Home and Community-Based Service Use by Vulnerable Older Adults

Raven H. Weaver

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Karen A. Roberto, PhD (Chair)
Rosemary Blieszner, PhD
Jyoti Savla, PhD

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Home and community based services (HCBS) are designed to provide services that meet the increasing and diverse needs of the older adult population who wish to age-in-place for as long as possible in their homes and community. Yet, little is known about the choices people make when selecting services. The purpose of this study was to assess HCBS use among vulnerable older adults. Andersen’s (1995) behavioral model of health services use provided theoretical guidance for selecting and explaining predisposing, enabling, and need-based variables associated with service use within the Community Living Program (CLP) federal initiative. Through consumer direction of services, 18 routine or one-time services were offered to 76 participants enrolled in the Virginia CLP. Two-step cluster analysis identified four distinct profiles of service users, ranging in size from 7 to 34 members. Services used within the groups ranged from 11 to 16 services. Use of personal care services ($p=.033$) and respite ($p=.010$) were significantly associated with group membership differentiation. Within each cluster, the percentage of participants using each service varied greatly. The most important variables that differentiated service user membership were caregiver relationship to participant, participant living arrangement, participant disability type, and length of time caregiver provided care. Between-cluster membership was significantly different with regard to average service cost per day for services used ($p=.002$) and the likelihood of moving to a nursing home if services were not provided ($p=.034$). Findings inform future research and have implications for practitioners assisting vulnerable older adults in selecting services to meet different care needs.
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CHAPTER I

Background and Purpose of Study

The United States is experiencing a major demographic shift with its population aging at an unprecedented rate. Until 2029, an American turns 65 every eight seconds, which equates to approximately 10,000 people every day (Pew Research Center, 2010). By 2040, over 79 million people 65 years and older will live in the United States, an increase from the 35 million in 2000 (Administration on Aging, 2012). Population aging, resulting from decreased fertility rates, increased life expectancy and improved management of chronic disease, and in-migration patterns, means care is likely to be needed for more older people for a longer time. However, because of factors such as decreasing birth rates and increasing employment rates of women, fewer family members are available to provide informal care (Alkema, 2013). At the same time, there is a growing shortage of professional and front-line workers trained to provide geriatric care (Stone, 2011). Furthermore, the costs associated with long-term care (LTC; see Appendix A for a list of all acronyms used in document) are significant, yet the current cohort of older adults’ personal savings are often inadequate to pay for LTC services (Alkema, 2013). Thus, society has not prepared well for the repercussions of population aging, and does not have adequate services and supports in place to meet the needs of all older adults.

As people grow older, they frequently rely on others for help and assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Despite their increasing dependence and need for assistance (Tang & Lee, 2010), almost all older adults want to remain in their own home for as long as possible (Farber, Shinkle, Lynott, Fox-Grage, & Harrell, 2011). More than 70% of individuals who reach the age of 65 will experience the need for some type of LTC service for an average of 3.5 years (Tell, 2013). LTC encompasses “a
continuum of medical and social services designed to support the needs of people living with chronic health problems that affect their ability to perform everyday activities” (McCall, 2001, p. 3) including traditional medical services, social services, and housing. The broad range of services and supports include direct, hands-on care and supervisory or standby assistance, the use of assistive devices and technology, such as electronic monitoring systems, and home modifications (Stone, 2011). The three primary sources that older adults rely on to meet their LTC needs are (a) individual and family support (e.g., money, caregiving), (b) Medicare for acute and post-acute needs, and (c) Medicaid for LTC needs (Alkema, 2013).

Informal caregiving provided by family and friends is a critical component of the LTC system that enables individuals to remain in their homes. Spouses are usually first among family members to take on the caregiving role, followed by an adult child (Family Caregiver Alliance, 2012) who is usually the daughter (Kaye, Harrington, & LaPlante, 2010). Use of home and community-based services (HCBS), designed to supplement the care provided by family members, has the potential to delay or avoid institutional living and result in less financial burden for care recipients and their family (e.g., Lehning & Austin, 2010; Robison, Shugrue, Porter, Fortinisky, & Curry, 2012). This study focuses on HCBS use as a means of enabling older adults to delay nursing home placement and avoid spend-down of their resources to meet Medicaid eligibility requirements.

**Rationale for In-Home Care**

The home provides many older adults with a sense of security and familiarity (Fishman et al., 2012; Wiles, Leibing, Guberman, Reeve, & Allen, 2011). The “attachment to place is not just an internal or emotional state, it has a material impact; it is a tangible resource for aging in place” (Wiles et al., 2011, p. 365). Older adults’ preferences to age-in-place and remain in their
current residence extend beyond just a personal preference for a familiar setting. Economic benefits (Gonyea, 2005; Kaye et al., 2010; Lehning & Austin, 2010; Robison et al., 2012) and psychological benefits (Muramatsu, Yin, Campbell, Hoyem, Jacob, & Ross 2007) provide additional support for why older individuals prefer alternative approaches to meet their care needs over institutionalized care. Thus, a logical step toward ensuring more autonomy and a sense of independence is to provide accessible services for older adults within the home environment, enhancing their ability to age-in-place for as long as possible.

There also is a significant economic incentive to delay moving to a care facility, as the cost of institutional care is extremely expensive when compared to HCBS expenditures. In 2012, the median annual cost for LTC ranged from $39,600 to $81,030, depending on the type and level of care needed (Genworth Financial, 2012). The average annual rate for a semi-private room was estimated at $81,030 and for a private room at $90,520 (Metlife Mature Market Institute, 2012). Conversely, the average annual rate to attend adult day services five days a week was $18,200. For home care, the average annual rate based on four hours of paid care per day, five days per week ranged from $20,800 for a homemaker to $21,840 for a home health aide (Metlife Mature Market Institute, 2012).

In 2010, Medicaid LTC expenditures exceeded $129 billion, with approximately 55% designated for institutional LTC compared to 45% for HCBS options (Scan Foundation, 2013b). Comparatively, Medicare spends $64 billion annually in support of institutional care; family out-of-pocket expenses exceed $63 billion; local and veteran organizations spend $10 billion; and private insurance pays $7 billion (Scan Foundation, 2013a). While the cost of institutional LTC is nearly double that of HCBS, estimated expenditure per nursing home resident compared to community resident is nearly three times greater (Kaye et al., 2010).
Aging policies in the United States are slowly changing to reflect the shift in personal preference and economic motivations to move away from institutional toward in-home care. The ultimate goal of HCBS is to provide a person-centered, effective, efficient, and coordinated care system which plays a critical role in addressing the diverse needs of older adults who prefer to remain in their homes and to avoid institutionalization (Alkema, 2013; Casado, van Vulpen, & Davis, 2011; Castora-Binkley, Noelker, Ejaz, & Rose, 2010; Gonyea, 2005; Ruggiano, 2012). Care needs of older adults are diverse, spanning the continuum from assistance with ADLs and IADLs to palliative and hospice care (McNabney, Willging, Fried, & Durso, 2009). HCBS options provide an array of services to address the diverse needs of nearly 80% of older adults requiring LTC that live in the community (NORC Public Policy, 2008).

Recognizing that institutional care is often used as a last resort, offering HCBS options has the capability to promote independence, agency, and choice for older adults and their family caregivers. Individuals’ transitions from a completely independent to a more dependent living situation involve changes in environment, social relationships, sense of self, and perceptions of control. When faced with the challenge of needing assistance, older adults’ sense of independence may be compromised. One approach to supporting agency and choice in life decisions is through person-centered and consumer directed care. Originating from the independent living movement, consumer directed care capitalizes on the belief that individuals should be able to manage their needs by selecting and directing services as they deem necessary (Coffey, 2008). Consumer direction involves collaboration between older adult, professional healthcare staff, and family to promote maximum independence and positive well-being. The person-centered and consumer directed care movement strives to promote agency and choice
throughout the different stages of an individuals’ transition process from independent to more dependent living.

**Purpose of Study**

The transition to needing increased support and care is one of the most salient challenges that individuals face in old age. The increasing demand for and rising costs of LTC services contribute to the need to better understand the effectiveness of HCBS to deter nursing home placement. Concerns about how to finance programs and services that enable aging-in-place overwhelm care providers and policymakers. Identifying distinct profiles of service users is crucial to improving the effectiveness and HCBS. Unfortunately, the literature on service use among vulnerable older adults is limited and often findings are inconsistent across studies.

The purpose of this study was to assess how LTC services and supports can be packaged and delivered to meet the care needs of vulnerable older adults. Specifically, I examined whether service use clustered around a set of individual and relational characteristics of older adults to form distinct profiles of older adult service users. Following this analysis, I examined between-cluster characteristics and identified ways of organizing services and service delivery that had greater potential to meet older adults’ care needs.

Andersen’s behavioral model of health services use emphasizes the role of individual characteristics that influence health behavior, which result in outcomes influenced by the external environment and system of health care (Andersen, 1995). This investigation relied on this model for theoretical guidance to help select and explain factors associated with service use within the context of the Community Living Programs (CLP) federal initiative.

CLP was designed to address care needs of the aging population and high cost of institutional care by supporting older adults who wish to receive care in their home communities.
It was implemented in 28 states, including the Commonwealth of Virginia, to assist individuals at risk of both nursing home placement and Medicaid spend-down. The CLP program was housed within local Area Agencies on Aging (AAA) whose staff served as service coordinators for participants enrolled in the program. Through consumer direction of services, 18 routine or one-time or intermittent services were offered to enrolled participants. Each participant was allocated $1,200 per month to use at their discretion or that of their caregiver. Consumer direction permitted participants to choose whether services were provided by a family member or an agency. AAA service coordinators helped older adults and their caregivers coordinate and implement services that they chose.

**Research Questions**

Relying on Andersen’s (1995) model for theoretical guidance, I assessed the relationship between older adult/caregiver characteristics and services used by older adults. Cluster analysis was used to determine whether defined types (groups) were present in a data set (Aldenderfer & Blashfield, 1984). Findings advance scientific knowledge about HCBS service user profiles among consumer directing older adults striving to avoid nursing home placement and Medicaid spend-down. This study sought to answer the following research questions:

**Research Question 1:** (Cluster formation)

*What variables differentiate service user membership? What HCBS are used by older adults that cluster around a set of specified variables?*

**Research Question 2:** (Outcome focus)

*Do groups defined by clusters differ on outcome measures that assess perceived health status and program cost-effectiveness?*
CHAPTER II

Review of the Literature

Providing services that address the comprehensive healthcare needs of the growing population of older adults in the United States is a primary concern for federal and state policymakers and professional care providers. In this chapter, I review policies that promote eligibility, availability, and access to home and community-based services (HCBS). The chapter begins with a historic overview of long-term care (LTC) policies that have been instrumental in designing and developing the infrastructure to support older adults’ preference to age-in-place. These policies and programs led to the development of Medicaid waiver programs, which support the use of HCBS programs by individuals eligible for Medicaid. Characteristics of HCBS users and service use by vulnerable older adults are discussed, followed by the benefit of and barriers to HCBS programs. The chapter concludes with a discussion of the theoretical framework and research questions for the present study.

Long-Term Care Policy Overview

The Social Security Act of 1935 is considered the landmark piece of legislation for old age policy. This program, intended as supplemental income for retired workers or spouses and widows of retired workers, is credited with decreasing poverty and inequality among older adults (Harrington Meyer, 2005; Wacker & Roberto, 2014). However, it was not until almost 30 years later that advances in old age policy gained momentum. Considered a “politically friendly time in history” for older adults (Wacker & Roberto, 2014, p. 17), Congress enacted the Older Americans Act (OAA), Medicare, and Medicaid in the mid-1960s. The OAA created a network of community social services and provided grants for community planning, research and development, and training for personnel in the field of aging (Administration on Aging, n.d.-b).
Medicare was established to provide healthcare insurance primarily for adults 65 years of age and older and Medicaid was established to help with medical costs for people with limited income and resources, including older adults (Department of Health and Human Services, 2013).

The “accepted deservingness” of older adults continued to be recognized through the 1980s (Binstock, 2005; Gonyea, 2005; Hudson, 2005), despite the financial challenge of maintaining programs focused on minimizing poverty and inequality (Harrington Meyer, 2005). In the 1990s, political conservatism and pushback from policymakers resulted in limited government support and funding of old age policies; older adults became the scapegoat for the tension, burden, and concerns stemming from other problems facing society (Binstock, 2005).

According to Binstock (1983, p. 136), “the media, political speeches, public policy studies, and the writings of scholars” viewed older adults as taking away resources from other deserving groups.

The focus on community-based care and health promotion began at the turn of the 21st century and continues to dominate, evident by the federal programs described below. The concept of LTC expanded to include a broad range of services and supports provided in the home, residential, or institutional settings that help older adults with chronic illness and disabilities remain as functionally independent as possible (Stone, 2011). Federal initiatives have supported family caregivers and improved the skills of the formal workforce to provide essential care and services for older adults. HCBS options for LTC are the focus of this literature review. HCBS options include personal assistance with ADLs and IADLS, supervision and coordination of care, and assistive technology (Alkema, 2013).
Older Americans Act

With the passing of the Older Americans Act (OAA) in 1965, a network of services for older adults was established. The goal of the OAA was to provide a coordinated system of services with a partnership among federal, state, and local governments (National Committee to Preserve Social Security & Medicare, 2013). While most services and programs were available at no or little cost, efforts to reach individuals in greatest need of assistance have proven to be a challenge, particularly in rural, poor, and isolated communities (Wacker & Roberto, 2011). The OAA consists of a range of services and supports designed to address mental, physical, social, and nutritional health of older adults and to improve housing, employment, and transportation opportunities for older adults. HCBS objectives were imbedded within the OAA to promote independence and individual responsibility in planning and managing one’s life (National Committee to Preserve Social Security & Medicare, 2013).

The 2006 reauthorization of the OAA enhanced service delivery options and promoted older adults’ involvement in self-selection of services and care providers. For example, the Choices for Independence initiative empowered individuals to make informed decisions and supported disease prevention and health promotion services to avoid premature entry into nursing homes (Department for Health and Human Services, 2006). It also promoted efforts to determine cost-effective modifications to LTC systems, and it supports comprehensive coordinated LTC efforts (Administration on Aging, 2006). Title IV of the OAA was renamed Activities for Health, Independences, and Longevity (originally named Research and Development Projects) to reflect the new direction of the aging network that addresses healthy aging for people of all aging by promoting personal responsibility for longevity. Programs received grant funding to promote innovative ideas that increased knowledge about the aging
process and identified older population’s preferences (Wacker & Roberto, 2011). Amendments to Title IV also improved community capacity for aging-in-place, transportation, and training and support for personnel in the field of aging, and increased family caregiver supports and technology-based assistance (Administration on Aging, 2006; Wacker & Roberto, 2011).

Up for reauthorization in 2014, possible changes to the OAA would strengthen the core programs. Provisions to the bill include implementing a 12% federal funding increase and expanding definitions of targeted populations in greatest economic and social need (National Committee to Preserve Social Security & Medicare, 2013; Notarstefano, 2013). Reauthorization of the law also encourages evidence-based research for fall prevention and chronic disease self-management and promotes efficient and effective coordination of services, such as transportation services, among other efforts to assist older Americans (Notarstefano, 2013). Although reauthorization of the OAA has bipartisan support, funding issues are a major concern. The provisions to the bill require greater assistance to older adults, which by association, requires more financial support. Regardless, the proposed changes reflect a shift to more preventive services and supports that benefit older adults in their pursuit of remaining in their homes as they grow old.

**Medicare and Medicaid**

Medicaid and Medicare also were enacted in 1965. Medicare is a health care entitlement program for individuals 65 years and older and young individuals with disabilities. When home care is considered necessary and medically reasonable, Medicare will cover services delivered from Medicare-certified providers (Department of Health and Human Services, 2010). Originally, Medicare set a post-hospitalization limit for home care of 100 visits per year (Social Security Bulletin, 2000). The 1980 Omnibus Budget Reconciliation Act eliminated the
requirement for prior hospitalization and established unlimited home health visits each year (Social Security Bulletin, 2000). When the prospective payment system went into effect in 1983, hospitals sent older patients home “quicker and sicker” (Qian, Russell, Valiyeva, & Miller, 2011), which increased use of home care (McCall, Korb, Petersons, & Moore, 2003). In response to the growing federal costs of providing home care, the Balanced Budget Act (BBA) of 1997 established a per-beneficiary limit for reimbursement of home care visits. While the BBA sought to reduce the total Medicare spending for home health care substantially, it also increased allowable changes for in-home care (McCall et al., 2003; Social Security Bulletin, 2000).

Unlike Medicare, Medicaid is a means-tested program that provides health care for individuals with low-income and persons with functional or mental disabilities, including older adults (Medicaid.gov, n.d.-a). Medicaid insurance is the primary source of payment for many individuals requiring LTC, with Medicaid expenditures totaling 62% of all LTC expenses in 2011 (Alkema, 2013). Each state determines criteria for what constitutes an institutional level of need beyond the federal minimum standards (Medicaid.gov, n.d.-a). Individuals who have too much income or too many assets must spend-down, or use up their money to meet Medicaid income eligibility requirement to receive care through Medicaid services (Alkema, 2013; Kaye et al., 2010; Weiner et al., 2013), which is one of the greatest frustrations and challenges for individuals in need of care (Tell, 2013). To avoid the Medicaid spend-down, individuals often depend on, and ultimately exhaust, unpaid family support or they go without the services they need (Weiner et al., 2013).

Since its inception, the Medicaid program has expanded access to home and community-based care options to help deter nursing home placement. Yet, federal and state governments

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1 Medicaid.gov is an open access website that provides up-to-date information about the programs. Information provided by Medicaid.gov was current, as of January 23, 2014.
allocate more Medicaid dollars for nursing home care than for HCBS options (Robison et al., 2012; Ruggiano, 2012; Stone, 2011). Because of this imbalance, it can be difficult for community-dwelling older adults who are Medicaid-eligible to find Medicaid HCBS in their communities.

**Development of Medicaid HCBS Programs**

Medicaid HCBS are designed for individuals with disabilities, which includes the older adult population. These programs remain optional for states and vary widely in implementation across states. However, all states are mandated by law to provide home health care for any individual who is eligible for institutional care under Medicaid eligibility criteria (Crowley, 2003; Kitchener, Ng, & Harrington, 2007). The HCBS waiver option was established in 1981 and became a formal state option in 2005 under the Deficit Reduction Act (DRA). The DRA legislation capitalized on the shift toward HCBS options that enhanced the feasibility of older adults being able to remain in their home and communities. HCBS waivers offer consumer direction options, which in theory provide the flexibility necessary to address the increasingly diverse needs of the aging population (Ruggiano, 2012). Consumer direction is based on the belief that individuals should be able to manage their needs by selecting and directing services as they deem necessary (Coffey, 2008).

In 2007, more than 2.8 million people benefited from HCBS programs (Harrington, Ng, LaPlante, & Kaye, 2012). Different HCBS options are available through Medicaid Section 1915 (c) Home and Community-Based Waivers, (i) State Plan HCBS, (j) Self-directed personal assistance services, and (k) Community First Choice (CFC). The 2010 Affordable Care Act (ACA) modified existing HCBS programs and established the Community First Choice (CFC) option (Section 1915(k)) in an effort to improve the overall flexibility of HCBS options and to
re-balance the LTC system (Harrington et al., 2012). The federal government provides modest financial incentives to states that adopt some of the reforms, such as the CFC options. However, the incentive is rather small when considering the financial challenges involved with reorienting a state’s LTC system to adopt more preventive care options.

To be eligible for the waiver option Section 1915 (c), individuals must be at an institutional level of care, services must cost less than institutional care, and provider standards must be adequate and reasonable (Medicaid.gov, n.d.-b). Standard services offered through HCBS waiver programs include case management and coordination, homemaker services, home health care, personal care, adult day services, rehabilitation, as well as support services for caregivers (Medicaid.gov, n.d.-b). This option enables an integrated care setting that promotes person-centered care and addresses the medical and non-medical needs and preferences of the recipient (Medicaid.gov, n.d.-b). Waiver options operate through each state’s basic Medicaid plan, which provides greater variability with regard to financial eligibility criteria (Lockhart, Giles-Sims, & Klopfenstein, 2009). There is unequal access to the benefits, as state officials determine the total number, geographic scope, and participating groups of beneficiaries (Lockhart et al., 2009). In 2009, more than 1.3 million people benefited from HCBS waivers, including 648,168 older adults throughout the United States and 18,672 older adults in Virginia (Ng, Harrington, Musumeci, & Reaves 2012). Currently, 48 states and the District of Columbia operate at least one HCBS-waiver program (Harrington et al., 2012; Medicaid.gov, n.d.-b).

The optional state plan Section 1915 (i) provides personal care service (PCS) benefits for eligible citizens (Kitchener et al., 2007; Medicaid.gov, n.d.-c). States define criteria to determine who is eligible to receive services that are typically nonmedical assistance services (Kitchener et al., 2007). Originally, all individuals eligible for the benefit were required to receive PCS
(Kitchener et al., 2007). However, the ACA removed this requirement and does not allow states to impose limits on the number of eligible people in the program (Harrington et al., 2012). Now, states can define needs-based criteria to target particular groups of people and have “targeted benefits” so long as the services meet each group’s needs (Harrington et al., 2012; Medicaid.gov, n.d.-c). In addition, states can choose to consolidate HCBS waivers with the state plan option. Thus, states have more flexibility in deciding what and how many services are offered, which may potentially improve individuals’ access to services (Harrington et al., 2012).

Self-direction options are provided under Section 1915 (j) and require person-centered planning, a written document that specifies the service plan, a specified budget under the control and direction of the individual, and assistance with and information about self-direction to support individuals and their families (Medicaid.gov, n.d.-e). Each state determines the number of individuals allowed to self-direct their personal care programs (Medicaid.gov, n.d.-e). These self-directing options are available under both the state plan benefit and waiver option.

The intention of CFC (Section 1915(k)) is to provide services “in the most integrated setting approach to each care recipient” (Harrington et al., 2012, p. 173). The program embraces a person-centered plan of care and allows states to choose one or both types (agency-based or self-directed) of service delivery models. Thus, it is similar to the Cash and Counseling option (see p. 15), in that they both allow for flexible self-direction of services. CFC is optional, but if implemented by a state, the program must be provided to individuals statewide, regardless of age, disability type, severity, or income restrictions (Harrington et al., 2012). Also, having this option prohibits states from having a waiting list. The many advantages of the program are complemented with disadvantages (e.g., not mandatory) and concerns about eligibility criteria (Harrington et al., 2012). It is too early in the life of the program to assess its effectiveness.
Examples of HCBS Programs

Beginning in the 1990s, a noticeable shift in service provision from traditional agency-based services to consumer directed care was indicative of individuals’ desire to maintain a sense of agency and choice throughout the life course (Stone, 2011). These programs began offering nontraditional services, such as the option to hire friends and family to provide care, home modification, alternative therapies, and nutritional counseling, and were implemented throughout the United States (e.g., Ruggiano, 2012; Stone, 2011; Tang & Lee, 2010).

Cash and Counseling. In 1996, the Robert Wood Johnson Foundation and the Department of Health and Human Services established the Cash and Counseling demonstration program. Frail older adults were a central focus of this initiative that allowed self-direction of services and gave individuals the authority to “hire, fire, supervise, and manage service providers who may be family members” at their discretion (Harrington et al., 2012, p.172). Carlson, Foster, Dale, and Brown (2007) evaluated the initial Cash and Counseling demonstration implementation phase by comparing members of the treatment group (Cash and Counseling) to control group (traditional Medicaid services). Hiring family members and friends resulted in an increased ability to obtain care more efficiently than from traditional programs (Carlson et al., 2007). Older adults appreciated the option to pay family caregivers for care they already provided, especially since family caregivers already knew the extent of skilled care needed (San Antonio, Eckert, & Simon-Rusinowitz, 2006). Furthermore, older adults trusted family members more than “strangers” in their homes and felt that family caregivers provided more reliable and flexible care than agency care (San Antonio et al., 2006). The Cash and Counseling program encouraged participants to make decisions, or enabled them to appoint a representative to
advocate on their behalf (Carlson et al., 2007). Regardless of approach, it was the program’s intent to circumvent decisions made by an agency.

Participants of the Cash and Counseling demonstration who were offered flexibility and control reported greater consumers’ satisfaction with help and overall quality of life than individuals who were offered traditional services (Carlson et al., 2007; Schore, Foster, & Phillips, 2007). Cash and Counseling participants also reported fewer unmet needs than participants in the control group (Carlson et al., 2007). Overall, more than 85% of the participants from the initial Cash and Counseling demonstration phase reported they would recommend the program to others (Schore et al., 2007). The apparent success of the initial demonstration phase in Florida, New Jersey, and Arkansas resulted in 12 additional states participating in the Cash and Counseling program. Although federal support ended in 2009, all 15 states continue to offer consumer directed programs (De Milto, 2013).

**Independence Plus.** Modeled after the Cash and Counseling program, the *Independence Plus* initiative was established in 2002 to promote consumer direction of services. The prominent feature of this program was allowing individuals to control their spending budget and self-direct services (National Council on Disability, 2013). States were required to ensure beneficiaries received information needed to participate in person-centered planning and implement acceptable standards for providers and practice (Crowley, 2003). Elderly persons and people with disabilities were eligible to receive either the Independence Plus demonstration or HCBS waiver type, depending on what the state offered (Crowley, 2003). By 2009, 36 states incorporated the Independence Plus concept of self-direction in 94 waiver programs (National Council on Disability, n.d.).
Money Follows the Person. The Money Follows the Person (MFP) demonstration program was established through the 2005 DRA to shift Medicaid LTC spending from institutional care to HCBS (Lipson & Williams, 2011). The overall intent of MFP was to transition people from institutional residences to homes, apartments, or group homes and to improve the infrastructure of the LTC system so that Medicaid funds could “follow the person” (Irvin et al., 2012; Lipson & Williams, 2011). MFP participants receive HCBS through either the state plan or waiver program (Irvin et al., 2012). In 2011, nearly 20,000 people had transitioned back into the community, but the 65% increase from 2010 was primarily attributed to transitioning of individuals younger than 65 years (Irvin et al., 2012). Compared with institutional care, individuals who transitioned to community living consistently reported improved quality of life, a greater sense of choice and control, and fewer unmet care needs (Irvin et al., 2012). Originally, eligible participants had to be living in LTC facilities for at least six month but the 2010 ACA expanded eligibility to include individuals residing in a care facility for three or more months (Harrington et al., 2012; Medicaid.gov, n.d.-d). The ACA authorized additional federal funds through 2016, totaling $2.25 billion to continue awarding MFP grants to states (Harrington et al., 2012; Lipson & Williams, 2011; Medicaid.gov, n.d.-d). MFP grants were initially awarded to 30 states and D.C. (Lipson & Williams, 2011), with an additional 13 states awarded grants in 2011 (Irvin et al., 2012).

Community Living Program. The most recent initiative to provide consumer direction options and support LTC rebalancing efforts was the Community Living Program (CLP). As discussed in Chapter 1, 28 states were awarded CLP grants from the Administration on Aging (AoA) between 2007 and 2009 to implement programs designed to reduce the risk of premature nursing home entry and spend-down to Medicaid. Although not a Medicaid HCBS, the CLP
targeted individuals at risk of nursing home placement and Medicaid spend-down (Administration on Aging, n.d.-a). The CLP provided access to a range of publically supported LTC services and a monthly allowance to purchase available services that address individuals’ specific needs. The CLP intent was to complement the on-going family caregiving efforts and supplement available personal and financial resources (Administration on Aging, n.d.-a).

Implemented on a much smaller scale than the other consumer direction demonstration programs, the CLP program enrolled more than 5,500 people by the end of 2012 (Aging and Disability Resource Center, 2012). Federal funds invested in the CLP initiative exceeded $23 million, and states matched more than $11 million (Aging and Disability Resource Center, 2012). Funding was not renewed after the original grant period because of federal budget cuts.

In sum, HCBS programs are evident of federal government efforts to encourage consumer direction and promote individuals’ choice in life decisions. They reflect the shift toward providing more preventive care services to address the comprehensive needs of older adults before the situation becomes unmanageable. States with established HCBS programs had lower overall LTC costs because these states were able to curb institutional spending over time (Kaye, LaPlante, & Harrington, 2009). However, most HCBS programs overlook persons with low levels of need and do not capitalize on the potential of preventive service options that delay nursing home placement. Enabling HCBS programs to maintain a greater proportion of their clients without discharging to LTC facilities would require more resources so they could offer a greater range of services (Robison et al., 2012). These expansions would challenge the longstanding structural limitations to the Medicaid program and instead, yet would promote increased availability of HCBS rather than institutional options (Crisp, Eiken, Gerst, & Justice, 2003).
Characteristics of HCBS Users

Eligibility for Medicaid HCBS waiver options is predicated on Medicaid eligibility, which means that availability of services is restricted through means-testing. Typical HCBS users are of advanced age, female, White, have low income, live alone, and have a range of health conditions, functional dependence, and cognitive impairments (Gaugler, Kane, Kane, & Newcomer, 2005; Hong, Hasche, & Lee, 2011; Li, 2006; Muramatsu et al., 2007; Robison et al., 2012). Use of HCBS varies across race and ethnic groups, with older White Americans more likely users of HCBS than older African Americans or older adults of Hispanic/Latino origin (Caffrey, Sengupta, Moss, Harris-Kojetin, & Valverde, 2011).

Service Use by Vulnerable Older Adults

Within the last decade, the number of individuals served through Medicaid HCBS programs increased from 2.1 million in 2000 to 2.8 million in 2007, including 1.2 million just through HCBS waivers (Harrington et al., 2012). While it is relatively straightforward to assess how many people received HCBS, clarity about when and why certain types of services are used has not emerged from the literature.

The behavioral model of health services use, originally developed in 1968 by Andersen (1995), provided a framework for examining what factors contribute to service use. Within the context of the external environment and system of health care, population characteristics are associated with health behavior and use of health services that influence outcomes, such as health status, cost-effectiveness, or consumer satisfaction (Andersen, 1995). Population characteristics include predisposing characteristics (e.g., demographic characteristics, social structures, health beliefs), enabling resources (e.g., personal/family, community), and need (both perceived and evaluated). Health behavior encompasses personal health practices and use of
health services (Andersen, 1995). Andersen’s (1995) model of health service use is frequently used as a predictive mechanism to identify factors associated with service use. Research using this model has identified a plethora of factors associated with service use (McAuley, Spector, & Van Nostrand, 2009).

Availability of informal family caregiving is an enabling resource, with subtle differences found between spouse and adult child caregivers’ use of services in support of the care of their older relatives. Robinson, Buckwalter, and Reed (2013) found that spouses were significantly less likely to use services, compared to adult children or any other relative providing care. Spouses also were more likely to report that they did not need help with caregiving than were adult children (Robinson et al., 2013). Spouses may consider caregiving as an expected part of the marital relationship, and unlike adult children who are likely to be employed, spouse caregivers in late life are likely to have exited the workforce. Thus, availability of time may contribute to spouses’ willingness to provide care and not use formal services (Robinson et al., 2013).

Spouse and adult child caregivers with more social support relied on outside help more and reported fewer unmet needs for services that address the needs of care recipients compared to caregivers with less social support (Casado et al., 2011; Robinson et al., 2013). For example, perceived social support was associated with having greater opportunities to obtain “diverse information about service options” (Hong et al., 2011, p.1325); caregivers who perceived a higher level of social support were more likely to be multiple service users (Hong et al., 2011).

Service use also is attributed to accessibility and availability of services. Individuals living in rural regions reported lower levels of use, primarily because of limited availability of services (Li, 2006). Transportation issues concerning cost and inflexible service hours and
limited medical transportation programs were identified barriers to health care access in rural areas (e.g., Goins, Williams, Carter, Spencer, & Solovleva, 2006; Li, 2006; Li, Chadiha, & Morrow-Howell, 2005). However, when services were available, older adults in rural areas were more likely to use multiple services than were older adults in urban areas (Hong et al., 2011).

**Benefits of HCBS**

The ultimate goal of HCBS is to provide a person-centered, effective, efficient, and coordinated care system that addresses the diverse needs of older adults who desire to avoid institutionalization and remain in the community (Alkema, 2013; Casado et al., 2011; Castora-Binkley et al., 2010; Gonyea, 2005). The preference for HCBS among older adults is well supported (Alkema, 2013; Casado et al., 2011; Gonyea, 2005), with nearly 90% of older adults indicating that they want to remain in their own home for as long as possible (Farber et al., 2011).

**Consumer Direction**

Although HCBS vary in implementation and tangible outcomes, consumer directed HCBS have been found to be more diverse, flexible, and accepting of non-traditional services, such as the hiring of family and friends, nutritional counseling, and home modifications (Ruggiano, 2012; Stone, 2011) than traditional community services and programs. For example, comparing consumer directed and traditional agency-directed HCBS options yielded the same health and functional outcomes, but consumer direction yielded greater consumer satisfaction and well-being (Lehning & Austin, 2010; Stone, 2011; Ruggiano, 2012).

Consumer directed HCBS is grounded in a strength-based approach that utilizes the expertise older adults have regarding their own health and care needs, allowing them to determine their service and decisions about care options (Ruggiano, 2012). More so than agency-
directed services, consumer directed care resulted in greater feelings of empowerment and higher perceived quality of life (Stone, 2011). In addition, individuals in consumer directed programs were more likely to receive services they wanted and to report that their needs were met (Weiner, Anderson, & Khatbusky, 2007) than individuals receiving agency-directed care. Although quality of care was not deemed different for agency versus consumer directed care, older but not younger populations reported greater satisfaction with consumer directed services (Weiner et al., 2007). Seemingly, when older adults are given the right to self-direct (Ruggiano, 2012), they appreciated having a voice in determining their care services.

Nontraditional services offered through HCBS programs also have the potential to increase consumer satisfaction and promote a proactive approach toward health and well-being. This may enable older adults to age-in-place and receive care and services to address their specific needs. For example, coverage for nontraditional services such as home modification contributed to independent living of older adults (Hong, 2010; Tang & Lee, 2010). Although not frequently sought, individuals who used home repair services were less likely to perceive a need for relocation in the future (Tang & Lee, 2010).

**Support for Family Caregivers**

Families have long been the de-facto social units that provide care for older adults, with nearly 62 million family caregivers in the United States in 2009 (Alkema, 2013). Kaye and colleagues (2010) reported that when unpaid family care was available, older adults tended to rely exclusively on this option, as opposed to involving formal service providers. In fact, nearly 9 out of 10 community-dwelling individuals in need of LTC services rely on informal support as a primary source of help (Kaye et al., 2010). The estimated cost savings of having family care is
$375 billion annually, making family caregivers an essential unpaid component of the LTC system (Alkema, 2013).

With so many individuals taking on caregiving roles, it is important to attend to the health and well-being of both care recipient and caregiver. When the needs of caregivers and care recipients remain unmet, adverse caregiving outcomes may occur (Li et al., 2005). However, when older adults are able to use HCBS, the risk of caregiver burden may potentially be reduced (Casado et al., 2011). Policy changes since 2000 have recognized the value and importance of informal caregivers through the implementation of programs such as the National Family Caregiver Support Program and the New Freedom Initiative (Castora-Binkley et al., 2010). The New Freedom Initiative called for the expansion of HCBS to encompass caregiver needs (Castora-Binkley et al., 2010). Caregiver support programs provide respite, training, education, counseling, support groups, and referral services for family caregivers (Casado et al., 2011; Castora-Binkley et al., 2010).

Providing community-based care and assistance that address the needs of the family caregiver has the potential to extend the duration of time they are able to provide care. HCBS options that provided adequate supports and services to address the needs of informal family caregivers resulted in better informal care for the older adults, as well as deterred nursing home placement (Muramatsu et al., 2007). Caregivers for care recipients who used consumer direction reported reduced financial, emotional, and physical strains and stressors (Foster et al., 2003). With consideration to the extent of care required to support older adults, addressing the needs of informal caregivers often enables older adults’ ability to pursue an economically sustainable option of aging-in-place.
When family members provide care, older adults are able to retain a sense of autonomy as their need for care increases (Crist, 2005). For example, the Cash and Counseling Demonstration program allowed participants to pay family members in return for providing care services. Overall, caregivers who were able to self-select which supportive services to use reported better health and satisfaction with life, less physical, financial and emotion strain, and increased satisfaction with arrangement of care (Foster, Brown, Phillips, & Carlson, 2005). Care recipients reported similar benefits and expressed less concern about inadequate care than participants who relied on traditional agency services (Castora-Binkley et al., 2010). The option of consumer directed care acknowledges an individual’s desire to maintain a sense of agency and choice throughout the life course (Stone, 2011).

**Cost-Effectiveness**

HCBS options are a cost-effective alternative to institutionalized care (Gonyea, 2005; Kaye et al., 2010; Lehning & Austin, 2010; Robison et al., 2012). Expenditure per community resident compared to nursing home resident is estimated to be one-third less costly (AARP Public Policy Institute, 2012; Kaye et al., 2010; Lehning & Austin, 2010). Although the cost of LTC depends on the extent and type of care needed (Genworth Financial, 2012), the national average for annual HCBS expenditures was estimated to be nearly half the cost of nursing facility spending, at $28.7 billion and $51.4 billion, respectively (AARP Public Policy Institute, 2012).

**Barriers for HCBS**

Despite the reported benefits that older adults attribute to HCBS use, a plethora of research highlights the shortcomings of HCBS. Barriers facing the HCBS system include funding and availability, underutilization of services resulting in unmet need (e.g., Casado et al.,
2011; Kaye et al., 2010; Wiener et al., 2013) and concerns about care provided by the informal and formal workforce (e.g., Lehning & Austin, 2010; Robison et al., 2012; Ruggiano, 2012; Stone, 2011; Tell, 2013). It is important to address the availability, access, and awareness of HCBS options to increase the effectiveness of meeting the comprehensive needs of older adults, including those of the caregiver.

**Funding and Availability**

Funding concerns drive efforts to rebalance spending for LTC programs and services. In response to recent economic downturns, Medicaid LTC expenses became a major target for cutting program costs (Robison et al., 2012). Despite the cost-effectiveness of HCBS options (Lehning & Austin, 2010), the majority of Medicaid LTC funds is still spent on institutional care (Robison et al., 2012; Ruggiano, 2012; Stone, 2011). HCBS Medicaid spending has increased over the past two decades (Stone, 2011) in all 50 states (Robison et al., 2012), but the federal government’s response to expanding Medicaid supported HCBS programs has been slow. Efforts to rebalance the proportion of Medicaid spending vary widely across states, ranging from 20% to 80% on HCBS (National Council on Medicaid Home Care, 2013). Policymakers are concerned about increasing the availability of HCBS that provide preventive services. They fear that older adults will come “out of the woodwork” requesting services and assistance beyond the states’ capacity to provide care (Lehning & Austin, 2010; Ng, Harrington, & Kitchener, 2010). On the state level, however, states that increased the capacity of HCBS programs and reduced the availability of institutions experienced the greatest success in rebalancing high costs of the LTC system (Lockhart et al., 2009).

The rationale behind HCBS has changed from an alternative to nursing home care to a permanent alternative or “end in itself” that provides clients with more options (Kane, Lum,
Kane, Homyak, Parashuram, & Wysocki, 2013). Nursing home care no longer is considered the only point of entry for LTC services and supports (Reinhard, 2010). However, low-levels of need continue to be overlooked, as Medicaid HCBS waivers are only available to individuals who meet their state’s functional and financial eligibility requirements. For some individuals who are not yet eligible for waiver programs, it is difficult to obtain affordable services.

Furthermore, waiting lists inhibit the use of HCBS. Although the definition of and criteria for waiting lists vary from state to state (Ng et al., 2012), program enrollment caps limit the number of people who can receive services. There was a 19% overall increase on waiver waiting lists between 2010 and 2011 (Ng et al., 2012) and the average wait time for a waiver specifically for older adults was nine months (Ng et al., 2010).

**Underutilization and Unmet Need**

Despite an increase in HCBS options under Medicaid within the past decade (Kane et al., 2013), studies have consistently shown low levels of HCBS use by older adults (e.g., Casado et al., 2011; Tang & Lee, 2010). Factors that contribute to the lack of service use include lack of perceived need, limited access to services, unawareness of available services, or limitations for eligibility (e.g., Casado et al., 2011; Harrington et al., 2012; Hong et al., 2011; Wiener et al., 2013). Determining gaps in service use that result in unmet needs is important for addressing the health and well-being of older adults. In 2008, 20% of community-dwelling older adults reported they did not receive the care they needed (Lehning & Austin, 2010). Rather than a complete absence of help or all needs going unmet, individuals reported a lack of sufficient help (e.g., Kaye et al., 2010; Robison et al., 2012), suggesting the need for improved service coordination to address individuals’ comprehensive needs. The attitudes and lack of knowledge by staff and
physicians about HCBS options may contribute to continuing unmet needs of their patients (Casado et al., 2011; Tell, 2013). If staff and physicians are unaware of HCBS options, they are less likely to recommend them, creating a barrier for service use that have the potential to address the comprehensive health needs of individuals. In fact, a lack of available services to accommodate changing health needs has been associated with residential transitions (Kaye et al., 2010; Robison et al., 2012). Raising awareness and increasing education about HCBS options have been identified as individual-level, modifiable risk factors for nursing home admission (Ryan, Puri, & Liu, 2013).

**Informal and Formal Care**

With individuals living longer and experiencing more chronic health problems, the complexity of care is increasing (Haber, 2010). Despite advances in medical technology, cutbacks in healthcare reimbursement (Haber, 2010) may place even greater burden on family caregivers. Furthermore, the complexity of the LTC system presents various challenges for older adults and their families when accessing HCBS options (Low, Yap, & Brodaty, 2011). For example, informal caregivers may have negative experiences of accessing and using formal services because of confusion and lack of knowledge about accessing and affording services (Wiles, 2002). Family caregivers may feel a lack of support, experience caregiver burnout, or experience health problems of their own that prevent them from continuing to provide care (Robison et al., 2012). If family members are unable or unwilling to provide the necessary care due to the demands of employment obligations or the complexity of the care needed, informal care may be inadequate (Robison et al., 2012). Chen and Thompson (2010) observed that older adults relied on family care until the situation became unmanageable. Thus, family caregivers often turn to community services and supports as a last resort because of issues of privacy,
preference for familiarity of caregiver, and beliefs about filial obligation to provide care (Cho, 2007; Crist, 2005; San Antonio et al., 2006).

Care provided by the formal workforce presents its own set of challenges. For instance, agency-based HCBS have been considered inefficient and inflexible by care recipients, as it can be difficult to obtain care outside of regular work-day hours (Robison et al., 2012). Furthermore, quality of care provided is associated with quality of the workforce, yet there is an imminent LTC workforce shortage in the United States, exacerbated by low retention and high turnover rates (Lehning & Austin, 2010; Stone, 2011). Rural areas have the highest LTC turnover rates, often reaching over 50% annually, resulting in limited services that reach fewer older adults (Li, 2006). Other factors that contribute to the formal LTC workforce shortage include lack of geriatric training, weak federal training requirements, and low pay and limited benefits for potential workers (Lehning & Austin, 2010; Stone, 2011; Tell, 2013) as well as a work environment that lacks respect, flexibility, career advancement, and adequate education and training opportunities (Stone, 2011). Another barrier for many healthcare professionals is the need to overcome the stereotype that older adults cannot self-direct their services (Ruggiano, 2012). Hesitation to promote consumer directed care inhibits the ability of clients to control basic aspects of their care, resulting in unsatisfied consumers (Robison et al., 2012).

While consumer directed HCBS may not be for everyone, individual circumstances should determine the feasibility of such control, which can instill a sense of respect, dignity, worth, and self-determination within older adults (Ruggiano, 2012). An adequately prepared workforce has the ability to equip older adults with knowledge to make well-informed healthcare decisions.
Rationale for Current Study

HCBS are designed to provide services that meet the increasing and diverse needs of the older adult population. As previously discussed, a variety of HCBS programs have been established to assist older adults to remain in their homes for as long as possible (Robison et al., 2012). Taking somewhat of a different approach, the CLP initiative embraced HCBS as a viable end in itself and targeted individuals who were nursing home eligible and who were at risk for spend-down to Medicaid. The purpose of the current study was to examine service use within the context of the Virginia CLP program. I examined service use by older adults, classified around a set of variables (i.e., predisposing characteristics, need, and enabling resources) that contributed to the formation of similar groups of older adults. After determining which variables contributed to formation and what services were used by older adults within each group, I examined whether services used by different groups had greater potential to meet older adults’ care needs, with regard to program-effectiveness and perceived health status.

Theoretical Framework and Research Questions

The behavioral model of health services use (Andersen, 1995) provided theoretical guidance for this current study. Although the original model focused on the family as the social unit using health care to understand social and economic variables, the individual later became the focal point of the model. Andersen (1995) explained that the shift to the individual unit of analysis occurred because of the need to address individuals’ predisposing demographic characteristics, which are influenced by family characteristics embedded in health beliefs and social structure.

In addition to predisposing characteristics, personal and community resources influence service use by the individual (Andersen, 1995). The environment, which includes the health care
system, is an externally driven variable that also influences individuals’ use of services. Through policies and programs, opportunities and benefits are limited to eligible individuals. Population characteristics and health behaviors are internally derived, yet some enabling resources (e.g., community support), health behaviors (e.g., personal health practices), and use of health services are variables that can be manipulated. Manipulated variables have the potential to influence reported outcomes of perceived and evaluated health and consumer satisfaction.

Examining service use in the context of predisposing characteristics, need, and enabling resources may provide insight into factors that facilitate or impede use of formal services provided by CLP. Variables from the CLP program evaluation were examined to explain service use clusters and outcomes (see Figure 1, p. 68). The CLP program removed several barriers of service use by offering services and financial assistance to participants. With respect to family/personal resources, having someone that provided care to the older adult was a requirement for inclusion in the program. Thus, enrollment in CLP enabled access to a variety of services, which is an essential factor that facilitates service use.

The predisposing characteristics included age of participant; need is both perceived and measured, which was assessed by primary disability type and the number of ADL limitations. Enabling resources included in the analysis were living situation, household income, caregivers’ relationship to care recipient, and length of time (in years) spent caregiving. Service use was measured by participants’ purchase of 18 available service options. Outcome variables focus on health status and program effectiveness as measured by reported likelihood of nursing home entry without CLP services and nursing home entry within the next three months, the reported number of existing unmet needs, and average cost per day for services used, per participant.
The purpose of this research was to answer the following questions about the CLP program implemented in Virginia:

**Research Question 1:** (Cluster formation)

*What variables differentiate service user membership? What HCBS are used by older adults that cluster around a set of specified variables?*

**Research Question 2:** (Outcome focus)

*Do groups defined by clusters differ on outcome measures that assess perceived health status and program cost-effectiveness?*
CHAPTER III

Methods

In this chapter, I present the study design and analytical approach to assess the packaging and delivery of LTC services and supports to meet the care needs of older adults. First, I present an overview of the original CLP study, which provides the context for the current study, and address the strengths and weaknesses of using secondary data. This is followed by a description of the study sample and the measures used for the current analyses. In the final section, I present the analysis plan for addressing my research questions and hypotheses.

Overview of Original Study: Purpose and Design

The Community Living Program (CLP) was a federal grant initiative implemented through the AoA from 2007-2009. It was designed to assist individuals at risk of nursing home placement and Medicaid spend-down to remain living in their communities (Administration on Aging, n.d.-a). The program’s long-term vision was to provide a person-centered and consumer directed LTC service system. CLP standards required a single entry point system for the clients’ comprehensive needs, quality assurance, and program evaluation (Administration on Aging, n.d.-a). With the intention to complement and support on-going effort by family caregivers, the service elements of the program provided flexible dollars to purchase services tailored to the individuals’ needs, offered the Cash and Counseling model to clients, and targeted eligibility criteria to reach at-risk individuals (Administration on Aging, n.d.-a). States received grants to implement the CLP program and worked in partnership with Area Agencies on Aging (AAA) to develop programs.

The Commonwealth of Virginia received a CLP grant in 2009 to implement the program at three AAAs (CLP1) and received a second round of funding to increase the number of
program sites to 10 AAAs in 2010 (CLP2). CLP supported Virginia’s effort to control the high cost of institutional care and rebalance LTC spending.

To be eligible, participants were required to be aged 65 or older and have an informal support system/caregiver demonstrating difficulty in meeting the participants’ needs. Care recipients needed to be dependent in two to four ADLs or display cognitive/emotional impairments, such as the need for prompting or supervision, impairments in decision-making ability, and inability to avoid injury in emergency situations. Financial limitations restricted eligibility to individuals with an income at or below 300% of the Social Security Income and clearly defined the range of eligible liquid assets. Persons eligible for Medicaid or Medicaid Waiver programs were not eligible for enrollment in this study.

Participant received a monthly allotment of up to $1,200 to use at their discretion or the discretion of their informal caregiver. They could save up to half of each month’s allowance for a more expensive service purchase, with a maximum of $5,000. Although a fiscal intermediary handled payment for services, the consumer direction model enabled participants to choose what services to use and who provided the services, whether it was a family member, an agency, or an Area Agency on Aging (AAA). A service coordinator supported the older adults and their caregivers as they selected services to use, which helped coordinate and implement services.

Eighteen routine or one-time services were available for older adults and their families to use through consumer direction. Overall, participants purchased 16 of the available 18 services; recreational devices and senior apartment rent support were never purchased. These services included personal care, companion/homemaker, personal emergency response system (PERS), adult day care (ADC), transportation, home delivered meals, assisted living costs, disposable medical supplies, home modification/house rehabilitation, prescription medications, assistive
devices, chore, nutritional supplements, respite care, groceries, and dental care (optional by AAA). On average, the participants purchased 3.08 services ($SD=1.33$; range 1-9).

Virginia’s Division for the Aging contracted with the Center for Gerontology at Virginia Tech to conduct an independent evaluation of the Virginia CLP program. Evaluation data were drawn from several sources, including a statewide computer database, the fiscal management database, service coordinators, and participants and their proxies. The Virginia Tech team contacted participants via telephone approximately 3 months after enrollment to assess their satisfaction about the program, the services provided, and program’s effectiveness in meeting their needs. The outcome evaluation measured program success “with regard to participant access, cost of implementation, and quality of services provided” (Brossoie & Roberto, 2012).

Enrollment from CLP1 and CLP2 totaled 153 participants, ranging from 66 to 96 years of age. Six participants were enrolled in both CLP1 and CLP2, but only data from their first year of enrollment were included as part of the evaluation to avoid duplicative data. At the time of the evaluation, 4% of the potential respondents were deceased, 4% refused to participate, and 8.8% were not contacted because they enrolled after the 12-month evaluation period (Brossoie & Roberto, 2012). A total of 114 participants or their proxies (i.e., caregivers) completed the evaluation survey (proxies completed 86% of all surveys). Overall, 98% of Virginia CLP participants reported being satisfied or very satisfied with the program and 95% were deterrence from nursing home entry. When asked whether the program improved their quality of life, 96% of participants reported a little or a lot of improvement (Brossoie & Roberto, 2012). Compared to Medicaid reimbursement for nursing home placement, the program costs were much lower. Thus, the CLP met the challenges of financing home care to avoid nursing home placement and Medicaid spend-down.
Strengths and Weaknesses of Secondary Data Analysis

The growing diversity of scholars’ interest supports the use of secondary analysis, as it allows a fresh look at existing data that has potential to uncover new findings (Mroczek, Pitzer, Miller, Turiano, & Finderman, 2011). The strengths and weaknesses of using secondary data are weighted differently by circumstances and the nature of the research (Dale, Arber, & Procter, 1988). The use of secondary data is a cost-saving approach that allows researchers to build from others’ body of work and efforts (Dale et al., 1988; Mroczek et al., 2011). It makes creative use of existing data, as long as it is interpreted within a close context of the original study’s intention (Russell & Matthews, 2011). Secondary analysis allows researcher to select from the full battery of measures and hone in on variables of interest to different research questions.

However, the use of secondary data is not a short-cut for contributing to the scientific knowledge base and understanding (Dale et al., 1988). A secondary analyst must spend ample time becoming familiar with the dataset another researcher designed and collected; if the data were not cleaned well and the dataset was poorly managed and maintained, using it may become burdensome (Mroczek et al., 2011). The use of secondary data limits the researcher to analyzing pre-existing data collected for a specific purpose. Secondary analysis is rarely experimental, as the independent variable cannot be directly manipulated (Mroczek et al., 2011). Thus, the original study’s sampling frame needs to be clearly articulated to avoid accidental unrepresentativeness (Dale et al., 1988). The exact variables of interest may not be available, which limits the secondary analyst to the available measures from the original study (Mroczek et al., 2011). The specific structure of survey questions and definitions of terms may bias the data and cannot be modified when doing secondary analysis (Dale et al., 1988). The nuances and structure of questions may be overlooked when being analyzed by someone other than the
original researcher (Pienta, O’Rourke, & Franks, 2011). However, this is a limitation of closed-ended survey questionnaires in general, as it is a struggle to assess what study participants thought the question meant, which often cannot be answered (Russell & Matthews, 2011). When using secondary data it is important to become “fully aware of the nature of data” (Dale et al., 1988, p. xi), assess the method of collection, and be cognizant of the limitations regarding interpretation of results.

I conducted secondary analyses of data originally collected to evaluate Virginia’s Community Living Program (CLP) pilot program. I had direct access to the program investigators when uncertainties arose about the “nature of data” and clarification was needed. The current study expanded upon the original study’s purpose, using participant data from the original survey questionnaire. Variables included in the original study aligned with the intent of my research and provided the data needed to answer two questions of interest about service use by older adults and their families. However, the structure of the questions asked of participants influenced the analysis plan and interpretation of the findings. For example, during the initial assessment, participants were asked to report categorically only their primary disability (e.g., cognitive, physical, or unspecified disability). Thus, the influence of having multiple disabilities or a specific type of disability could not be assessed. As part of the 3-month follow-up survey, participants and their primary caregiver identified which services were purchased through the CLP program, but were not asked about the regularity of service use or if the older adults relied on other people or services outside of the CLP for support. Therefore, I could not assess the frequency of service use or the extent of their formal service use.

Methods

Study Sample
The analysis for this study is based on data from 76 CLP participants who were enrolled for 31 days or more, purchased 2 or more services, and completed the satisfaction survey administered approximately 3 months after enrollment. Participants ranged in age from 66 to 95 years ($M = 83.2; SD = 6.25$) and nearly two-thirds of the participants were women ($n = 57; 75.0\%$). The majority of participants identified themselves as White not Hispanic ($n = 63; 82.9\%$); 11 participants identified themselves as Black not Hispanic ($14.5\%$); 1 participant reported being White Hispanic ($1.3\%$) and 1 participant reported being Asian ($1.3\%$). Almost half of the participants were married ($36; 47.4\%$) and one-third lived with only their spouse ($29; 38.2\%$). Almost one-third of the participants ($n = 29; 32.9\%$) lived alone. Reported household income was $20,000+ for more than half of the participants ($n = 39; 51.3\%$). More detailed background information about the study participants is provided in Table 1 (see p. 68).

The primary disability types experienced by participants were physical disability ($n = 42; 55.3\%$), cognitive disability ($n = 31; 40.8\%$), and unspecified disability ($3; 3.9\%$). Participants reported an average of 4.51 ADL limitations ($SD = 1.77$) and 4.77 chronic health conditions ($SD = 1.84$). Sixteen of the 18 available services were purchased by participants. They used an average of 3.02 services ($SD = 1.28$; range 2-9). After being enrolled in CLP for approximately 3 months, 74 participants reported having an average of 1.39 existing unmet needs ($SD = 1.48$; range 0-6).

**Measures**

Evaluation data were drawn from several sources, including a statewide computer database, the fiscal management database, service coordinators, and participants and their proxies. Study variables came from the enrollment questionnaire or the 3-month enrollment survey. Program costs per participant calculated for evaluation purposes also were included as
part of the measures used for this study. A detailed description of the measures is provided in Appendix B. Information garnered from the enrollment questionnaire included demographic information about the participants, health data, and information about their caregiver. Items from the 3-month enrollment survey included the type and number of services purchased, the participants’ health conditions, participants’ perceptions of unmet needs, and the participants’ assessment of the effectiveness of the program with regard to allowing them to maintain their current living arrangements.

Analysis Plan

I used cluster analysis to answer the first set of research questions, “What variables differentiate service user membership? What HCBS are used by older adults that cluster around a set of specified variables?” This statistical technique is used to discover structure in data to determine when identified groups are estimated to be actual and not imposed by the method of analysis (Aldenderfer & Blashfield, 1984). For this analysis, I used two-step cluster analysis, which is the only cluster technique that can handle both continuous and categorical variables (Norušis, 2004). For categorical variables, assessment of similarity was determined by using frequencies of occurrence to inform the clustering process. I examined service use by older adults, classified around a set of demographic, health-related, and caregiver variables that contributed to formation of the clusters. Once identified, the composition of each cluster was examined to determine which variables were most important in differentiating one cluster from the other clusters (Norušis, 2004, p. 384).

Seven variables were examined: age, living situation, household income, primary disability type, number of ADL limitations, caregiver relationship to participant, and length of time in years spent caregiving. Guided by Andersen’s model of health service use, descriptive
statistics were prepared for the selected variables in this analysis. I hypothesized that the
following variables will inform the formation of clusters: age (predisposing characteristics);
primary disability type and number of ADL limitations (need); and living arrangement,
household income, caregiver relationship to participant, and length of time in years spent
caring (enabling resources).

To address the second research question, “Do groups defined by clusters differ on
outcome measures that assess perceived health status and program cost-effectiveness?” I
examined between-cluster membership to determine whether certain profiles had greater
potential to meet older adults’ care needs. The outcome variables of interest were average cost
per day for services used, reported number of existing unmet need, likelihood of nursing home
entry without CLP services and likelihood of nursing home entry within the next three months. I
hypothesized that on average, different profile membership would yield different results with
regard to program effectiveness. For the second research question, I used one-way ANOVA to
assess the differences between cluster membership and the dependent variables.
CHAPTER IV

Results and Discussion

In this chapter, the results of this study are presented in manuscript form. The intent is to submit the manuscript to the *Journal of Aging & Social Policy*. Papers submitted to this journal often evaluate policy initiatives that have been implemented. Journal requirements include:

- Expectation for authors to emphasize reporting research findings, yet balance attention between policy and research
- The article is required to be framed in a policy context, with a full discussion of the policy implications of research findings
- Explain the research methods clearly but concisely
- Data analysis and reporting of research findings organized to contribute to an understanding of the central policy issue
- Encouraged to place the manuscript in an international context
- May report research that reflects experiences in a single country, but papers should reflect the international literature on both underlying aging processes and policy developments

See Appendix C for guidelines for submission to the *Journal of Aging & Social Policy*.
Article: Home and Community-based Service Use by Vulnerable Older Adults

Abstract

Guided by the Anderson’s model of health service use, this study assessed home and community-based services usage as well as identified the typology of older adults most likely to use specific groupings of services among 76 participants in the Virginia Community Living Program. Two-step cluster analysis identified four distinct profiles of service users. The most important variables that differentiated service user membership were enabling resources such as caregiver relationship to participant, participant living arrangement, and length of time caregiver provided assistance, as well as disability type. Between-cluster membership differed on average service cost per day for services used and likelihood of nursing home placement if services were not provided. Findings have implications for policy and practitioners assisting vulnerable older adults in tailoring services to meet different care needs.

Keywords: home and community-based services, older adults, Community Living Program, service utilization, cluster analysis
INTRODUCTION

As people grow older, they frequently rely on others for help and assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) or rely on long-term care (LTC) services to allow them to live in their own homes for as long as possible (Farber, Shinkle, Lynott, Fox-Grage, & Harrell, 2011). LTC encompasses a broad range of services and supports, including direct, hands-on care and supervisory or standby assistance, the use of assistive devices and technology, such as electronic monitoring systems, and home modifications (Stone, 2011). Recognizing that institutional care is often the least desirable option for older adults in need of assistance with daily activities, offering home and community-based services (HCBS) options can promote independence, agency, and choice for older adults and their family caregivers. Thus, HCBS are considered a viable LTC option that have the potential to delay or avoid institutional living and result in less financial burden for care recipients and their family (e.g., Lehning & Austin, 2010; Robison, Shugrue, Porter, Fortinsky, & Curry, 2012).

With the number of the persons aged 65 and older in the United States expected to exceed 79 million by 2040 (Administration on Aging, 2012), society has not prepared well for the repercussions of population aging, and does not have adequate services and supports in place to meet the needs of older adults. The costs associated with LTC are significant, and the current generation of older adults often has inadequate personal savings to pay for LTC services (Alkema, 2013). The three primary sources that older adults rely on to meet their LTC needs are (a) individual and family support (e.g., money, caregiving), (b) Medicare for acute and post-acute needs, and (c) Medicaid for LTC needs (Alkema, 2013). One of the greatest frustrations and challenges for individuals in need of care revolves around eligibility requirements for
Medicaid (Tell, 2013): individuals who exceed the income and assets eligibility criteria must “spend-down” or deplete their financial resources (Alkema, 2013; Kaye, Harrington, & LaPlante, 2010; Weiner et al., 2013). Thus, individuals often go without the services they need or else depend on, and ultimately exhaust, unpaid family support (Weiner et al., 2013).

Families are a critical component of the LTC system; they have long been the de-facto social units that provide care for older adults, with nearly 62 million family caregivers in the United States in 2009 (Alkema, 2013). Spouses are usually first among family members to take on the caregiving role, followed by an adult child (Family Caregiver Alliance, 2012b) who is usually the daughter (Kaye et al., 2010). The estimated cost savings of having family care is $375 billion annually (Alkema, 2013). Many HCBS options are supported by Medicaid, a means-tested program that provides health care for individuals with low-income and persons with functional or mental disabilities, including older adults (Medicaid.gov, n.d.). HCBS services are designed to supplement informal care provided by family and friends. Yet, Kaye and colleagues (2010) reported that when unpaid family care was available, older adults tended to rely exclusively on this option, as opposed to involving formal service providers.

The purpose of this study was to advance understanding HCBS use by vulnerable older adults as a means of supporting older adults to delay nursing home placement and avoid spend-down of their resources to meet Medicaid eligibility requirements. Andersen’s (1995) behavioral model of health services use provided theoretical guidance in the selection and explanation of factors associated with service selection within the Community Living Program (CLP) federal initiative.
POLICY AND PROGRAM OVERVIEW

In the United States, the focus on community-based care and health promotion began at the turn of the 21st century and continues to dominate, with various policies that promote eligibility, availability, and access to home and community-based services (HCBS). The ultimate goal of HCBS is to provide a person-centered, effective, efficient, and coordinated care system that plays a critical role in addressing the diverse needs of older adults who prefer to remain in their homes and to avoid institutionalization (Alkema, 2013; Casado, van Vulpen, & Davis, 2011; Castora-Binkley, Noelker, Ejaz, & Rose, 2010; Gonyea, 2005; Ruggiano, 2012). In 2009, approximately 3.25 million people benefited from Medicaid HCBS programs such as Cash and Counseling (Carlson, Foster, Dale, & Brown, 2007), Independence Plus (Crowley, 2003), and Money Follows the Person (Crisp, Eiken, Gerst, & Justice, 2003), with approximately 1.3 million benefiting from waiver programs (Ng, Harrington, Musumeci, & Reaves, 2012).

The most recent federal initiative to provide consumer direction options and support LTC rebalancing efforts was the Community Living Program (CLP). Grants from the Administration on Aging were awarded to 28 states between 2007 and 2009 to implement programs designed to reduce the risk of premature nursing home entry and spend-down to Medicaid eligibility. Although not a Medicaid HCBS, the CLP targeted individuals at risk of nursing home placement and Medicaid spend-down (Administration on Aging, n.d.). The CLP provided access to a range of publically supported LTC services and a monthly allowance of $1,200 to purchase available services that addressed individuals’ specific needs. The intent of the program was to complement on-going family caregiving efforts and supplement available personal and financial resources (Administration on Aging, n.d.). Implemented on a much smaller scale than other consumer direction demonstration programs, the CLP program enrolled more than 5,500 people.
by the end of 2012 (Aging and Disability Resource Center, 2012). Federal funds invested in the CLP initiative exceeded $23 million, and states matched more than $11 million (Aging and Disability Resource Center, 2012). Funding was not renewed after the original grant period because of federal budget cuts.

**HCBS USER CHARACTERISTICS**

The number of individuals served through Medicaid HCBS programs increased from 2.1 million in 2000 to 2.8 million in 2007, including 1.2 million just through HCBS waivers (Harrington, Ng, LaPlante, & Kaye, 2012). Typical HCBS users are of advanced age, female, White, have low income, live alone, and have a range of health conditions, functional dependence, and cognitive impairments (Gaugler, Kane, Kane, & Newcomer, 2005; Hong, Hasche, & Lee, 2011; Li, 2006; Muramatsu et al., 2007; Robison et al., 2012). Use of HCBS varies across race and ethnic groups, with older White Americans more likely users of HCBS than older African Americans or older adults of Hispanic/Latino origin (Caffrey, Sengupta, Moss, Harris-Kojetin, & Valverde, 2011).

Nearly 80% of older adults requiring LTC that live in the community use HCBS options to address their diverse needs (NORC Public Policy, 2008). While it is relatively straightforward to assess how many people received HCBS, clarity about when and why certain types of services are used has not emerged from the literature. Factors that contribute to service use have been examined within the behavioral model of health services use framework (Andersen, 1968). Within the context of the external environment and system of health care, population characteristics, which include predisposing characteristics, enabling resources, and need are associated with health behavior and use of health services that influence outcomes, such as health status, cost-effectiveness, or consumer satisfaction (Andersen, 1995).
Service use has been attributed to accessibility and availability of services. For example, compared to urban older adults, individuals living in rural regions reported lower levels of use, primarily because of limited availability of services (Li, 2006). Transportation issues concerning cost and inflexible service hours and limited medical transportation programs were identified barriers to health care access in rural areas (e.g., Goins, Williams, Carter, Spencer, & Solovleva, 2006; Li, 2006; Li, Chadiha, & Morrow-Howell, 2005). However, when services were available, older adults in rural areas were more likely to use multiple services than were older adults in urban areas (Hong et al., 2011).

Availability of informal family caregiving is an enabling resource, with subtle differences found between spouse and adult child caregivers’ use of services in support of the care of their older relatives. Robinson, Buckwalter, and Reed (2013) found that spouses were significantly less likely to use services, compared to adult children or any other relative providing care. Spouses also were more likely to report that they did not need help with caregiving than were adult children (Robinson et al., 2013). Spouses may consider caregiving as an expected part of the marital relationship, and unlike adult children who are likely to be employed, spouse caregivers in late life are likely to have exited the workforce. Thus, availability of time may contribute to spouses’ willingness to provide care and not use formal services (Robinson et al., 2013).

Spouse and adult children caregivers with more social support relied on outside help more and reported fewer unmet needs for services that address the needs of care recipients compared to caregivers with less social support (Casado et al., 2011; Robinson et al., 2013). For example, perceived social support was associated with having greater opportunities to obtain “diverse information about service options” (Hong et al., 2011, p.1325); caregivers who
perceived a higher level of social support were more likely to be multiple service users (Hong et al., 2011).

HCBS options have been found to be a cost-effective alternative to institutionalized care (Gonyea, 2005; Kaye et al., 2010; Lehning & Austin, 2010; Robison et al., 2012). However, studies have consistently shown low levels of HCBS use by older adults (e.g., Casado et al., 2011; Tang & Lee, 2010). Low levels of service use are associated with lack of perceived need, limited access to services, unawareness of available services, or limitations on eligibility (e.g., Casado et al., 2011; Harrington et al., 2012; Wiener et al., 2013). In 2008, 20% of community-dwelling older adults reported they did not receive the care they needed (Lehning & Austin, 2010). Individuals reported a lack of sufficient help (e.g., Kaye et al., 2010; Robison et al., 2012), suggesting the need for improved service coordination to address individuals’ comprehensive needs.

THEORETICAL FRAMEWORK AND RESEARCH QUESTIONS

The basic premise of the behavioral model of health services use is a function of individuals’ predisposition to use services, level of need, and factors that enable or impede use (Andersen, 1968; see Figure 1). Often used as a predictive mechanism, the model’s different components identified variables frequently associated with health service use. However, the model also has explanatory potential to identify essential factors that contribute to use (Andersen, 1995). Based on this model, the following research questions were addressed: What variables differentiate service user membership? What HCBS are used by older adults that cluster around a set of specified variables? and Do groups defined by clusters differ on outcome measures that assess perceived health status and program cost-effectiveness?
METHODS

The data for this study were originally collected to evaluate Virginia’s Community Living Program (CLP) pilot program. The Commonwealth of Virginia received a CLP grant in 2009 to implement the program at three Area Agencies on Aging (AAAs) (CLP1) and in 2010 received a second round of funding to increase the number of program sites to 10 AAAs (CLP2). CLP supported Virginia’s effort to control the high cost of institutional care and rebalance LTC spending. Through consumer direction of services, 18 routine or one-time services were offered to enrolled participants. All participants were allocated the same amount of money to use at their discretion or that of their caregiver. The sample for the current study includes participants who were enrolled in CLP for 31 days or more, purchased 2 or more services, completed the satisfaction survey administered approximately 3 months after enrollment, and provided responses for all variables of interest. This research was approved by the institutional review board of Virginia Polytechnic Institute and State University (Appendix D).

Study Sample

The 76 study participants ranged in age from 66 to 95 years ($M = 83.2; SD = 6.25$) and nearly two-thirds of the participants were women ($n = 57; 75.0\%$). The majority of participants identified themselves as White not Hispanic ($n = 63; 82.9\%$); 11 participants indicated a Black not Hispanic identity (14.5\%); 1 participant was a White Hispanic person (1.3\%) and 1 participant was Asian (1.3\%). Almost half of the participants were married (36; 47.4\%) and one-third lived with only their spouse ($n = 29; 38.2\%$); just over one-third of the participants were widowed ($n = 30; 39.5\%$). Reported household income was $20,000+ for more than half of the participants ($n = 39; 51.3\%$). The participants’ primary health concern was physical disability ($n = 42; 55.3\%$) or cognitive disability ($n = 31; 40.8\%$). They reported an average of 4.51 ADL
limitations \( (SD = 1.77) \) and 4.77 chronic health conditions \( (SD = 1.84) \). Overall, participants purchased an average of 3.08 services \( (SD = 1.33) \) and reported an average of 1.39 existing unmet needs \( (SD = 1.48) \). More detailed background information about the study participants is provided in Table 1 (see p. 69).

**Measures**

Evaluation data were drawn from several sources, including a statewide computer database that provided participant characteristics and service enrollment information, the program’s fiscal management database, service coordinator staff, and participants or their proxies. Study variables came from the enrollment questionnaire and the 3-month enrollment survey. Program costs per participant calculated for evaluation purposes also were included as a measure of program effectiveness. *Predisposing characteristics* included participant’s age; *need* was assessed by primary disability type and number of ADL limitations. *Enabling resources* included living situation, household income, caregivers’ relationship to care recipient, and length of time (in years) spent caregiving. *Service use* was measured by participants’ selection of 18 available service options. *Outcome* variables assessed health status and program effectiveness as measured by reported likelihood of nursing home entry without CLP services and nursing home entry within the next three months, the reported number of existing unmet needs, and the average cost per day for services used.

**Cluster Analysis**

To answer the first research question, *What variables differentiate service user membership? What HCBS are used by older adults that cluster around a set of specified variables?*, two-step cluster analysis was conducted with IBM SPSS Statistics 21 to identify profiles of service users. In the first step, a Clusters Features Tree was constructed by taking
information on the seven variables for the first case and placing it at the base (Brawijaya Professional Statistical Analysis, 2011). Then, information for each successive case was used to create groupings based on similarity using log-likelihood with the Mahalanobis distance measure. For the second step, the Akaike’s information criterion (AIC) determined that four clusters would be the “best” fit for the data. The seven input variables from the CLP program evaluation were selected based on the theoretical guidance of the behavioral model of health service use (see Figure 1): age, primary disability, number of ADL limitations, living situation, household income, caregiver relationship to participant, and length of time (years) spent caregiving. Clusters were evaluated based on sex, number of chronic health conditions, and service use per individual.

RESULTS

Four patterns of service usage among older adults were found (range of members = 7 to 34) (see Table 1 for demographic characteristics for each group). The number of services used by participants in each clusters varied and ranged from 11-16 services. None of the participants purchased recreational devices or senior apartment rent support services. Participants most frequently selected routine service options of personal care services (PCS) and homemaker/companion services (63% and 49%, respectively). However, only the use of PCS was significantly associated with membership differentiation ($p = .033$). The other 14 services were selected by less than 26% of the participants overall. Thus, the following description of service selection by cluster is in addition to these two services. Tables 1 and 2 provide more detailed information about the participants and frequency of service selection by cluster. Figure 2 shows the most frequently selected services by participants in each cluster.
**Characteristics of Cluster 1: Typical Older Adults**

The average age of persons in the *typical older adults* cluster \((n = 19; 25\% \text{ of overall study sample})\) was 80.9 years \((SD = 6.90)\). Their household income was dispersed, but the majority reported an annual income of $20,000 or more. Most *typical older adults* lived alone or with their spouse and reported having physical disabilities, an average of 4.21 ADL limitations, and 4.47 chronic health conditions. Caregivers for *typical older adults* were primarily adult children who most frequently reported providing care for 1 to 4 years. Although members of this group were younger than the overall sample, it included 2 members who reported needing care for 10-14 years and 1 member who needed care for more than 15 years.

*Typical older adults* purchased 14 of the 16 services, with an average of 2.95 services per member. One-time/intermittent services were most frequently selected, including home modification, disposable medical supplies, chore services, assistive devices, and prescription medication. Transportation, a routine-service, was also frequently selected by members of this group. These service selections suggest that *typical older adults* were aware of their current (e.g., assistive devices, chore services) and future needs (e.g. home modification) in order to maintain independence.

**Characteristics of Cluster 2: Living with Others**

The average age of the 16 older adults *living with others* \((21.1\% \text{ of overall study sample})\) was 83.6 years. Like the *typical older adults*, they also showed variability in household income, with reported income spanning the entire range. Older adults *living with others* had either physical or cognitive disabilities, reported 5.56 ADL limitations, and 4.74 chronic health conditions. They primarily lived with relatives; an adult child was the caregiver for most
participants. The majority of their caregivers reported providing care for between 1 to 4 years or 5 to 9 years, indicating that they had been providing care for quite some time.

Selection of 16 services indicated diverse needs of older adults living with others. Each participant used an average of 3.75 services. The most frequently selected services were assistive devices, disposable medical supplies, PERS, home modification, and respite. Respite was purchased by 4 participants and was significantly associated with membership differentiation ($p = .010$).

**Characteristics of Cluster 3: Greater Financial Resources**

The 34 members (44.7% of overall study sample) of the greater financial resources group reported an average age of 83.7 years. Participants had a household income of between $15,000-19,999 or $20,000 or more, suggesting that members of this cluster had greater financial resources than the other three groups. More than half of the members reported cognitive disability, while the other members reported a physical disability. They reported an average of 4.24 ADL limitations and 4.79 chronic health conditions. The majority of the greater financial resources participants lived with their spouse. Half of the caregivers were spouse and the other half were adult child; the majority of caregivers provided care for 1-4 years.

Fifteen services were purchased by the CLP participants with greater financial resources. On average, each member used 2.79 services. They purchased more routine services (i.e., PERS, ADC, and transportation) than one-time/intermittent services, with the exception of prescription medication, which was frequently selected.

**Characteristics of Cluster 4: Extended Kin and Friend Support**

All 7 members of the extended kin and friend support group (9.2% of overall study sample) had physical disabilities, lived alone, and reported high household income. With an
average age of 86.4, participants were older than the overall sample. Similar to the overall sample, they reported an average of 4.29 ADL limitations ($SD = 1.98$). These individuals reported an average of 5.57 chronic health conditions ($SD = 1.51$), which was higher than the overall sample. All members of the extended kin and friend support group reported having a household income of at least $11,000. Their primary caregivers were relatives or friends; caregivers provided assistance for 5 to 9 years or less.

Only 11 types of services were selected by members of the extended kin and friend support group. On average, each member used 3.29 services. The services most frequently purchased were disposable medical supplies and assistive devices, both one-time/intermittent services, as well as home delivered meals, a routine service. These service selections represent a group of cognitively healthy older adults.

**Differences between Clusters**

In order of importance, caregiver relationship to participant, participant living arrangement, participant disability type, and length of time caregiver reported providing care differentiated service user cluster membership. The majority the typical older adults (Cluster 1) and those living with others (Cluster 2) had an adult child providing care. The relationship of caregivers to participants with greater financial resources (Cluster 3) was either a spouse or adult child, whereas all extended kin and friend support members (Cluster 4) had another relative or friend as their primary caregiver. Typical older adults represented the most variability in living arrangement. The majority of individuals who lived with relatives were from the living with others group, while individuals living with only their spouse were predominately from the greater financial resources group. All members of extended kin and friend support group lived alone. Overall, fewer services were selected for older adults when caregivers were spouses ($M =$
2.85; \( SD = 1.49 \) compared to adult child \((M = 3.15; SD = 1.23)\). The fewest number of services were purchased by members with greater financial resources, which included the majority of participants who had a spouse caregiver.

Reflective of their living arrangement, none of the extended kin and friend support members reported cognitive disabilities as their primary disability. About an equal number of older adults living with others reported either physical or cognitive disability as their primary disability; the majority of greater financial resources members had cognitive disabilities. Only typical older adults reported having an unspecified disability, in addition to cognitive or physical disability.

Overall, participants relied on their caregivers for between 1 to 4 years. Members in greater financial resources and extended kin and friend support clusters grouped around the lower end of the range of years spent providing care, suggesting the need for care was a relatively more recent development than typical older adults and participants living with others. Typical older adults and participants living with others reported receiving care for 10 or more years.

**Cluster Membership and Outcome Variables**

To answer the second research question, *Do groups defined by clusters differ on outcome measures that assess perceived health status and program cost-effectiveness?*, participant data within each group was combined for each reported outcome variable. One-way ANOVA was used to assess group differences on the dependent variables.

Program effectiveness was assessed using cost per day for services used and number of existing unmet needs. Between-cluster differences were significant for average service cost per day \((F (3, 72) = 5.530, p = .002)\). The average cost per day for typical older adults was $21.06,
which was significantly lower than the average for participants living with others (M = $31.14; p = .006) and with greater financial resources ($30.31; p = .002). The average cost per day for older adults with extended kin and friend support was $29.07, which did not differ significantly from the other groups (see Figure 3, pg. 72). The clusters did not differ on existing unmet needs (F (3, 70) = .517, p = .672). However, extended kin and friend support members reported the lowest average of unmet needs (M = .86; SD = 0.69), which may be associated with their primary limitation reported as physical disability, which is more easily addressed with services, compared to cognitive limitations.

Two dependent variables assessed perceived health status. The perceived likelihood of moving to a nursing home if CLP services were not provided was significantly different across clusters (F (3, 70) = 3.055, p = .034). Members of the greater financial resources group reported the lowest likelihood, compared to members of extended kin and friend support, which reported the greatest likelihood (p = .101). With the small number of participants in the extended kin and friend support group, it is likely that the trend toward significance would continue if there were more participants. There was no significant difference among clusters on the perceived likelihood of moving to a nursing home within the next 3 months (F (3, 70) = .185, p = .907). The overwhelming majority of participants (n = 60; 81.1%) indicated that moving was not at all likely within the next 3 months.

DISCUSSION

This study assessed service use by older adults and their primary caregiver within the context of the Virginia CLP program. The CLP initiative was unique in its efforts to delay nursing home entry by targeting individuals at risk of nursing home placement and Medicaid spend-down. For eligible participants, the CLP removed several common barriers to service use
by raising awareness, increasing availability, and ensuring affordability of services. The CLP initiative offered coordinated services that supplemented informal care. Thus, it capitalized on the strengths of informal caregiving by giving vulnerable older adults and their caregivers control over service selection and service providers.

Andersen’s (1995) model of health service use is commonly employed to identify factors associated with individual service use, based on the influence of individual characteristics and health behaviors. In this study, groups of similar service users, rather than individual users, were identified based on predisposing characteristics, level of need, and enabling resources variables frequently included in the service use model. Four distinct profiles of vulnerable older adults were formed on the basis of three enabling variables: caregiver relationship of participant, living arrangement of participant, and length of time caregiver provided care. Findings pointed to the value of targeting enabling resources of vulnerable older adults in selecting CLP services to address their needs as a potential means to increase service use and influence reported outcomes (e.g., health, participant satisfaction).

For most participants, care was provided by family members. The majority of participants with family support did not perceive a high likelihood of nursing home entry if CLP services were not provided. In fact, the majority of participants indicated that nursing home entry within the next 3 months was not at all likely, suggesting a continued expectation for families to provide care (Kaye et al., 2010; Weiner et al., 2013). As commonly reported in the literature, the majority of typical older adults (Cluster 1), persons living with others (Cluster 2), and older adults with greater financial resources (Cluster 3) received care from spouses or adult children (Family Caregiver Alliance, 2012a; Kaye et al., 2010). Conversely, members of the extended kin and friend support group (Cluster 4) did not rely on close family members for support; rather
they lived alone and relied on friends or other relatives. They reported a high likelihood of nursing home entry without CLP services, suggesting community programs like CLP are critical sources of care for individuals without a family support network. Many LTC policies were developed with the assumption that familial support is a reliable source of providing care for vulnerable older adults. However, the National Alliance for Caregiving and AARP (2009) found that 14% of care was provided by non-family members, signifying the necessity of formal services to supplement informal care provided outside of the realm of traditional family structures.

More than half of the participants had been receiving care for between 1 and 4 years, but differences were noticeable among clusters. All participants in the greater financial resources and extended kin and friend support clusters grouped around the lower end of years receiving care, while typical older adults and older adults living with others reported higher years receiving care. The physical strains associated with providing care have been well documented in the literature (Family Caregiver Alliance, 2012a), including the deterioration in mental, psychological, physical, emotional, and spiritual health of caregivers (Hawranik & Strain, 2007). Thus, it is crucial to target support services for caregivers providing care particularly for longer durations. Support services such as respite and adult day care may prevent caregiver burnout in the early years and help sustain caregivers providing care for a long time.

The majority of older adults either lived with their spouse or lived alone. However, members of the distinct clusters tended to have the same living arrangement (e.g., members of living with others primarily lived with relatives), with the exception of typical older adults, which included participants in a variety of living arrangements. Regardless of specific living arrangement, the CLP consumer directed care model allowed older adults to identify the services
they need to deter institutionalization. Previous research noted that compared to persons who used traditional agency-based services, individuals in consumer directed HCBS programs were more likely to receive services they wanted and to report that their needs were met (Carlson et al., 2007; Weiner, Anderson, & Khatutsky, 2007). Findings from the current study provide further support that has found consumer direction to be associated with improved overall quality of life (Carlson et al., 2007) and older adults’ ability to age-in-place (Robison et al., 2012).

Regardless of cluster membership, almost all participants selected PCS and nearly half selected homemaker/companion services. Beyond these two services, older adults used a variety of the available services, but no one service was consistently selected by all of the participants. The broad selection of services demonstrates the variation in participants’ level of need and highlights the need to provide various service options to address the diverse needs of community-dwelling vulnerable older adults (Alkema, Reyes, & Wilber, 2006; Casado et al., 2011). After participating in CLP for 3 months, older adult reported existing unmet needs even with the 18 service offerings, reinforcing the need for communities to offer a range of one-time and long-term service options to older adults and their caregivers and provide them with information about the available services options.

Beyond PCS and homemaker/companion services which were the two more commonly selected by participants, subtle differences in service selection between groups were evident (see Figure 2, p. 71). Routine services were more frequently selected for use by older adults with greater financial resources and extended kin and friend support than by members in other groups. Members with greater financial resources, which included the majority of participants with spouse caregivers, selected the fewest number of services compared to participants with adult child, other relative, or friend caregivers, which supports previous findings that spouses
rely on fewer services to assist them with their caregiving responsibilities (Robinson et al., 2013). On average, the service use cost per day for services used was significantly lower for typical older adults compared to older adults living with others and those with greater financial resources. Characterized as typical older adults, members of this group primarily relied on care provided by an adult child and used an average number of services; one-time/intermittent services were most frequently selected, as well as routine transportation service. Respite and routine services tended to be among the most expensive services offered to the CLP participants, which may explain the higher cost per day for services used for members living with others and with greater financial resources, respectively.

Of the three main components of the behavioral health service use model, enabling resources were important indicators for entry into the HCBS system for CLP participants. Enabling variables are more malleable than either predisposing or need variables and have the potential to be influenced by supplemental services and supports provided. Recognizing cluster membership provides practitioners with valuable information about the unique context in which vulnerable older adults receive care. Having an understanding of the collective characteristics of particular service users provides practitioners with a starting point to assist older adults in selecting appropriate care options.

The examination of service use among consumer directing vulnerable adults provided insight into service selection and further evidence in support of the use of HCBS; however, the use of secondary data limited the selection of variables and subsequent data analysis used in the present study. Participants were asked to report only their primary disability type, which overlooked the dynamic interplay of various types of disabilities. In addition, questions that participants were asked during the 3-month follow-up survey created limitations for analyzing
vulnerable older adults’ service use. Participants and their primary caregiver only reported which services were purchases through the CLP program; thus, information was not available about the regularity that each service was used or if participants relied on other people or services for support. Future research is warranted that elaborates on the complex interplay among individual needs, informal care, and frequency of formal service use and the long-term outcomes for both individual users and their caregivers.

**CONCLUSION AND IMPLICATIONS**

The current state of LTC has many challenges to address in order to meet the needs of aging baby boomers and future generations of older adults. Preventive service options have the potential to meet the needs of older adults but are not widely implemented or federally supported. Although the Affordable Care Act of 2010 takes a more preventive approach to health care than other health care policies, additional efforts must be made to promote preventive HCBS options for vulnerable older adults. Community services that supplement informal caregiver efforts need to maximize the positive outcomes of the current context of care. Thus, capitalizing on the modifiable aspects of enabling resources may result in more preventive strategies for interventions that address older adults’ context of care (e.g., enabling resources).

Furthermore, PCS and homemaker/companion services were essential services for CLP participants, suggesting the importance for service agencies to prioritize the widespread availability of these two services to support aging-in-place (Farber et al., 2011).

At the policy level, long-term services and supports have reached a crossroad to determine how preventive services can be incorporated efficiently in the delivery of aging services to vulnerable older adults. With the costs of LTC continuing to increase, many programs overlook low-levels of need, which contributes to an infrastructural barrier that inhibits the use
of HCBS. In the midst of federal budget cuts it has been difficult to maintain strides in policy reform that positively influence older adults and their families, such as providing support for family caregivers (Castora-Binkley et al., 2010). However, HCBS options are more cost-effective than institutional LTC services (Kaye et al., 2010; Lehning & Austin, 2010; Robison et al., 2012). Eliminating funding for the CLP illustrates the lack of federal support for preventive programs, as the CLP was designed to target vulnerable older adults before their level of need increased to necessitate nursing home placement.

Older individuals deserve affordable, accessible, and comprehensive LTC services and supports. Service agencies must be able to identify and address the comprehensive needs of clients before their need for care requires institutionalization. Improving the traditional LTC system with programs like CLP will advance services and supports toward providing a more effective and efficient system of care for vulnerable older adults than automatic institutionalization does. Policymakers are encouraged to adopt and support the shift toward consumer directed preventive HCBS options that have the potential for enabling older adults to remain in their homes for as long as possible, ultimately enhancing their quality of life.
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doi:10.1111/phn.12041


Figure 1. Variables used to examine service use among vulnerable older adults. Adapted from Andersen (1995).
<table>
<thead>
<tr>
<th>Variable</th>
<th>Cluster 1: Typical Older Adults</th>
<th>Cluster 2: Living with Others</th>
<th>Cluster 3: Greater Financial Resources</th>
<th>Cluster 4: Extended Kin and Friend Support</th>
<th>Total sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>( n = 19 )</td>
<td>( n = 16 )</td>
<td>( n = 34 )</td>
<td>( n = 7 )</td>
<td>( N = 76 )</td>
</tr>
<tr>
<td>Age</td>
<td>( M = 80.89, SD = 6.90 )</td>
<td>( M = 83.63, SD = 7.39 )</td>
<td>( M = 83.71, SD = 4.92 )</td>
<td>( M = 86.43, SD = 6.71 )</td>
<td>( M = 83.24, SD = 6.25 )</td>
</tr>
<tr>
<td># of ADL limitations</td>
<td>( M = 4.21, SD = 1.77 )</td>
<td>( M = 5.56, SD = .96 )</td>
<td>( M = 4.24, SD = 1.92 )</td>
<td>( M = 4.29, SD = 1.98 )</td>
<td>( M = 4.51, SD = 1.77 )</td>
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<tr>
<td># of Health Conditions</td>
<td>( M = 4.47, SD = 2.17 )</td>
<td>( M = 4.77, SD = 1.97 )</td>
<td>( M = 4.79, SD = 1.90 )</td>
<td>( M = 5.57, SD = 1.51 )</td>
<td>( M = 4.77, SD = 1.84 )</td>
</tr>
<tr>
<td>Variable</td>
<td>( n )</td>
<td>( % )</td>
<td>( n )</td>
<td>( % )</td>
<td>( n )</td>
</tr>
<tr>
<td>Female</td>
<td>14</td>
<td>73.7</td>
<td>14</td>
<td>87.5</td>
<td>57</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>19</td>
<td>55.8</td>
<td>75.0</td>
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<td>Primary Disability</td>
<td></td>
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<td></td>
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<td>Cognitive Disability</td>
<td>4</td>
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<td>7</td>
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<td>31</td>
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<td>Physical Disability</td>
<td>12</td>
<td>63.2</td>
<td>9</td>
<td>56.2</td>
<td>42</td>
</tr>
<tr>
<td>Unspecified Disability</td>
<td>3</td>
<td>15.8</td>
<td>-</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Living Arrangement</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>9</td>
<td>47.4</td>
<td>-</td>
<td>-</td>
<td>25</td>
</tr>
<tr>
<td>Spouse only</td>
<td>6</td>
<td>31.6</td>
<td>-</td>
<td>67.6</td>
<td>29</td>
</tr>
<tr>
<td>Spouse and others</td>
<td>2</td>
<td>10.5</td>
<td>2</td>
<td>12.5</td>
<td>6</td>
</tr>
<tr>
<td>Relatives</td>
<td>2</td>
<td>10.5</td>
<td>13</td>
<td>81.3</td>
<td>15</td>
</tr>
<tr>
<td>Non-relative</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>6.2</td>
<td>1</td>
</tr>
<tr>
<td>Household Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$7,000-$9,499</td>
<td>5</td>
<td>26.3</td>
<td>1</td>
<td>6.3</td>
<td>6</td>
</tr>
<tr>
<td>$9,500-$10,999</td>
<td>0</td>
<td>-</td>
<td>2</td>
<td>12.5</td>
<td>2</td>
</tr>
<tr>
<td>$11,000-$14,999</td>
<td>4</td>
<td>21.1</td>
<td>5</td>
<td>31.2</td>
<td>11</td>
</tr>
<tr>
<td>$15,000-$19,999</td>
<td>0</td>
<td>2</td>
<td>14</td>
<td>41.2</td>
<td>18</td>
</tr>
<tr>
<td>$20,000+</td>
<td>10</td>
<td>52.6</td>
<td>6</td>
<td>37.5</td>
<td>39</td>
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<tr>
<td>Relationship to Participant</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>5</td>
<td>26.3</td>
<td>1</td>
<td>6.3</td>
<td>23</td>
</tr>
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<td>Child</td>
<td>14</td>
<td>73.7</td>
<td>15</td>
<td>93.7</td>
<td>46</td>
</tr>
<tr>
<td>Other Relative</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>4</td>
</tr>
<tr>
<td>Friend</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Length of Time Providing Care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 1 year</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>6.3</td>
<td>2</td>
</tr>
<tr>
<td>1-4 years</td>
<td>8</td>
<td>42.1</td>
<td>7</td>
<td>43.8</td>
<td>6</td>
</tr>
<tr>
<td>5-9 years</td>
<td>2</td>
<td>10.5</td>
<td>5</td>
<td>31.2</td>
<td>1</td>
</tr>
<tr>
<td>10-14 years</td>
<td>3</td>
<td>15.8</td>
<td>2</td>
<td>12.5</td>
<td>5</td>
</tr>
<tr>
<td>15+ years</td>
<td>1</td>
<td>5.3</td>
<td>1</td>
<td>6.3</td>
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</tr>
<tr>
<td>Not Provided/Refused</td>
<td>5</td>
<td>26.3</td>
<td>-</td>
<td>-</td>
<td>5</td>
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Table 1
Population Characteristics by Cluster.
Table 2
Frequency of Service Selection

<table>
<thead>
<tr>
<th>Service</th>
<th>Cluster 1: Typical Older Adults (n = 19)</th>
<th>Cluster 2: Living with Others (n = 16)</th>
<th>Cluster 3: Great Financial Resources (n = 34)</th>
<th>Cluster 4: Extended Kin and Friend Support (n = 7)</th>
<th>Total sample (N = 76)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n %</td>
<td>n %</td>
<td>n %</td>
<td>n %</td>
<td>n %</td>
</tr>
<tr>
<td>Routine Service</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal Care Services</td>
<td>10  53%</td>
<td>13  81%</td>
<td>18  53%</td>
<td>7  100%</td>
<td>48  63%</td>
</tr>
<tr>
<td>Homemaker/Companion</td>
<td>12  63%</td>
<td>7  43%</td>
<td>15  44%</td>
<td>3  43%</td>
<td>37  49%</td>
</tr>
<tr>
<td>PERS</td>
<td>1  5%</td>
<td>4  25%</td>
<td>8  24%</td>
<td>1  14%</td>
<td>14  18%</td>
</tr>
<tr>
<td>ADC</td>
<td>1  5%</td>
<td>3  19%</td>
<td>8  24%</td>
<td>-</td>
<td>12  16%</td>
</tr>
<tr>
<td>Transportation</td>
<td>4  21%</td>
<td>2  14%</td>
<td>7  20%</td>
<td>1  14%</td>
<td>14  18%</td>
</tr>
<tr>
<td>Home Delivered Meals</td>
<td>1  5%</td>
<td>2  13%</td>
<td>2  6%</td>
<td>2  29%</td>
<td>7  9%</td>
</tr>
<tr>
<td>Assisted Living Subsidy</td>
<td>-</td>
<td>1  6%</td>
<td>2  6%</td>
<td>-</td>
<td>3  4%</td>
</tr>
<tr>
<td>One-time/ Intermittent Service</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disposable Medical Supplies</td>
<td>5  26%</td>
<td>6  38%</td>
<td>4  12%</td>
<td>3  43%</td>
<td>18  24%</td>
</tr>
<tr>
<td>Home Modification</td>
<td>6  32%</td>
<td>4  25%</td>
<td>5  15%</td>
<td>1  14%</td>
<td>16  21%</td>
</tr>
<tr>
<td>Prescription Medication</td>
<td>4  21%</td>
<td>3  19%</td>
<td>12  35%</td>
<td>1  14%</td>
<td>20  26%</td>
</tr>
<tr>
<td>Assistive Device</td>
<td>4  21%</td>
<td>6  38%</td>
<td>4  12%</td>
<td>2  29%</td>
<td>16  21%</td>
</tr>
<tr>
<td>Chore</td>
<td>5  26%</td>
<td>1  6%</td>
<td>6  18%</td>
<td>-</td>
<td>12  16%</td>
</tr>
<tr>
<td>Nutritional Supplement</td>
<td>1  5%</td>
<td>2  13%</td>
<td>2  6%</td>
<td>1  14%</td>
<td>6  8%</td>
</tr>
<tr>
<td>Respite</td>
<td>-</td>
<td>4  25%</td>
<td>1  3%</td>
<td>-</td>
<td>5  7%</td>
</tr>
<tr>
<td>Groceries</td>
<td>1  5%</td>
<td>1  6%</td>
<td>1  3%</td>
<td>1  14%</td>
<td>4  5%</td>
</tr>
<tr>
<td>Dental Care</td>
<td>1  5%</td>
<td>2  13%</td>
<td>-</td>
<td>-</td>
<td>3  4%</td>
</tr>
<tr>
<td>TOTAL # of Services Selected</td>
<td>14</td>
<td>16</td>
<td>15</td>
<td>11</td>
<td>16</td>
</tr>
</tbody>
</table>
Figure 2. Frequently selected services by participants in each cluster.
Figure 3. Average cost per day of services purchased by participants in each cluster.
REFERENCES


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http://www.aoa.gov/AoARoot/AoA_Programs/OAA/oaa.aspx


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http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Balancing/Money-Follows-the-Person.html

http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Self-Directed-Personal-Assistant-Services-1915-j.html


## Appendix A

### Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>AAA</td>
<td>Area Agency on Aging</td>
</tr>
<tr>
<td>ACA</td>
<td>Affordable Care Act</td>
</tr>
<tr>
<td>ADLs</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>AoA</td>
<td>Administration on Aging</td>
</tr>
<tr>
<td>BBA</td>
<td>Balanced Budget Act</td>
</tr>
<tr>
<td>CFC</td>
<td>Community First Choice</td>
</tr>
<tr>
<td>CLP</td>
<td>Community Living Programs</td>
</tr>
<tr>
<td>DRA</td>
<td>Deficit Reduction Act</td>
</tr>
<tr>
<td>HCBS</td>
<td>Home and Community-Based Services</td>
</tr>
<tr>
<td>IADLs</td>
<td>Instrumental Activities of Daily Living</td>
</tr>
<tr>
<td>LTC</td>
<td>Long Term Care</td>
</tr>
<tr>
<td>MFP</td>
<td>Money Follows the Person</td>
</tr>
<tr>
<td>OAA</td>
<td>Older Americans Act</td>
</tr>
<tr>
<td>PCS</td>
<td>Personal Care Service</td>
</tr>
</tbody>
</table>
Appendix B

Measures

Information about services purchased by participants was derived from data provided by service coordinators. Services available for purchase on a routine or one-time intermittent basis were:

- Adult day care (ADC)
- Assisted living costs
- Assistive devices
- Chore
- Companion/homemaker (C/H)
- Dental care (optional by AAA)
- Disposable medical supplies
- Groceries
- Home delivered meals
- Home modification/ house rehabilitation
- Nutritional supplements
- Personal care
- Personal emergency response system (PERS)
- Prescription medications
- Recreational devices and senior apartment rent support
- Respite
- Transportation

Health Conditions

**Do you (participant) have any of the following health conditions**

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<thead>
<tr>
<th>Condition</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. cancer, a malignant tumor or leukemia?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. chronic lung disease such as chronic bronchitis, COPD, emphysema, or asthma?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>3. depression?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. diabetes or high blood sugar?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. heart attack, by-pass/valve surgery, stroke, etc?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. high blood pressure or hypertension?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. memory problems?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. osteoporosis?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. stomach or intestinal disorders?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. arthritis?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Do you have any other health problems that have not been mentioned?</td>
<td></td>
<td></td>
</tr>
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</table>

**Unmet needs**

**Do you (participant) have any personal care needs that are**

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Don’t</th>
<th>Refuse</th>
</tr>
</thead>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Yes</td>
<td>No</td>
<td>Don’t Know</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-----</td>
<td>----</td>
<td>------------</td>
</tr>
<tr>
<td>Do you <em>(participant)</em> ever go without a bath or shower when you need one?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you <em>(participant)</em> ever go without a meal when you need one?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you <em>(participant)</em> ever go without taking your medicine when you need it?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are you ever <em>(participant)</em> unable to use the bathroom when you need to?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you <em>(participant)</em> ever talked with your support coordinator about any special equipment or changes to your home that might make your life easier?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you <em>(participant)</em> need more help with things around the house than you are now receiving?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you <em>(participant)</em> feel safe in your home?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can you <em>(participant)</em> get to places you need to go by using the transportation services?</td>
<td></td>
<td></td>
<td></td>
</tr>
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</table>

**General Program Questions**

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<th>Question</th>
<th>Not at all Likely</th>
<th>Somewhat Likely</th>
<th>Very Likely</th>
<th>Almost Certain</th>
<th>Unknown (DK)</th>
<th>Refuse</th>
</tr>
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<tbody>
<tr>
<td>How likely is it that you would have gone into a nursing home without these services?</td>
<td></td>
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<tr>
<td>How likely is it that you will enter a nursing home in the next 3 months?</td>
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</tbody>
</table>
Appendix C

Journal Submission Guidelines

Author instructions for submission to the *Journal of Aging & Social Policy* were retrieved from http://www.tandfonline.com/action/authorSubmission?journalCode=wasp20&page=instructions#.U0A9RvldW4I:

Please note that *Journal of Aging & Social Policy* uses CrossCheck™ software to screen papers for unoriginal material. By submitting your paper to *Journal of Aging & Social Policy* you are agreeing to any necessary originality checks your paper may have to undergo during the peer review and production processes.

**Manuscript Content.** The Journal is broadly concerned with efforts of both the public and private sectors to address the implications of population aging. The Journal welcomes manuscripts that call attention to needs that merit greater attention from policymakers, analyze significant policy options to achieve policy goals, and evaluate policy initiatives that have been implemented. The Journal welcomes manuscripts concerned with all of the major issues that affect older people, including financial security, employment, retirement, health (physical and mental), long-term care, housing, and transportation. In addition, the Journal welcomes manuscripts on the experiences of older people with other institutional sectors that receive less widespread attention.

The Journal publishes both research articles and commentaries. In research articles, a major emphasis is on the reporting of research findings. Authors of research articles are expected to provide balanced attention to policy and research. Articles must be framed in a policy context; a full discussion of the policy implications of research findings is expected. Authors should explain their research methods clearly but concisely. The data analysis and reporting of research findings should be organized to contribute to an understanding of the central policy issue.

Through commentaries, authors can offer their opinions on policy issues. Commentaries may offer arguments for policy goals, recommendations regarding promising policy options, or interpretation of the results of policy initiatives. Commentaries typically are shorter than research papers.

In writing about policy developments, authors should emphasize underlying issues rather than matters requiring immediate action. Authors should anticipate the Journal’s long lead time for publication by emphasizing content that is likely to remain of interest to readers for several years after it is written.

Because the scope of the Journal is global, manuscripts that address policy issues in nations around the world are welcome. Historically, the Journal has been based in the United States with most of its authors and subscribers located there. Most articles have addressed issues as they are experienced in the United States. However, the number of international authors who contribute to the Journal is increasing and the international literature is expanding. All authors are encouraged to place their manuscripts in an international context. Manuscripts may report research that reflects experiences in a single country, but papers should reflect the international literature on both underlying aging processes and policy developments. Please consult our guidance on keywords here.

**Submission of Manuscripts.** *Journal of Aging & Social Policy* receives all manuscript submissions electronically via its Editorial Manager site located at http://www.editorialmanager.com/jasp. Editorial Manager allows for rapid submission of original and revised manuscripts, and facilitates the review process and internal communication between authors, editors, and reviewers via a web-base platform. Editorial Manager technical support can be accessed
Submission of a manuscript to this journal represents a certification on the part of the author(s) that it is an original work, and that neither this manuscript nor a version of it has been published elsewhere or is being considered for publication elsewhere.

All manuscripts must be typed, double-spaced with a one-inch margin on all sides, and follow the current American Psychological Association (APA) style. Each manuscript should be accompanied by a title page including complete author name(s), affiliations, mailing address, phone, fax and e-mail information (for multiple author papers, provide complete information for each author and indicate the corresponding author). Manuscripts should not be longer than 20 pages (lengthier manuscripts may be considered at the discretion of the Editor). Manuscripts should include an abstract of approximately 100 words on a separate sheet of paper. Below the abstract, provide 3-10 key words for indexing purposes.

Submitted manuscripts will undergo blind peer review. Authors should avoid placing any form of identification either on the body of the manuscript or on the required abstract. Manuscripts that do not conform to these requirements will be returned to the authors for correction and will delay the review process.

As an author, you are required to secure permission if you want to reproduce any figure, table, or extract from another source. This applies to direct reproduction as well as “derivative reproduction” (where you have created a new figure or table which derives substantially from copyrighted sources).

References. References should be double-spaced, placed in alphabetical order, and listed on separate pages following the text. They should refer only to material cited in the manuscript and should follow the current APA style. In text, reference citations should include author and year of publication. Identify subsequent citations in the text in the same way as the first, not using ibid., op. cit., or loc. cit. If five authors or fewer, give names of all authors. For six authors or more, use “et al.” after the first author’s name. In the reference list, cite all authors.

The following are examples of reference style in the reference list:

Books

Periodicals

Tables and Figures. Tables and figures should not be embedded in the text but should be included on separate sheets or files. A short descriptive title should appear above each table with a clear legend and any footnotes suitably identified below. All units must be included. Figures should be completely labeled, taking into account necessary size reduction.
Illustrations submitted (line drawings, halftones, photos, etc.) should be clean originals or digital files. Digital files are recommended for highest quality reproduction and should follow these guidelines:

- 300 dpi or higher
- Sized to fit on journal page
- EPS, TIFF, or PSD format only
- Submitted as separate files, not embedded in text files

Color illustrations will be considered for publication; however, the author will be required to bear the full cost involved in color art reproduction. Color art can be purchased for online-only reproduction or for print + online reproduction. Color reprints can only be ordered if print + online reproduction costs are paid. Rates for color art reproduction are: Online-Only Reproduction: $225 for the first page with color; $100 per page for the next three pages of color. A maximum charge of $525 applies. Print + Online Reproduction: $900 for the first page of color; $450 per page for the next three pages of color. A custom quote will be provided for articles with more than four pages of color.

Proofs. Page proofs are sent to the designated author using Taylor & Francis’ Central Article Tracking System (CATS). They should be carefully checked and returned within 48 hours.

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Appendix D

IRB Approval Letter

MEMORANDUM

DATE: February 11, 2014
TO: Karen A Roberto, Raven Weaver
FROM: Virginia Tech Institutional Review Board (FWA00000572, expires April 25, 2018)
PROTOCOL TITLE: Service Use by Vulnerable Older Adults
IRB NUMBER: 14-167

Effective February 11, 2014, the Virginia Tech Institution Review Board (IRB) Chair, David M Moore, approved the New Application request for the above-mentioned research protocol.

This approval provides permission to begin the human subject activities outlined in the IRB-approved protocol and supporting documents.

Plans to deviate from the approved protocol and/or supporting documents must be submitted to the IRB as an amendment request and approved by the IRB prior to the implementation of any changes, regardless of how minor, except where necessary to eliminate apparent immediate hazards to the subjects. Report within 5 business days to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.

All investigators (listed above) are required to comply with the researcher requirements outlined at:

http://www.irb.vt.edu/pages/responsibilities.htm

(Please review responsibilities before the commencement of your research.)

PROTOCOL INFORMATION:

Approved As: Exempt, under 45 CFR 46.110 category(ies) 4
Protocol Approval Date: February 11, 2014
Protocol Expiration Date: N/A
Continuing Review Due Date*: N/A

*Date a Continuing Review application is due to the IRB office if human subject activities covered under this protocol, including data analysis, are to continue beyond the Protocol Expiration Date.

FEDERALLY FUNDED RESEARCH REQUIREMENTS:

Per federal regulations, 45 CFR 46.103(f), the IRB is required to compare all federally funded grant proposals/work statements to the IRB protocol(s) which cover the human research activities included in the proposal / work statement before funds are released. Note that this requirement does not apply to Exempt and Interim IRB protocols, or grants for which VT is not the primary awardee.

The table on the following page indicates whether grant proposals are related to this IRB protocol, and which of the listed proposals, if any, have been compared to this IRB protocol, if required.