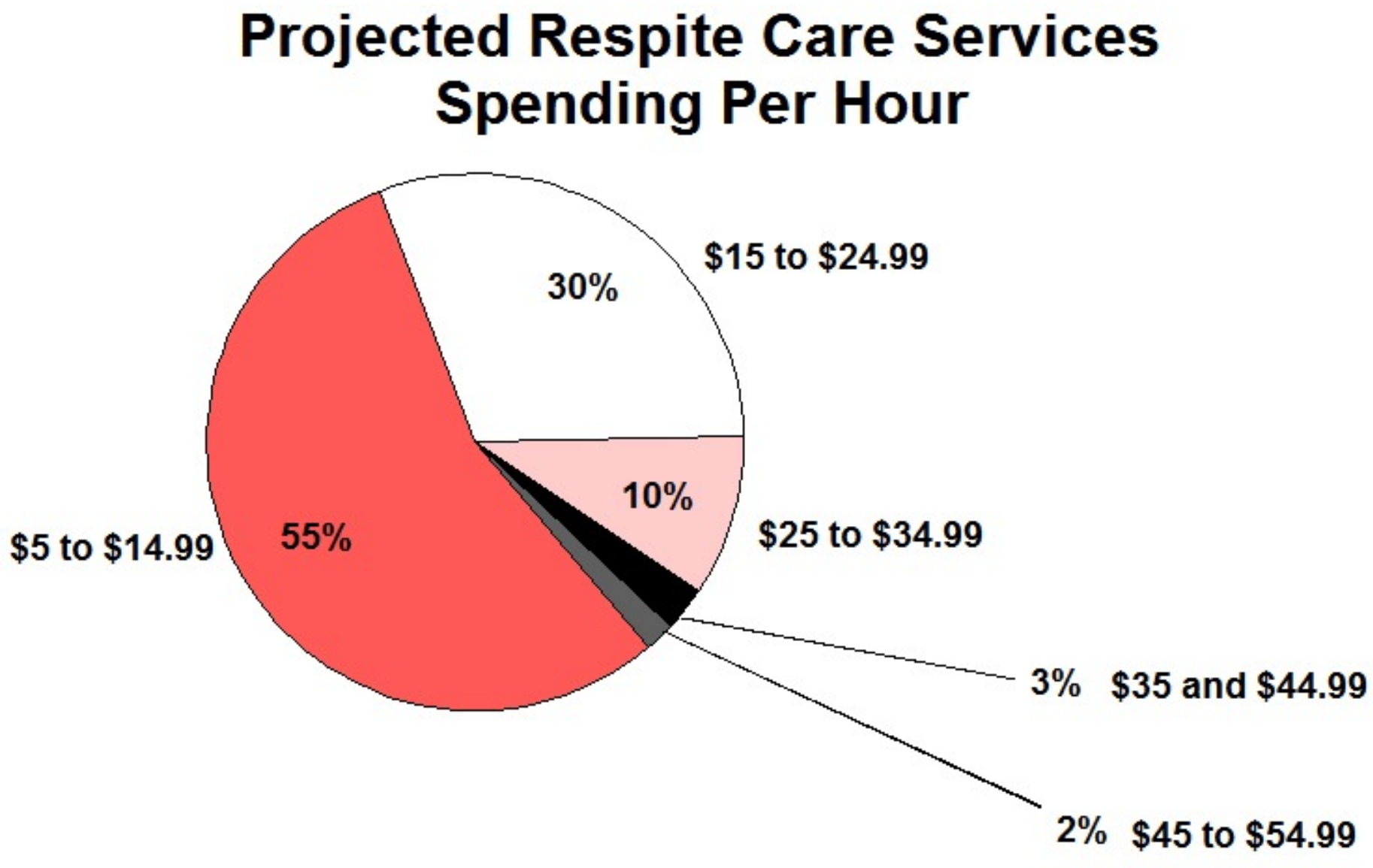
HCBS Waiver services to support families were broken down by theme into three categories: respite care services, “family support” services, and family training and counseling services. After examination of 163 services, a composite definition of each category was created.



Respite Services

Service titles for what we deemed respite services included: respite, center based respite, crisis respite, out of home respite, and respite nursing care. The goal of respite is to avoid institutionalization. Generally, respite cannot be provided to individuals in an inpatient of a hospital, nursing home facility, or ICF/MR (Intermediate Care Facilities for individuals with Mental Retardation). Respite care services are provided to temporarily relieve primary caregivers. This short-term care is provided so the family member may rest, when the family member needs support when the individual with a disability is experiencing severe behavioral challenges, or when unavoidable circumstances, such as a family emergency, warrant relief from care giving. Respite care allows for the continuation of an individual’s routines and community activities. Some examples of respite care include assistance with toileting, feeding, daily living skills, grooming and personal hygiene, meal preparation, medications, and supervision.

Nursing respite services are for those individuals with chronic or acute health diagnoses that require skilled nursing for brief periods of time. This type of service occurs because of complex care needs including intravenous nutrition or drug therapy, ventilator dependence, device-based



respiratory support and tracheotomy care.

Crisis or emergency respite services are for behavioral or medical intervention. It can include, assessment of factors contributing to the crisis, development and implementation of an intervention plan, development and intervention of a transition plan, and recommendations for revisions to the individual service plan to prevent future crisis situations and to maintain community placement.

Typically respite care is scheduled in advanced but can also be used in a crisis or emergency situation. Usually in these situations, out of home respite, also called center-based respite, can be used to provide temporary or short-term relief of no more than 30 consecutive days. These facilities, which must be licensed, can be used when families take vacations or have a sudden emergency such as a family death.

Family Support Services

After examination of five services, a composite definition of “family support” services was created. Service titles for what we deemed “family support” services included: family and individual support services, family support services, and family support navigation. “Family support” services and family and individual support services were designed to directly support and assist an individual to relieve the caregiver as well as enhance family functioning. They are typically low-cost and are often intermittent. They can be provided in or out of the individual’s home as they aim to increase independence, productivity, and community inclusion. In addition to relief for the caregiver, “family support” services can include training and shared supports. Examples of supports provided under this category included support groups, after school care, or the purchase of materials necessary to maintain the individual at home that are not covered under other categories.

Meanwhile, family support navigation is somewhat different. Massachusetts’ Adult Supports Waiver defines this service as

the provision of unbiased expert information and referral supports that are designed to assist families to identify needs and to facilitate and gain access to local generic supports through coordination between the family and other service providers. The Family Navigator acts as a guide and resource development expert to insure that families have knowledge and access to a broad array of generic community resources, provides assistance in navigating the system, and recognizes and promotes the value of natural supports. Family Navigators respond to the specific ethnic and linguistic needs of families in the geographic area where they reside and offer timely and relevant information to families regarding available resources in the community. They assist families to identify their strengths and develop individualized family emergency contingency plans. The Family Navigator provides opportunities for families to develop collaborative networks with other families and acts as a resource developer for the family. The Family Support Navigator manages the access to and use of state funds for respite. This service is only available to participants who reside in the family home... This service can not be self-directed.

Family Training and Counseling Services

After examination of 44 services, a composite definition of family training and counseling was created. Service titles for what we deemed family training and counseling services included: adult life planning, family and caregiver training and education, unpaid caregiver training and

counseling, family adjustment counseling, natural supports training, parent education, and staff/ family consultation and training. In both training and counseling services family is generally defined as the persons who live with or provide care to a person served on the waiver, including a parent, spouse or domestic partner, children, relatives, foster family, or in-laws.

Aimed at safely maintaining an individual at home, training often included information and instruction about use of equipment, techniques to assist in caring for the individual’s needs, or treatment regimens. Treatment regimens may include stress management, parenting, family dynamics, community integration, behavioral intervention strategies, mental health, or caring for medically fragile individuals. Services may also include the costs of registration for conferences, educational workshops, or parent support/information organizations specific to the individual’s disability. However, this does not include travel, meals or overnight lodging for these events.

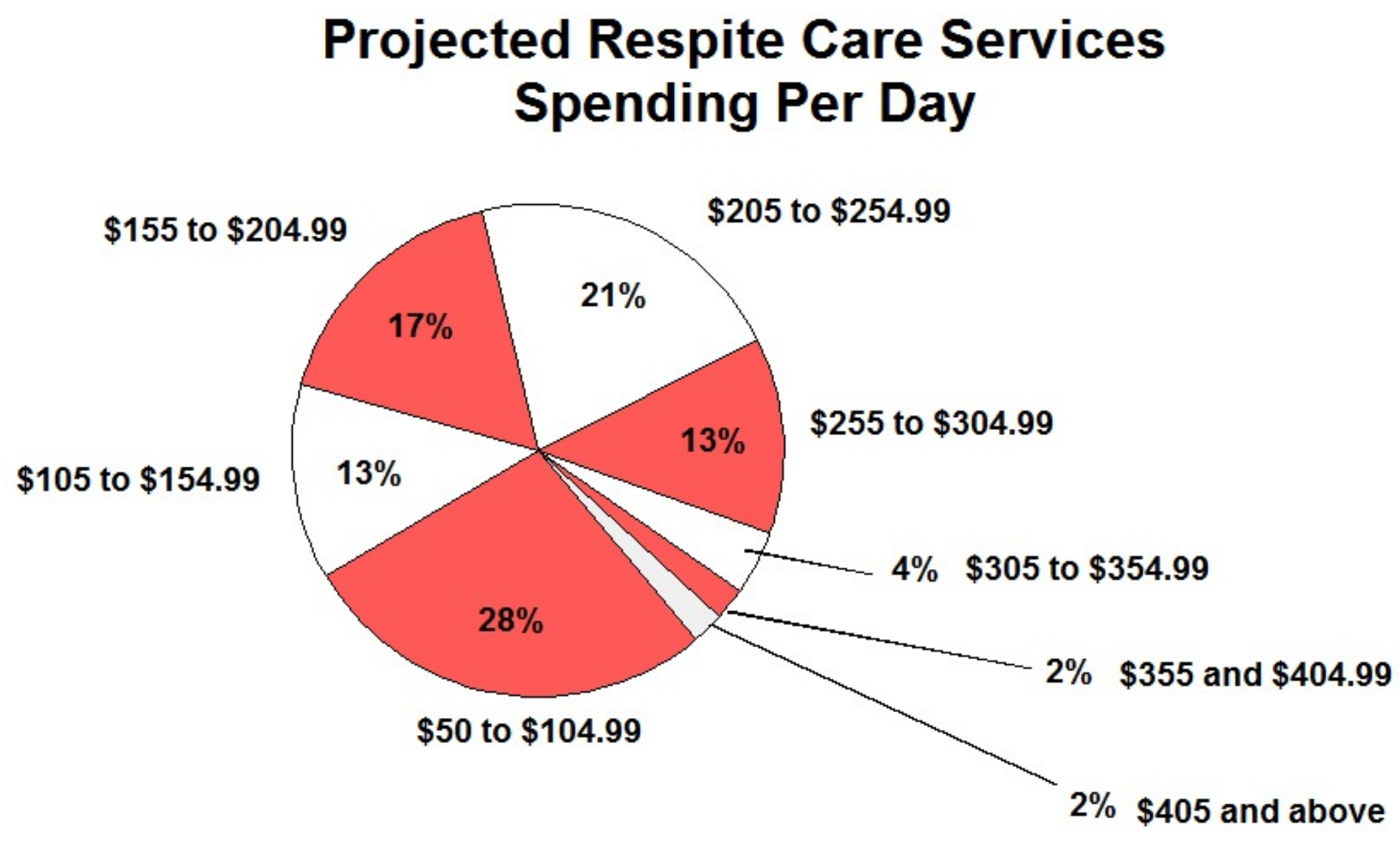
Counseling as described by these services is aimed at the development of problem-solving skills, coping mechanisms for both the initial diagnosis and continuous stressors, and healthy relationships. The aim of these counseling services is to increase the likelihood that individuals remain in their own home by maximizing the family’s emotional/social adjustment and well-being.

Among these services, Maryland’s Children with Autism Spectrum Waiver’s adult life planning service is a bit unique in that is specifically aimed at helping families and individuals of those with autism who are aging out of the school system under IDEA by giving them the resources and training needed. According to the waiver

this service will emphasize the development of a plan for decision-making in the adult autism/developmental disabilities system. The plan will incorporate self-determination, independence, choice, community integration, and provide better coordination with the Maryland adult system of ‘employment first’...ALP practitioners will work with families to develop of a treatment plan incorporating the principles of self-determination, Person-Centered Planning and Circles of Support in decision-making and planning for adulthood. The treatment plan is developed to incorporate federal and state supports with generic and natural supports, including parents, siblings, and others for increased independence, choice, and the child’s need for services and supports preparing them for exiting this Autism Waiver.

Service Provision and Projected Spending

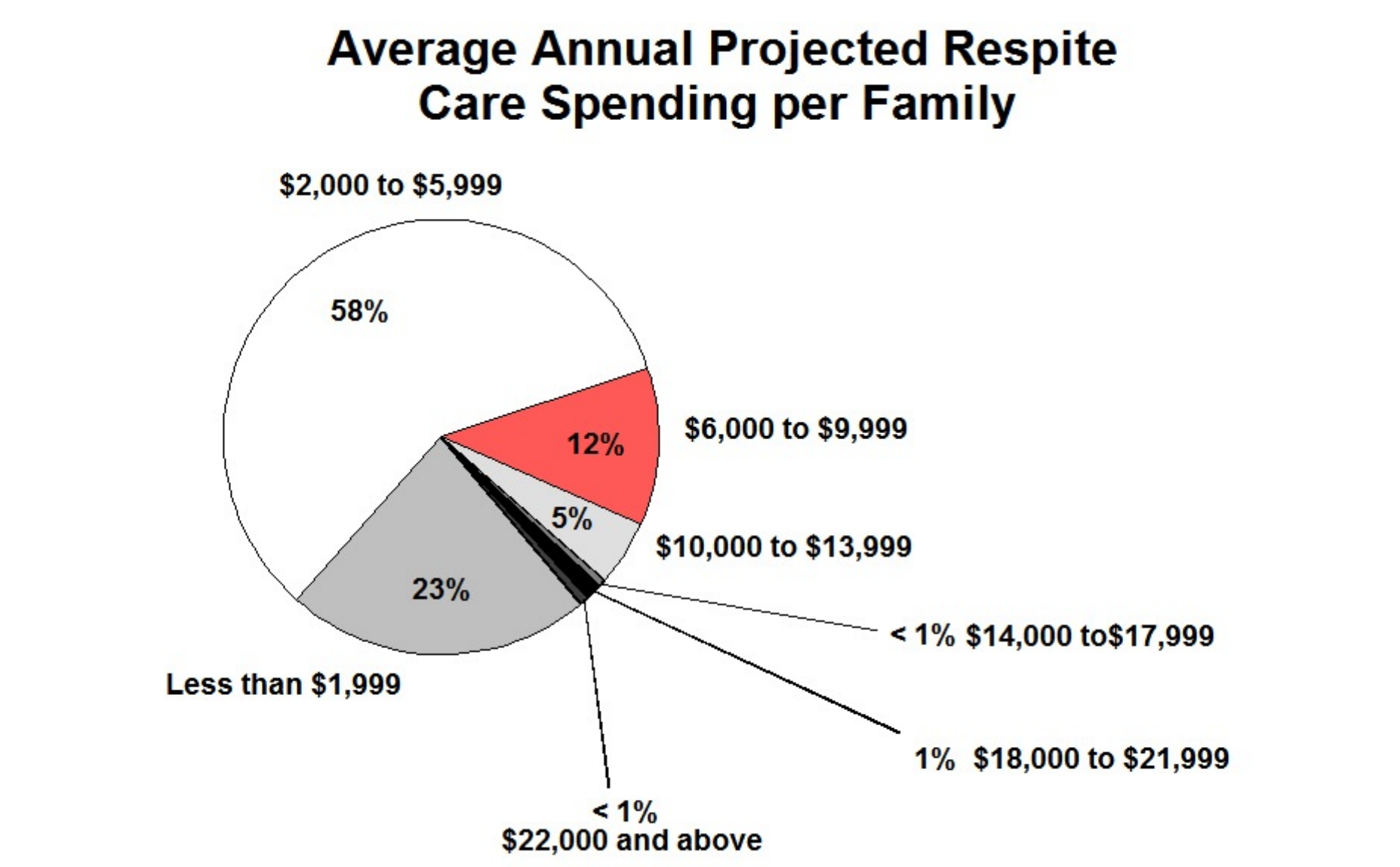
Out of 95 FY 2011 HCBS Waivers, 82 waivers from 41 states provided some sort of service to support families. Two hundred and ten district services were identified in three categories (respite, “family support,” family training and counseling). Of of these 82 waivers, 80 waivers (39 states) provided respite care service, 5 “family support” services (3 states), and 33 family training and counseling (20 states). This totaled 210 services in the three categories. An estimated \$966K or 3% of total FY 2011 HCBS funding analyzed was projected by the states for spending



on these services. Among these 82 waivers, there was an average projected spending of \$7,551 per family.

Further examination of these three types of services – respite care services, “family support” services, and family training and counseling services – indicated great variation. Five Waivers provided some sort of “family support” in five services. Only 1.7% of all total HCBS Waiver spending in the 95 waivers analyzed was projected for “family support” services. An estimated 12,277 participants received “family support” services and the average spending per family was \$17,422. Thirty-three Waivers provided some sort of family training and counseling in 43 services. Only .08% of all total HCBS Waiver spending in the 95 Waivers analyzed was projected for family training and counseling services. An estimated 13,023 participants across the 95 waivers received these services and the average spending per family was \$2,967.

Eighty Waivers provided some sort of respite care in 162 services and only 1.3% of total FY 2011 HCBS Waiver spending across the 95 waivers analyzed was projected for respite care services. An estimated 102,590 participants received these services. The average annual spending per family was \$4,385, with more than 81% of waivers spending \$6,000 or less. Some states offered multiple respite rates depending on level of support needed, or credentials of the respite provider. One hundred sixty two distinct respite services were provided across the 80 waivers. One state provided an average monthly rate of \$309 per family. Overnight respite rates ranged from \$52 a day to \$2,167 a day for 10 participants in Tennessee’s Self Determination waiver¹. Other Waivers reimbursed between \$54 a day for respite care up to \$370 per day (see graph). The majority of waiver respite services were paid for using an hourly or 15 minute increment rate These rates



ranged from a low of \$5.06 an hour in Iowa to a high of \$48.72 an hour in Oregon.

Conclusion

As states, especially those who are facing financial crises, look to reduce spending they will rely on and demand more from families. Yet, funding for services that support families only constituted 3% of total HCBS Waiver spending in FY 2011 in the 95 waivers we analyzed. This low percentage of overall spending for services that support families reflects the priorities of state Medicaid HCBS Waivers.

At the same time, many families expect more from the I/DD long term care system than generations before because of system improvement and changes in funding priorities (Rizzolo, Hemp, & Braddock, 2006). Yet, we have found a large variability in the average projected spending per family. This is also true for the average projected spending per hour for respite services. The variability across states in the services provided and the rates paid demonstrates the flexibility that is the hallmark of family support services.

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¹ In FY 2012 TN’s daily overnight respite rate was projected by the state to be \$188 per day.

