The Effectiveness of Participant-Directed Home and Community-Based Services for Young Adults with Long-Term Care Disabilities: Analysis of a Randomized Control Trial

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BOSTON COLLEGE School of Social Work

# THE EFFECTIVENESS OF PARTICIPANT-DIRECTED HOME AND COMMUNITY-BASED SERVICES FOR YOUNG ADULTS WITH LONG-TERM CARE DISABILITIES: ANALYSIS OF A RANDOMIZED CONTROL TRIAL

A dissertation by

## MELISSA LINDLEY HARRY, MSW

Submitted in partial fulfillment of the requirements for a degree of Doctor of Philosophy

MARCH 2016

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Dissertation Co-Chairs: Dr. Kevin J. Mahoney & Dr. Ce Shen

#### Abstract

For young adults with disabilities, who face barriers in achieving markers of adulthood, a service gap has been identified during the transition to adulthood. Preliminary qualitative evidence suggests that participant-directed home and community-based services (PD-HCBS), which can be easily modified to meet an individual's needs, might aid these young adults as they transition into adulthood and provide an option to fill the service gap. However, research was needed to determine if young adults are significantly affected by having the option to develop an individualized spending plan and manage their own budget. In this study, secondary data analysis was employed in evaluating the effectiveness of the Cash and Counseling budget authority model of PD-HCBS for young adults aged 18 to 35 with long-term care disabilities and eligible for Medicaid who were enrolled in the Cash and Counseling Demonstration and Evaluation randomized control trial (n = 831). Using a theoretical framework based on the developmental life stage of young adulthood, theories of self-determination and consumer direction, and past research on PD-HCBS, I examined young adults' outcomes on community involvement,

satisfaction ratings, unmet needs for assistance, and health status compared to peers through self-reports or through proxy respondents. Multivariate logistic regression results showed that Cash and Counseling significantly increased the likelihood of young adults attending school or college at a preferred level, being very satisfied with when care was received, care arrangement, transportation, help around the house and community, personal care, and getting along with paid attendants, and having fewer unmet needs with health care at home and with transportation than controls receiving agency-based care. Bivariate logistic regression models also showed Cash and Counseling members were significantly more likely to attend activities at a preferred level, be very satisfied with life, and have lower likelihoods of unmet personal care needs. These findings support the effectiveness of the Cash and Counseling model with young adults with disabilities and as an option to help fill the service gap for this population. Future research and intervention could address how other influential factors identified affect outcomes and test PD-HCBS during different aspects of the transition to adulthood.

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# LIST OF ABBREVIATIONS

ACA:	Affordable Care Act
ADL:	Activities of Daily Living
CCDE:	Cash and Counseling Demonstration and Evaluation
CDTE:	Consumer-Directed Theory of Empowerment
HCBS:	Home and Community-Based Services
IDEA:	Individuals with Disabilities Education Act
IADL:	Instrumental Activities of Daily Living
PD-HCBS:	Participant-Directed Home and Community-Based Services
SDT:	Self-Determination Theory

### **Chapter I. Introduction**

#### Purpose

Young adulthood has been defined as being between the ages of 18 to 40 in Erikson's (1950) Stages of Development, or at least to age 30 or 35 for modern young adults (Côté, 2006; Konstam, 2015). It has also been referred to as *emerging adulthood* for the ages between the late teens through the 20's (Arnett, 2015), and *early adulthood* from ages 18 to 34 (Furstenberg, Rumbaut, & Settersten, 2005). The U.S. Census Bureau (2014) reported that approximately 4.4 million, or 6%, of the over 72.9 million young adults aged 18 to 34 in the United States in 2014 had a disability. Many of these young adults have severe disabilities affecting activities of daily living requiring specialized long-term health care services to meet personal care needs sufficiently (Kaufman & Pinzon, 2007). According to data from the 2013 American Community Survey, when compared to peers without disabilities, adults with disabilities aged 21 to 64 face higher rates of poverty (28.2% versus 12.5%) and of achieving only a high school diploma (34.2% versus 25.4%), and lower rates of employment (34.5% versus 76.8%), college attendance (31.4% versus 32.3% for achieving some college or an associate degree; 13.5% versus 32.1% for a bachelor's degree or more education), and earning potential (median full-time annual earnings of \$38,300 versus \$43,300; median household income of \$39,400 versus \$62,000) (Erickson, Lee, & von Schrader, 2015). According to Erickson et al. (2015), adults with self-care disabilities had the lowest employment rate (15.6%) and percentage actively looking for work (4.6%), while those with independent living disabilities had the lowest rate of full-time/full-year employment (7.2%) and the

highest percentage of individuals having only a high school diploma or equivalent (36.5%). This suggests that the disparity in socioeconomic and education attainment in adulthood between people with and without disabilities might more intensely affect young adults with severe disabilities who need assistance with activities of daily living and require long-term care.

Numerous barriers to self-sufficiency and other markers of adulthood continue to confront young people with disabilities (Blomquist, 2007; Hendey & Pascall, 2001; Stewart et al., 2012; Stewart et al., 2001). This is even though research has shown that many of these young adults report having educational, independent living, community involvement, employment, and relational goals similar to able-bodied peers (Blomquist, 2007). Research is available on the differential experience of the transition to adulthood for young adults with a wide range of disabilities (Blomquist, 2007; Chiang, Cheung, Li, & Tsai, 2012; Gray et al., 2014; Hendey & Pascall, 2001; Lin, Ting Lee, & Adirim, 2015; Stewart et al., 2012; Stewart, Law, Rosenbaum, & Willms, 2001). In addition to the financial costs associated with having a disability to the individual, their families, and society (Eiken, Sredl, Burwell, & Gold, 2011; Erickson et al., 2015), there are also mental health comorbidity issues in childhood (Brereton, Tonge, & Einfeld, 2006), and in adulthood (Crocker, Prokić, Morin, & Reyes, 2014; Einfeld et al., 2006; Guetzloe, 1991; Kemp, 2006; Korff, Ormel, Katon, & Lin, 1992; Shen, Smyer, Mahoney, Loughlin, et al., 2008; Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008; Schmitz, Wang, Malla, & Lesage, 2009), as well as community involvement and independent living barriers (Blomquist, 2007; Gray et al., 2014; Hendey & Pascall, 2001; Lin et al., 2015). Taken

together, it is evident that improving outcomes for young adults with disabilities is a challenge that needs to be addressed.

The transition to adulthood has been identified as a critical area for policy change and intervention targeting youth with disabilities in order to improve independent living, employment, and educational attainment in adulthood for this population (O'Day & Stapleton, 2009; U.S. Department of Education, 2007). Young adults with disabilities can experience two specific types of transitions (Stewart et al., 2012). One transition is the typical experience of becoming an adult with new responsibilities and roles that tends to take place over an extended period for this group (Croke & Thompson, 2011; King, Baldwin, Currie, & Evans, 2005). Many young adults with disabilities also transition from secondary school and pediatric support services into adult support and health services (Smith & Routel, 2010; Stewart et al., 2012).

Improving the transition to adulthood for young people with disabilities has been identified as an area of concern in the U.S. education system where the amended Individuals with Disabilities Education Act (IDEA) (2004) placed an emphasis on increasing self-determination and incorporating transition components into secondary education. IDEA transition services include identifying employment and adult living objectives in Individualized Education Program plans for youth with disabilities, making community resource linkages, and providing outside agency and other service referrals (U.S. Department of Education, 2007). However, because IDEA only covers students with disabilities up to or through the age of 22, dependent on the state, transition services typically end upon completion of secondary school. After IDEA supports have ended, a service gap has been described between secondary/pediatric and adult services, as few

resources exist for youth with disabilities upon high school graduation (Cheak-Zamora, Teti, & First, 2015; O'Brien, 2013; O'Day & Stapleton, 2009; Stewart, Law, Rosenbaum, & Willms, 2001). Individuals can also spend excessive amounts of time on waitlists, in some cases years, for waiver services (O'Brien, 2013; Serres & Howatt, 2015a). This service gap has also been recognized internationally (F. Mitchell, 2015). As described by Stewart et al. (2001) for young adults with congenital disabilities, the gap that exists between secondary school and adult care services is like falling off a "cliff" (p. 12), where a "chasm or gulf" (p. 12) in service availability and options persists between secondary school and adult care services. More programs and policies are needed to bridge this gap between adolescence and adulthood for youth and young adults with disabilities requiring long-term care (Harry, MacDonald, et al., 2016; F. Mitchell, 2015; O'Brien, 2013; O'Day & Stapleton, 2009; Smith & Routel, 2010; Stewart et al., 2001).

A number of recommendations for transition service options for youth and young adults with disabilities have been reported in the literature. King et al. (2005) recommend a conceptual model representing a continuum of service care composed of short and longterm goals coupled with a multifaceted and interdisciplinary person-environment approach to assist young adults with disabilities through the transition from secondary school into adulthood. Others advocate for the importance of self-determination for youth and young adults in attaining successful transitions (Carter, Lane, Pierson, & Stang, 2008; Hui & Tsang, 2012; Wehmeyer & Palmer, 2003; Wehmeyer, Palmer, Shogren, Williams-Diehm, & Soukup, 2013; Wehmeyer & Schwartz, 1997), as well as person or student-centered planning (Cobb & Allwell, 2009; Croke & Thompson, 2011). Personcentered planning encompasses a constellation of approaches for including people with disabilities and their families in planning their own lives and futures (O'Brien & Lovett, 1993). Essentially, people with disabilities, with the support of their family members and other community members as needed and wanted, are encouraged to take action and make positive changes in their lives based on their own needs and wants, rather than having those needs and wants dictated to or for them (O'Brien & Lovett, 1993). These options seem especially relevant for youth and young adults with disabilities. Others focus on providing services within a life-course perspective (Stewart et al., 2012), and supporting programs that provide youth with employment, vocational rehabilitation, and community linkages (Brewer et al., 2011).

Upon completion of high school, some young adults, particularly those with intellectual or developmental disabilities, enter into day programs or sheltered work environments (Migliore, Mank, Grossi, & Rogan, 2007). Others take part in supported employment (Mank, Cioffi, & Yovanoff, 2003; Plotner & Oertle, 2011) and community living (Medicaid.gov, n.d.c). Although not a specific form of transition services, individualized budgets have been posited as a self-determined support for young adults in transition (Smith & Routel, 2010). One individualized budget option, participant-directed (sometimes referred to as consumer-directed or self-directed) personal care services, which can be personalized and flexibly tailored to an individual's particular situation (Brown et al., 2007), may provide an additional option to help fill the service gap experienced by young adults with disabilities (Harry, MacDonald, et al., 2016).

Personal care services based on a participant-directed budget may act as a flexible service bridge between adolescence and adulthood for young adults with severe disabilities requiring long-term care, improving the transition to adulthood. Participantdirection may do so by providing additional long-term home and community-based service (HCBS) options for these young adults (Harry, MacDonald, et al., 2016). HCBS focuses on providing supports for individuals with disabilities to live at home, in group homes, or otherwise in the community (Medicaid.org, n.d.c), supported traditionally through agency-based services. By comparison, participant direction of personal care services, goods, and supports is an additional option for long-term care HCBS delivery (Crisp et al., 2010). More specifically, participant-directed HCBS (PD-HCBS) allow for individualized care services that can be adapted to meet the health and personal care needs of participants of all eligible ages and with a wide range of disabilities, giving them control over the services they need to live at home in the community.

The current body of research on PD-HCBS for youth and young adults has been qualitative in nature, providing positive exploratory results through rich data on the perceptions of individuals. Findings from these qualitative studies suggest that PD-HCBS may improve aspects of the transition to adulthood for young adults, such as facilitating social and community involvement and addressing unmet needs by increasing choice and control while providing needed care and services (Harry, MacDonald, et al., 2016; F. Mitchell, 2012, 2013, 2015; Orentlicher & Frattarola-Saulino, 2014; Robinson et al., 2012). However, most previous research on PD-HCBS in the United States has focused on either adults or children separately, only recently focusing on young adults exclusively (Harry, MacDonald, et al., 2016; Orentlicher & Frattarola-Saulino, 2014). Furthermore, research employing comparison or control groups, random assignment, and larger samples is required to ascertain whether young adults are significantly positively affected by enrollment in PD-HCBS programs when compared to their peers receiving other types of supports, such as traditional, agency-based services. As state Medicaid expansion continues under the Affordable Care Act (ACA), more young people will become eligible for PD-HCBS waivers and state plans (Rudowitz & Musumeci, 2015). States like Minnesota are also continuing to make changes based on the Supreme Court's 1999 Olmstead decision (State of Minnesota Olmstead Plan, 2016), which supported the community integration of people with disabilities, including by making unjustified institutionalization a form of discrimination against people with disabilities and mandating that community-based services must be offered through public entities (Olmstead v. L.C. 1999). Along with providing evidence of the effectiveness of participant direction, additional research could help with developing new, or modifying existing, programs in the spirit of the Olmstead decision to best meet the needs of this group of young people.

My purpose with this dissertation was to study whether the PD-HCBS option is an effective approach to fill the post-secondary school service gap by providing needed supports for young adults with severe disabilities requiring long-term care services. I did so by undertaking a robust examination of the outcomes for Medicaid-eligible young adults aged 18 to 35 with long-term care disabilities who were enrolled in the Cash and Counseling Demonstration and Evaluation (CCDE) randomized control trial. In a demonstration that took place in Florida, New Jersey, and Arkansas between 1999 and 2003, the CCDE examined the effectiveness of one PD-HCBS option, Cash and Counseling, compared to agency-based care as usual for HCBS personal care services provided by Medicaid (Brown et al., 2007). In this dissertation, I examined the effectiveness of the Cash and Counseling model of PD-HCBS with young adults by

analyzing the nine-month outcomes between randomly assigned Cash and Counseling treatment group members and control group members receiving agency-based care as reported by young adult participants or their proxy respondents. I did so based on previous research and using theoretical and empirical work on young adulthood as a developmental life stage (Arnett, 2015; Côté, 2006; Erikson, 1950; Furstenberg et al., 2005; Konstam, 2015), the effects of self-determination in participant-directed programs (Nerney & Shumway, 1996), determinants of self-determination (Ryan & Deci, 2000), and the effects of consumer direction on community integration and quality of life (Kosciulek, 1999; Kosciulek, 2005; Kosciulek & Merz, 2001).

### **Study Significance**

The significance of this dissertation to society, as well as to the social work professionals who aid these young adults, is gaining a better understanding of the effects of PD-HCBS for young adults with severe disabilities requiring long-term care during the transition to adulthood and in young adulthood. Improving our understanding of the outcomes for young adults in PD-HCBS could help in the expansion, development, enhancement, and modification of participant-directed services to better meet the needs of this population. Findings, if significant, may motivate social workers and other stakeholders in long-term care services to support and expand this form of service as a viable option for filling the transition service gap for young adults with disabilities. Increased knowledge may also provide new areas for research on the transition to adulthood.

#### **Specific Aims**

The primary aim of this dissertation is to address gaps in the literature in order to gain a better understanding of the effects of PD-HCBS programs for young adults with severe disabilities affecting activities of daily living, who are eligible for Medicaid and require long-term care, over the transition to adulthood. To do so, I examined the effects of PD-HCBS with young adults enrolled in the CCDE in four specific areas. These included examining how enrollment in the Cash and Counseling model of PD-HCBS affected 1) community involvement, 2) satisfaction ratings, 3) unmet needs for assistance, and 4) young adults' health status rating compared to peers between CCDE treatment and control group respondents at nine-month follow-up.

## **Research Questions**

In order to fill the identified research gaps regarding the effectiveness of PD-HCBS for young adults with severe disabilities affecting activities of daily living during the transition to adulthood and in young adulthood, in this dissertation I employed quantitative methods in answering four guiding research questions associated with study aims:

- Do young adult participants randomly assigned to the Cash and Counseling treatment groups have greater likelihoods of community involvement than those in the control groups at nine-month CCDE follow-up, including when controlling for baseline demographic and related variables?
- 2. Do young adult participants randomly assigned to the Cash and Counseling treatment groups have greater likelihoods of being very satisfied with life and the

program than those in the control groups at nine-month CCDE follow-up, including when controlling for baseline demographic and related variables?

- 3. Do young adult participants randomly assigned to Cash and Counseling treatment groups have lower likelihoods of unmet needs for assistance than those in the control groups at nine-month CCDE follow-up, including when controlling for baseline demographic and related variables?
- 4. Do young adult participants randomly assigned to Cash and Counseling treatment groups have a lower likelihood of having a poor or fair health status compared to their peers than those in control groups at nine-month CCDE follow-up, including when controlling for baseline demographic and related variables?

#### **Chapter II. Literature Review**

#### A Historical Perspective of PD-HCBS in the United States

In the early years of the United States, Elizabethan Poor Laws dictated the treatment of people with disabilities, who were thought of as morally corrupt and were hidden away or abandoned by families unwilling to offer support (Lightfoot, 2009). As described by Lightfoot (2009), institutionalization in sanitariums and state hospitals became the primary means of care for much of the country's population of people with psychiatric and intellectual or developmental disabilities in the later eighteenth century. However, the twentieth century saw vast changes in the treatment of people with disabilities. Lightfoot went on to explain how the civil rights movements of the 1960's helped pave the way for disability rights movement advocates who facilitated the passage of the 1973 Vocational Rehabilitation Act. This civil rights legislation prohibited discrimination against those with disabilities and placed into law the rights of reasonable accommodations and community accessibility for people with disabilities, rights later expanded under the Americans With Disabilities Act (ADA) of 1990 (Lightfoot, 2009). Contemporaneously, the independent living movement, which developed out of the disability rights movement, originated the idea of PD-HCBS (Squillace, 2000). It did so with an emphasis on "self-determination, choice, independence, control, and decisionmaking authority" (Squillace, 2000, p. 21) in long-term care for people with disabilities.

Participant direction was a reaction to and a "major paradigm shift" (Crisp et al., 2010, p. 1-1) from public HCBS long-term care programs. Although public HCBS focused on providing services to people with disabilities at home or in their community,

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these services were not self-determined. As described by Crisp et al. (2010), public HCBS long-term care was instead based on a medical model that traditionally viewed people with disabilities as lesser and unable to make their own choices regarding personal care, requiring professionals to make those decisions for them. Crisp et al. stated PD-HCBS is an alternative to this medical model that focuses on helping participants live at home in the community through hiring individuals personally chosen by participants, designating representatives trusted by participants to help with program-related decisions as needed, and offering supports to assist participants with administering and managing their services. This is in contrast to group homes, other residential types of HCBS facilities, and agency-based HCBS where care is typically received at times convenient to agency caregivers, caregivers are initially unknown to participants, and care is managed, in some cases dictated, by the agency or other professionals (Crisp et al., 2010). Thus, participant direction is a barrier-breaking option that puts control back into the hands of people with disabilities who have historically had little choice in setting the policies or choosing the services necessary for their everyday functioning.

Participant direction emphasizes participant choice and control through providing program participants with budget and/or employer authority (Crisp et al., 2010). Employer authority gives participants, or their designated representatives, control over the hiring, training, and firing of personal care attendants, who could be family members, friends, or other individuals within program guidelines. Budget authority not only encompasses employer authority, but also allows enrolled participants, and participant representatives if designated, to manage an individualized monthly allowance for purchasing participants' needed personal care goods and supports, as well as home and vehicle modifications and other services that let them live more independently (Crisp et al., 2010). Consequently, PD-HCBS programs with budget authority offer the greatest amount of self-determined options for participants to make personal care decisions that enhance independence. In addition to choosing their own paid caregivers, with PD-HCBS participants can choose the days and times they receive care and what services they receive based on their allocated budget and within state guidelines, an inherent flexibility that is not often found in agency-based HCBS programs (Brown et al., 2007).

#### Medicaid-Based PD-HCBS Delivery in the U.S.

HCBS programs for Medicaid-eligible individuals in the U.S. are offered through state plans and HCBS waivers (Crisp et al., 2010). Medicaid, a means-tested entitlement program that provides medical assistance to people with low incomes in the U.S., is a state and federal partnership that was added to the Social Security Act in the Social Security Amendments of 1965 as Title XIX Grants to States for Medical Assistance Programs. Under Title XIX, §1902 of the Social Security Act, entitled State Plans for Medical Assistance, laid out specific rules requiring states to develop and submit state plans for providing medical assistance with both mandatory (e.g., nursing homes, assisted living) and optional (e.g., personal care assistance) components that, when approved by the Centers for Medicare and Medicaid (CMS), had to be offered to all eligible individuals (Crisp et al., 2010). Joint funding from these entitlement programs comes from the federal government and the states using guidelines set forth in the Federal Medical Assistance Percentages (FMAPs) based on state capita income (Medicaid.gov, n.d.b). The FMAPs dictate how much federal funding states with compliant plans may receive for Medicaid programs. States currently receive an average of 57% FMAP,

ranging from 50 to 75%, with states with higher per capita incomes receiving less and those with lower per capita incomes receiving more, potentially up to the maximum of 82% (Medicaid.gov, n.d.b).

The Social Security Act did not initially contain language related to HCBS or self-direction. These sections were added later as a need was identified for deinstitutionalization and more community-based and independent-living options for Medicaid recipients requiring long-term care (Duckett & Guy, 2000). In the 1970's, some states started offering participant-directed personal care programs with employer authority for eligible Medicaid recipients within their state plans, allowing these individuals to choose and pay for their own personal care attendants in the community (Crisp et al., 2010; Doty, Kasper, & Litvak, 1996). In 1981, Congress instituted the HCBS waiver program by amending the Social Security Act in §2176 of the Omnibus Budget Reconciliation Act of 1981 to include §1915(c) (Duckett & Guy, 2000; Medicaid.gov, n.d.c; Miller, 1992). §1915(c) made HCBS widely available to individuals eligible for state-based Medicaid who had severe disabilities and were at an institutional or nursing home-level of care, providing them with options for supports to live within their community rather than in institutions (Medicaid.gov, n.d.c). Under §1915(c), states could develop §1915(c) HCBS waivers for individuals at a nursing home or institutional level of care based on federal guidelines (Crisp et al., 2010; Medicaid.gov, n.d.c). Through \$1915(c) waivers, these individuals could procure services from agencies that provided access to in-home personal care attendants and/or specialized nursing services to help continue living independently in their own homes, in residential group homes, or other community-based residential facilities (Crisp et al., 2010; Medicaid.gov, n.d.c).

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Starting in 1997, CMS granted Medicaid state plans the option to offer HCBS through a "consumer-directed service delivery model" (Crisp et al., 2010, p. 2-1). Following federal guidelines, states could develop and implement specialized state plans with self-directing HCBS personal care assistance components. According to Crisp et al. (2010), employer authority was initially the predominant form of personal care PD-HCBS. The Deficit Reduction Act of 2005 expanded upon employer authority by allowing states the opportunity to offer plans with budget authority to eligible participants.

State plans and HCBS waivers with self-directed options are now a growing service sector in long-term care for people with disabilities of all ages eligible for Medicaid. Although not a mandatory component of HCBS (CMS, 2014), there are 277 PD-HCBS option programs currently available in the 50 U.S. states (National Resource Center for Participant-Directed Services, 2013). In addition, as a result of the positive findings on the Cash and Counseling model that were identified in the CCDE (e.g., Brown et al., 2007), §1915(i) and §1915(j) state plan options were added to the Social Security Act in the Deficit Reduction Act of 2005 (Crisp et al., 2010). The Affordable Care Act of 2010 further modified §1915(i) to expand access to HCBS (CMS, 2010), as well as added the §1915(k) Community First Choice State Plan Option (Medicaid.gov, n.d.a; Medicaid.gov, 2014). Together these sections allow for more state control of selfdirection options for people with disabilities within state plans. Self-directed budget or payment programs are also available internationally, such as in Germany, the United Kingdom, and the Netherlands (Alakeson, 2010; Harkes, Brown, & Horsburgh 2012; Kodner, 2003), including those designed for young adults with disabilities in Scotland

and Australia (Cowen, Murray, & Duffy, 2011; F. Mitchell, 2012, 2013, 2015; Robinson et al., 2012).

#### The Cash and Counseling PD-HCBS Option

Cash and Counseling is a state-based PD-HCBS option that grants eligible participants both budget and employer authority over a monthly dollar amount similar to that which would be received for traditional, agency-based services (Brown et al., 2007). Medicaid eligibility is typically required for enrollment. Although eligibility rules and budget authority options can differ by state, such as what goods and services can be purchased with the allowance, in general Cash and Counseling allows for a number of basic tenets. These include: hiring, paying, training, managing, and firing attendants of participants' choosing; managing an individualized budget similar to the amount of money that would be paid for traditional, agency-based services for the individual; using the budget for purchasing needed personal care and independent living goods, services, and accommodations; receiving assistance with financial budget counseling from program counselors; and utilizing payroll services if needed (Brown et al., 2007; Dale & Brown, 2006; Doty, Mahoney, & Sciegaj, 2010). The primary link between the participant and the program are counselors, also called support brokers, who provide a range of services for self-directing participants. For example, as described by Brown et al. (2007), through phone calls or home visits in the CCDE:

Counselors interacted with consumers to (1) develop, review, and revise written plans for spending the monthly allowance in permissible ways; (2) offer advice about recruiting, hiring, and training workers; (3) offer advice about other services available in the community, among other issues; (4) monitor consumers' well-being; and (5) monitor use of the allowance. (p. 12) Participants can also designate decision-making representatives to act on their behalf in the program, such as a parent, spouse, child, or other individual that participants trust with helping manage their care (Brown et al., 2007). These individuals are chosen to represent and/or work with participants in managing participants' enrollment in PD-HCBS budget programs based on the Cash and Counseling model. Representatives who are legal guardians or other legally responsible individuals are required by state law to act as program representatives for enrolled participants. In some states, such as in Arkansas, representatives are restricted from being paid attendants in Cash and Counseling programs due to the potential conflict of interest associated with both representing participants and receiving funds as a paid attendant (Brown et al., 2007). Brown et al. (2007) went on to explain that during the CCDE, New Jersey and Arkansas did not allow representatives to also be paid attendants for participants. These dual relationships could open up opportunities for abuse of participant funds and were therefore avoided.

#### Findings on the Cash and Counseling Model of PD-HCBS

Previous research has shown that PD-HCBS based on a Cash and Counseling model reduces unmet instrumental activities of daily living (IADL) and personal care needs, improves satisfaction ratings, and is either at least as good as or better than agency-based care as usual for a host of health problems related to long-term care (Brown et al., 2007; Carlson, Foster, Dale, & Brown, 2007; Shen, Smyer, Mahoney, Loughlin, et al., 2008; Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008). Many of these significant findings extended over the three demonstration states and age groups studied. This was the case even though states had different median Cash and Counseling monthly allowance amounts (Florida = \$829 for adults and \$831 for children; New Jersey =

1.097; Arkansas = 313), and some individuals in the treatment groups had not received a budget by nine-month follow-up (Brown et al., 2007). The majority of these individuals were instead receiving agency-based services at follow-up while still part of the treatment groups (Dale & Brown, 2007). Findings from the CCDE showed that compared to control group members receiving traditional, agency-based services or usual care, non-elderly adult Cash and Counseling treatment group participants (defined as ages 18 to 59 in Florida and 18 to 64 in Arkansas and New Jersey) reported greater satisfaction ratings on life and a range of other areas, including aspects of the programs, had lower incidences of health problems like bedsores and urinary tract infections, and lower reported unmet needs for assistance with IADLs and personal care after the nine-month trial (Brown et al., 2007; Carlson et al., 2007; Foster, Brown, Phillips, Schore, & Carlson, 2003a; Foster, Brown, Phillips, Schore, & Carlson, 2003b). An additional reason for reductions in unmet needs may be that participants in Cash and Counseling sometimes used their budgets to purchase labor-saving devices, thus reducing their need for human assistance. Only elderly adults in Florida did not have significantly greater satisfaction ratings than control group members in that age group, which may be because 58% of these individuals in the treatment group had not received their allowance by follow-up and were instead relying on agency-based personal care services (Brown et al., 2007).

Studies were also conducted with demonstration workers, on intervention costs, and with additional subgroups. Workers hired by participants in the Cash and Counseling treatment groups also benefited from the program model, where they had many outcomes that were either equivalent to or better than those of workers in the control groups (Brown et al., 2007; Foster, Dale, & Brown, 2007). Cash and Counseling has also been shown to reduce costs related to hospitalization and other institutional forms of long-term care (Brown et al., 2007; Dale & Brown, 2006; Dale, Brown, Phillips, Schore, & Carlson, 2003). Personal care HCBS outlays for the Cash and Counseling treatment groups were greater initially in the CCDE, although in most cases not significantly so from the control groups (Brown et al., 2007). This was likely due to participants in the treatment groups actually receiving needed care (Dale & Brown, 2007; Dale et al., 2003). As reported by Brown et al. (2007), other Medicaid costs were lower for treatment group members, such as those related to long-term care and other health services. Long-term cost savings were also found, particularly in Arkansas (Dale et al., 2003; Doty et al., 2010). In addition, the program was found to be effective with children with developmental disabilities in Florida (Foster, Dale, Brown, Phillips, Schore, & Carlson, 2004), and elderly adults in Arkansas and nonelderly adults in New Jersey with mental health diagnoses (Shen, Smyer, Mahoney, Loughlin, et al., 2008; Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008).

Policy makers were originally concerned about a *substitution effect*, where paying family members of participants could reduce the amount of unpaid care provided by these individuals compared to when they had provided informal unpaid care prior to the program (Linsk, Keigher, Simon-Rusinowitz, & England, 1992; Simon-Rusinowitz, Mahoney, Loughlin, & Sadler, 2005). Policy makers worried that "families [would] reduce their efforts when services are provided and let the formal service system take over" (Linsk et al., 1992, p. 30). However, Linsk et al. (1992) stated that research on the substitution effect prior to the CCDE had shown little to no evidence of its existence. In fact, the CCDE found that, on average, paid attendants in each of the three states, some of

whom had been informal caregivers prior to the demonstration, reported spending over twice as much time providing unpaid care for the participant in a week than was paid for by the Cash and Counseling program (Brown et al., 2007). For instance, Brown et al. (2007) reported that for adults aged 18 and over, directly hired paid workers in the New Jersey treatment group worked an average of 46.4 hours a week, of which an average of only 19.9 hours were paid, while agency-based workers in that state only worked an average of 16.2 hours a week total, with no unpaid hours. This suggests that paid caregivers in Cash and Counseling were invested in providing assistance to participants, even when unpaid. When looking at total paid and unpaid hours of care participants had received in the past two weeks, treatment group participants did report fewer hours of total assistance, although this difference was only significant for working-age adults in Arkansas and elderly adults in Florida (Brown et al., 2007). Brown et al. posited that "the lower total hours of care for the treatment group may be due to increased use of equipment that can substitute for human assistance or to greater efficiency of the care provided" (p. 45). Participants in the treatment groups also received fewer hours of unpaid assistance, where significant differences were seen in Arkansas, for children in Florida, and for the elderly in New Jersey (Brown et al., 2007). However, aside for the nonsignificant differences for working-age adults in Arkansas and elderly adults in Florida, participants in the treatment groups did report receiving significantly more hours of paid care than control group members (Brown et al., 2007).

Brown et al. (2007) also showed that live-in caregivers in both the treatment and control groups continued to provide needed care as well, with a two-week average of 145.5 hours across the treatment groups and 150.6 hours across the control groups, where

children in Florida had the highest number of hours (see Brown et al., 2007, Table VI.1 p. 74). Some participants qualitatively described the primary reason for participants receiving unpaid care as more time being required to complete the actual care needed versus the amount of time allotted by the program (Eckert, San Antonio, & Siegel, 2004). Being able to hire attendants that were invested in participants' care, such as family members, through Cash and Counseling appeared to ensure that care was completed even if some of it was unpaid (Eckert et al., 2004; San Antonio & Niles, 2005). Together, these findings illustrate that paid family caregivers in Cash and Counseling continued to provide care over the amount they were paid for, negating the potential substitution effect (Simon-Rusinowitz et al., 2005).

Qualitative findings showed further positive short-term outcome experiences for participants in Cash and Counseling (Eckert et al., 2004; San Antonio, Eckert, Niles, & Siegel, 2003; San Antonio, Eckert, & Simon-Rusinowitz, 2006; San Antonio & Niles, 2005; San Antonio, Simon-Rusinowitz, Loughlin, Eckert, & Mahoney, 2007). For instance, as part of the CCDE, three qualitative studies were conducted through in-depth interviews with *care units* in each demonstration state. These care units included CCDE treatment group participants and/or participant representatives, paid attendants, and program counselors, with 27 care units interviewed in Arkansas (Eckert et al., 2004), 25 in New Jersey (San Antonio et al., 2003), and 24 in Florida (San Antonio & Niles, 2005). A subset of interview data from the Arkansas care units was also examined separately for 13 elderly adults and their familial caregivers (San Antonio et al., 2006).

Some of the major themes identified in these qualitative studies include those unique to PD-HCBS. In particular, participants placed a strong emphasis on the importance of family or "family-like" (Eckert et al., 2004, p. 179) relationships that were felt to contribute to trusting and familial working relationships between the participant and paid care attendant (San Antonio et al., 2003; San Antonio et al., 2006; San Antonio & Niles, 2005). Helping relationships were also often established prior to Cash and Counseling, and family and other caregivers were reported as able and willing to help out in a supportive and caring manner (Eckert et al., 2004; San Antonio et al., 2003; San Antonio et al., 2006; San Antonio & Niles, 2005). The support of a variety of community members was also felt to be very important for participants (Eckert et al., 2004; San Antonio et al., 2003; San Antonio & Niles, 2005). In addition, participants reported how they found satisfaction in making decisions for themselves about personal care services and monthly budget spending, supporting their desire of "maintaining as much independence as possible" (Eckert et al., 2004, p. 181). Eckert et al. (2004) also described how participants who had been self-employed previously highly valued having the ability to be their own employer and make employment-related decisions.

The qualitative studies showed that the Cash and Counseling program offered benefits not found in traditional, agency-based care. These included participants having flexibility with scheduling, trusting their caregivers, and actually receiving needed care, something that did not always happen with agency-based services (Eckert et al., 2004; San Antonio et al., 2003; San Antonio & Niles, 2005). Furthermore, having choice, control, and flexibility in making a wide range of purchases with their budget in order to meet their individualized needs was a very important aspect of the program for some participants (San Antonio et al., 2003; San Antonio & Niles, 2005).

Regarding overall program satisfaction, participants and care units reported

generally positive feelings about the program in each of the studies, although there were some areas for improvement. For instance, some problems encountered by participants included having a hard time finding someone to hire (in some cases because the hourly pay rate was thought to be too low by workers, as reported by some respondents), communication issues with the financial counselor, and difficulties "differentiating the roles of representative and paid worker" (Eckert et al., 2004, p. 199). In a few cases, conflict existed between participants and familial care attendants (San Antonio & Niles, 2005). In New Jersey, cultural and language issues also created problems with participants' ability to communicate effectively with program counselors, though the state was addressing this barrier (San Antonio et al., 2003).

#### Long-Term Experiences with Cash and Counseling

Positive qualitative long-term experiences with Cash and Counseling have also been reported. Researchers examined the long-term experiences, defined as being enrolled in one of the original Cash and Counseling demonstration programs for at least five years, for 11 young adult participants ages 23 to 34 with intellectual and other disabilities as described by unpaid familial program representatives (Harry, MacDonald, et al., 2016), and 17 adult participants ages 40 to 83 with physical or cognitive disabilities (Harry, Kong, et al., 2016). Both participants and representatives described the program helping improve participants' health outcomes and reducing unmet needs by granting participants the option of hiring individuals invested in their health, well-being, and overall care (Harry, Kong, et al., 2016; Harry, MacDonald, et al., 2016). For young adults, family members such as mothers, fathers, siblings, aunts, and cousins were the primary paid and unpaid caregivers, individuals who were deeply invested in young adults' care (Harry, MacDonald, et al., 2016). Harry, MacDonald, et al. (2016) explained that representatives described the Cash and Counseling-based PD-HCBS program as allowing young adults to hire trusted and familiar individuals who acted as personal caregivers and supported community involvement for young adult participants. Previous research with adult participants in the short-term qualitative studies had shown participants had a preference for family members as caregivers (Eckert et al., 2004; San Antonio et al., 2003; San Antonio et al., 2006). Adult participants aged 40 to 83 reported hiring more unrelated individuals as care attendants over the long-term, although some paid caregivers were family members, such as mothers, daughters, and daughters or sisters-in-law (Harry, Kong, et al., 2016). Both participants and representatives reported continued satisfaction with the program over time and emphasized the importance of the choice and control offered by the program (Harry, Kong, et al., 2016; Harry, MacDonald, et al., 2016). Both studies also showed that participants and representatives valued the independence the program granted participants, the relationships participants built and sustained through the program, and how the program ensured participants could continue living in their community. Additionally, enrollment in Cash and Counseling appeared to improve community involvement for both young and older adults due to the program allowing paid attendants to take participants into the community at times and to places chosen by participants, something that not all traditional, agency-based programs allowed. Harry, Kong, et al. (2016) also found that the program appeared capable of adapting to older participants' changing health needs and disability trajectories over time.

One of the long-term outcome studies did find some areas for program improvement. Specifically, program rules could be better clarified for representatives, particularly around what could and could not be purchased with the budget and who could be hired as care attendants (Harry, MacDonald, et al., 2016). However, program participants in the study of adults aged 40 to 83 did not express a lack of understanding program rules (Harry, Kong, et al., 2016).

The long-term studies did have some limitations. Participants and representatives were interviewed by telephone and in only one state's Cash and Counseling-based PD-HCBS program. The young adult study by Harry, MacDonald, et al. (2016) also only examined outcomes for those with severe communicative disabilities and interviewed familial program representatives of young adults, rather than a broader sample of stakeholders, such as parents, caregivers, and other service providers that were included in the studies conducted by others with this age group (F. Mitchell, 2012, 2013, 2015; Orentlicher & Frattarola-Saulino, 2014; Robinson et al., 2012), or with young adults themselves. Harry et al. did recommend examining whether findings extend to a broader range of young adults in other PD-HCBS programs. Finally, the study of adults 40 to 83 did not include participants with program representatives (Harry, Kong, et al., 2016), individuals who may have had different experiences in the program than participants managing the program themselves.

### **Young Adults and PD-HCBS**

The participant-directed services provided by one of the Cash and Counselingbased demonstration programs did appear to bridge the service gap during the transition to adulthood by providing Medicaid-eligible young adults with severe disabilities with individualized personal care services within the homes of family members, as described by familial program representatives of young adults (Harry, MacDonald, et al., 2016). A number of other recent qualitative studies have also been conducted with young adults managing participant-directed budgets during the transition to adulthood (F. Mitchell, 2012, 2013, 2015; Orentlicher & Frattarola-Saulino, 2014; Robinson et al., 2012). The findings from these studies show similar promise for this option to fill the service gap.

For six youth with disabilities aged 14 to 21 in Scotland, and as described by their parents, as well as advocates, policymakers, and others involved with self-directed care such as program managers, F. Mitchell (2012, 2013, 2015) found that increased choice and control was a primary benefit of the program. Young adults often made choices with the support or assistance of parents, particularly mothers, with varying levels of parental involvement (F. Mitchell, 2012). This varied level of shared choice-making was also found when examining choice-making by young adults with degenerative disabilities in a hospice setting, which was not participant-directed (W. Mitchell, 2011). F. Mitchell (2015) identified a range of facilitators and barriers to informed choice in self-directed supports for young adults, their family members, and providers. Ideally, in self-direction young adults should be able to make decisions for themselves through experiential knowledge and informed choices, including choices based on discussion with support people (F. Mitchell, 2015; W. Mitchell, 2011). Advocacy, as well as self-advocacy, was another important aspect of choice and control for young adults, although a number of barriers that could inhibit choice and control for young adults were identified (F. Mitchell, 2012, 2015). F. Mitchell (2012, 2015) described these barriers as including a lack of information access, negative attitudes presented by parents regarding choices made by young adults, professionals exhibiting deficit-focused attitudes regarding young adults' abilities, programmatic, bureaucratic, and geographic location-based problems, as

well as insufficient support for young adults who require more assistance with decisionmaking. While F. Mitchell (2012, 2013, 2015) presented helpful information, the sample for the study was small at only six youth and young adults and their associated stakeholders. Researchers also only focused on youth ages 14 to 21 who were currently transitioning out of pediatric/secondary school services. The findings did not extend to post-transition experiences.

Robinson et al. (2012) included a larger sample and age range in their study of a budget authority transition program in Australia. As described by Robinson et al. for 29 Australian young adults aged 20 to 36 with brain trauma and physical disabilities, choice and control was again a dominant theme in qualitative data analysis. Young adults had the flexibility to tailor their budgets to meet individual needs, such as purchasing home exercise equipment and meeting educational goals, as well as fulfilling needs related to emotional and psychological well-being. Limitations of the study included focusing on only one program, examining short-term outcomes, and not having a wider range of disability types represented in the sample.

Orentlicher and Frattarola-Saulino (2014) recently presented preliminary findings from a qualitative participatory action study conducted with young adults aged 18 and older with developmental disabilities as self-advocates, their family members, and service providers regarding experiences with participant-directed budgets in the eastern United States. Their preliminary results suggest participant-directed budgets improved young adults' hopes for the future, as well as facilitated an interdependent support network within their families. Orentlicher and Frattarola-Saulino also described some degree of insecurity about program funding, issues with balancing relationships with young adults' need for independence, and changing health concerns, including for familial caregivers. Final results are pending publication.

#### **Research Findings Summary**

Collectively, this growing body of research provides evidence of the effectiveness of participant direction, including the Cash and Counseling model of PD-HCBS, with multiple populations. National and international findings with young adults also suggest that participant-budget programs appear to provide an option for filling the service gap for young adults with disabilities transitioning out of secondary school and pediatric care. Qualitative research conducted thus far has shown participants, representatives, and others involved with PD-HCBS are generally satisfied with (Harry, MacDonald, et al., 2016; Robinson et al., 2012), or optimistic about (F. Mitchell, 2012; Orentlicher & Frattarola-Saulino, 2014), this option for young adults. Respondents also described young adults as receiving needed personal and health-related care and connecting with community (Harry, MacDonald, et al., 2016; Robinson et al., 2012). However, research is lacking on quantitative outcomes for young adults within PD-HCBS programs. Further research is therefore needed on the effectiveness of PD-HCBS models like Cash and Counseling for young adults with disabilities, including during the transition to adulthood and in young adulthood. Data collected in the CCDE, which evaluated the Cash and Counseling PD-HCBS option, presents an opportunity to examine these outcomes.

## **Theoretical Framework**

The discussion of the theoretical framework underlying this dissertation is presented in two parts. I first outline the theoretical foundation upon which this dissertation was based. This includes theories and frameworks related to: the developmental life stage of young adulthood (Arnett, 2015; Côté, 2006; Erikson, 1950; Furstenberg et al., 2005; Konstam, 2015); self-determination and participant direction in publicly funded HCBS (Nerney & Shumway, 1996); self-determination and human motivation (Ryan & Deci, 2000); and participant direction's effects on community integration and quality of life (Kosciulek, 1999; Kosciulek, 2005; Kosciulek & Merz, 2001). I then present a conceptual model for this dissertation developed based upon these theories and previous research on Cash and Counseling.

### **Developmental Life Stage of Young Adulthood**

Young adulthood, whether referred to as *emerging* or *early* adulthood, is a developmental life stage that is believed to extend into the late 20's or at least the mid 30's for modern young adults (Arnett, 2015; Côté, 2006; Erikson, 1950; Furstenberg et al., 2005; Konstam, 2015). It is characterized by self-development and an exploration of identity, social ties, purpose in life, employment options, and continuing education, as well as starting families, stepping into adult roles for the first time, and the potential for instability in all of these things (Arnett, 2015; Furstenberg et al., 2005; Konstam, 2015). An extension of what was originally described as adolescence during the time of industrialization, young adulthood is considered a result of the "economic and social conditions" (Furstenberg et al., 2005, p. 3) of modern post-industrialization. These conditions appear to lengthen the time frames for, and disrupt the order of, starting families and attaining education, employment, and independent living, making achieving financial self-sufficiency a more "protracted affair" (Furstenberg et al., 2005, p. 5) for modern young adults than for previous generations.

While common knowledge once assumed that the childhood pruning back of neural connections in the brain called apoptosis, or programmed cell death (Society for Neuroscience, 2008, p. 13), ended before adolescence, research has shown that the typical human brain continues the process of "apoptosis…into adulthood" (p. 13). Research utilizing advancements in magnetic resonance imaging in the last decade has shown that the human brain continues maturing into the 20's and 30's (Lenroot & Giedd, 2006; Tamnes et al., 2010; Toga, Thompson, & Sowell, 2006). Some areas of the brain do not reach full development until the 30's or 40's (Bartzokis et al., 2001; Sowell et al., 2003; Walhovd et al., 2005, as cited in Tamnes et al., 2010), although changes are less pronounced with time. This new information on the biological process of extended brain development sheds additional light on the prolonged time it can take to reach full adulthood for modern young adults (Furstenberg et al., 2005; Konstam, 2015).

Furthermore, young adults with disabilities tend to take longer to reach independent living and self-sufficiency markers of adulthood than peers without disabilities (Blomquist, 2007; Hendey & Pascall, 2001; Hirst & Baldwin, 1994; Stewart et al., 2012). Stewart et al. (2012) described a range of barriers these young adults can experience during the transition to adulthood, such as those found in the environment young adults interact with, disability type and how severely young adults are affected by it, a lack of access to information, having few choices or experiencing barriers to making choices, lack of discussions between providers and parents, the need for provider education, and young adults' personal attitudes that can become self-imposed barriers. Due to these important factors, it is appropriate for research, as in this dissertation, to focus on the age range of 18 to 35 in order to more fully capture this biological and social transition period for young adults with severe disabilities requiring long-term care.

# Self-Determination

The concept of self-determination that undergirds participant direction is an important theoretical basis for any examination of PD-HCBS. According to the Merriam-Webster (2015) dictionary, self-determination means having "free choice of one's own acts or states without external compulsion." However, Lightfoot (2009) pointed out that people with disabilities have not historically had many self-determined options. The independent living movement helped place the current emphasis on self-determination and community-based living, with a focus on dignity, ability, and inclusion of people with disabilities within the local community (Lightfoot, 2009). Self-determination has also been found to be a vital component of services for youth with disabilities while they transition into adulthood (Wehmeyer & Palmer, 2003; Wehmeyer et al., 2013; Wehmeyer & Schwartz, 1997), creating a rationale for the target population and research hypotheses examined in this dissertation.

The four principles of self-determination for people with disabilities in publicly funded support programs developed by Nerney and Shumway (1996) provide a central context for research on Cash and Counseling and PD-HCBS programs in general. These principles include people with disabilities having:

### FREEDOM

The ability of individuals, with freely chosen family and or friends, to plan a life with necessary support rather than purchase a program. **AUTHORITY** The ability of a person with a disability (with a social support network or circle if needed) to control a certain sum of dollars in order to purchase these supports. **SUPPORT** 

The arranging of resources and personnel-both formal and informal-that will

assist an individual with a disability to live a life in the community rich in community association and contribution. RESPONSIBILITY

The acceptance of a valued role in a person's community through competitive employment, organizational affiliations, spiritual development, and general caring for others in the community, as well as accountability for spending public dollars in ways that are life enhancing for persons with disabilities. (Nerney & Shumway, 1996, p. 4)

Cash and Counseling inherently supports Nerney and Shumway's (1996) principles. Essentially, Cash and Counseling is a program of participant-directed selfdetermination that provides HCBS needed by participants at the same time as giving participants freedom, authority, support, and responsibility over how their public HCBS dollars are spent (Brown et al., 2007). These principles also present a mechanism for the basis of how Cash and Counseling-based PD-HCBS functions: self-determination for participants in making choices regarding personal care through budget and employer authority, with supports available if needed. In detail, budget plans in Cash and Counseling are developed based on the person's unique needs as described by Brown et al. (2007), an example of person-centered planning, rather than a one-size-fits-all approach (O'Brien & Lovett, 1993). In Cash and Counseling, participants can make choices themselves or delegate decisions to representatives, all while having access to supportive services for managing their budgets and paying employees. In this dissertation, Nerney and Shumway's (1996) principles of self-determination embodied in the Cash and Counseling model of participant direction informed all comparisons between treatment and control group participants' nine-month CCDE follow-up outcomes.

Another theoretical framework on self-determination that is relevant to this dissertation is Self-Determination Theory (SDT). SDT was developed by Ryan and Deci (2000) in the field of psychology and applied to youth with disabilities by Hui and Tsang (2012). SDT is a macro-level theory that contains five micro-level theories: Cognitive Evaluation Theory, Organismic Integration Theory, Causality Orientations Theory, Basic Psychological Needs Theory, and Goal Contents Theory. As a whole, SDT is primarily concerned with the basis of human motivation that promotes self-determination on a continuum from non-self-determined to self-determined (Ryan & Deci, 2000). According to Ryan and Deci, self-determination is the ability to self-regulate and make autonomous choices in regards to one's life. Specifically, Ryan and Deci use SDT to theorize that human motivation, the desire to achieve one's inherent potential in a multitude of areas, is affected both intrinsically within and by an individual, and extrinsically, such as through the social or familial environments. SDT also allows for understanding how various factors either inhibit or support human motivation by respectively constraining or facilitating an individual's sense of personal autonomy, relatedness to others, and competence (Ryan & Deci, 2000). Each micro-level theory expands upon these factors.

Self-direction of HCBS through the Cash and Counseling option may provide an opportunity for young adults with disabilities to increase their self-determination by improving external environmental supports, as posited in the SDT (Ryan & Deci, 2000). Related research has discovered that patterns in disability trajectories can vary widely based on multiple factors unrelated to the disability itself (Nusselder, Looman, & Mackenbach, 2005). This is an important finding since it suggests external means of changing disability trajectories exist independent from the individual. PD-HCBS programs based on a Cash and Counseling model have already shown significant findings for improving participant health and well-being for people with disabilities (e.g., Brown et al., 2007; Carlson et al., 2007; Shen, Smyer, Mahoney, Loughlin, et al., 2008; Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008). The augmentation of external supports provided by Cash and Counseling may also result in changes to a participant's internal motivation, resulting in increased community involvement and feelings of satisfaction with enrollment in PD-HCBS programs. More specifically, having selfdetermination over a budget that can be used for such a wide array of personal care needs may positively affect many areas of young adults' lives. PD-HCBS may increase the opportunities for making life choices and potentially improve disability trajectories by providing freedom of choice and control, freedoms that could help break down some socio-environmental barriers to community involvement experienced by people with disabilities. This dissertation study is an initial examination of quantitative community involvement outcomes related to the self-determination inherent within PD-HCBS for young adults.

## The Consumer-Directed Theory of Empowerment

The Consumer Directed Theory of Empowerment (CDTE) presents an examination of how PD-HCBS affects quality of life, feelings of empowerment, and community integration (Kosciulek, 1999; Kosciulek, 2005; Kosciulek & Merz, 2001). The CDTE's primary hypothesis is that people with disabilities who are able to self-direct care through consumer direction by deciding when, how, and by whom vocational rehabilitation services are received would report higher levels of community integration, empowerment, and quality of life than individuals with disabilities who received care through traditional, non-self-directed services (Kosciulek, 1999). The main theory underlying this hypothesis was that being able to make executive decisions and control access to vocational rehabilitative services would improve community integration, be empowering, and improve overall quality of life for individuals who have disabilities. This theory was based on the assumption that it is preferable for people with disabilities to be able to make decisions for themselves rather than having to rely on others to make those decisions for them.

When Kosciulek (2005) tested the structural model for the CDTE with a sample of 721 individuals self-directing vocational rehabilitation services, the model was supported by significant relationships between each of the four constructs. Consumer direction significantly positively affected quality of life, community integration, and feelings of empowerment. Kosciulek found that consumer direction and community integration also significantly affected quality of life by way of feelings of empowerment for the sample. As described by Kosciulek:

Theoretically, these results illustrate that consumer direction and community integration have direct and indirect effects on [quality of life] QOL, both of which are statistically significant. In practice, this finding means that consumer QOL is enhanced by (a) increased control over all aspects of life (NICDLTS, 1996) and (b) full integration into home and family environments, social and leisure activities, and productive activity such as work (Willer et al., 1993). In relation to the purpose of this investigation (i.e., to test the CDTE in a [vocational rehabilitation] systems context), the results provide evidence that the CDTE model shown...is a valid theoretical model. (p. 47)

The CDTE is a theoretical framework that has the potential to provide an additional level of understanding and validity to the examination of how participant direction can improve the quality of life for young adults with disabilities by linking participant direction and improved quality of life with community involvement, including by way of personal empowerment (Kosciulek 1999; Kosciulek, 2005; Kosciulek & Merz, 2001). Research has applied the CDTE to business administration (Pranic, 2008), correctional services in Jamaica (Rhone, 2007), and consumer-directed personal care services for people with physical disabilities (Fleming-Castaldy, 2008). In this dissertation, the CDTE informs the evaluation of the effectiveness of PD-HCBS with community involvement and satisfaction for young adults in the CCDE.

## **Conceptual Model**

Presenting a conceptual model in a dissertation allows others to see the connections between the underlying theoretical framework and important concepts or constructs (Grant & Osanloo, 2014). As described by Grant and Osanloo (2014), the theoretical framework and conceptual model are distinct yet interconnected components of a dissertation:

We distinguish the two terms by clarifying that a theoretical framework is derived from an existing theory (or theories) in the literature that has already been tested and validated by others and is considered a generally acceptable theory in the scholarly literature. As Merriam (2001) proposed, it is the researcher's lens with which to view the world. It is the responsibility of the doctoral student to make a unique application of the selected theory (or theories) so as to apply theoretical constructs to his or her dissertation study...a conceptual framework, in our view, is the researcher's understanding of how the research problem will best be explored, the specific direction the research will have to take, and the relationship between the different variables in the study. (pp. 15-16)

The theories presented here may improve our understanding of the influence PD-HCBS has on a number of areas where previous research has found PD-HCBS to be especially effective, in particular improving community involvement, meeting unmet needs, improving health, and supporting satisfaction (e.g., Brown et al., 2007; Carlson et al., 2007; Foster et al., 2003a, 2003b; Harry, Kong, et al., 2016; Harry, MacDonald, et al., 2016). These relationships are outlined in the conceptual model shown in Figure 1 (p.37), which connects the theoretical and research-based foundations of this dissertation with the CCDE outcomes examined.

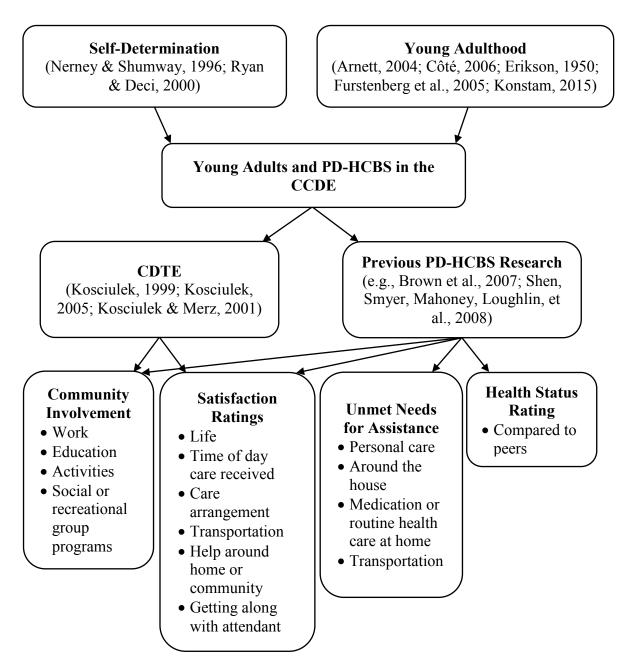


Figure 1. Dissertation conceptual model.

As shown in Figure 1 (p. 37), theoretical works and principles related to selfdetermination (Nerney & Shumway, 1996; Ryan & Deci, 2000) and young adulthood as a developmental life stage (Arnett, 2015; Côté, 2006; Erikson, 1950; Furstenberg et al., 2005; Konstam, 2015) guided the overall examination of PD-HCBS for young adults. The CDTE guided the focus on young adults' community involvement and satisfaction ratings (Kosciulek, 1999; Kosciulek, 2005; Kosciulek & Merz, 2001), as well as previous research on PD-HCBS with young adults (Harry, MacDonald, et al., 2016; Robinson et al., 2012), which, combined with previous research on Cash and Counseling with other age groups (e.g., Brown et al., 2007; Shen, Smyer, Mahoney, Loughlin, et al., 2008; Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008), also guided the analyses on unmet needs for assistance and health status rating compared to peers, as well as satisfaction ratings.

## Hypotheses

The study aims, hypotheses, and guiding research questions on the effects of the Cash and Counseling model of PD-HCBS for young adults are based on the underlying theoretical framework, previous research, and the conceptual model (Figure 1, p. 37). In this dissertation, I examined the following four aims and related hypotheses in answering the four guiding research questions. I did so by analyzing secondary baseline and ninemonth follow-up interview data from the CCDE randomized control trial.

*Aim 1: Identify whether participant direction significantly affects community involvement for young adults:* 

**Hypothesis 1 (H<sub>1</sub>):** Young adult participants in the Cash and Counseling treatment groups, or in cases where they could not speak for themselves, the

participant's proxy, will be more likely than those in the control groups at ninemonth follow-up to report community involvement through:

H<sub>1A</sub>) being employed for pay;

H<sub>1B</sub>) attending school or college;

 $H_{1C}$ ) and taking part in recreational, cultural, religious, social, or volunteer activities as much as young adults would have liked;

 $H_{1D}$ ) and currently participating in a social or recreational group program.

Aim 2: Identify whether participant direction significantly affects satisfaction ratings:

**Hypothesis 2 (H<sub>2</sub>):** Young adult participants in the Cash and Counseling treatment groups, or in cases where they could not speak for themselves, the participant's proxy, will be more likely than those in the control groups at nine-month follow-up to report being very satisfied with:

 $H_{2A}$ ) the way they are spending their life;

H<sub>2B</sub>) times of day that paid attendants performed duties;

H<sub>2C</sub>) care arrangement;

H<sub>2D</sub>) transportation;

 $H_{2E}$ ) the way paid attendants carried out personal care duties;

 $H_{2F}$ ) the way paid attendants helped around the house or in the community;

 $H_{2G}$ ) and getting along with paid attendants.

*Aim 3: Identify whether participant direction significantly affects unmet needs for assistance:* 

**Hypothesis 3 (H<sub>3</sub>):** Young adult participants in the Cash and Counseling treatment groups, or in cases where they could not speak for themselves, the participant's proxy, will be less likely than those in the control groups at nine-month follow-up to report unmet needs for assistance with:

H<sub>3A</sub>) personal care;

H<sub>3B</sub>) help around the house;

 $H_{3C}$ ) help with medication or routine health care at home;

 $H_{3D}$ ) and help with transportation.

*Aim 4: Identify whether participant direction significantly affects health ratings:* 

**Hypothesis 4 (H<sub>4</sub>):** Young adult participants in the Cash and Counseling treatment groups, or in cases where they could not speak for themselves, the participant's proxy, will be less likely than those in the control groups at nine-month follow-up to report young adults' health as poor or fair compared to their peers.

## **Chapter III. Methods**

#### **Study Design**

In this dissertation, I employed secondary data analysis on previously-collected and de-identified data from structured telephone interviews completed by Mathematica Policy Research, Inc. between 1999 and 2003 in Florida, New Jersey, and Arkansas in the CCDE (Brown et al., 2007). As described by Brown et al. (2007), the CCDE was a randomized control trial conducted under a §1115 research and evaluation waiver funded by the Robert Wood Johnson Foundation and the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. A total of 5,581 adults with disabilities interested in the idea of PD-HCBS, and an additional 1,002 children with primarily developmental disabilities in Florida, enrolled in the demonstration (Brown et al., 2007). Participants were randomly assigned to either a treatment group, who had the opportunity to receive the Cash and Counseling intervention, or a control group, who received agency-based care as usual, with a one to one ratio in each of the three demonstration states (Dale & Brown, 2007). According to Brown et al. (2007), two of the demonstration states, New Jersey and Arkansas, offered treatment group members Cash and Counseling through self-direction options within Medicaid State Plans for personal care assistance as an alternative to the respective State Plan for personal care services. In Florida, Cash and Counseling was offered as an alternative to individuals already receiving services through three Medicaid \$1915(c)waiver programs. The specification of allowance amounts received by Cash and

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Counseling treatment group members also differed between states as described by Brown

et al. (2007):

Arkansas and New Jersey calculated program cash allowances by multiplying the number of hours in consumers' Medicaid PCS [personal care service] plans by an hourly rate that was set below the average rates paid to agencies. (The difference was used to pay for counseling services and for the fiscal agent in the demonstration programs.) Plan hours were capped at 16 per week in Arkansas. and at 25 per week in New Jersey, absent special authorization for additional hours. Florida based its allowances on all the benefits in consumers' HCBS care plans or recent Medicaid waiver claims with the exception of those for case management/support coordination. Claims were to be used to calculate allowances if they were historically stable and consistent with the consumers' current care plans. Claims were used to calculate the allowances of consumers who were eligible because of their physical disabilities. In practice, however, claims were *not* used to calculate the allowances of consumers with developmental disabilities, because those consumers' care plans were being systematically revised at the time that the demonstration began. (The revisions resulted from a substantial increase in state funding for the HCBS waiver programs serving people with developmental disabilities.) (pp. 9-10)

Randomized control trials, a gold standard among research designs, allow for the assumption that participants have an equal opportunity to be assigned to either treatment or control groups (Singleton & Straits, 2010). As long as numbers are large enough, demographic participant characteristics are distributed evenly across groups through probability sampling. Causal inference can also be drawn from data collected in randomized control trials (Singleton & Straits, 2010), which is important when undertaking comparative intervention evaluations such as in the CCDE. However, limitations to this study design include an inability to prolong the study over an extended time period, such as a number of years, to examine long-term effects.

De-identified secondary data files from the CCDE offered free to the general public were accessed and downloaded through the Cash and Counseling website of the National Resource Center for Participant-Directed Services at Boston College in Chestnut Hill, Massachusetts (Cash and Counseling, 2005). Analyses focused on baseline and nine-month follow-up CCDE interview data to identify significant differences between treatment and control group members at follow-up on the outlined hypotheses.
Limitations of secondary data analysis include restrictions in the data types and variables available for analysis related to study aims, guiding research questions, and hypotheses.
The CCDE was also not designed to examine young adulthood or transition-related services.

## Procedures

Data were originally collected by Mathematica from CCDE treatment and control groups in each state's respective program through structured telephone interviews conducted at baseline and nine-month follow-up (Brown et al., 2007). As described by Brown et al. (2007), doing so allowed for a comparison between treatment and control group members over time. All participants taking part in the CCDE, or their proxy respondent, took part in the baseline interviews as a prerequisite to study participation (Brown & Dale, 2007). Arkansas' nine-month follow-up interviews were conducted between September 1999 and March 2002, while Florida's were conducted between March 2001 and May 2003, and New Jersey's from August 2000 to June 2003 (Brown et al., 2007). Interviews were conducted either with participants themselves or with proxy respondents who spoke on behalf of participants, individuals whom Brown and Dale (2007) described as typically being an informal caregiver or a family member of the participant. According to Brown and Dale, "proxies were often used [in the CCDE interviews] due to the high proportion of sample members who had difficulty speaking, hearing, or understanding" (p. 421). As Brown and Dale explained:

In the spirit of consumer direction, we encourage[d] sample members to respond to our surveys themselves, if possible. However, even though individuals with mild to moderate cognitive impairments can state consistent preferences about their care (see McHorney 1996; Feinberg and Whitlach 2001), many consumers in our sample were too cognitively or physically impaired to respond to the detailed survey that we administered. (pp. 424-425)

Brown and Dale (2007) went on to state that including proxy respondents allowed the study to obtain responses for participants from whom data could not have been collected otherwise. The authors also cautioned that some proxy responses, particularly regarding satisfaction and care quality ratings for participants, may be more reflective of the satisfaction levels of proxies, rather than those of participants, and that "our surveybased results pertaining to care quality often reflect the family members or caregivers inference about the sample members' opinion" (p. 441). However, Squillace, Mahoney, Shoop, Simon-Rusinowitz, and Desmond (2001) found no significant difference between participant and proxy respondents when answering questions regarding how satisfied they were with personal care received:

After controlling for differences in demographics, disability level, and cognition, consumers functioning independently and consumers with surrogate representatives responded similarly to questions about satisfaction with personal care. This finding suggests that surrogates do represent consumers' views in this domain. (p. 236)

Some proxy respondents in the CCDE also acted as formal participant representatives within the state's respective Cash and Counseling program, while most proxy respondents were non-representatives, only taking part in the interviews on the participant's behalf. Other proxy respondents were paid personal care attendants for participants. However, proxy respondents who were also paid attendants in the demonstration were not asked a number of questions, such as those relating to participant satisfaction and unmet needs, in order to reduce conflict of interest in their responses (Brown & Dale, 2007). Furthermore, paid proxies were not asked questions on participants' ability to work for pay, go to school, or take part in recreational, cultural, religious, social, or volunteer activities as much as they would like. Consequently, this reduced the available sample size on these questions and most of the hypotheses analyzed in this dissertation.

Young adults with more severe disabilities, particularly intellectual disabilities, may have required representatives to assist with managing PD-HCBS program responsibilities and may have had different outcomes than those young adults able to take part in interviews themselves. Previous research on young adults and decision making did suggest that parents or guardians representing young adults played a role in decision making (F. Mitchell, 2013, 2015; W. Mitchell, 2011). Most CCDE participants falling between the ages of 18 and 35 had a proxy respondent take part in at least one interview for them, an indication of disability severity. In the original CCDE, Brown et al. (2007) explained that:

Another indication of impairments is the high proportion of consumers for whom proxy respondents completed the baseline interviews for them. For elderly adults, the rate ranged from 50 to 60 percent across the three states. For younger adults, it was much lower in Arkansas and in New Jersey, but very high among Florida's younger adults [aged 18 to 59], 89 percent of whom had developmental disabilities. (p. 31)

Therefore, in this dissertation I followed Brown et al. and handled this potential influence by controlling for the type of respondent who took part in at least half of baseline CCDE interviews: young adult participants; or proxies, either program representatives or nonrepresentatives, who responded to baseline interviews for young adults who likely had more severe disability.

#### Sampling

The sample of young adults in the CCDE varied across the three demonstration states due to differences in sample selection by state. Arkansas and New Jersey enrolled only adults aged 18 or over with primarily physical disabilities, and in some cases cognitive, into the demonstration, while Florida targeted two groups: elderly and nonelderly adults with physical disabilities, and children and adults with developmental disabilities (Brown et al., 2007). These differences in sample selection are important for interpreting the results of this study.

A total of 831 young adult participants aged 18 to 35 from Florida, Arkansas, and New Jersey took part in both baseline and nine-month follow-up CCDE interviews. These individuals either responded to telephone interview themselves or had another individual respond for them. Although 950 young adults aged 18 to 35 took part in the CCDE's baseline interviews, 119 were lost to follow-up across Florida (n = 69), New Jersey (n = 29), and Arkansas (n = 21). Of those lost to follow-up, 64% (n = 44) in Florida and 59% (n = 17) in New Jersey were in the control group at baseline, while 57% (n = 12) were in the treatment group in Arkansas. One young adult in Florida, where children were also enrolled, turned 18 between baseline and nine-month follow-up and was included in the analyses. No participants aged 35 at baseline aged-out of the sample other than those lost to follow-up. Also, in this dissertation, the analyses on unmet needs, satisfaction ratings, and community involvement relating to young adults working for pay, attending school or college, or taking part in activities as much as they would have liked excluded paid proxy respondents (n = 80), similar to Shen, Smyer, Mahoney, Simon-Rusinowitz, et al. (2008) and like in the original CCDE (Brown & Dale, 2007). This brought the maximum sample size for those analyses to 751.

Like Carlson et al. (2007) and Brown et al. (2007) in the original CCDE, in this dissertation I examined "the effects of having the opportunity to receive the monthly allowance (by virtue of being assigned to the evaluation treatment group), rather than of actually receiving it" (Foster et al., 2003a, p. 9). This was necessary based on the intentto-treat nature of the study, where although many members of the treatment groups had not received their monthly budget by nine-month follow-up due to a variety of issues across the three states, they were still included in the study in order to keep intact the treatment and control groups (Brown et al., 2007). Specifically, 46% of nonelderly treatment group adults in Florida, 33% in New Jersey, and 11% in Arkansas had not yet received a budget by nine-month follow-up, which "understates the impacts of actual participation in the program" (Brown et al., 2007, p. xvii). The majority of these individuals were receiving paid care from other sources while awaiting their Cash and Counseling allowance (Carlson et al., 2007). Previous research in the CCDE found similar outcomes between treatment and control groups in Arkansas when comparing the subgroup of participants who received paid care at nine-month follow-up with a sample including those who did not have paid care at follow-up (Foster et al., 2003a).

Due to missing data from nonresponse or intentional skip patterns for some variables, particularly those related to program and life satisfaction at baseline and ninemonth follow-up, the sample size for each multivariate analysis differed from the overall sample, as well as from related bivariate models. Limitations regarding sampling include issues concerning the introduction of potential bias due to differing sample sizes and capping the sample at ages 18 to 35, which may artificially truncate the transition to adulthood time period for young people with severe disabilities.

## Measurement

## **Dependent Variables**

Dependent variables were operationalized by the following variables recoded from those recorded in the CCDE nine-month follow-up interviews. Of note is that the CCDE data analysts used a wide range of values for missing data, with over 30 missing data options, although many were not included in the data for the sample studied here. The variables were recoded to drop missing data values that did not exist for the sample and to recode those missing data values that did exist into Stata format for listwise deletion. Table A1 (Appendix A, pp. 229-230) presents the possible values for each recoded dependent variable. Nine-month follow-up dependent variable frequencies by state and random assignment are shown in Table 1 (pp. 49-53).

**H**<sub>1</sub>: **Community involvement.** Community involvement was measured by four variables from the nine-month follow-up CCDE interviews (Table A1, Appendix A, pp. 229-230). Questions asked included whether or not young adults were working for pay, attending school or college, or taking part in recreational, cultural, religious, social, or volunteer activities as much as they would like (each binary: *Yes/No*) (adapted from Connally, 1994; Goode, 1988; and Woodill et al., 1994, as cited by Foster et al., 2003a). The question in this area on ability to attend activities was prefaced by the statement: *Sometimes people cannot do things that they would like or need to do because of their health or because they do not have enough personal assistance*. This statement was also

# Table 1

# Nine-Month Follow-Up Dependent Variable Frequencies by State and Random Assignment Group

	Florida (n = 547)		New Jersey $(n = 180)$		Arkansas $(n = 104)$	
	Treatment	Control	Treatment	Control	Treatment	Control
Dependent Variables	(n = 286)	(n = 261)	(n = 88)	(n = 92)	(n = 51)	(n = 53)
H <sub>1</sub> Community involvement	( )		(****)		( )	(****)
$H_{1A}$ Working for pay as much as would like						
No	55.9%	73.6%	65.9%	71.7%	76.5%	92.5%
Yes	21.0%	21.1%	6.8%	17.4%	5.9%	5.7%
Missing	23.1%	5.4%	27.3%	10.9%	17.6%	1.9%
$H_{1B}$ Going to school or college as much as						
would like						
No	46.5%	60.5%	46.6%	67.4%	54.9%	73.6%
Yes	28.0%	28.0%	21.6%	22.8%	27.5%	22.6%
Missing	25.5%	11.5%	31.8%	9.8%	17.6%	3.8%
H <sub>1C</sub> Attended activities as much as would like						
No	42.0%	57.1%	54.5%	71.7%	60.8%	73.6%
Yes	39.9%	39.1%	20.5%	23.9%	23.5%	22.6%
Missing	18.2%	3.8%	25.0%	4.3%	15.7%	3.8%
H <sub>1D</sub> Attended social or recreational group						
programs						
No	57.0%	59.8%	81.8%	69.6%	80.4%	83.0%
Yes	43.0%	38.7%	18.2%	30.4%	19.6%	17.0%
Missing	-	1.5%	-	-	-	-
H <sub>2</sub> Satisfaction Ratings <sup>a</sup>						
H <sub>2A</sub> Way spending life						
Other response:	21.2%	34.5%	42.1%	56.5%	35.3%	62.3% (continued)

		Florida $(n = 547)$		New Jersey $(n = 180)$		Arkansas $(n = 104)$	
	Treatment	Control	Treatment	Control	Treatment	Control	
Dependent Variables	(n = 286)	( <i>n</i> = 261)	(n = 88)	(n = 92)	(n = 51)	(n = 53)	
Very dissatisfied	(2.4%)	(7.7%)	(10.2%)	(13.0%)	(5.9%)	(17.0%)	
Somewhat dissatisfied	(3.8%)	(6.1%)	(8.0%)	(12.0%)	(5.9%)	(18.9%)	
Somewhat satisfied	(15.0%)	(20.7%)	(23.9%)	(31.5%)	(23.5%)	(26.4%)	
Very satisfied	38.8%	38.3%	26.1%	18.5%	45.1%	26.4%	
Missing	39.9%	27.2%	31.8%	25.0%	19.6%	11.3%	
H <sub>2B</sub> Care arrangement							
Other response:	18.4%	34.5%	29.6%	46.8%	17.7%	49.1%	
Very dissatisfied	(1.7%)	(6.1%)	(-)	(10.9%)	(3.9%)	(15.1%)	
Somewhat dissatisfied	(2.4%)	(4.6%)	(5.7%)	(9.8%)	(2.0%)	(9.4%)	
Somewhat satisfied	(14.3%)	(23.8%)	(23.9%)	(26.1%)	(11.8%)	(24.5%)	
Very satisfied	42.0%	36.4%	39.8%	27.2%	62.7%	39.6%	
Missing	39.5%	29.1%	30.7%	26.1%	19.6%	11.3%	
$H_{2C}$ Transportation							
Other response:	18.2%	24.2%	21.6%	38.0%	23.5%	37.7%	
Very dissatisfied	(2.8%)	(5.4%)	(8.0%)	(6.5%)	(7.8%)	(13.2%)	
Somewhat dissatisfied	(4.2%)	(5.4%)	(3.4%)	(5.4%)	(2.0%)	(7.5%)	
Somewhat satisfied	(11.2%)	(13.4%)	(10.2%)	(26.1%)	(13.7%)	(17.0%)	
Very satisfied	37.4%	39.8%	46.6%	31.5%	56.9%	45.3%	
Missing	44.4%	36.0%	31.8%	30.4%	19.6%	17.0%	
$H_{2D}$ Times of day care received							
Other response:	5.9%	12.6%	14.7%	16.4%	13.8%	18.8%	
Very dissatisfied	(0.3%)	(1.5%)	(1.1%)	(2.2%)	(2.0%)	(9.4%)	
Somewhat dissatisfied	(0.7%)	(1.9%)	(1.1%)	(2.2%)	(-)	(-)	
Somewhat satisfied	(4.9%)	(9.2%)	(12.5%)	(12.0%)	(11.8%)	(9.4%) (continu	

 Table 1 Nine-Month Follow-Up Dependent Variable Frequencies by State and Random Assignment Group (continued)

	Florida ( <i>n</i> = 547)		New Jersey $(n = 180)$		Arkansas $(n = 104)$	
	Treatment	Control	Treatment	Control	Treatment	Control
Dependent Variables	(n = 286)	( <i>n</i> = 261)	(n = 88)	( <i>n</i> = 92)	(n = 51)	(n = 53)
Very satisfied	38.5%	35.2%	47.7%	31.5%	60.8%	32.1%
Missing	55.6%	52.1%	37.5%	52.2%	25.5%	49.1%
$H_{2E}$ The way paid attendants carried out						
personal care duties						
Other response:	3.4%	10.6%	3.4%	7.6%	9.8%	18.9%
Very dissatisfied	(0.3%)	(1.5%)	(-)	(1.1%)	(2.0%)	(1.9%)
Somewhat dissatisfied	(0.3%)	(1.1%)	(-)	(1.1%)	(-)	(1.9%)
Somewhat satisfied	(2.8%)	(8.0%)	(3.4%)	(5.4%)	(7.8%)	(15.1%)
Very satisfied	33.2%	26.4%	58.0%	37.0%	60.8%	28.3%
Missing	63.3%	62.8%	38.6%	55.4%	29.4%	52.8%
H <sub>2F</sub> Paid help around the house or community						
Other response:	6.2%	10.4%	6.8%	14.1%	9.8%	20.8%
Very dissatisfied	(0.3%)	(0.8%)	(1.1%)	(1.1%)	(2.0%)	(1.9%)
Somewhat dissatisfied	(0.3%)	(1.9%)	(-)	(-)	(-)	(1.9%)
Somewhat satisfied	(5.6%)	(7.7%)	(5.7%)	(13.0%)	(7.8%)	(17.0%)
Very satisfied	32.2%	28.4%	53.4%	31.5%	62.7%	22.6%
Missing	61.5%	61.3%	39.8%	54.3%	27.5%	56.6%
H <sub>2G</sub> Getting along with paid attendant						
Other response:	2.4%	6.2%	5.7%	9.8%	13.8%	11.3%
Very dissatisfied	(0.3%)	(0.8%)	(-)	(-)	(2.0%)	(1.9%)
Somewhat dissatisfied	(-)	(0.8%)	(-)	(1.1%)	(-)	(-)
Somewhat satisfied	(2.1%)	(4.6%)	(5.7%)	(8.7%)	(11.8)	(9.4%)
Very satisfied	42.3%	41.8%	56.8%	39.1%	60.8%	39.6%
Missing	55.2%	52.1%	37.5%	51.1%	25.5%	49.1%
						(continue

 Table 1 Nine-Month Follow-Up Dependent Variable Frequencies by State and Random Assignment Group (continued)

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	Florida ( <i>n</i> = 547)		New Jersey $(n = 180)$		Arkansas $(n = 104)$	
	Treatment	Control	Treatment	Control	Treatment	Control
Dependent Variables	(n = 286)	( <i>n</i> = 261)	(n = 88)	(n = 92)	(n = 51)	(n = 53)
H <sub>3</sub> Unmet Needs for Assistance						
H <sub>3A</sub> Personal care						
No	62.9%	66.3%	42.0%	40.2%	56.9%	66.0%
Yes	21.0%	32.2%	35.2%	55.4%	27.5%	32.1%
Missing	16.1%	1.5%	22.7%	4.3%	15.7%	1.9%
$H_{3B}$ Around the house						
No	52.1%	59.0%	36.4%	40.2%	52.9%	58.5%
Yes	31.1%	37.5%	40.9%	54.3%	31.4%	39.6%
Missing	16.8%	3.4%	22.7%	5.4%	15.7%	1.9%
$H_{3C}$ Medications or routine health care at						
home						
No	71.3%	73.6%	52.3%	48.9%	66.7%	67.9%
Yes	12.6%	24.9%	23.9%	46.7%	17.6%	30.2%
Missing	16.1%	1.5%	23.9%	4.3%	15.7%	1.9%
H <sub>3D</sub> Transportation						
No	57.7%	59.4%	45.5%	45.7%	60.8%	56.6%
Yes	26.2%	38.3%	31.8%	51.1%	23.5%	41.5%
Missing	16.1%	2.2%	22.7%	3.3%	15.7%	1.9%
H <sub>4</sub> Health Status Ratings						
Poor/fair health compared to peers:	33.9%	37.5%	54.5%	56.5%	58.9%	58.4%
Poor	(9.8%)	(13.9%)	(35.2%)	(26.1%)	(37.3%)	(35.8%)
Fair	(24.1%)	(23.6%)	(19.3%)	(30.4%)	(21.6%)	(22.6%)
Good/excellent health compared to peers:	65.1%	62.0%	43.2%	41.3%	39.2%	41.5%
Good	(40.6%)	(40.2%)	(33.0%)	(34.8%)	(31.4%)	(28.3%) (continued

		Florida $(n = 547)$		New Jersey $(n = 180)$		Arkansas $(n = 104)$	
Dependent Variables	Treatment $(n = 286)$	Control $(n = 261)$	Treatment $(n = 88)$	Control $(n = 92)$	Treatment $(n = 51)$	Control $(n = 53)$	
Excellent	(24.5%)	(21.8%)	(10.2%)	(6.5%)	(7.8%)	(13.2%)	
Missing	1.0%	0.8%	2.3%	2.2%	2.0%	-	

Table 1 Nine-Month Follow-Up Dependent Variable Frequencies by State and Random Assignment Group (continued)

*Note*. Rounded to nearest tenth place. Percentages may not add up to 100% due to rounding. Hyphens (-) signify 0% or no participants in that category.

<sup>a</sup>Category Other includes Very Dissatisfied, Somewhat Dissatisfied, Somewhat Satisfied.

included as a probe for the other two questions on employment and education. In addition, a fourth question asked whether young adults were attending social or recreational group programs at follow-up (binary: *Yes/No*).

Regarding inter-item reliability, Cronbach's alpha was .61 for the three questions on going to work, school, or activities as much as participants would like, a questionable level of internal consistency reliability. Adding the question on young adults attending social or recreational group programs gave an alpha of .52, a poor level of internal consistency.

Construct validity was examined for all four community involvement variables together using exploratory principal axis factor (PAF) analysis with orthogonal varimax rotation, which provides uncorrelated factors (Polit, 2010). Results showed that the three variables on whether young adults were employed, going to school, or attending activities as much as they would like loaded well on one factor (Table A2, Appendix A, p. 231). Attending social or recreational group programs, which had a low loading on the first factor with the other three variables and also loaded slightly on a second factor, had the highest communality at .948. All items had good commonality values above .68, representing large amounts of shared explained variance. However, the likelihood ratio test was significant, showing a poor fit with the independent and saturated matrices differing:  $\gamma^2$  (6, n = 646) = 231.30, p < .001. Bartlett's test of sphericity was also significant in this case, which, according to Polit (2010), suggests that the correlation matrix was not an identity matrix and that factor analysis was appropriate with these variables:  $\chi^2$  (6, n = 646) = 230.94, p < .001. The Kaiser–Meyer–Olkin (KMO) measure of sampling adequacy was .65, which is considered a mediocre level of factorability.

Also, the second factor had a low percentage of variance explained and a low eigenvalue, illustrating that it contributed little in the reported two-factor solution.

A second factor analysis was run with just the three questions on going to work, school, or activities as much as participants would like that resulted in a one-factor solution (Table A2, Appendix A, p. 231). Factor loadings and commonalities were similar to the analysis including all four questions. KMO dropped just slightly to .64, still a mediocre level of factorability, and the likelihood ratio test remained significant:  $\chi^2$  (3, n = 646) = 211.89, p < .001. Bartlett's test of sphericity also still showed that the variables were correlated sufficiently for factor analysis:  $\chi^2$  (3, n = 646) = 211.56, p < .001. Moreover, the amount of variance explained increased by 6.1%, suggesting a three-item construct would be preferred to one with all four variables.

The EFA findings support a one-factor solution on the community involvement variables, with an improved fit if the variable for young adults attending social or recreational group programs was dropped from the factor analysis. However, the reported inter-item reliability for these four items was poor. In this dissertation, in order to examine the effectiveness of the Cash and Counseling model on each individual variable, these four items were analyzed individually under the conceptual heading of community involvement, rather than grouped together as a scale measure of a construct derived from factor analysis.

 $H_2$ : Satisfaction ratings. Satisfaction ratings were measured by nine-month CCDE follow-up interview questions on how satisfied participants were with life, their care arrangement, the times of day paid attendants performed their duties, transportation, the way paid attendants carried out personal care duties, help received around the home and community, and getting along with paid attendants (adapted from Benjamin, 1996; Connally, 1994; Eustis et al., 1993; Goode, 1988; and Woodill et al., 1994, as cited by Foster et al., 2003a). Each question was asked in two parts, first whether participants were *Satisfied* or *Dissatisfied*, then to what extent, *Very* or *Somewhat*. Less than .05% of respondents lacked *Very* or *Somewhat* data in relation to a specific satisfaction rating. Due to a high rate (over 50%) of *Very Satisfied* responses for each variable in the sample, follow-up satisfaction ratings originally ranging from *Very Dissatisfied* to *Very Satisfied* were recoded as binary variables using the technique employed by Brown & Dale (2007), Carlson et al. (2007), and Shen, Smyer, Mahoney, Loughlin, et al. (2008): *Very Satisfied* = 1; *Somewhat Satisfied*, *Somewhat Dissatisfied*, and *Very Dissatisfied* (along with *Satisfied* and *Dissatisfied* responses lacking the modifier of *Very* or *Somewhat*) = 0 or *Other* (Table A1, Appendix A, pp. 229-230). Together, these items had an acceptable level of internal consistency reliability with a Cronbach's alpha of .78.

When the construct validity of the recoded satisfaction variables was examined using PAF and orthogonal varimax rotation, a three-factor solution was identified (Table A3, Appendix A, p. 232). However, loadings on the third factor were all below .200 and some were negative. The third factor also explained a low percentage of variance and had a low eigenvalue. Being very satisfied with life, care arrangement, and transportation loaded more highly on factor one, while being very satisfied with times of day paid attendants performed their duties, the way paid attendants carried out personal care duties, help received around the house or community, and getting along with paid attendants loaded higher on the second extracted factor. In addition, one item, being very satisfied with the times of day paid attendants performed their duties, loaded on both factors one and two to a similar degree. Item commonalities illustrated that shared common factor variance did vary between items and factors. Regarding goodness of fit, a likelihood ratio test was significant, showing that the independent and saturated matrices differed:  $\chi^2$  (21, n = 292) = 529.46, p < .001. KMO was also .79, a middling level of factorability, although the sample was small and Bartlett's test of sphericity supported the appropriateness of factor analysis:  $\chi^2$  (21, n = 292) = 527.63, p < .001.

While these findings and the acceptable Cronbach's alpha of .78 suggest that the seven recoded satisfaction variables could measure two constructs related to satisfaction, the variables themselves are not easily categorized into two specific constructs. Factor one could represent satisfaction with critical functional areas affected by the program, namely how satisfied participants were with the way they were spending their life, their care arrangements, and transportation. The second factor could represent satisfaction with aspects of the program in which they were enrolled, including with the times of day care was received, their personal care, help received around the house or community, and how participants got along with paid attendants. However, rather than lose the sensitivity afforded by analyzing these variables separately, a scale was not developed in this dissertation for the two-factor solution identified here. Combining items into a test scale also resulted in highly skewed values. These seven items were instead analyzed separately, which allowed for comparisons on these questions between the satisfaction ratings reported here and with other populations in the CCDE.

H<sub>3</sub>: Unmet needs for assistance. Unmet needs for assistance signified areas where participants were experiencing difficulty meeting their needs for help with personal care and three IADLs in the two weeks preceding follow-up interviews. Thus,

unmet needs for assistance was measured in two parts. First, whether participants needed more help with personal care, such as eating or bathing (binary: *Yes/No*). Second, the following three variables were adapted in the CCDE from Allen and Mor (1997) (as cited by Foster et al., 2003a) and from items on the Lawton IADL scale (Lawton & Brody, 1969). These included whether participants needed more help: with doing things around the house such as preparing meals, laundry, and housework, which included a query on yardwork for participant respondents; with medications, including reminders to take it, or with routine health care at home, such as checking blood pressure or doing exercises; or with transportation, which included transportation to a doctor's office, shopping, school, work, or recreational and social activities (each binary: *Yes/No*) (Table A1, Appendix A, pp. 229-230).

Creating a scale based on the three unmet IADL questions was also attempted. However, Cronbach's alpha was .63, representing a questionable level of internal consistency reliability for these three items. In addition, the resulting scale variable was positively skewed regardless of transformation, making the scale inappropriate for ordinary least squares regression. When the variable for unmet needs with personal care was added to the three unmet IADL items, Cronbach's alpha increased to .71, an acceptable level of internal consistency reliability.

Construct validity was assessed for the four unmet needs for assistance variables using PAF with orthogonal varimax rotation. Results showed a one-factor solution with adequate factor loadings, eigenvalue, and proportion of variance explained (Table A4, Appendix A, p. 233). Item communalities illustrated that the variables explained between .562 and .770 of the shared variance in the single factor. Regarding fit, KMO was .72, a middling level of factorability. Factor analysis was supported by a significant Bartlett's test of sphericity:  $\chi^2$  (6, n = 734) = 572.12, p < .001. However, a likelihood ratio test was significant, again showing that independent and saturated matrices were significantly different:  $\chi^2$  (6, n = 734) = 572.91, p < .001.

Together with the acceptable Cronbach's alpha of .71, these findings lend some support to a four item, one-factor construct measuring unmet needs for assistance for the young adults in this sample. Nevertheless, these four items were analyzed separately here in order to assess the effectiveness of the Cash and Counseling model on each individual unmet need, as well as to allow for comparison with findings on these questions from other CCDE subgroups previously studied. Doing so also allowed for greater precision in assessing specific unmet needs for the population under study.

**H<sub>4</sub>: Participant health status.** Participants' health status was measured by respondent reports of how healthy participants felt or believed themselves to be, including views from proxy respondents, compared to their peers at the time of nine-month follow-up interviews (adapted from Shaughnessy et al., 1994, as cited by Foster et al., 2003a). Over 50% of respondents reported that young adults had good or excellent health compared to their peers at nine-month follow-up. To allow for comparisons with past research, this dependent variable was recoded to be binary based on the recoding completed by Brown et al. (2007) in the CCDE, where *Poor/Fair* = 1, and *Good/Excellent* = 0 (Table A1, Appendix A, pp. 229-230).

**Construct validity for dependent variables.** Construct validity was assessed for all 16 dependent variables together by testing the convergent and discriminant validity of these items using PAF with orthogonal varimax rotation. Results, presented in Table A5

(Appendix A, p. 234), showed seven factors with loadings above .300, but that five factors represented most dependent variables at the preferred level of .400 or higher (Polit, 2010). Similarly themed variables also tended to factor together as expected, with a few exceptions. Measures of young adults meeting their preferred levels of employment, education, and activity attendance all loaded together on the third factor. However, the variable for participants attending social or recreational group programs at follow-up did not load at the .300 or higher level on any factor, which reflected the poor inter-item reliability finding when this item was analyzed with the other three community involvement variables reported previously. Satisfaction variables factored on mainly factors one and four, with being very satisfied with the times of day paid attendants performed their duties also factoring alone on the sixth factor, but with only a .333 factor loading. Also, while the four unmet needs for assistance dependent variables all loaded together on factor two, unmet needs with transportation also factored with some of the satisfaction variables under the fourth factor to a greater extant (-.447) than with the other unmet needs variables (.375). Additionally, unmet needs for medication or routine health care at home factored alone on a seventh factor, but to a lesser extent (.301) than with the other unmet needs variables (.491). Finally, participants being in poor or fair health compared to their peers at follow-up factored alone under a fifth factor.

Eigenvalues were low for factors three through seven, with concomitant low percentages of variance explained for these factors. KMO was middling at .78, while a significant likelihood ratio test comparing independent versus saturated models showed they were different and a poor fit:  $\chi^2$  (120, n = 249) = 1029.70, p < .001. Bartlett's test of sphericity showed that the variables were correlated sufficiently for factor analysis:  $\chi^2$  (120, n = 249) = 1025.46, p < .001. Together with the individual construct validity results reported for community involvement, satisfaction ratings, and unmet needs for assistance, these findings suggest that the sixteen dependent variables tested here did a fair job of discriminating between and converging within factors, with some cross over and exceptions. However, if these items or similar items were tested together as constructs in future research, rather than the single items grouped together here under thematic titles, confirmatory factor analysis could be employed to improve construct validity.

### **Independent Variables**

A number of baseline control variables from the CCDE baseline interviews were recoded and employed in the multivariate logistic regression analyses. Table A6 (Appendix A, p. 235) shows the recoded baseline variable values used in this study. Frequencies for the recoded baseline variables are presented in (Table 2, pp. 62-65).

The primary independent variable, or main effect, used in the analyses was treatment status (Table A6, Appendix A, p. 235 and Table 2, pp. 62-65). Treatment status was a binary indicator variable for whether a participant was randomly assigned to a Cash and Counseling treatment group (*Yes*) or to a control group (*No*), who received traditional, agency-based services or usual care. Of note, 104 participants were missing baseline random assignment data. Because complete data on random assignment was available at nine-month follow-up, I created the treatment status indictor for the analyses presented here based on the nine-month follow-up random assignment variable, checking it with the baseline version to ensure accuracy with the available baseline data. Additional baseline demographic control variables included: state (*Florida, New Jersey*, and *Arkansas*); sex of young adults (*female* or *male*); and a mean-centered age variable

# Table 2

		rida	New J			ansas
	`	547)	( <i>n</i> =	/	· · · · · · · · · · · · · · · · · · ·	104)
	Treatment	Control	Treatment	Control	Treatment	Control
Baseline Control Variables	(n = 286)	(n = 261)	(n = 88)	(n = 92)	(n = 51)	(n = 53)
Attended social or recreational group						
programs in the past year						
No	54.5%	52.5%	77.3%	79.3%	80.4%	88.7%
Yes	45.5%	47.5%	22.7%	20.7%	17.6%	9.4%
Proxy did not know	-	-	-	-	2.0%	1.9%
Ever worked for pay by baseline						
No	14.3%	12.6%	50.0%	47.8%	15.7%	20.8%
Yes	85.7%	87.4%	50.0%	52.2%	84.3%	79.2%
Health rating compared to peers <sup>a</sup>						
Poor/Fair:	33.2%	34.9%	52.3%	53.3%	54.9%	60.3%
Poor	(12.2%)	(11.1%)	(29.6%)	(23.9%)	(29.4%)	(37.7%)
Fair	(21.0%)	(23.8%)	(22.7%)	(29.4%)	(25.5%)	(22.6%)
Good/Excellent:	66.8%	64.3%	44.3%	46.7%	45.1%	39.7%
Good	(40.2%)	(42.5%)	(31.8%)	(30.4%)	(35.3%)	(34.0%)
Excellent	(26.6%)	(21.8%)	(12.5%)	(16.3%)	(9.8%)	(5.7%)
Missing	-	0.8%	3.4%	-	-	-
Hispanic ethnicity						
No	79.7%	74.3%	70.5%	76.1%	98.0%	100%
Yes	19.9%	25.3%	27.3%	22.8%	2.0%	-
Don't know/missing	0.3%	0.4%	2.3%	1.1%	-	-
Needed help getting out of bed in last week						
Got help	34.6%	42.5%	59.1%	58.7%	58.8%	49.1% (continued

Frequencies for Baseline Control Variables Related to Dependent Variables by State and Random Assignment Group

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		rida	New J	~		insas
		547)	( <i>n</i> =	/	(	104)
	Treatment	Control	Treatment	Control	Treatment	Control
Control Variables	(n = 286)	( <i>n</i> = 261)	(n = 88)	( <i>n</i> = 92)	(n = 51)	(n = 53)
No help	65.4%	55.9%	37.5%	41.3%	39.2%	47.2%
Did not get out of bed at all	-	1.5%	2.3%	-	2.0%	3.8%
Skipped, client in coma	-	-	1.1%	-	-	-
Needed more help around the house or						
community						
No	26.6%	31.8%	15.9%	17.4%	39.2%	37.7%
Yes	69.9%	65.1%	80.7%	82.6%	56.9%	62.3%
Missing	3.5%	3.1%	3.4%	-	3.9%	-
Needed more help with personal care						
No	27.3%	31.8%	19.3%	19.6%	31.4%	26.4%
Yes	52.8%	48.7%	71.6%	75.0%	62.7%	66.0%
Missing	19.9%	19.5%	9.1%	5.4%	5.9%	7.5%
Needed more help with transportation						
No	38.5%	39.1%	26.1%	22.8%	35.3%	45.3%
Yes	53.1%	50.6%	47.7%	62.0%	45.1%	37.7%
System missing	8.4%	10.3%	26.1%	15.2%	19.6%	17.0%
Race - recoded						
White	71.3%	75.1%	60.2%	50.0%	70.6%	58.5%
Black	19.6%	17.6%	25.0%	30.4%	23.5%	39.6%
Other or multiracial	8.7%	6.5%	14.8%	17.4%	5.9%	1.9%
System missing	0.4%	0.8%	-	2.2%	-	-
-						(continued

Table 2 Frequencies for Baseline Control Variables Related to Dependent Variables by State and Random Assignment Group(continued)

 Table 2 Frequencies for Baseline Control Variables Related to Dependent Variables by State and Random Assignment Group

		rida		lersey		ansas
	<u>(n =</u>	/	<u>(n =</u>	/		104)
	Treatment	Control	Treatment	Control	Treatment	Control
Control Variables	(n = 286)	(n = 261)	(n = 88)	(n = 92)	(n = 51)	(n = 53)
Received paid help through Medicaid or other						
publicly funded program in last week						
No	47.9%	46.0%	17.0%	20.7%	56.9%	58.5%
Yes	52.1%	53.3%	83.0%	79.3%	43.1%	41.5%
Missing	-	0.8%	-	-	-	-
Respondent type at baseline						
Young adult	38	29	32	36	29	32
Proxy	248	232	56	56	22	21
Satisfaction with the care arrangement						
Satisfied:	74.1%	73.5%	67.0%	61.9%	60.8%	62.3%
Somewhat satisfied	(32.5%)	(26.4%)	(31.8%)	(30.4%)	(29.4%)	(35.9%)
Very satisfied	(41.6%)	(47.1%)	(35.2%)	(31.5%)	(31.4%)	(26.4%)
Dissatisfied:	19.5%	18.1%	31.8%	30.4%	21.6%	22.6%
Somewhat dissatisfied	(8.0%)	(12.3%)	(22.7%)	(21.7%)	(9.8%)	(11.3%)
Very dissatisfied	(11.5%)	(5.8%)	(9.1%)	(8.7%)	(11.8%)	(11.3%)
Missing	6.4%	8.4%	1.2%	7.7%	17.6%	15.1%
Satisfaction with tasks						
Satisfied:	37.0%	44.8%	56.8%	71.7%	35.3%	39.6%
Somewhat satisfied	(11.5%)	(11.1%)	(21.6%)	(31.5%)	(9.8%)	(15.1%)
Very satisfied	(25.5%)	(33.7%)	(35.2%)	(40.2%)	(25.5%)	(24.5%)
Dissatisfied:	7.7%	5.0%	25.0%	10.9%	7.8%	9.5%
Somewhat dissatisfied	(2.5%)	(3.5%)	(15.9%)	(6.5%)	(7.8%)	(3.8%)
Very dissatisfied	(5.2%)	(1.5%)	(9.1%)	(4.4%)	-	(5.7%)
· · · · · · · · · · · · · · · · · · ·	()	()	(*****)	()		(continued

		rida 547)		Jersey 180)	Arka ( <i>n</i> =	
Control Variables	Treatment $(n = 286)$	Control $(n = 261)$	Treatment $(n = 88)$	Control $(n = 92)$	Treatment $(n = 51)$	Control $(n = 53)$
Missing	55.3%	50.2%	18.2%	17.4%	56.9%	50.9%
Satisfaction with times of day attendant works						
Satisfied:	35.7%	39.8%	53.5%	58.7%	29.5%	26.4%
Somewhat satisfied	(14.0%)	(13.4%)	(23.9%)	(30.4%)	(11.8%)	(11.3%)
Very satisfied	(21.7%)	(26.4%)	(29.6%)	(28.3%)	(17.7%)	(15.1%)
Dissatisfied:	8.1%	9.2%	27.3%	22.8%	13.7%	20.8%
Somewhat dissatisfied	(3.9%)	(6.5%)	(21.6%)	(16.3%)	(9.8%)	(17.0%)
Very dissatisfied	(4.2%)	(2.7%)	(5.7%)	(6.5%)	(3.9%)	(3.8%)
Missing	56.2%	51.0%	19.2%	18.5%	56.8%	52.8%
Satisfaction with way spending life						
Satisfied:	10.8%	7.7%	11.4%	27.2%	41.2%	30.2%
Somewhat satisfied	(2.8%)	(2.7%)	(9.1%)	(19.6%)	(27.5%)	(18.9%)
Very satisfied	(8.0%)	(5.0%)	(2.3%)	(7.6%)	(13.7%)	(11.3%)
Dissatisfied:	2.5%	3.1%	23.9%	11.9%	15.7%	28.3%
Somewhat dissatisfied	(2.5%)	(1.9%)	(14.8%)	(5.4%)	(9.8%)	(18.9%)
Very dissatisfied	(-)	(1.2%)	(9.1%)	(6.5%)	(5.9%)	(9.4%)
Missing	86.7%	89.2%	64.7%	60.9%	43.1%	41.5%
Sex						
Female	38.1%	48.3%	46.6%	47.8%	45.1%	47.2%
Male	61.9%	51.7%	53.4%	52.2%	54.9%	52.8%

Note. Rounded to nearest tenth place. Percentages may not add up to 100% due to rounding Hyphens (-) signify 0% or no aBaseline health rating compared to peers was included in all second models.

added due to multicollinearity in all second models for the untransformed 18 to 35 age variable. These variables were also available at nine-month follow-up and as such were checked for accuracy. Baseline variables further included the type of respondent (*young adult participant* or *proxy*) who had taken part in over 50% of the baseline interviews. This variable combined two categories of proxy respondents (*non-representative proxies*) and *representative proxies*) due to a small number of non-representative baseline proxy respondents in Florida and Arkansas, and a lack of representative proxy respondents at baseline in New Jersey. While the respondent type at follow-up was missing for 180 young adults, Brown and Dale (2007) explained that having a proxy at baseline was highly correlated with, although not strictly predictive of, having a proxy take part in follow-up interviews.

Baseline control variables relating to specific dependent variables were also included as control variables for those dependent variables (Table A6, Appendix A, p. 235). Table 2 (pp. 62-65) presents frequencies for these variables in each of the three demonstration states between treatment and control groups. These baseline variables included whether participants reported ever working for pay (*Yes/No*) (H<sub>1A</sub>); if participants had taken part in social or recreational group programs in the past year (*Yes/No*) (H<sub>1D</sub>); if participants needed more help with personal care than received (e.g., help with eating, getting out of bed, using the toilet, dressing, grooming, and bathing)( *Yes/No*) (H<sub>3A</sub>); if participants needed more help with things around the house or community than received (e.g., needing more help preparing meals, doing housework, laundry, shopping, yardwork and other chores, or paying bills) (*Yes/No*) (H<sub>3B</sub>); and if participants needed more help with transportation than received (e.g., needing more help

getting rides, such as to go shopping or to a doctor's office, or using public transportation) (*Yes/No*) ( $H_{3C}$ ). Together, the three baseline unmet needs questions had a Cronbach's alpha of .68, representing a questionable level of internal consistency reliability. Like the follow-up satisfaction questions, baseline satisfaction questions were also asked in two parts, first whether participants were *Satisfied* or *Dissatisfied*, then to what extent, Very or Somewhat. Baseline satisfaction questions included satisfaction: with how participants were spending their life  $(H_{2A})$ ; the times of day attendant worked  $(H_{2B})$ ; care arrangement  $(H_{2C} \& H_{2G})$ ; and the way tasks were carried out  $(H_{2F})$ . Less than .05% of baseline satisfaction measures, aside from baseline life satisfaction, were missing Very and Somewhat data for related Satisfied and Dissatisfied responses. Of note, baseline life satisfaction was only asked of participants who took part in baseline interviews themselves. Unlike the nine-month follow-up satisfaction variables, recoded baseline satisfaction control variables, which ranged from Very Dissatisfied to Very Satisfied, did not have 50% or more respondents reporting being Very Satisfied. Rather, over 50% of respondents reported being either Somewhat Satisfied or Very Satisfied for each item at baseline. As such, these baseline variables were recoded where: Satisfied, Somewhat Satisfied or Very Satisfied = Satisfied or 0, and Dissatisfied, Somewhat *Dissatisfied* or *Very Dissatisfied* = *Dissatisfied* or 1.

As shown in Table A6 (Appendix A, p. 235), baseline demographic control variables were employed to create two variables based on ethnicity and race that were also used by Brown et al. (2007), who had one ethnicity variable for those identifying as being of Hispanic descent, and a race variable for those who identified as White, Black, or another race. However, 28 individuals in the sample examined here identified as

Hispanic, but lacked any race data, which would have dropped these individuals from the analysis due to missing data on race. A recent Pew Research Center (2015) study found that 67% of the 2,438 individuals of Hispanic descent surveyed felt that being Hispanic represented both their racial and ethnic backgrounds together, with an additional 19% stating being Hispanic was related only to their ethnic background, and 11% feeling it represented only their racial background. Considering the coding conducted by Brown et al. and this new information on the racial and ethnic identification of people of Hispanic descent, I created two variables, with frequencies presented in Table 2 (pp. 62-65). One was a combined race variable that included respondents who identified young adults as White, Black, or another race than White or Black or who were multiracial, where the third category *other or multiracial* included those who identified as Asian, American Indian/Alaskan Native, Native Hawaiian/Pacific Islander, other uncodable race, respondents who identified as more than one race, and the 28 respondents who identified as the ethnic group Hispanic, but not with any race category. I also included a Hispanic ethnicity indicator variable for those respondents who identified young adults as being Hispanic (Yes/No).

A baseline health status variable was also constructed (Table A6, Appendix A, p. 235). Over 50% of respondents stated participants had *Good* or *Excellent* health compared to their peers at baseline (Table 2, pp. 62-65). As a result, this baseline variable was recoded into binary format where *Poor/Fair* = 1 and *Good/Excellent* = 0, similar to Brown et al. (2007). Additional baseline variables included whether participants lived in a rural area (*Yes/No*), whether participants needed help with getting out of bed in the last week, an activity of daily living (ADL) (*Yes/No*), and whether participants had received

paid help through Medicaid or other publicly funded program in the previous week (*Yes/No*), as employed by Shen, Smyer, Mahoney, Loughlin, et al. (2008).

Due to the possibility of a quadratic effect of participant age on the dependent variables, logistic regression analyses screening for quadratic effects were undertaken for each multivariate model by including a continuous age variable, an age-squared variable, and a cubed age variable in test analyses. In three cases, the quadratic effect for squared age was statistically significant, meaning there was a curvilinear or parabolic relationship between age and three dependent variables: working for pay as much as participants would like, taking part in recreational, cultural, religious, social, or volunteer activities as much as participants would like, and life satisfaction. Consequently, mean-centered age and squared mean-centered age variables were included in the second models for these three dependent variables. Mean-centering the variables reduced multicollinearity between the two age variables (Menard, 2010), as well as lowered the collinearity of age to acceptable levels for models only including mean-centered age.

Variables relating to socioeconomic status or specific disability type were not available. However, a necessary factor for CCDE enrollment was state Medicaid eligibility and difficulty with activities of daily living. Also, having a proxy respondent likely indicated more severe disability as described by Brown et al. (2007). All demographic control variables listed here were also used as control variables in other analyses of CCDE data (e.g., Brown et al., 2007; Shen, Smyer, Mahoney, Loughlin, et al., 2008).

### **Analysis Methods**

CCDE secondary data were analyzed using IBM SPSS Statistics 22.0 (IBM Corp., 2013) for descriptive univariate statistics and Stata 13 SE (StataCorp, 2013) for bivariate and multivariate analyses, as well as factor analysis relating to the dependent variables. Descriptive statistics provided an overall picture of participant characteristics. The distribution of data, data diagnostics, variable measurements, and sample sizes were all examined when selecting appropriate inferential statistical analyses.

Bivariate analyses included Spearman's *rho* correlations for continuous and ordinal variables using pairwise deletion. Pearson's and likelihood ratio chi-square cross tabulations, reporting *phi* for the effect size, were also run for each binary dependent variable and the main effect of treatment status. Multivariate analyses were employed to test predictors of dependent outcome variables while controlling for a range of variables when prerequisite assumptions were met for multivariate regression. Specifically, two forms of regression were used during data analysis. Logistic regression was employed for binary dependent variables meeting the assumptions required for multivariate logistic regression (H<sub>1</sub>, H<sub>2</sub>, H<sub>3</sub>, and H<sub>4</sub>). When more than 50% of respondents identified with one category, dependent variables were recoded to represent binary conditions for logistic regression (H<sub>2</sub> and H<sub>4</sub>). Multinomial logistic regression was employed with each of the satisfaction dependent variables in H<sub>2</sub> and with the health status rating dependent variable in H<sub>4</sub> as a cross validation check to ensure that collapsing of dependent variable categories into binary form for logistic regression was appropriate. Finally, Wald tests in Stata assessed the significance of individual predictors in each logistic regression model (Polit, 2010).

A 95% confidence level was employed with a corresponding alpha of .05 in the one-tailed statistical analyses, similar to Carlson et al. (2007). To prevent Type I errors, I also employed some of the methods from the original CCDE, again like Carlson et al., and only considered an outcome to be a favorable program effect it was in the expected direction and if other significant findings were identified in the same area (see Brown & Dale, 2007). Additionally, like Brown and Dale (2007) and Carlson et al., I did not apply the same standard to adverse effects. However, I did not examine differences in significance levels by state due to small sample sizes in New Jersey and Arkansas for the multivariate models. Instead, significant differences in predicted probabilities for treatment status between states are presented in the study findings, although significance levels by random assignment group within each state are not reported.

Calculating the power required to find specific effect sizes within a sample using logistic regression is not straightforward. However, in this dissertation, I followed Polit's (2010) recommendation for the sample to contain at a minimum 15, but preferably 20 or more cases for each predictor in the multivariate logistic regression models. This allowed for a maximum of 12 independent variables based on the dependent variable in the multivariate models with the smallest sample,  $H_{2A}$  life satisfaction (n = 180). In order to maintain parsimonious models while maximizing model fit, multivariate models had at least 11 baseline control variables or 12 if a baseline measure of the dependent variable existed. Models with identified quadratic effects for age had an additional squared meancentered age variable, which increased the number of variables in the multivariate model on young adults working for pay as much as they would like to 13. Also, the multivariate model for life satisfaction did not include the baseline respondent type variable, as all

respondents to the baseline question on life satisfaction were young adults, which, combined with the inclusion of the squared mean-centered age variable for the quadratic effect of age, gave the life satisfaction multivariate model 12 baseline control variables. Issues of varying sample sizes between models and hypotheses could bias results, although the use of random assignment in the CCDE should mitigate the influence of sampling differences between respondents.

Two regression models were run for each dependent variable: first models included bivariate logistic regression analyses with the main effect of treatment status; and second models employed multivariate logistic regression including the main effect of treatment status and baseline control variables. Each model was estimated using full maximum likelihood estimation. Individual equations for second models are presented in Table A7 (Appendix A, pp. 236-238). The base regression equation for the second models was as follows:

$$\begin{split} &Y(Dependent \ variable) = \beta_0(intercept) + \beta_1 X_1(treatment \ group \ member) + \\ &\beta_2 X_2(state) + \beta_3 X_3(sex) + \beta_4 X_4(race) + \beta_5 X_5(Hispanic) + \beta_6 X_6(respondent \ type) + \\ &\beta_7 X_7(mean-centered \ age) + \beta_8 X_8(health \ status \ compared \ to \ peers) + \beta_9 X_9(help \ getting \ in \ or \ out \ of \ bed) + \beta_{10} X_{10}(publicly \ funded \ paid \ help) + \beta_{11} X_{11}(lived \ in \ rural \ location) + \beta_{12} X_{12}(related \ baseline \ measure \ of \ dependent \ variable, \ if \ available) \end{split}$$

Prior to reporting analyses, all relevant assumptions for multivariate logistic regression were assessed for the variables included in the models. These included independence of observations, lack of multicollinearity, proper model specification and calibration, and a lack of influential outliers and linear relationships between continuous and dependent variables (Polit, 2010).

The assumption of independence of observations was met through the random assignment to treatment or control groups in the CCDE (Polit, 2010) (e.g. Brown et al., 2007; Shen, Smyer, Mahoney, Loughlin, et al., 2008; Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008). Collinearity was assessed by examining variance inflation factors (VIF) for the second models. Particular interest was paid to variables with VIF values greater than five, where values lower than four or five are preferred.

Logistic regression lacks an equivalent to the  $R^2$  measure of variance accounted for in a model that is relied upon for determining goodness of model fit and effect size in ordinary least squares regression. Consequently, model specification was examined in a number of ways in this study. The significance of the prediction squared value was assessed for each second model, where a nonsignificant result showed that the "prediction squared has no explanatory power" (Stata, n.d., para. 7), meaning that the model was properly specified. Adjusted count  $R^2$  was assessed to determine the percent reduction in prediction error for the second models. Because samples sizes differed between models one and two, likelihood ratio tests employed the reduced sample from the second models in comparing the nested main effect, treatment status. Goodness of fit was further assessed through comparing observed and predicted probabilities with Hosmer–Lemeshow goodness of fit tests for models with samples of at least 400 and acceptable numbers of other model-related values, as recommended by Polit (2010). Long and Freese (2014) suggest that groups of 10 are typically used in the calculation of the Hosmer–Lemeshow statistic and that other measures should also be employed in

assessing fit. Correct classification rates were also examined, and the area under the Receiver Operating Characteristic (ROC) curves, Bayesian information criterions (BIC), and McFadden's adjusted  $R^2$  were compared between first and second models.

Influential outliers for the final models were screened by examining standardized residuals and Cook's distance (D) for errors or patterns and assessing their influence on the main effect of treatment status. A commonly used threshold for standardized residuals is beyond -2.58 to +2.58 away from the mean (Polit, 2010), and 1.0 for Cook's D (Cook & Weisberg, 1982), although others do exist (Hosmer, Lemeshow, & Sturdivant, 2013). Standards like 4/n and 2(k+1)/n for producing Cook's D preferred maximum values are recommended for analyses with small sample sizes due to the assignment of quite low maximum Cook's D values for large samples, such as < .05, which can result in many cases being classified as outliers (Hosmer et al., 2013). However, in the second models with small samples reported here, the 4/n and 2(k+1)/n standards for Cook's D values produced numerous outlying cases. In this dissertation, I used a slightly more conservative -2.5 to 2.5 threshold for standardized residuals, focusing on those that made up more than 5% of the sample. For Cook's D, I screened for "covariate patterns whose values for one or more of the diagnostic statistics fall well away from the rest of the values" (Hosmer et al., 2013, p. 193). Specifically, I conducted sensitivity analyses with differing thresholds of Cook's D, typically greater than .1, .2, or .3, based on visually outlying values graphically observed in each of the second models, comparing the change in model correct classification rates and the main effect's log odds, standard errors, and alphas between models employing various thresholds and a model including all cases (Hamilton, 2009; Hosmer et al., 2013). For models with small sample sizes, namely the

second model on life satisfaction, I also tested the 4/*n* standard for Cook's *D* values and reported the effect of employing this standard, which excluded the majority of cases from the model, in comparison to other thresholds. Like Brown and Dale (2007) for continuous dependent variables, outliers were considered influential if they affected the treatment status variable, in this case strongly influencing the main effect's log odds, standard error, and alpha level. However, rather than exclude these outliers, I instead reported the logistic regression findings including these outliers, similar to Brown and Dale.

Polit (2010) recommends screening for potential nonlinear relationships between dependent variables and continuous independent variables in logistic regression by employing a logit step test. This involves creating and testing a categorical variable of approximately interval values for each continuous variable within the regression models. However, age had 17 values, a prime number that made creating equal categories impossible. Consequently, logit step tests were not conducted for these analyses. Instead, I screened for any nonlinear effects of age and addressed the identified quadratic relationships by adding a squared mean-centered age variable into those analyses. I also graphed the predicted probabilities by age for each quadratic effect.

### **Missing Data**

A number of nine-month follow-up dependent variables and baseline control variables had missing data (see Table 1, pp. 49-53, and Table 2, pp. 62-65). Most demographic control variables lacked missing data. However, race information was missing for six young adults. Five young adults had *don't know* responses for Hispanic ethnicity. Other demographic variables had less than 5% missing data. Missing data was most pronounced for baseline satisfaction variables, as well as measures of unmet needs

for assistance. As detailed by Brown and Dale (2007), paid proxy respondents were not asked questions on satisfaction with paid caregivers or unmet needs, which reduced the sample of young adults with responses for these items in the treatment groups, while those who did not receive paid care, mainly in the control group, were excluded from analyses involving satisfaction with paid care. Satisfaction with paid caregivers was also not elicited from proxies who were unable to answer for participants according to Brown and Dale. Furthermore, questions on health, satisfaction, and self-care were not asked of respondents for participants who had passed away by nine-month follow-up (Brown & Dale, 2007). Finally, questions on whether young adults were employed, going to school or college, or attending activities as much as they would like were not asked of paid proxies.

In handing missing data, I employed the methods used in the CCDE, principally excluding cases for participants lacking data on individual outcome variables (Brown & Dale, 2007). As described by Shen, Smyer, Mahoney, Loughlin, et al. (2008), "restricting the sample to enrollees with available data on a given outcome variable could demonstrate differences between" (p. 95) those enrolled in the treatment and control groups. Brown and Dale (2007) also described substituting the mean for baseline demographic variables with missing data, which requires rounding for categorical variables. Mean substitution is a less robust technique than multiple imputation, such as maximum likelihood imputation, and can unduly influence parameter estimates (Enders, 2010). Rather than follow the precedent of Brown and Dale and employ mean substation on the few demographic baseline variables with missing data, which missing data, which were all missing less than 5% of cases, in this dissertation I employed listwise deletion of these cases. Log

odds, standard errors, and alpha levels changed only minimally between test analyses employing mean substitution and listwise deletion on these variables, with no effect on the significance of the main effect, treatment status. For baseline control variables with large amounts of missing data due to skip patterns related to proxy respondents being unable to answer the questions for young adults, such as the satisfaction and unmet need questions at baseline, listwise deletion was again employed. Primary limitations of listwise deletion include excluding respondents from the analyses, which can substantially reduce both sample sizes and statistical power, the requirement for data to be missing completely at random, which interview instrument skip patterns could disallow, and a distortion of parameter estimates caused by removing the cases with missing data (Enders, 2010).

### **Human Subjects Review**

Approval from Boston College's Institutional Review Board (IRB) was received for the analyses conducted in this dissertation. Because the analyses involved publicly available, de-identified secondary data, informed consent was unnecessary. The study recounted in this dissertation complied with all regulations and requirements from the Boston College IRB and the Boston College School of Social Work.

### **Chapter IV: Findings**

In this chapter, I first present demographic statistics for the sample of young adults ages 18 to 35 who took part in the CCDE and were included in the analyses here. I then move on to preliminary bivariate analyses, which include correlations for continuous and ordinal variables, and cross tabulations for the categorical dependent variables and main effect of treatment status. Next, I present findings from bivariate and multivariate logistic regression analyses for each hypothesis, discussions which include examinations of the main effect of treatment status and reporting of significant baseline control variables, predicted probabilities, model fit, screening for influential outliers, and comparisons between binary logistic regression and multinomial logistic regression results for the satisfaction and health status ratings. I close this chapter with an examination of the differences in multivariate predicted probabilities between CCDE treatment and control groups for each hypothesis.

### **Demographic Characteristics of the Sample**

Table 3 (pp. 79-82) presents descriptive demographic statistics for the full sample of young adults aged 18 to 35 (n = 831). As expected based on enrollment in the CCDE, Florida had the largest number of young adults of the three demonstration states (n = 547), followed by New Jersey (n = 180), then Arkansas (n = 104). There were some differences in demographic distributions between states. For example, the racial and ethnic diversity of the Arkansas sample was limited compared to Florida and New Jersey. Also, few participants were of races other than Black or White in the sample. This resulted in the combining of some race categories in the analyses. In addition, the majority of baseline respondents acting as proxies for young adults in each state, whether

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# Table 3

		rida 547)		Jersey 180)		ansas 104)
Demographics	Treatment $(n = 286)$	Control $(n = 261)$	Treatment $(n = 88)$	Control $(n = 92)$	Treatment $(n = 51)$	Control $(n = 53)$
Baseline			. ,		, ,	
Age: Mean $(SD^a)$	25.64 (5.13)	24.89 (4.74)	26.90 (5.22)	25.83 (4.93)	27.02 (5.46)	26.91 (4.99)
Education (Could list more	~ /		~ /	~ /	~ /	
than one)						
College bachelor's degree	11.5%	10.3%	6.8%	4.3%	2.0%	5.7%
Some college or vocational	30.1%	33.7%	13.6%	19.6%	29.4%	28.3%
training						
College graduate or professional degree	6.6%	7.7%	3.4%	-	2.0%	1.9%
High school graduate or GED	27.6%	28.4%	30.7%	26.1%	31.4%	37.7%
Missing	24.1%	19.9%	45.5%	50.0%	35.3%	26.4%
Female	38.1%	48.3%	46.6%	47.8%	45.1%	47.2%
Hispanic ethnicity	19.9%	25.3%	27.3%	22.8%	2.0%	-
Lived (Could list more than one):						
Alone With others:	4.5%	3.4%	13.6%	12.1%	17.6%	18.9%
Spouse or partner	_	0.4%	1.1%	2.2%	5.9%	1.9%
Child(ren) or child(ren)-	- 1.0%	0.4%	6.8%	9.8%	9.8%	9.4%
in-law	1.070	0.070	0.070	9.0/0	9.070	7.4/0
Parent(s)	85.3%	85.8%	69.3%	68.5%	56.9%	52.8% (continued)

Participant Demographics from Baseline and Nine-Month Follow-Up Interviews by State and Random Assignment Group

	Flor			Jersey	Arka	
-	( <i>n</i> =	547)	( <i>n</i> =	180)	( <i>n</i> =	104)
	Treatment	Control	Treatment	Control	Treatment	Control
Demographics	(n = 286)	(n = 261)	(n = 88)	(n = 92)	(n = 51)	(n = 53)
Grandparent(s)	4.9%	6.1%	4.5%	4.3%	2.0%	1.9%
Sibling(s)	31.5%	39.8%	30.7%	30.4%	21.6%	30.2%
Other relative(s)	11.2%	10.7%	11.4%	13.0%	11.8%	1.9%
Nonrelative(s) (May	9.1%	5.0%	9.1%	5.4%	9.8%	15.1%
include employees)						
Group situation	2.4%	-	1.1%	-	-	-
Lived rurally	17.5%	15.3%	10.2%	18.5%	41.2%	30.2%
Race (Could list more than						
one)						
White	72.7%	77.4%	63.6%	50.0%	72.6%	58.5%
Black	20.3%	18.0%	27.3%	30.4%	41.5%	39.6%
Other race	8.7%	6.5%	14.8%	17.4%	5.9%	1.9%
Asian	2.8%	1.9%	5.7%	6.5%	-	-
American Indian, Alaskan	2.1%	1.5%	1.1%	1.1%	3.9%	1.9%
Native, or Pacific Islander						
Other race not listed	1.8%	-	-	-	-	-
Hispanic ethnicity only	2.1%	2.7%	5.7%	9.8%	2.0%	-
System missing	0.3%	0.8%	-	2.2%	-	-
Respondent type at baseline:						
Non-representative proxy <sup>b</sup>	40 (14.0%)	25 (9.6%)	56 (63.6%)	56 (60.9%)	6 (11.8%)	2 (3.8%)
Mother	24	15	43	43	3	-
Father	8	3	5	10	_	_

Table 3 Participant Demographics from Baseline and Nine-Month Follow-Up Interviews by State and Random Assignment Group(continued)

Table 3 Participant Demographics from Baseline and Nine-Month Follow-Up Interviews by State and Random Assignment Group

		rida 547)		Jersey 180)		ansas 104)
		/	(	Control		/
Domographics	Treatment $(n - 286)$	Control $(n - 2(1))$	Treatment $(n - 88)$		Treatment $(r = 51)$	Control $(r = 52)$
Demographics	(n = 286)	(n = 261)	(n = 88)	(n = 92)	(n = 51)	(n = 53)
Daughter	-	-	2	-	-	-
Sister/sister-in-law	1	4	-	-	1	-
Brother/brother-in-law	-	-	-	-	-	-
Grandparent	1	-	1	2	-	1
Other relative	2	1	2	-	2	1
Nonrelative	1	-	2	-	-	-
Missing	3	2	1	1	0	0
Representative proxy <sup>b</sup>	208 (72.7%)	207 (79.3%)	-	-	16 (31.4%)	19 (35.8%)
Mother	164	166	-	-	11	16
Father	27	18	-	-	1	2
Daughter	-	1	-	-	-	-
Sister/sister-in-law	5	3	-	-	-	1
Brother/brother-in-law	-	-	-	-	1	-
Grandparent	2	9	-	-	-	-
Other relative	3	4	-	-	-	-
Nonrelative	-	2	-	-	-	-
Missing	7	4	-	-	3	0
Young adult	38 (13.3%)	29 (11.1%)	32 (36.4%)	36 (39.1%)	29 (56.9%)	32 (60.4%)
Nine-Month Follow-Up		× ,	( )			, , , , , , , , , , , , , , , , , , ,
Cash and Counseling Groups:						
Dropped out of treatment group by follow-up	23.1%	n/a	17.0%	n/a	9.8%	n/a
Median allowance <sup>c</sup>	\$829	n/a	\$1,097	n/a	\$313	n/a ( <i>continued</i>

	Flor $(n = $	rida 547)	New J $(n = 1)$	2	Arkansas $(n = 104)$		
Demographics	Treatment $(n = 286)$	Control $(n = 261)$	Treatment $(n = 88)$	Control $(n = 92)$	Treatment $(n = 51)$	Control $(n = 53)$	
Paid caregiver was:		· · ·	· · ·	· · ·	· · ·		
A relative	40.6%	n/a	51.1%	n/a	68.6%	n/a	
Unrelated	34.6%	n/a	40.9%	n/a	25.5%	n/a	
Skipped	24.7%	n/a	7.8%	n/a	6.0%	n/a	
Received benefit by follow-	60.1%	n/a	70.5%	n/a	94.1%	n/a	
up							
Deceased at follow-up	0.3%	0.4%	1.1%	2.2%	2.0%	-	
Follow-up proxy also paid caregiver	16.1%	0.8%	22.7%	3.3%	15.7%	1.9%	

Note. Rounded to nearest tenth place. Percentages may not add up to 100% due to rounding or multiple allowed responses. Hyphens (-) signify 0% or no participants in that demographic category, while n/a means variable data was not applicable for the control groups. <sup>a</sup>Standard deviation.

<sup>b</sup>Count data.

<sup>c</sup>For adults in the CCDE (Brown et al., 2007).

representatives or non-representatives, were mothers, followed by fathers, then other family members. The majority of paid caregivers in the treatment groups were also relatives of young adults. Arkansas, which enrolled mostly adults with physical disabilities, had the highest rate of young adult self-respondents at baseline of the three states, followed by New Jersey, then Florida. Arkansas also had the highest percentage of young adult participants who had received the monthly benefit by nine-month follow-up at 94%, compared to approximately 71% in New Jersey and 60% in Florida, similar to the CCDE findings for nonelderly adults (Brown et al., 2007). Also like in the CCDE, Florida had the highest percentage of young adult participants who dropped out of the treatment group prior to nine-month follow-up at 23%, followed by New Jersey at 17%, while Arkansas had the lowest treatment group dropout rate at 9.8%, even though Arkansas also had the lowest median monthly allowance amount at \$313 for adults (Brown et al., 2007). As described by Brown et al. (2007), this was likely due to more participants in Arkansas receiving a budget by nine-month follow-up than in other states.

### **Preliminary Bivariate Analyses**

## Correlations

Table 4 (pp. 84-85) presents Spearman's *rho* pairwise correlations for the continuous and ordinal variables in the models prior to any recoding. Most correlations between variables were very weak to moderate. All nine-month follow-up satisfaction variables significantly correlated with one another, as did all baseline satisfaction variables. Only a few correlations for variables included together in second models were strong, such as the significant correlation between baseline and nine-month health ratings compared to peers ( $r_2 = .62$ , p < .001), where higher baseline health ratings were strongly

# Table 4

Spearman's Rho Correlations for Continuous and Ordinal Variables

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1 Age <sup>a</sup>	1.00													
2 Baseline	04	1.00												
health rating <sup>b</sup>	*	***												
3 Follow-up	<b>-</b> .08 <sup>*</sup>	.62***	1.00											
health rating <sup>b</sup>	*	***	***											
4 Baseline life satisfaction <sup>c</sup>	<b>-</b> .18 <sup>*</sup>	.38***	.39***	1.00										
5 Baseline	.06	.24***	.06	.25**	1.00									
day/time care														
received														
satisfaction <sup>c</sup>														
6 Baseline task	02	.17***	$.10^{*}$	.32***	.54***	1.00								
satisfaction <sup>c</sup>		***	***	***	***	***								
7 Baseline care arrangement	.01	.22***	.17***	.49***	.48***	.46***	1.00							
satisfaction		***	***	***	*	***	***							
8 Follow-up life satisfaction <sup>c</sup>	02	.20***	.25***	.54***		.19***	.25***	1.00						
9 Follow-up	.04	.03	.07	.22**	.16**	.14*	.22***	.46***	1.00					
care arrangement														
satisfaction <sup>c</sup> 10 Follow-up	.05	001	.06	.20*	.17**	.15*	.20***	.36***	.46***	1.00				
Transportation satisfaction <sup>c</sup>	.05	001	.00	.20	.1/	.15	.20	.50	.+0	1.00				

(continued)

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Table 4 Spearman's Rho Correlations for Continuous and Ordinal Variables (continued)

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14
11 Follow-up	.03	03	.06	05	.18**	.06	.15**	.26***	.45***	.28***	1.00			
times care received satisfaction <sup>c</sup>														
12 Follow-up	.004	.10	.004	02	.19**	.17**	.09	.33***	.41***	.29***	.39***	1.00		
personal care satisfaction <sup>c</sup>														
13 Follow-up	.01	.06	.002	.02	.09	.22***	.10	.33***	.39***	.31***	.34***	.68***	1.00	
help at home satisfaction <sup>c</sup>														
14 Follow-up getting along	.05	.01	.02	.06	.11	.13*	.14**	.24***	.35***	.20***	.34***	.54***	.51***	1.00
with paid help satisfaction <sup>c</sup>						0.1 ***								

*Note*. Rounded to nearest hundredth place.  ${}^{*}p < .05$ ;  ${}^{**}p < .01$ ;  ${}^{***}p < .001$ .

<sup>a</sup>Participant age (18 to 35).

<sup>b</sup>Health ratings compared to peers at baseline and nine-month follow-up (0 = Poor; 1 = Fair; 2 = Good; 3 = Excellent). <sup>c</sup>Satisfaction ratings at baseline and nine-month follow-up (0 = Very Dissatisfied; 1 = Somewhat Dissatisfied; 2 = Somewhat Satisfied; 3 = Very Satisfied). correlated with higher follow-up health ratings. Also, for baseline and follow-up life satisfaction, higher life satisfaction ratings at baseline were significantly correlated with higher life satisfaction ratings at follow-up ( $r_2 = .54$ , p < .001). Other significant correlations for second model variables were weak, such as where higher baseline health status ratings were significantly associated with higher life satisfaction ratings at follow-up ( $r_2 = .20$ , p < .001).

### **Cross Tabulation Analyses**

Chi-square cross tabulation analyses for dependent variables and the main effect of treatment status are shown in Table 5 (pp. 87-88). Both Pearson and likelihood ratio chi-square results are presented for comparison with bivariate logistic regression models. Participants in the Cash and Counseling treatment groups had significantly greater reports of attending recreational, cultural, religious, social, or volunteer activities as much as young adults would like than control group members, which was a small positive effect ( $\phi = .07, p = .048$ ). In addition, all bivariate analyses for satisfaction rating variables showed statistically significant differences between treatment and control group members with small positive effect sizes, illustrating that Cash and Counseling treatment group members were significantly more likely to be very satisfied in these areas than control group members at nine-month follow-up. Being in the treatment groups was also significantly associated with young adults having fewer unmet needs related to personal care ( $\phi = -.09$ , p = .016), transportation ( $\phi = -.10$ , p = .005), and medication or routine health care at home ( $\phi = -.14$ , p < .001) than those in the control groups, each with small negative effect sizes. Other dependent variables did not reach statistical significance.

# Table 5

## Chi-Square Cross Tabulation Analyses for Dependent Variables and Random Assignment Group

	D	Treatment	Control	Pearson's	$LR^{a}_{2}$	ıb
Dependent Variables	Response	Group	Group	$\chi^2$	$\chi^2$	$\phi^b$
Community Involvement						
Worked for pay as much as would like to	Yes	69 (21%)	74 (19%)	.33	.33	.02
(n = 707)	No	257 (79%)	307 (81%)			
Attended school or college as much as would like to	Yes	113 (36%)	106 (29%)	3.61	3.61	.07
(n = 680)	No	202 (64%)	259 (71%)			
Attended recreational, cultural, religious, social, or	Yes	144 (42%)	136 (35%)	3.91*	3.91*	.07
volunteer activities as much as would like to $(n = 733)$	No	199 (58%)	254 (65%)			
Attended social or recreational group programs	Yes	149 (35%)	138 (34%)	.05	.05	.01
$(n = 827)^{\circ}$	No	276 (65%)	264 (66%)			
Satisfaction Ratings		~ /				
Satisfaction with way spending life $(n = 579)$	Very satisfied	157 (58%)	131 (43%)	12.47***	12.51***	.15
	Other	116 (42%)	175 (57%)			
Satisfaction with care arrangement $(n = 575)$	Very satisfied	187 (68%)	141 (47%)	25.28***	26.08***	.21
	Other	88 (32%)	159 (53%)			
Satisfaction with transportation $(n = 535)$	Very satisfied	177 (68%)	157 (57%)	6.88**	6.90**	.11
	Other	83 (32%)	118 (43%)			
Satisfaction with time of day help received $(n = 416)$	Very satisfied	183 (83%)	138 (70%)	9.60**	9.62**	.15
	Other	37 (17%)	58 (30%)		(co)	

(continued)

		Treatment	Control	Pearson's	LR <sup>a</sup>	-
Dependent Variables	Response	Group	Group	$\chi^2$	$\chi^2$	$\phi^b$
Satisfaction with the way paid attendants carried out	Very	177 (91%)	118 (72%)	20.68***	20.97***	.24
personal care duties	satisfied					
(n = 358)	Other	18 (9%)	45 (28%)			
Satisfaction with paid help around the house or	Very	171 (86%)	115 (69%)	13.98***	$14.00^{***}$	.20
community	satisfied	· · · ·	× ,			
(n = 366)	Other	29 (15%)	51 (31%)			
Satisfaction with the way gets along with paid help	Very	202 (91%)	166 (84%)	$5.04^{*}$	$5.06^{*}$	.11
( <i>n</i> = 418)	satisfied					
	Other	19 (9%)	31 (16%)			
Unmet Needs for Assistance		( )				
Personal care	Yes	105 (30%)	152 (38%)	$5.79^{*}$	$5.82^{*}$	09
(n = 748)	No	246 (70%)	245 (62%)			
Help around the house	Yes	141 (40%)	169 (43%)	.60	.60	03
(n = 740)	No	208 (60%)	222 (57%)			
Medications or routine health care at home	Yes	66 (19%)	124 (31%)	15.02***	15.25***	14
(n = 747)	No	284 (81%)	273 (69%)			
Transportation	Yes	115 (33%)	169 (43%)	7.76**	7.79**	10
(n = 747)	No	236 (67%)	227 (57%)			
Nine-Month Health Rating Compared to Peers	Poor/Fair	175 (42%)	180 (45%)	.76	.76	.03
$(n = 821)^{\circ}$	Good/	244 (58%)	222 (55%)		., 0	
	Excellent	211 (3070)	222 (3370)			

Table 5 Chi-Square Cross Tabulation Analyses for Dependent Variables and Random Assignment Group (continued)

*Note*. Rounded to nearest hundredth place.  ${}^{*}p < .05$ ,  ${}^{**}p < .01$ ,  ${}^{***}p < .001$ .

<sup>a</sup>Likelihood ratio

<sup>b</sup>Phi.

<sup>c</sup>Sample included participants with proxies who were also paid attendants at nine-month follow-up.

#### **Logistic Regression**

The bivariate cross tabulation analyses suggest that the Cash and Counseling model of PD-HCBS was significantly better than, or, where results were not significant, at least as good as care as usual in a number of areas for young adults with disabilities enrolled in the demonstration. However, while the CCDE utilized the most rigorous research design, a classic experiment with randomization, threats to internal validity still exist, such as confounding variables, maturation, history, testing, and social desirability. Consequently, more robust multivariate analyses were necessary to control for other factors that may have influenced responses to the dependent variables.

### **Community Involvement**

In answering the research question on whether young adult participants randomly assigned to Cash and Counseling treatment groups in the CCDE had higher likelihoods of community involvement than those in the control groups at nine-month follow-up, including when controlling for baseline demographic and related variables, I tested the first set of hypotheses. I did so by examining whether young adults in the Cash and Counseling treatment groups were working for pay, going to school or college, or taking part in recreational, cultural, religious, social, or volunteer activities as much as they would like, or were attending social or recreational group programs more so than those in the control groups at nine-month follow-up. I did so based on the developmental life stage of young adulthood (Arnett, 2015; Côté, 2006; Erikson, 1950; Furstenberg et al., 2005; Konstam, 2015), the CDTE (Kosciulek, 1999; Kosciulek, 2005; Kosciulek & Merz, 2001), as well as theories and principles of self-determination (Nerney & Shumway, 1996; Ryan & Deci, 2000). Significant findings would suggest greater opportunities for

community involvement for young adults enrolled in Cash and Counseling than those receiving traditional, agency-based care.

**Employment.** As shown in Table 6 (pp. 91-92), the first bivariate logistic regression model tested the main effect of treatment status with reports that young adults worked for pay as much as they would like at nine-month follow-up. Although in the expected direction, where being assigned to the Cash and Counseling treatment groups was associated with 11% greater odds that young adults worked as much as desired, the relationship was not significant (z = .58, p = .57, CI = .77 - 1.61). The nonsignificant bivariate model was the same as both the Pearson's and likelihood ratio chi-square cross tabulations presented in Table 5 (pp. 87-88):  $\chi^2$  (1, n = 707) = .33, p = .57. The second multivariate logistic regression model, which included the main effect of treatment status, baseline control variables, and whether participants had ever worked for pay at baseline, is also presented in Table 6 (pp. 91-92). Being in the Cash and Counseling treatment groups was associated with an 11% increase in the odds that young adults worked for pay as much as they would like at nine-month follow-up compared to those in the control groups when also compared to other baseline control variable reference categories and when holding mean-centered age and mean-centered age-squared constant (z = .49, p =.627, CI = .74 - 1.66):  $\chi^2$  (15, n = 696) = 87.32, p < .001. Although this finding was in the hypothesized direction, it was not significant.

Other baseline control variables did significantly predict whether young adults were achieving their desired level of paid work by nine-month follow-up (Table 6, pp. 91-92). Young adults from Arkansas were 89% less likely compared to those from Florida (z = -4.46, p < .001). When reference groups were changed (not shown in the

# Table 6

# Community Involvement: Binary Logistic Regression Analyses

	Worked for Pay as Much as Would Like		Attended School or College as Much as Would Like		Took Part in Activities as much as Would Like <sup>a</sup>		Attended Social or Recreational Group Programs	
		Odds		Odds		Odds		Odds
Models	β	Ratio	β	Ratio	β	Ratio	β	Ratio
Model 1 (Main Effect) <sup>b</sup>	•						·	
Cash and Counseling treatment group	.11	1.11	.31	1.37	.30*	1.35	.03	1.03
member								
Change in -2LL <sup>c</sup>	-355.83		-425.52		-485.51		-533.88	
n	707		680		733		827	
Model 2 (Main Effect & Baseline								
Control Variables) <sup>d</sup>								
Cash and Counseling treatment group	.10	1.11	.35*	1.42	.24	1.27	01	.99
member								
Could not get out of bed without help	43	.65	08	.92	49**	.61	41 <sup>*</sup>	.66
Ever worked for pay <sup>e</sup>	.91**	2.49	-	-	-	-	-	-
Female	02	.98	.07	1.08	17	.84	17	.85
Hispanic	.16	1.17	.05	1.06	.16	1.17	38	.69
Lived rurally	11	.89	.03	1.03	.13	1.14	23	.80
Mean-centered age	.01	1.01	09***	.91	.02	1.02	004	1.00
Mean-centered age squared	02**	.98	-	-	<b>-</b> .01 <sup>**</sup>	.99	-	-
Poor/fair health compared to peers	30	.74	26	.78	38*	.68	16	.85
Publicly funded paid help	19	.83	24	.79	50***	.61	.12	1.13
Race								
Black	24	.78	50*	.60	36	.70	18	.83
Other or multiracial	.56	1.75	.19	1.21	01	.99	09	.91
								continued

Table 6 Community Involvement: Binary Logistic Regression Analyses (continued)

	Worked for Pay as Much as Would Like		Attended School or College as Much as Would Like		Took Part in Activities as much as Would Like <sup>a</sup>		Attended Social or Recreational Group Programs	
		Odds		Odds		Odds		Odds
Models	β	Ratio	β	Ratio	β	Ratio	β	Ratio
State								
New Jersey	89**	.41	49	.62	82**	.44	20	.82
Arkansas	-2.20***	.11	80*	.45	-1.19 <sup>***</sup>	.30	35	.70
Took part in social or recreational group programs in the past year <sup>f</sup>	-	-	-	-	-	-	1.84***	6.31
Young adult respondent	1.51***	4.52	1.39***	4.00	.86***	2.37	18	.83
Change in -2LL <sup>c</sup>	-302.95***		-386.60***		-436.41***		-433.29***	
n	69	96	66	59	72	23	81	3

*Note.* Rounded to nearest hundredth place. p < .05, p < .01, p < .001. Hyphens (-) denote variables not included in a model. Reference category was *No*.

<sup>a</sup>Activities included: recreational, cultural, religious, social, or volunteer.

<sup>b</sup>Comparison was a control group member.

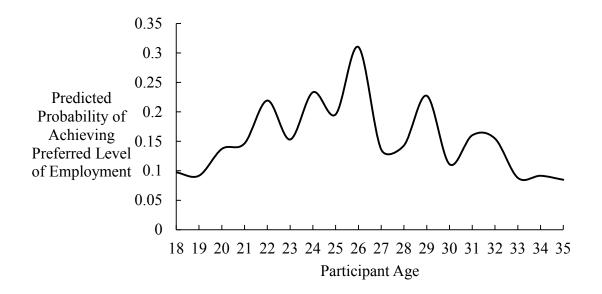
<sup>c</sup>Least Likelihood – compared to the null model.

<sup>d</sup>Comparison was a proxy respondent for a White non-Hispanic male control group member from Florida of average age who was in good/excellent health compared to peers, could get out of bed without help, did not receive publicly funded paid help, and did not live rurally at baseline.

<sup>e</sup>Comparison had not worked for pay at baseline.

<sup>f</sup>Comparison had not taken part in social or recreational group programs in the past year at baseline.

table), those from Arkansas were 73% less likely compared to young adults from New Jersey ( $\beta = -1.31$ , OR = .27, z = -2.51, p = .012). Similarly, young adults from New Jersey had 59% lower odds than those from Florida (z = -2.65, p = .008). These findings suggest state-based differences in employment opportunities. The odds were significantly greater for young adults who responded to baseline interviews compared to those with proxy respondents at baseline by a factor of 4.52 or 352% (z = 5.65, p < .001). This suggests that young adults who were capable of responding for themselves at baseline were more likely to have met their preferred amount of paid work than were those with baseline proxy respondents or had differing opinions from proxies. Participants with proxy respondents may also have had more severe disability and less opportunities for paid employment. Additionally, the quadratic relationship represented by the significant squared mean-centered age variable showed that around one year (-.02/.01 = 2/2 = 1)after the mean age of 25.72, or around the age of 27, the relationship between going to school as much as young adults would like and age went from positive to negative, where there was a 2% decrease in likelihood (z = -3.18, p = .001). This nonlinear relationship is represented by predicted probabilities for ages 18 to 35 in Figure 2 (p. 94). However, mean-centered age was not a significant predictor in the second model. Additionally, mean-centered age was not significant when entered into the model alone ( $\beta = -.01$ , OR =.99, z = -0.56, p = .576). Finally, whether young adults had ever worked for pay at baseline also significantly increased the odds by 149% compared to those who had never worked for pay prior to baseline interviews (z = 2.85, p = .004). This finding suggests that prior employment before enrolling in the demonstration was an important contributor to young adults working at desired levels at follow-up.



*Figure 2*. Predicted probability of achieving a preferred level of employment by participant age. This figure illustrates the nonlinear effect of age on the probability of young adults working for pay as much as they would like at CCDE follow-up.

Predicted probabilities by state, random assignment, and baseline respondent type are presented in Table 7 (p. 95). Here we can observe the significant difference between young adults and proxy respondents at baseline by state. Differences in probabilities between young adults and proxies at baseline were quite pronounced in Florida and to a somewhat smaller extent in New Jersey, followed by Arkansas. Young adults who took part in baseline interviews did have higher probabilities of responding affirmatively to working as much as they would like regardless of random assignment. However, all young adults had generally low probability rates, ranging from 2% to 49%, which suggests unmet needs for employment with this population. The differences in probabilities between treatment and control groups in each state were also small, reflecting the nonsignificant effect of treatment status on working for pay at follow-up.

## Table 7

*Worked for Pay as Much as Young Adults would Like at Follow-Up: Multivariate Predicted Probabilities by Baseline Respondent Type, State, and Random Assignment Group<sup>a</sup>* 

	Random	Baseline Respondent Type				
	Assignment	Predicted Probability				
State	Group	Young Adult	Proxy	Difference		
Florida	Treatment	.49 (.3662)	.18 (.1323)	.31		
	Control	.46 (.3360)	.16 (.1221)	.30		
	Difference	.03	.02			
New Jersey	Treatment	.28 (.1640)	.08 (.0313)	.20		
	Control	.26 (.1537)	.07 (.0312)	.19		
	Difference	.02	.01			
Arkansas	Treatment	.10 (.0217)	.02 (.0005)	.08		
	Control	.09 (.0216)	.02 (.0004)	.07		
	Difference	.01	.00			

Note. Rounded to nearest hundredth place.

<sup>a</sup>Comparison was a proxy respondent for a White non-Hispanic male control group member from Florida of average age who was in good/excellent health compared to peers, could get out of bed without help, did not receive publicly funded paid help, did not live rurally, and had not worked for pay at baseline.

When examining multivariate predicted probabilities by treatment status and state as shown in Table 8 (p. 96), the minimal differences in probabilities between treatment and control groups within each state further reflect the nonsignificant main effect. However, the significant differences between states found in model two are reflected in these probabilities. Although all probability levels were low in general, Florida treatment and control groups had significantly higher probabilities than both New Jersey and Arkansas, and Arkansas also had significantly lower probabilities than New Jersey regardless of random assignment. Probabilities were particularly low for young adults in Arkansas, where the sample from that state only had a 3% probability of working for pay as much as they would like. New Jersey was slightly higher at 10% for the control group and 11% for the treatment group, with Florida showing probabilities of 24% for the treatment group and 22% for the control. Together, these low probabilities with little difference between random assignment groups within each state suggest that more could be done to assist young adults with disabilities in achieving their desired level of paid employment.

### Table 8

	Predicted Probability			
Outcome	Florida	New Jersey	Arkansas	
Met desired levels of:				
Paid employment <sup>a</sup>				
Treatment group	.24 (.1830)	.11 (.0518)	.03 (.0006)	
Control group	.22 (.1628)	.10 (.0516)	.03 (.0006)	
Difference	.02	.01	.00	
School or college				
Treatment group	.40 (.3346)	.29 (.1938)	.23 (.1333)	
Control group	.32 (.2538)	.22 (.1430)	.17 (.0925)	
Difference	.08	.07	.06	
Activities				
Treatment group	.48 (.4154)	.29 (.2038)	.22 (.1231)	
Control group	.42 (.3548)	.24 (.1632)	.18 (.1026)	
Difference	.06	.05	.04	
Attended social or recreational				
group programs <sup>b</sup>				
Treatment group	.34 (.2840)	.29 (.2038)	.26 (.1538)	
Control group	.34 (.2840)	.30 (.2139)	.27 (.1538)	
Difference	.00	01	01	

Community Involvement: Multivariate Predicted Probabilities by State and Random Assignment Group

*Note*. Rounded to nearest hundredth place. Comparison was a proxy respondent for a White non-Hispanic male control group member from Florida of average age who was in good/excellent health compared to peers, could get out of bed without help, did not receive publicly funded paid help, and did not live rurally at baseline.

<sup>a</sup>Comparison had not worked for pay at baseline.

<sup>b</sup>Comparison had not taken part in social or recreational group programs in the past year at baseline.

The second model had a good fit with the data. A Hosmer-Lemeshow goodness of fit test was nonsignificant, showing a desirable model fit:  $\chi^2$  (10, n = 696) = 5.41, p =.71. BIC, while high, decreased by 14.15 from model one (724.77) to model two (710.63), giving very strong support for the second model. A likelihood ratio test between the same individuals included in both models further illustrated they were significantly different:  $\chi^2$  (14) = 86.75, p < .001. In addition, the area under the ROC curve was .74 for the second model, representing fair level of predictive power that was greater than .51 for the first model. The variable of squared prediction was also not significant, suggesting model two was specified correctly (z = 1.20, p = .23). Multicollinearity was not observed with a mean VIF of 1.76. Most VIF scores were below two, with the highest VIF values 3.21 for participants ever having worked for pay and 2.45 for having a publicly paid attendant at baseline. McFadden's adjusted  $R^2$  was .08, an improvement over model one (-.005). The second model also reduced prediction error by 7% compared to 0% in the first model. Due to an imbalance in sensitivity (14.49%) and specificity (98.03%), estimates were adjusted for a prior probability of 138 correctly classified cases, giving a new probability level of .20 (138/696 = .20), rather than the standard .50 probability level. As a result, the correct classification rate dropped from 81.19% to 65.52%, although with more balanced sensitivity (71.01%) and specificity (64.16%).

*Influential outlier screening.* When examining potentially influential outliers, the second model had 22 cases with standardized residuals outside of the -2.5 to 2.5 range, less than 5% of the sample and within the parameters of a normal distribution. Graphical screening of Cook's *D* values showed that most cases fell in a gradually more clustered pattern below .2, with 19 potential outliers greater than .2, of which 18 had *Yes* responses

to the dependent variable. Six cases were above .3, with three of those cases above .4. Careful screening of these cases did not identify any overt causes for the outlying values. Sensitivity test regression analyses were run first excluding the 19 cases with outlying Cook's *D* values greater than .2, then the 6 cases with outlying Cook's *D* values greater than .3. Excluding the 19 cases dropped the Arkansas category from the analysis. Small changes were noted in the log odds and significance levels for the treatment status variable for both test analyses, although excluding these cases did not make treatment status significant. Lastly, the balanced correct classification rate was 66.09% when excluding 19 cases and 65.37% when excluding 6 cases, both similar to the model including these cases reported here (65.52%).

School or college attendance. The bivariate logistic regression model in Table 6 (pp. 91-92) showed that while Cash and Counseling treatment group members had 37% greater odds of going to school or college as much as they would like than control group respondents at nine-month follow-up, which was in the expected direction, this relationship was not significant (z = 1.90, p = .06, CI = .99 - 1.89). The nonsignificant bivariate model again replicated both the Pearson's and likelihood ratio chi-squares from Table 5 (pp. 87-88):  $\chi^2$  (1, n = 680) = 3.61, p = .06. The second multivariate model, also presented in Table 6 (pp. 91-92), showed being in the Cash and Counseling treatment groups was significantly associated with 42% greater odds of young adults attending school or college as much as they would like at follow-up than those in the control groups when also compared to all other baseline control variable reference categories and when holding mean-centered age constant (z = 1.98, p = .048, CI = 1.00 - 2.00):  $\chi^2$  (13, n = 669) = 68.42, p < .001. This finding was in the expected direction.

A number of baseline control variables in the second model were also significant predictors (Table 6, pp. 91-92). Young adults from Arkansas had 55% lower odds of attaining a desired level of school or college attendance than those in Florida (z = -2.59, p = .01). Being Black was associated with 40% lower odds compared to White young adults (z = -2.23, p = .026), illustrating a barrier to education based on race. Young adult respondents at baseline also had greater odds than those with proxy respondents by a factor of 4.00 or 300% (z = 5.92, p < .001), suggesting that young adults who could answer for themselves at baseline were more likely to have their personal desire for education met at follow-up compared to those with baseline proxy respondents. Meancentered age was also significant, where a one year increase from the mean age (25.73) was associated with a 9% decrease in the odds that young adults were going to college or school as much as they preferred (z = -4.72, p < .001).

Multivariate predicted probabilities based on state, respondent type, and random assignment for the second model are shown in Table 9 (p. 100). Of note, probability rates for baseline young adult respondents, whether in the treatment or control groups and regardless of state, were considerably higher than for baseline proxy respondents. For example, young adults in the Florida treatment group who took part in baseline interviews had a 65% probability of going to school or college as much as they would like compared to young adults in the same group with a proxy respondent, who had a 31% probability. However, significant differences in probabilities between treatment and control groups were similar between respondent types across the three demonstration states. Differences in probabilities between just treatment and control groups across the three states were small as also shown in Table 8 (p. 96). All three treatment groups had slightly higher probabilities than the respective control groups, reflecting the significant

main effect. In general, Florida had the highest probabilities, followed by New Jersey,

then Arkansas.

### Table 9

Attended School or College as Much as Young Adults would Like at Follow-Up: Multivariate Predicted Probabilities by Baseline Respondent Type, State, and Random Assignment Group

	Random	Baseline Respondent Type						
	Assignment	Pre	Predicted Probability					
State	Group	Young Adult	Proxy	Difference				
Florida	Treatment	.65 (.5476)	.31 (.2538)	.34				
	Control	.56 (.4568)	.24 (.1930)	.32				
	Difference	.09	.07					
New Jersey	Treatment	.53 (.4066)	.22 (.1331)	.31				
	Control	.44 (.3256)	.17 (.1024)	.27				
	Difference	.09	.05					
Arkansas	Treatment	.45 (.3259)	.17 (.0826)	.28				
	Control	.37 (.2449)	.13 (.0620)	.24				
	Difference	.08	.04					

*Note*. Rounded to nearest hundredth place. Comparison was a proxy respondent for a White non-Hispanic male control group member from Florida of average age who was in good/excellent health compared to peers, could get out of bed without help, did not receive publicly funded paid help, and did not live rurally at baseline.

Model two showed a better fit in some areas than the first model, although not in all fit aspects. A Hosmer–Lemeshow goodness of fit test was nonsignificant, illustrating a good fit:  $\chi^2(10, n = 669) = 13.86, p = .09$ . Also, a likelihood ratio test confirmed that models one and two were significantly different:  $\chi^2(12) = 64.94, p < .001$ . However, the area under the ROC curve was only .69, a poor level of predictive power that was improved over .54 for the first model. In addition, model one had weak support over model two with an increase of 13.20 in BIC between the first (864.07) and second

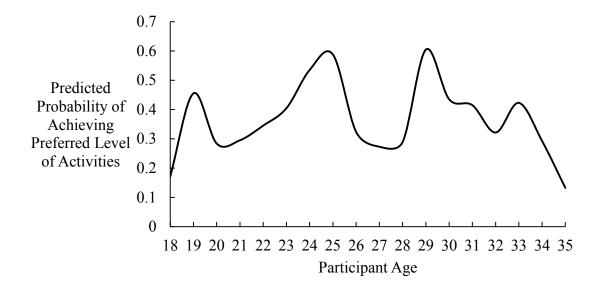
(864.28) models, both high. The linear predicted value squared for the second model was nonsignificant (z = 1.95, p = .051), although close to the p < .05 level, suggesting the potential for a specification error. Mean VIF for the second model was 1.56, with the highest VIF value 2.21 for receiving publicly funded paid help at baseline, showing a lack of multicollinearity. McFadden's adjusted  $R^2$  was .05, a small improvement over model one (-.003), and prediction error was reduced by 13% compared to 0% in the first model. Finally, the correct classification rate dropped from 71.75% to 62.78% when the imbalance in sensitivity (22.22%) and specificity (95.36%) was corrected (sensitivity = 63.89%, specificity = 62.25%) based on a probability of .32 (216/669= .32).

*Influential outlier screening.* When screening for potentially influential outliers, the second model had 13 cases with standardized residuals outside of the -2.5 to 2.5 range, less than 5% of the sample. Visual screening of Cook's *D* values showed that the majority fell below .15, with four cases having visually outlying values, all either .33 or .41. These four individuals were males from the Florida control group with *Yes* responses to the dependent variable. Excluding these four cases from the second model resulted in a decrease in the significant alpha from .048 to .021 for the main effect of treatment group assignment. The balanced correct classification rate also improved slightly from 62.78% to 63.91%. The more conservative model reported here contains these outliers.

Activity attendance. The first bivariate logistic regression model (Table 6, pp. 91-92) shows that being in the Cash and Counseling treatment groups was significantly associated with a 35% increase in the odds of young adults attending recreational, cultural, religious, social, or volunteer activities as much as they would like compared to control group members at nine-month follow-up. The significant bivariate model was

also the same as the Pearson's and likelihood ratio chi-squares shown in Table 5 (pp. 87-88):  $\chi^2$  (1, n = 773) = 3.91, p = .048. However, the multivariate model in Table 6 (pp. 91-92) showed that while random assignment to the treatment groups was associated with a 27% increase in the odds that young adults were taking part in activities as much as they would like compared to those in control groups at follow-up, which was in the expected direction, this relationship was no longer significant when compared to all other baseline control variable reference categories and when holding mean-centered age and meancentered age-squared constant (z = 1.46, p = .145, CI = .92 - 1.76):  $\chi^2$  (14, n = 723) = 89.61, p < .001.

Table 6 (pp. 91-92) shows that a number of baseline control variables did significantly predict participants' attending activities as much as they would like at follow-up. State of enrollment was once again a significant predictor, where young adults from Arkansas had 70% lower odds (z = -3.87, p < .001) and those from New Jersey had 56% lower odds (z = -3.33, p = .001) compared to those in Florida, where the population of young adults had primarily developmental disabilities. Young adult respondents at baseline were also 137% more likely than those with baseline proxies to attend activities at a preferred level at follow-up (z = 3.87, p < .001). Furthermore, the squared meancentered age term was significant (z = -3.21, p = .001). This finding represents a quadratic effect where there was a 1% drop in likelihood around .25 years (-.01/.02 = .5/2 = .25) after the mean age of 25.72 when the relationship between age and attending activities became negative. This relationship is illustrated by predicted probabilities in Figure 3 (p. 103). In addition, Table 6 (pp. 91-92) illustrates that those with poor or fair health at baseline had 32% lower odds (z = -2.21, p = .027), and those who needed assistance to get out of bed at baseline had 39% lower odds (z = -2.82, p = .005), suggesting that being in worse health and needing more assistance with mobility may have restricted opportunities for taking part in activities. Finally, receiving publicly funded paid help at baseline was associated with 40% lower odds (z = -2.89, p = .004).



*Figure 3*. Predicted probability of achieving a preferred level of activity by participant age. Shows the nonlinear effect of age on the predicted probability of young adults attending activities as much as preferred at CCDE follow-up.

Table 10 (p. 104) presents multivariate predicted probabilities based on treatment group assignment, state, and baseline respondent type. Similar to other examinations of predicted probabilities and the significant difference between respondent type at baseline on the dependent variable, baseline young adult respondents, regardless of random assignment or state, had higher probabilities of going to recreational, cultural, religious, social, or volunteer activities as much as they would like at follow-up compared to young adults with baseline proxy respondents. In addition, as also shown in Table 8 (p. 96), Florida had the highest probability rates of activity attendance, followed by New Jersey, then Arkansas, indicative of the significant differences seen between states. Probability rates were fairly low, with small differences between treatment and control groups reflected in the nonsignificant multivariate finding on the effect of treatment status.

### Table 10

Going to Activities as Much as Young Adults would Like at Follow-Up: Multivariate Predicted Probabilities by Baseline Respondent Type, State, and Random Assignment Group

	Random	Baseline Respondent Type						
	Assignment	Pre	Predicted Probability					
State	Group	Young Adult	Proxy	Difference				
Florida	Treatment	.63 (.5374)	.42 (.3649)	.21				
	Control	.58 (.4669)	.37 (.3143)	.21				
	Difference	.05	.05					
New Jersey	Treatment	.43 (.3155)	.24 (.1533)	.19				
	Control	.38 (.2649)	.20 (.1328)	.18				
	Difference	.05	.05					
Arkansas	Treatment	.35 (.2247)	.18 (.0928)	.17				
	Control	.29 (.1841)	.15 (.0723)	.14				
	Difference	.06	.03					

*Note*. Rounded to nearest hundredth place. Comparison was a proxy respondent for a White non-Hispanic male control group member from Florida of average age who was in good/excellent health compared to peers, could get out of bed without help, did not receive publicly funded paid help, and did not live rurally at baseline.

Regarding goodness of fit, a nonsignificant Hosmer–Lemeshow test illustrated a good fit for the second model:  $\chi^2$  (10, n = 723) = 6.91, p = .54. BIC also decreased by 12.66 between models one (984.22) and two (971.57), giving very strong support for the second model, although BIC values were high for both models. A likelihood ratio test between models one and two did find that the two models were significantly different:  $\chi^2$  (13) = 85.80, p < .001. The area under the ROC curve was .70 for the second model, a

fair level of predictive power that was improved from the first model, which was .54. A nonsignificant linear predicted value squared also showed there was not a specification error (z = -.36, p = .716). Mean VIF was 1.61, representing a lack of multicollinearity where receiving publicly funded paid help at baseline had the largest VIF value at 2.27. McFadden's adjusted  $R^2$  was .06, a small improvement from model one (.00). The second model also reduced prediction error by 14% compared to 0% in the first model. Finally, the rate of cases correctly classified dropped from 67.22% to 64.04% in the second model when the imbalance in sensitivity (41.88%) and specificity (82.96%) was corrected (sensitivity = 64.62%, specificity = 63.68%) by adjusting for a .38 probability (277/723 = .38).

*Influential outlier screening.* When examining potentially influential outliers, the second model had only three cases with standardized residuals outside of the -2.5 to 2.5 range. Reviewing a graph of Cook's D values showed that the majority clustered below .2, with only two cases visibly outlying, both with Cook's D values of .37. These two cases were for non-Hispanic Black male participants in the Florida control group who responded *Yes* to the dependent variable. When an analysis was run excluding the outlying Cook's D cases, the log odds for the main effect of treatment status changed slightly and the alpha dropped from .145 to .095, although still not significant at the p < .05 level. The balanced correct classification rate also improved by 1%, from 64.04% to 65.05%. The model reported here included these non-influential outliers.

**Social or recreational group program attendance.** Presented in Table 6 (pp. 91-92), the first bivariate logistic regression model showed that being in the Cash and Counseling treatment groups was associated with 3% greater odds of young adults

attending social or recreational group programs at nine-month follow-up compared to controls, in the expected direction, although this relationship was not significant (z = .22, p = .83, CI = .25 - .32). The nonsignificant bivariate model also replicated the Pearson's and likelihood ratio chi-squares (Table 5, pp. 87-88):  $\chi^2$  (1, n = 827) = .05, p = .83. The second multivariate model, also presented in Table 6 (pp. 91-92), shows that when compared to all baseline control variable reference categories and when mean-centered age was held constant, being in the Cash and Counseling treatment groups was associated with 1% lower odds of young adults attending social or recreational group programs at follow-up than for control group members, in the opposite direction than predicted (z = .09, p = .93, CI = .71 - 1.37):  $\chi^2$  (14, n = 813) = 185.49, p < .001. However, this relationship was not significant.

Two baseline control variables were significant predictors of whether or not young adults attended social or recreational group programs at follow-up (Table 6, pp. 91-92). Those who needed assistance with getting out of bed at baseline had 34% lower odds of attending a program (z = -2.27, p = .023). Additionally, having taken part in a social or recreational group program in the year prior to baseline was significantly associated with 531% greater odds of young adults attending this sort of program at follow-up (z = 10.56, p < .001), suggesting that past attendance significantly predicted current attendance at follow-up.

As presented in Table 8 (p. 96), multivariate predicted probabilities were similar between treatment and control groups within each state. Young adults in the New Jersey and Arkansas treatment groups had just 1% lower probabilities of attending social or recreational group programs at follow-up than those in the control groups, while the probability did not differ between treatment and control groups in Florida. Although generally low, probability levels were highest for young adults from Florida, followed by New Jersey, then Arkansas irrespective of random assignment.

The second model had a good level of fit based on a nonsignificant Hosmer-Lemeshow test:  $\gamma^2$  (10, n = 813) = 12.74, p = .12. BIC also decreased by 114.11 between models one (1081.20) and two (967.09), which, while BIC values were still high, gave very strong support for the second model. A likelihood ratio test showed that models one and two were significantly different:  $\chi^2$  (13) = 185.38, p < .001. Specification errors were also not found for the second model based on a nonsignificant linear predicted value squared (z = 1.24, p = .216). The second model had fair predictive power with an area under the ROC curve of .77, better than .50 for the first model. Multicollinearity was unlikely to be a problem with a mean VIF of 1.56, where the baseline measure of whether young adults received publicly paid help at baseline again had the largest VIF value at 2.29. McFadden's adjusted  $R^2$  was .15, improved from model one (-.004). The second model also reduced prediction error by 28% compared to 0% for the first model. Finally, the rate of cases correctly classified dropped only slightly from 74.91% to 74.78% when an imbalance in sensitivity (62.68%) and specificity (81.47%) was addressed (sensitivity = 66.90%, specificity = 79.02%) by adjusting for a .35 probability (284/813 = .35).

*Influential outlier screening.* Screening for potentially influential outliers showed that the second model had 22 cases with standardized residuals outside the -2.5 to 2.5 range, less than 5% of the sample. When examining Cook's *D* values, the majority clustered below .1, with 25 between .1 and .15, and two visibly outlying at .25. Twenty-four had *Yes* responses to the dependent variable, although none reporting having taken

part in social or recreational activities in the past year at baseline. Little changes were noted to the treatment status variable when these 25 cases were excluded from the analysis. However, the balanced correct classification rate increased from 74.78% to 77.16%. The model reported here includes these non-influential outliers.

## **Satisfaction Ratings**

I addressed the research question regarding whether young adult participants in the Cash and Counseling treatment groups in the CCDE had greater likelihoods of satisfaction with life and the program than for control group participants at nine-month follow-up based on the CDTE (Kosciulek, 1999; Kosciulek, 2005; Kosciulek & Merz, 2001), theories and principles of self-determination (Nerney & Shumway, 1996; Ryan & Deci, 2000), young adulthood (e.g., Furstenberg et al., 2005; Konstam, 2015), and previous research on PD-HCBS and participant satisfaction (Brown et al., 2007; Harry, MacDonald, et al., 2016; Robinson et al., 2012; Shen, Smyer, Mahoney, Loughlin, et al., 2008; Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008). My second set of hypotheses predicted that, compared to young adults in the control groups receiving agency-based care, young adults enrolled in Cash and Counseling would have significantly greater odds of being very satisfied with life and six program-related areas at nine-month follow-up. These hypotheses were tested with logistic regression.

**Life satisfaction.** Findings from a bivariate logistic regression model, presented in Table 11 (pp. 109-110), show that being in the Cash and Counseling treatment groups was significantly associated with an 81% increase in the odds that young adults were very satisfied with the way they were spending their lives compared to control group members at nine-month follow-up (z = 3.52, p < .001, CI = .93 - 3.97), in the expected direction.

# Satisfaction Ratings: Binary Logistic Regression Analyses Part I

Table 11

				Very Sati	sfied with:			
	W	ay	Times of	Day Care				
	Spendi	ng Life	Rece	eived	Care Arra	ingement	Transp	ortation
		Odds		Odds		Odds		Odds
Models	β	Ratio	β	Ratio	β	Ratio	β	Ratio
Model 1 (Main Effect) <sup>a</sup>								
Cash and Counseling	.59***	1.81	.73**	2.08	.87***	2.40	.47**	1.60
treatment group member								
Change in -2LL <sup>b</sup>	-395.	$07^{***}$	-218	.70 <sup>**</sup>	-379.	79 <sup>***</sup>	-350	0.68***
n		79	4	16	57		5	35
Model 2 (Main Effect &								
Baseline Control Variables) <sup>c</sup>								
Cash and Counseling	.65	1.92	.99**	2.70	1.01***	2.74	.56**	1.75
treatment group member								
Could not get out of bed	.49	1.64	34	.71	08	.92	39 <sup>*</sup>	.68
without help								
Dissatisfied with life <sup>d</sup>	-2.13***	.12	-	-	-	-	-	-
Dissatisfied with times of day	-	-	69	.50	-	-	-	-
care was received <sup>d</sup>								
Dissatisfied with care	-	-	-	-	78**	.46	-	-
arrangement <sup>d</sup>								
Female	.01	1.01	.52	1.68	.28	1.33	.16	1.17
Hispanic	1.11	3.04	16	.85	.79**	2.20	.42	1.52
Lived rurally	.72	2.05	35	.71	12	.89	29	.75
Mean-centered age	.04	1.04	02	.98	.01	1.01	.02	1.02
Mean-centered age squared	02*	.98	-	-	-	-	-	-
								(continue

Table 11 Satisfaction Ratings: Binary Logistic Regression Analyses Part I (continued)

				Very Sati	sfied with:			
		/ay	Times of	Day Care				
	Spending Life		Received		Care Arrangement		Transportation	
		Odds		Odds		Odds		Odds
Models	β	Ratio	β	Ratio	β	Ratio	β	Ratio
Poor/fair health compared to	16	.85	.12	1.12	.05	1.06	.16	1.17
peers								
Publicly funded paid help	55	.58	00	1.00	26	.77	01	.99
Race								
Black	34	.71	28	.76	18 82 <sup>*</sup>	.84	.21	1.23
Other or multiracial	.14	1.15	-1.27*	.28	82*	.44	.07	1.07
State								
Arkansas	74	.48	66	.52	.33	1.39	.37	1.45
New Jersey	79	.45	39	.68	20	.82	09	.91
Young adult respondent	-	-	19	.82	11	.90	75**	.47
Change in -2LL <sup>b</sup>	-92.	99***	-132.33*		-333.10***		-331.26**	
n	1	80	20	51	5	33	5	27

*Note*. Rounded to nearest hundredth place. p < .05, p < .01, p < .001. Hyphens (-) denote variables not included in a model. Reference category was *Other*. Multivariate model on life satisfaction included baseline young adult self-respondents only. <sup>a</sup>Comparison was a control group member.

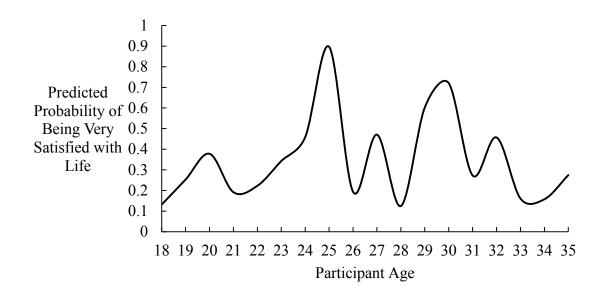
<sup>b</sup>Least Likelihood – compared to the null model.

<sup>c</sup>Comparison was a proxy respondent for a White non-Hispanic male control group member of average age from Florida who was in good/excellent health compared to peers, could get out of bed without help, did not receive publicly funded paid care, and did not live rurally at baseline.

<sup>d</sup>Comparison was satisfied at baseline.

This significant model was the same as the bivariate likelihood ratio chi-square reported in Table 5 (pp. 87-88):  $\chi^2$  (1, n = 579) = 12.51, p = .0004. The second multivariate logistic regression model is also shown in Table 11 (pp. 109-110), which only included young adults who responded to baseline interviews themselves. While young adults selfrespondents in the Cash and Counseling treatment groups had 92% greater odds of being very satisfied with their lives than those in the control groups at follow-up, again in the expected direction, this relationship was not significant at the p < .05 level when compared to all other baseline control variable reference categories and when holding mean-centered age and mean-centered age-squared constant (z = 1.75, p = .08, CI = .93 - 3.97):  $\chi^2$  (14, n = 180) = 53.67, p < .001.

Regarding the baseline control variables in Table 11 (pp. 109-110), a significant squared mean-centered age illustrates a quadratic relationship between age and young adults' self-reports of being very satisfied with life, where the relationship became negative around .25 (-.02/.04 = .5/2 = .25) years after the mean age of 25.72 with a 2% decrease in likelihood (z = -1.99, p = .046). This nonlinear relationship is also depicted in Figure 4 (p. 112) with predictive probabilities by participant age. The only other control variable that was a significant predictor was young adults being dissatisfied with life at baseline, which decreased the odds of being very satisfied at follow-up by 88% (z = -4.59, p < .001). This finding showed that being dissatisfied with life at baseline may have precluded becoming very satisfied in the short nine-month demonstration for this subset of young adult self-respondents.



*Figure 4*. Predicted probability of life satisfaction by age for baseline young adult respondents. Demonstrates the nonlinear effect of age by the predicted probability of young adults being very satisfied with life at follow-up.

Table 12 (p. 113) presents multivariate predicted probabilities by state and random assignment. Regardless of state, being in the Cash and Counseling treatment groups was associated with greater probabilities of young adults who responded to baseline interviews being very satisfied with the way they were spending their lives at follow-up compared to self-respondents in the control groups, although this relationship was not significant. Probability rates were somewhat low, where young adults in the Florida treatment group had the highest probabilities at 23%. Florida treatment group young adult baseline respondents also had the greatest difference in probability over the control group at 16%. Finally, probabilities, and differences in probabilities, were similar between New Jersey and Arkansas.

# Table 12

	Predicted Probability						
Very Satisfied Outcomes	Florida	New Jersey	Arkansas				
The way spending life <sup>a,b</sup>		2					
Treatment group	.54 (.3772)	.35 (.1753)	.36 (.1954)				
Control group	.38 (.2057)		.23 (.0837)				
Difference	.16	.12	.13				
Times of day care received <sup>c</sup>							
Treatment group	.88 (.8195)	.83 (.7492)	.79 (.6594)				
Control group	.73 (.6483)	· · · · · · · · · · · · · · · · · · ·	.59 (.3879)				
Difference	.15	.18	.20				
Care arrangement <sup>d</sup>							
Treatment group	.70 (.6377)	.65 (.5576)	.76 (.6687)				
Control group	.46 (.3853)		.54 (.4068)				
Difference	.24	.24	.22				
Transportation							
Treatment group	.69 (.6276)	.67 (.5777	.76 (.6686)				
Control group	.56 (.4963)	.54 (.4365)	.65 (.5377)				
Difference	.13	.13	.11				
Personal care							
Treatment group	.90 (.8495)	.97 (.94 - 1.00)	.91 (.8398)				
Control group	.69 (.5980)	.90 (.8298)	.72 (.5585)				
Difference	.21	.07	.19				
Help at home/community <sup>e</sup>							
Treatment group	.87 (.8095)	.92 (.8698)	.82 (.6896)				
Control group	.65 (.5377)	.74 (.6187)	.55 (.3278)				
Difference	.22	.18	.27				
Getting along with paid help <sup>d</sup>							
Treatment group	.95 (.9198)	.93 (.8898)	.89 (.8097)				
Control group	.89 (.8495)		.79 (.6493)				
Difference	.06	.07	.10				

Satisfaction Ratings: Multivariate Predicted Probabilities by State and Random Assignment Group

*Note*. Rounded to nearest hundredth place. Comparison was a proxy respondent for a White non-Hispanic male control group member of average age from Florida who was in good/excellent health compared to peers, could get out of bed without help, did not receive publicly funded paid care, and did not live rurally at baseline.

<sup>a</sup>Sample included baseline young adult self-respondents only.

<sup>b</sup>Comparison was satisfied with life at baseline.

<sup>c</sup>Comparison was satisfied with times of day care was received at baseline.

<sup>d</sup>Comparison was satisfied with care arrangement at baseline.

<sup>e</sup>Comparison was satisfied with tasks at baseline.

The second model appeared to have a good fit. A likelihood ratio test illustrated that the two models presented here were significantly different:  $\chi^2$  (13) = 49.96, *p* < .001. The second model also had good predictive power based on an area under the ROC curve of .80, improved over .57 for the first model. A nonsignificant linear predicted value squared showed there was not a specification error (*z* = .24, *p* = .809). Multicollinearity was unlikely to be a problem with a mean VIF of 1.90. The highest VIF was 3.00 for receiving publicly funded paid help at baseline. A McFadden's adjusted *R*<sup>2</sup> of .10 was improved over the first model. The rate of cases correctly classified dropped from 73.89% to 70.00% when sensitivity (63.77% to 73.91%) and specificity (80.18% to 67.57%) were balanced based on a .38 probability (69/180 = .38). Finally, BIC decreased by 538.99 between models one (802.86) and two (263.87), providing very strong support for the second model.

*Influential outlier screening.* Data screening showed that only three cases had standardized residuals outside of the -2.5 to 2.5 range, below 5% of the sample. Cook's *D* values had a wide dispersion, with most visually falling below .3, 18 greater than .3, and 27 greater than .2. Employing the 4/n convention gave a cut off of .02 that would have resulted in over 120 cases, the majority of the sample, being excluded from the analysis. Therefore, I instead conducted sensitivity analyses with Cook's *D* values above .2 and again above .3 to examine their influence. Both models dropped a number of variables due to perfect prediction and collinearity, which reduced the sample sizes. The correct classification rate could also not be calculated for either model. However, treatment status did became significant at the p < .05 level for both models tested. While the results

presented here included these influential outliers, this information suggests that the nonsignificant multivariate finding for treatment status may underestimate the actual effect participant direction had on life satisfaction in this sample.

Satisfaction with time of day care was received. The bivariate regression model in Table 11 (pp. 109-110) illustrates that, compared to those in the control groups, being in the Cash and Counseling treatment groups was significantly associated with a 108% increase in the odds of young adults being very satisfied with the time of day care was received at nine-month follow-up (z = 3.07, p = .002, CI = 1.30 - 3.32). This finding was as expected and the same as the significant likelihood ratio chi-square in Table 5 (pp. 87-88):  $\chi^2$  (1, n = 416) = 9.62, p = .002. The second multivariate logistic regression model, also in Table 11 (pp. 109-110), shows that when compared to all other baseline control variable reference categories and when mean-centered age was held constant in the model, being in the Cash and Counseling treatment groups significantly predicted that young adults were more likely to be very satisfied with when care was received by a factor of 2.70, or 170%, compared to control group participants at follow-up (z = 3.02, p= .003, CI = 1.42 - 5.13), again as predicted:  $\gamma^2$  (14, n = 261) = 28.32, p = .013.

Regarding the baseline control variables, only being another race than White or Black or being multiracial was significantly associated with satisfaction with when care was received (Table 11, pp. 109-110). These individuals had 72% lower odds of being very satisfied at follow-up than young adults who were White (z = -2.33, p = .02). Although being dissatisfied with the time of day care was received at baseline was associated with 50% lower odds of being very satisfied at follow-up, this finding was not significant at the p < .05 level (z = -1.95, p = .051). Multivariate predicted probabilities by state and random assignment are shown in Table 12 (p. 113). All three states had relatively high probabilities of treatment group participants being very satisfied with the time of day care was received, with Florida treatment group members having the highest probability at 88%, followed by those in the New Jersey and Arkansas treatment groups at 83% and 79%, respectively. This may reflect satisfaction with the flexibility and control treatment group members had over when care was received that is allowed for in the Cash and Counseling model of participant direction. Conversely, the largest difference in probability between random assignment groups was in Arkansas where treatment group members had a 20% greater probability than control group members, followed by the New Jersey treatment group at 18%, then the Florida treatment group at 15%.

An examination of goodness of fit for the second model showed conflicting information. In some cases the first model outperformed the second. For example, a significant difference was not found between models one and two when conducting a likelihood ratio test with the first model nested in the second:  $\chi^2$  (13) = 21.67, p = .061. McFadden's adjusted  $R^2$  also dropped from .01 in the first model to -.01 in the second model. Both models failed to reduce prediction error. However, the likelihood ratio test examining the null model nested within model two was significant:  $\chi^2$  (14) = 27.07, p = .0189. There was also a lack of specification error with a nonsignificant linear predicted value squared for the second model (z = .18, p = .861). Mean VIF for the second model was 1.96, with most variables having VIF values below 2.50, representing a lack of multicollinearity. However, the VIF value for receiving publicly funded paid help at baseline was 5.39, slightly higher than preferred. An area under the ROC curve of .71 showed that the second model had fair predictive power, compared to .59 for the first model. After correction based on a .75 probability rate (196/261 = .75), the rate of cases correctly classified dropped from 75.10% to 67.05% when sensitivity (94.90% to 67.86%) and specificity (15.38% to 64.62%) were balanced. There was also very strong support for the second model based on a 101.33 decrease in BIC between models one (449.47) and two (348.14).

*Influential outlier screening.* Seven cases had standardized residuals outside of the -2.5 to 2.5 range in the second model, less than 5% of the sample. Graphical screening of Cook's *D* values showed a wide dispersion of values below .25, with 13 cases in particular having outlying Cook's *D* values, eight greater than .3. These individuals were all coded as *Other* on the dependent variable and 10 were coded as *Satisfied* at baseline. When the 13 cases with Cook's *D* values over .25 were excluded from the analysis, the treatment status log odds increased by .68 and the alpha decreased from p = .003 to p < .001, although receiving publicly funded paid help at baseline was dropped from the analysis due to perfect prediction and collinearity. The balanced correct classification rate also improved from 67.05% to 72.22%. The model reported here included these cases.

Satisfaction with care arrangement. As presented in Table 11 (pp. 109-110), the bivariate logistic regression model illustrates that compared to those in the control groups, young adults in the Cash and Counseling treatment groups had a 140% increase in the odds of young adults being very satisfied with their care arrangement at nine-month follow-up (z = 5.04, p < .001, CI = 1.71 - 3.67), as expected. This model was also the same as the bivariate likelihood ratio chi-square shown in Table 5 (pp. 87-88):  $\chi^2$  (1, *n* 

= 575) = 26.08, p < .001. As shown in the multivariate logistic regression model (Table 11, pp. 109-110), being in the Cash and Counseling treatment groups was associated with a 174% greater likelihood that young adults were very satisfied with their care arrangement than control group members at follow-up when compared to all other baseline control variable reference categories and when holding mean-centered age constant (z = 5.29, p < .001, CI = 1.88 - 3.98), which was also in the expected direction:  $\chi^2$  (14, n = 533) = 61.71, p < .001.

A few other control variables significantly predicted care arrangement satisfaction (Table 11, pp. 109-110). Being of other races than White or Black or being multiracial decreased the odds that young adults were very satisfied by 56% compared to young adults who were White (z = -2.13, p = .034). Conversely, being Hispanic increased the likelihood by a factor of 2.20 compared to non-Hispanics (z = 2.89, p = .004). These findings suggest racial and cultural variations in the receipt of care. Finally, dissatisfaction with care arrangement at baseline was associated with 54% lower odds of being very satisfied at follow-up compared to those who were satisfied at baseline (z = -3.45, p = .001). This finding may illustrate that unsatisfactory care arrangements continued throughout the demonstration for some individuals.

Multivariate predicted probabilities by state and random assignment are presented in Table 12 (p. 113). Arkansas treatment group members had the highest probability of being very satisfied with care arrangements at 76%, followed by the treatment group members in Florida at 70%, then in New Jersey at 65%. Control group members had probabilities ranging from 41% in New Jersey to 54% in Arkansas. Florida and New Jersey treatment groups had a 24% greater probability than the control groups, while Arkansas treatment group members had a 22% greater probability.

The second model had a fair fit overall, with some improvements over the first model. For example, a Hosmer–Lemeshow goodness of fit test was nonsignificant:  $\gamma^2$ (10, n = 533) = 5.16, p = .74. Also, a significant likelihood ratio test found the two models to be different:  $\chi^2(13) = 33.68$ , p = .0013. Multicollinearity was not observed with a mean VIF of 1.58 and the highest VIF 2.36 for having publicly paid help at baseline. There was also no specification error based on a nonsignificant linear predicted value squared (z = -.54, p = .59). However, the area under the ROC curve was .69 for the second model, a poor level of predictive power and a small improvement over .61 for the first. McFadden's adjusted  $R^2$  was also only .04, a slight increase from the first model (.03). The second model reduced prediction error by 19% compared to 7% in the first. The rate of cases correctly classified dropped from 65.29% to 62.48% when sensitivity (75.41% to 60.98%) and specificity (51.75% to 64.47%) were balanced based on a .57 probability (305/533 = .57). Finally, BIC showed very strong support for the second model after a decrease of 12.10 between models one (772.30) and two (760.20), although both were higher than preferred.

*Influential outlier screening.* When screening for potentially influential outliers, just one case had a residual outside of the -2.5 to 2.5 range. Visually screening a graph of Cook's *D* values showed that most were below .1, with eight cases potentially outlying above .1 and one distinctly higher than the others at .15. There were no obvious reasons for the outlying values. When these eight cases were excluded from the second model, only slight changes were seen in the log odds, standard error, and alpha for treatment

status. The balanced correct classification rate also improved slightly from 62.48% to 63.43%. The model presented here included these non-influential cases.

**Satisfaction with transportation.** The first bivariate logistic regression model, presented in Table 11 (pp. 109-110), showed that being in the Cash and Counseling treatment groups significantly predicted that young adults were more likely to be very satisfied with transportation at nine-month follow-up by a factor of 1.60 compared to those in the control groups (z = 2.62, p = .019, CI = 1.13 - 2.28), as predicted. Again, this finding was the same as the bivariate likelihood ratio chi-square in Table 5 (pp. 87-88):  $\chi^2$  (1, n = 535) = 6.90, p = .009. The multivariate logistic regression model in Table 11 (pp. 109-110) illustrated that when compared to all other baseline control variable reference categories and when mean-centered age was held constant, being in the Cash and Counseling treatment groups significantly predicted a 75% greater likelihood that young adults were very satisfied with transportation at follow-up than those in the control groups (z = 2.95, p = .003, CI = 1.21 - 2.53):  $\chi^2$  (13, n = 527) = 34.12, p = .001. This finding was in the hypothesized direction.

In relation to other control variables in the second model (Table 11, pp. 109-110), young adult respondents at baseline were 53% less likely than baseline proxy respondents to be very satisfied with transportation at follow-up (z = -3.32, p = .001), suggesting that participants who could respond for themselves at baseline had differing views on transportation than baseline proxy respondents for young adults. Finally, needing help getting out of bed at baseline was associated with a 32% decrease in the likelihood of being very satisfied with transportation (z = -1.99, p = .047), illustrating that difficulty with this ADL affected how participants got around in their community as well.

Table 12 (p. 113) presents multivariate predicted probabilities based on state and random assignment. Arkansas treatment group members had the highest probability overall of being very satisfied with transportation at 76%, followed by Florida at 69%, then New Jersey at 67%, although significant differences between states were not found in the second model. Control group members in New Jersey had the lowest probability at 54%. Differences in probabilities were similar between states, with Arkansas having both the highest probabilities and smallest difference between groups.

Multivariate predicted probabilities by state, random assignment, and baseline respondent type are shown in Table 13 (p. 122). In general, compared to baseline young adult self-respondents, those with proxies had higher probabilities of very satisfied responses regarding transportation at follow-up, illustrating the significant difference found between young adult and proxy baseline respondents in the second model. For instance, a young adult responding at baseline who was assigned to the Arkansas treatment group had a 65% probability of being very satisfied with transportation at follow-up compared to 53% for baseline young adult respondents in that state's control group. The highest probability was 80% for young adults with baseline proxy respondents in the Arkansas treatment group, where the differences between random assignment group and respondent types were also the smallest. Young adults in the New Jersey control group members who took part in baseline interviews themselves had the lowest probability level at 41%, followed by young adult baseline respondents in the Florida control group at 43%. However, regardless of baseline respondent type, treatment group members had higher probabilities than those in the control groups, representing the significant difference between random assignment groups found in the second model.

#### Table 13

	Random	Baseli	Baseline Respondent Type					
	Assignment	Pre	Predicted Probability					
State	Group	Young Adult	Proxy	Difference				
Florida	Treatment	.57 (.4669)	.74 (.6780)	17				
	Control	.43 (.3255)	.62 (.5569)	19				
	Difference	14	.12					
New Jersey	Treatment	.55 (.4467)	.72 (.6282)	17				
	Control	.41 (.2953)	.60 (.4871)	19				
	Difference	.14	.12					
Arkansas	Treatment	.65 (.5478)	.80 (.7190)	15				
	Control	.53 (.3966)	.70 (.5882)	17				
	Difference	.12	.10					

Very Satisfied with Transportation: Multivariate Predicted Probabilities by Baseline Respondent Type, State, and Random Assignment Group

*Note.* Rounded to nearest hundredth place. Comparison was a proxy respondent for a White non-Hispanic male control group member of average age from Florida who was in good/excellent health compared to peers, could get out of bed without help, did not receive publicly funded paid care, and did not live rurally at baseline.

The fit of the second model was fair. A Hosmer–Lemeshow goodness of fit test was significant, illustrating a good fit:  $\chi^2$  (10, n = 527) = 6.87, p = .55. However, the area under the ROC curve was .65, which showed poor predictive power, but was improved over .56 for the first model. There was also no specification error based on a nonsignificant linear predicted value squared (z = 1.15, p = .248). Mean VIF was 1.59, with the highest VIF 2.23 for receiving probably funded paid care at baseline, suggesting that multicollinearity was not an issue for the second model. Yet McFadden's adjusted  $R^2$  was low at .01 and only slightly higher than the first model (.004). The second model also only reduced prediction error by 4% versus 0% in the first model. A likelihood ratio test between the two models was significant, illustrating they were different:  $\chi^2$  (12) = 25.71, p = .012. However, the first model had very strong support over the second based on an increase of 36.35 in BIC between models one (713.92) and two (750.26), with both

having high BIC values. Finally, the correct classification rate in the second model dropped from 63.95% to 59.20% when sensitivity (87.27% to 60.30%) and specificity (24.87% to 57.36%) were balanced based on a .63 probability (330/527 = .63).

*Influential outlier screening.* Screening for potentially influential outliers identified no cases with residuals outside of the -2.5 to 2.5 range. Visual screening showed that the majority of Cook's *D* values fell below .15, with four visually outlying values of either .21 or .28. Two individuals with potentially influential Cook's *D* values were Black males from the Florida control group with proxy respondents at baseline who were coded as *Other* for the dependent variable, while two were Black male participants from the Florida treatment group who responded to the baseline survey themselves and had *Very Satisfied* responses for the dependent variable. Excluding these four cases from the analysis only changed the log odds and standard error for treatment status slightly and decreased the significant alpha from .003 to .001. The balanced correct classification rate improved from 59.20% to 62.91%. These cases are included in the analysis reported here.

Satisfaction with the way paid attendants carried out personal care duties. As shown in the bivariate logistic regression model presented in Table 14 (pp. 124-125), being in the Cash and Counseling treatment groups was significantly associated with 275% greater odds that young adults were very satisfied with the way paid attendants carried out personal care duties compared to those in the control groups at nine-month follow-up (z = 4.36, p < .001, CI = 2.07 - 6.79), which was as hypothesized. This finding was again the same as the bivariate likelihood ratio chi-square in Table 5 (pp. 87-88):  $\chi^2$ (1, n = 358) = 20.97, p < .001. The second, multivariate logistic regression model in

# Table 14

# Satisfaction Ratings: Binary Logistic Regression Analyses Part II

			Very Satis	sfied With		
	Personal Care		-	Help Around House or Community		Along with Help
		Odds		Ödds		Odds
Models	β	Ratio	β	Ratio	β	Ratio
Model 1 (Main Effect) <sup>a</sup>						
Cash and Counseling treatment group member	1.32***	3.75	.96***	2.61	.69*	1.99
Change in -2LL <sup>b</sup>	-156.	$07^{***}$	-185.	19***	-15	0.53*
n	35	58	36	56		18
Model 2 (Main Effect & Baseline Control Variables) <sup>c</sup>						
Cash and Counseling treatment group member	1.35***	3.87	1.34***	3.81	.77*	2.16
Could not get out of bed without help	15	.86	.67	1.95	14	.87
Dissatisfied with tasks <sup>d</sup>	-	-	96*	.38	-	-
Dissatisfied with care arrangement <sup>d</sup>	-	-	-	-	<b>-</b> .81 <sup>*</sup>	.44
Female	.28	1.32	06	.94	.37	1.45
Hispanic	.48	1.62	.41	1.51	.87	2.39
Lived rurally	51	.60	.19	.82	09	.91
Mean-centered age	.01	1.01	.02	1.02	.06	1.06
Poor/fair health compared to peers	35	.70	12	.89	.25	1.28
Publicly funded paid help	58	.56	-1.62	.20	06	.94
Race						
Black	48	.62	.20	1.22	28	.76
Other or multiracial	02	.98	43	.65	<b>-</b> 1.29 <sup>*</sup>	.28
State						
Arkansas	.10	1.11	40	.67	50	.45
New Jersey	1.34**	3.82	.44	1.55	27	.76
						(continue

 Table 14. Satisfaction Ratings: Binary Logistic Regression Analyses Part II (continued)

		Very Satisfied With						
					Getting Along with			
	Person	Personal Care <sup>a</sup>		Community <sup>a</sup>		Paid Help <sup>a</sup>		
	Odds			Odds		Odds		
Models	β	Ratio	$\beta$	Ratio	β	Ratio		
Young adult respondent	68	.51	61	.54	54	.58		
Change in -2LL <sup>b</sup>	-136	-136.88***		-117.26**		27.50 <sup>**</sup>		
п	3.	351		243		398		

*Note*. Rounded to nearest hundredth place. p < .05, p < .01, p < .001. Hyphens (-) denote variables not included in a model. Reference category was *Other*.

<sup>a</sup>Comparison was a control group member.

<sup>b</sup>Least Likelihood – compared to the null model.

<sup>c</sup>Comparison was a proxy respondent for a White non-Hispanic male control group member of average age from Florida who was in good/excellent health compared to peers, could get out of bed without help, did not receive publicly funded paid care, and did not live rurally at baseline.

<sup>d</sup>Comparison was satisfied at baseline.

Table 14 (pp. 124-125) illustrates that when compared to all other baseline control variable reference categories, and when mean-centered age was held constant, random assignment to a Cash and Counseling treatment group was associated with 287% greater odds that young adults were very satisfied with how the paid attendants performed their personal care at follow-up compared to those in the control groups (z = 3.99, p < .001, CI = 1.99 - 7.54), as expected:  $\chi^2$  (13, n = 351) = 44.14, p < .001.

In regards to other baseline control variables presented in Table 14 (pp. 124-125), being from New Jersey significantly increased the odds that young adults were very satisfied by 282% compared to Florida (z = 2.73, p = .006). In addition, being from Arkansas decreased the odds by 74% compared to those in New Jersey ( $\beta = -1.24$ , OR = .26, z = -2.33, p = 02). These findings suggest differences in the perceived quality of personal care received based on state, which did have varied median allowances.

Predicted probabilities based on state and random assignment are displayed in Table 12 (p. 113). In general, being in the treatment groups was associated with a 90% to 97% probability that young adults were very satisfied with personal care at follow-up compared to probabilities that ranged from 69% to 90% in the control groups. New Jersey treatment group members had the highest probability at 97%, while Florida control group members had the lowest probability at 69%. The largest difference between treatment and control groups was in Florida, where treatment group members had a 21% greater probability than those in the control group. Arkansas treatment group members had a 19% greater probability, while those in New Jersey had a 7% greater probability than controls. Although significance levels for differences between states by random assignment group are not reported due to small samples sizes in Arkansas and New Jersey, differences between states regardless of group assigned were in some cases statistically significant as reported above.

Even though the second model had a fair fit, there were similarities with the first model. The two models were significantly different based on a significant likelihood ratio test:  $\chi^2$  (14) = 22.00, p = .0375. A nonsignificant linear predicted value squared illustrated there was not a specification error in the second model (z = -.43, p = .67). The second model also had good predictive power with an area under the ROC curve of .75, compared to .66 in the first model. Multicollinearity was unlikely to be an issue with a mean VIF of 1.73 and the highest VIF 2.80 for receiving publicly funded paid help at baseline. However, McFadden's adjusted  $R^2$  was .05, the same as the first model (.05). The second model also reduced prediction error by just 2%, only slightly greater than 0% in the first model. Additionally, the rate of cases correctly classified dropped from 83.48% to 69.52% when sensitivity (97.95% to 69.18%) and specificity (11.86% to 71.19%) were balanced based on a .83 probability (292/351 = .83). Finally, there was very strong support for the first bivariate model over the second based on a 31.91 increase in BIC between models one (323.90) and two (355.81).

*Influential outlier screening.* Screening for potentially influential outliers found that 13 cases in the second model had residuals outside of the preferred -2.5 to 2.5 range, less than 5% of the sample. Cook's *D* values were mainly clustered below .1, with 47 more widely distributed above .1. Of those 47, six had *Very Satisfied* responses to the dependent variable. Twenty-seven cases had Cook's *D* values greater than .2, two of which had large outlying values, both 1.23. These cases were proxy respondents for White non-Hispanic female participants in the Florida treatment group who had an *Other* 

response for the dependent variable. No issues for these cases could be found from visual appraisal. When excluding all 47 cases with Cook's *D* values above .1, control variables for treatment status, Hispanic ethnicity, and receiving publicly funded paid help at baseline were dropped from the model due to perfect prediction and collinearity. In addition, the variable categories for New Jersey and being another race than White or Black or being multiracial were dropped due to perfect prediction. Similarly, excluding the 28 cases with Cook's *D* values over .2 caused the treatment status variable to be dropped from the model due to collinearity and perfect prediction. The other race than White or Black or multiracial category was also dropped as a result of perfect prediction. The model presented here included all potentially influential cases.

Satisfaction with how paid attendants helped around the house or community. According to the bivariate logistic regression model in Table 14 (pp. 124-125), random assignment to the Cash and Counseling treatment groups was significantly associated with a 161% increase in the odds that young adults were very satisfied with how paid attendants helped them around the house or community at nine-month followup compared to controls (z = 3.67, p < .001, CI = 1.56 - 4.37), which was as hypothesized. This bivariate model was the same as the likelihood ratio chi-square in Table 5 (pp. 87-88):  $\chi^2$  (1, n = 366) = 14.00, p < .001. The second multivariate logistic regression model (Table 14, pp. 124-125) again illustrated the expected finding. Those in the Cash and Counseling treatment groups had 281% greater odds that young adults were very satisfied with help received at home or in the community at follow-up than control group members when compared to all other baseline control variable reference categories and when holding mean-centered age constant (z = 3.79, p < .001, CI = 1.91 - 7.61):  $\chi^2$ (14, n = 243) = 34.86, p = .0015.

In terms of the other control variables in the second model (Table 14, pp. 124-125), only reports of being dissatisfied with tasks at baseline was a significant predictor. Specifically, this group had 62% lower odds of young adults being very satisfied at follow-up compared to those who were satisfied with tasks at baseline (z = -2.30, p =.021). This suggests a satisfaction component on how tasks were completed separate from the intervention that may not have changed for some individuals over the nine-month demonstration.

Table 12 (p. 113) presents the multivariate predicted probabilities for the second model based on state and random assignment. Young adults in all three treatment groups had high probabilities of being very satisfied with help received around the house or community in the state's respective Cash and Counseling program, ranging from 82% to 92%. Arkansas control group members had the lowest probability at 55%, followed by control group members in Florida at 65%, and New Jersey control group members at 74%. Arkansas had the greatest difference in probability for treatment group members at 27%, with Florida treatment group members showing a 22% increase in probability over that state's control group, and New Jersey an 18% increase in probability, reflecting the significant difference between treatment and control groups in Table 14 (pp. 124-125).

The second model appeared to have a fair fit, although similarities were seen with the first model. For example, the models did not differ based on a nonsignificant likelihood ratio test:  $\chi^2$  (13) = 20.05, p = .094. In addition, McFadden's adjusted  $R^2$  was .02 in the second model, lower than in model one (.03). The second model did reduce prediction error by 15% compared to 0% in the first model. Furthermore, the nonsignificant linear predicted value squared illustrated the model did not have a specification error (z = -.48, p = .63). The area under the ROC curve was also .73, a fair level of predictive power that was improved over .62 for the first model. Multicollinearity was not a major issue with a mean VIF of 1.99 and most variables falling below 2.25, although the VIF for the measure of receiving publicly funded paid help at baseline was high at 5.85. The rate of cases correctly classified also dropped from 79.42% to 66.26% when sensitivity (96.74% to 66.30%) and specificity (25.42% to 66.10%) were balanced using a .76 probability level (184/243 = .76). Finally, there was very strong support for the second model based on a 65.26 decrease in BIC between models one (382.18) and two (316.92).

*Influential outlier screening.* When considering potentially influential outliers, six cases in the second model had standardized residuals outside of the -2.5 to 2.5 range, less than 5% of the sample. Cook's *D* values were widely dispersed under .2, with 10 cases between .2 and .3, and 14 above .3, with 23 coded *Other* for the dependent variable. Sensitivity analyses were conducted by first excluding the 24 cases with Cook's *D* values greater than .2, then the 14 cases with Cook's *D* values greater than .3. Both resulted in the baseline measure of receiving publicly funded paid help being dropped from the model due to perfect prediction and collinearity. In addition, the log odds for treatment status ranged from 2.28 to 3.51, large increases from the reported 1.34, suggesting these outliers were highly influential on the strength of the relationship between treatment status and the dependent variable, although the significance level stayed the same at *p* < .001. The model excluding 14 cases also improved the balanced corrected classification

rate from 66.26% to 73.15%, while the model excluding 25 cases showed an additional improvement at 75.73%. The model reported here includes these outliers.

Satisfaction with how participants got along with paid attendants. The bivariate logistic regression model shown in Table 14 (pp. 124-125) presents the hypothesized finding that being in the Cash and Counseling treatment groups was significantly associated with 99% greater odds of young adults being very satisfied with how well they got along with paid attendants compared to those in the control groups at nine-month follow-up (z = 2.22, p = .027, CI = 1.08 - 3.64). This finding was the same as the bivariate likelihood ratio chi-square in Table 5 (pp. 87-88):  $\chi^2$  (1, n = 418) = 5.06, p = .025. The second, multivariate logistic regression model, also displayed in Table 14 (pp. 124-125), again illustrated the expected finding. Compared to those in the control groups, being in the Cash and Counseling treatment groups was associated with 116% greater odds that young adults were very satisfied with how well they got along with their paid attendants at follow-up when also compared to all other baseline control variable reference categories and when holding mean-centered age constant (z = 2.23, p = .026, CI = 1.10 - 4.25):  $\chi^2$  (14, n = 398) = 29.98, p = .008.

Additional control variables were also significant predictors of satisfaction with young adults' relationships with paid attendants (Table 14, pp. 124-125). Being of another race than White or Black or being multiracial was associated with 72% lower odds compared to young adults who were White (z = -2.18, p = .029). Lastly, being dissatisfied with baseline care arrangements was associated with 56% lower odds that young adults were very satisfied with how they got along with their paid attendants at follow-up (z = -2.27, p = .023). Similar to other measures of baseline satisfaction, this

finding suggests that baseline levels of satisfaction with the care arrangement continued to influence satisfaction with young adults' relationships with paid attendants over the demonstration for some respondents.

Multivariate predicted probabilities based on state and random assignment, shown in Table 12 (p. 113), were generally high regardless of state or random assignment. However, young adults in the treatment groups had the highest probabilities, ranging from 89% in Arkansas to 95% in Florida. The Arkansas control group members had the lowest probability at 79%. These probabilities reflect the significant finding between random assignment groups.

The second model had an overall fair fit, even though some measures of fit showed little improvement over the first model. For instance, McFadden's adjusted  $R^2$ was .00, lower than the first model (.003). Both models also did not reduce prediction error. In addition, an increase of 31.67 in BIC between models one (313.13) and two (344.80) gave very strong support for the first model. A significant likelihood ratio test did show that models one and two did differ:  $\chi^2$  (13) = 25.50, p = .0198. An area under the ROC curve of .74 also gave the second model fair predictive power, which was improved over .58 for the first model. Furthermore, specification errors were not found in the second model based on a nonsignificant linear predicted value squared (z = .35, p = .73). Multicollinearity was also not an issue with a mean VIF of 1.66 and the highest VIF 2.70 for receiving publicly funded paid help at baseline. Finally, the rate of cases correctly classified decreased from 88.44% to 69.10% when sensitivity (99.72% to 69.89%) and specificity (2.17% to 63.04%) were balanced using a .88 probability level (352/398 = .88).

Influential outlier screening. Screening for potentially influential outliers identified 22 cases in the second model with residuals outside the -2.5 to 2.5 range, which was 5.5% of the sample and merited further examination. All 22 cases were coded as Other for the dependent variable and six as Dissatisfied with the care arrangement at baseline. Visual appraisal of Cook's D values showed a wide scattering for 51 potential outliers above .1. A total of 20 cases had Cook's D values above .3, all of which were coded as Other on the dependent variable. Sensitivity analyses were first conducted excluding the 51 cases with outlying standardized residuals and/or Cook's D values greater than .1. However, their exclusion resulted in a failure of the model due to perfect prediction for most control variables. Employing a .2 cutoff for Cook's D and excluding 37 cases from the model resulted in the following variables or categories being dropped due to perfect prediction and collinearity: treatment status, being another race than White or Black or being multiracial, Hispanic ethnicity, and receiving publicly funded paid help at baseline. Excluding Cook's D cases greater than .4, which included 24 total cases, caused the Hispanic ethnicity variable to be dropped from the analysis, while doubling the log odds for treatment status and reducing the significant alpha from .026 to .011. The balanced correct classification rate could not be calculated for any test model. The second model reported here included all potentially influential outliers.

**Comparison between binary and multinomial logistic regression satisfaction rating models.** Table 15 (p. 134) presents multinomial logistic regression coefficients for the main effect of treatment group assignment to assist with comparison and cross validation of the binary logistic regression results shown in Tables 11 (pp. 109-110) and 14 (pp. 124-125).

### Table 15

## Satisfaction Ratings by Random Assignment Group: Multinomial Logistic Regression Analyses

	Treatment Group Members						
				Model Tw	o (Main Effect an	nd Baseline	
	Mo	del One (Main E	ffect) <sup>a</sup>	(	Control Variables	) <sup>b</sup>	
	Very	Somewhat	Somewhat	Very	Somewhat	Somewhat	
Dependent Variables	Dissatisfied	Dissatisfied	Satisfied	Dissatisfied	Dissatisfied	Satisfied	
Way spending life <sup>c,d</sup>	95**	75*	43*	75	-1.31	45	
Times of day care received <sup>e</sup>	-1.58*	-1.13	54*	-2.31*	80	96*	
Care arrangement <sup>f</sup>	-1.86***	98**	66**	-2.44***	-1.28**	88***	
Transportation	47	48	47*	54	57	56*	
Personal care	-1.50	-2.01	-1.22***	-1.31	-1.80	-1.34***	
Help around house or community <sup>g</sup>	68	<b>-</b> 2.19 <sup>*</sup>	89**	-1.61	-3.10	-1.37**	
Getting along with paid help <sup>f</sup>	20	-15.34	58	42	-16.95	68	

*Note.* Rounded to nearest hundredth place. p < .05, p < .01, p < .001. Samples are the same as in logistic regression. Reference category was *Very Satisfied*.

<sup>a</sup>Comparison was a control group member.

<sup>b</sup>Comparison was a proxy respondent for a White non-Hispanic male control group member of average age from Florida who was in good/excellent health compared to peers, could get out of bed without help, did not receive publicly funded paid care, and did not live rurally at baseline.

<sup>c</sup>Model two included baseline young adult self-respondents only.

<sup>d</sup>Comparison was satisfied with life at baseline.

<sup>e</sup>Comparison was satisfied with the times of day care was received at baseline.

<sup>f</sup>Comparison was satisfied with the care arrangement at baseline.

<sup>g</sup>Comparison was satisfied with tasks at baseline.

As shown in Table 15 (p. 134), both bivariate and multivariate multinomial logistic regression models illustrated that when treatment group members were compared to those in the control groups, all categories were negatively associated with *very* satisfied responses, the reference category. Dependent variables on satisfaction with the times of day care was received, care arrangement, transportation, personal care, and help around the house and community were associated with significantly lower likelihoods of treatment group members being *somewhat satisfied* compared to controls in both models when compared to the reference category very satisfied. Table 1 (p. 49-53) does show that treatment group members had higher frequencies of being *very satisfied* on most satisfaction measures compared to controls across the three demonstration states at follow-up. Treatment status was also significantly associated with lower likelihoods of young adults being very dissatisfied, somewhat dissatisfied, and somewhat satisfied with the way they were spending their life compared to control group members in the bivariate multinomial model (Table 15, p. 134). However, like in the multivariate logistic regression model in Table 11 (pp. 109-110), these relationships lost significance in the second multinomial model including baseline control variables shown in Table 15 (p. 134) and when changing satisfaction reference groups (not shown). In addition, while the logistic regression models showed a significant effect of treatment group assignment on young adults being *very satisfied* with how they got along with paid help (Table 14, pp. 124-125), significant relationships were not seen in either multinomial models for this dependent variable in Table 15 (p. 134) or when changing reference groups. Only the significantly lower likelihoods of treatment group members having very dissatisfied responses compared to those in the control groups remained significant in the

multivariate models for satisfaction with the time of day care received and care arrangement, and care arrangement at the *somewhat dissatisfied* level. When reference groups were changed for other satisfaction ratings, a few additional significant associations were seen, such as treatment group members being significantly more likely than those in the control groups to be *very satisfied* with the times of day care was received when the reference group was changed to *very dissatisfied* ( $\beta = 2.31$ , z = 2.29 p= .022). Of note, Table 1 (pp. 49-53) illustrates that low percentages of treatment and control group members had *very dissatisfied* or *somewhat dissatisfied* responses to the follow-up satisfaction questions, with some satisfaction questions lacking either or both *very dissatisfied* and *somewhat dissatisfied* responses. These findings suggest that dichotomizing these variables for logistic regression was the appropriate course of action for examining the effects of Cash and Counseling on satisfaction ratings for this sample.

#### **Unmet Needs for Assistance**

With my third set of hypotheses, I answered the research question on whether young adult participants in the Cash and Counseling treatment groups in the CCDE had lower likelihoods of unmet needs for assistance than those in control groups at ninemonth follow-up. My analyses were based on findings from previous research that showed Cash and Counseling was effective in reducing participants' unmet needs (e.g. Brown et al., 2007; Shen, Smyer, Mahoney, Loughlin, et al., 2008; Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008), including a qualitative study with representatives of young adults in a Cash and Counseling-based program (Harry, MacDonald, et al., 2016), as well as theories and principles of self-determination (Nerney & Shumway, 1996; Ryan & Deci, 2000) and young adulthood (e.g., Furstenberg et al., 2005; Konstam, 2015). Specifically, I examined whether young adult participants in Cash and Counseling would be less likely than control group members to have unmet needs for assistance with personal care and with three IADLs: help around the house, with medication or routine health care at home, and transportation.

Unmet needs with personal care. As shown in the bivariate logistic regression model in Table 16 (pp. 138-139), young adults in the Cash and Counseling treatment groups were 31% less likely than those in the control groups to report unmet needs with personal care at nine-month follow-up (z = -2.40, p = .016, CI = .51 - .93), as hypothesized. This bivariate model was the same as the likelihood ratio chi-square in Table 5 (pp. 87-88):  $\chi^2$  (1, n = 748) = 5.82, p = .0159. However, the second, multivariate logistic regression model in Table 16 (pp. 138-139) did not support the hypothesis. Although young adults in the Cash and Counseling treatment groups had 29% lower odds of needing more help with personal care than those in the control groups at follow-up, in the predicted direction, this relationship was not significant when compared to all other baseline control variable reference categories and when holding mean-centered age constant (z = -1.89, p = .059, CI = .49 - 1.01):  $\chi^2$  (14, n = 618) = 110.85, p < .001.

The second model did have control variables that were significant predictors of unmet needs with personal care at follow-up (Table 16, pp. 138-139). Needing assistance with getting out of bed at baseline, a group with high personal care needs in general, was associated with 172% greater odds of having unmet personal care needs at follow-up (z = 5.19, p < .001). Needing more help with personal care at baseline also significantly increased the odds by 260% (z = 5.77, p < .001), suggesting that factors outside of the demonstration may have affected participants receipt of needed assistance in this area.

# Table 16

# Unmet Needs for Assistance: Binary Logistic Regression Analyses

			Unm	et Needs for	r Assistance	with		
						ation or		
			Help A			e Health		
	Persona	al Care	the H	louse	Care a	t Home	Transp	ortation
		Odds		Odds		Odds		Odds
Models	β	Ratio	β	Ratio	β	Ratio	β	Ratio
Model 1 (Main Effect) <sup>a</sup>	*							
Cash and Counseling	37*	.69	12	.89	67**	.51	42**	.65
treatment group member		J.		<i></i>		ماد ماد ماد		ale ale
Change in -2LL <sup>b</sup>	-478		-502		-415	.97***		.23**
п	74	8	74	10	74	47	74	47
Model 2 (Main Effect &								
Baseline Control								
Variables) <sup>c</sup>					**		**	
Cash and Counseling	35	.71	12	.88	<b>-</b> .61 <sup>**</sup>	.54	49**	.61
treatment group member	***						**	
Could not get out of bed	1.00***	2.72	.26	1.29	.33	1.39	.61**	1.85
without help					*			
Female	19	.83	12	.89	.46*	1.59	002	1.00
Hispanic	20	.82	12	.88	.61*	1.85	30	.74
Lived rurally	31	.74	22	.80	37	.69	62*	.54
Mean-centered age	.002	1.00	004	1.00	.02	1.02	03	.97
Needed more help:			***					
At home or in the community <sup>d</sup>	-	-	1.20***	3.32	-	-	-	-
With personal care <sup>d</sup>	1.28***	3.60	-	-	-	-	-	- (continuea

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				Unmet n	eeds with			
-					Medica	ation or		
			Help .	Around	Routine	e Health		
	Persor	nal Care	the I	House	Care a	t Home	Transp	ortation
-		Odds		Odds		Odds		Odds
Models	β	Ratio	β	Ratio	β	Ratio	β	Ratio
With transportation <sup>d</sup>	-	-	-	-	-	-	1.35***	3.86
Poor/fair health	.06	1.06	.07	1.08	.31	1.36	05	.95
compared to peers								
Publicly funded paid help	.26	1.30	.08	1.08	.20	1.22	.20	1.23
Race								
Black	09	.91	.19	1.20	.64**	1.89	.38	1.47
Other or multiracial	.51	1.67	.40	1.49	.69*	1.99	.74*	2.09
State								
Arkansas	08	.92	.13	1.13	.75*	2.12	03	.97
New Jersey	.43	1.54	.44*	1.55	.97***	2.63	.13	1.14
Young adult respondent	13	.88	05	.95	80**	.45	.12	1.13
Change in -2LL <sup>b</sup>	-359	.16***	-446	.57***	-372	.88***	-376	.75***
n	6	18	7	06	7.	36	6	45

 Table 16 Unmet Needs for Assistance: Binary Logistic Regression Analyses (continued)

*Note*. Rounded to nearest hundredth place. p < .05, p < .01, p < .001. Hyphens (-) denote variables not included in a model. Reference category was *No*.

<sup>a</sup>Comparison was a control group member.

<sup>b</sup>Least Likelihood – compared to the null model.

<sup>c</sup>Comparison was a proxy respondent for a White non-Hispanic male control group member of average age from Florida who was in good/excellent health compared to peers, could get out of bed without help, did not receive publicly funded paid care, and did not live rurally at baseline.

<sup>d</sup>Comparison did not need more help at baseline.

Table 17 (p. 140) presents multivariate predicted probabilities based on state and random assignment. In each of the three states, those in the treatment groups had lower probabilities of unmet needs compared to controls by a difference of 8%. Of the three states, New Jersey had the highest probabilities of unmet needs with personal care, with 41% for treatment group members and 49% for control group members. Arkansas had the lowest probability rates. However, neither state nor random assignment was a significant predictor in the second model.

Table 17

	Pr	edicted Probabili	ity
Outcomes	Florida	New Jersey	Arkansas
Unmet needs with:			
Personal care <sup>a</sup>			
Treatment group	.31 (.2438)	.41 (.3051)	.29 (.1841)
Control group	.39 (.3246)	.49 (.3960)	.37 (.2450)
Difference	08	08	08
Help around the house <sup>a</sup>			
Treatment group	.37 (.3143)	.47 (.3758)	.40 (.2752)
Control group	.40 (.3346)	.50 (.4160)	.43 (.3055)
Difference	03	03	03
Medication or routine health care			
Treatment group	.14 (.1017)	.29 (.2038)	.25 (.1435)
Control group	.22 (.1727)	.43 (.3353)	.38 (.2551)
Difference	08	14	13
Transportation <sup>a</sup>			
Treatment group	.30 (.2436)	.33 (.2243)	.29 (.1741)
Control group	.41 (.3447)	.44 (.3355)	.40 (.2654)
Difference	11	11	11

Unmet Needs for Assistance: Multivariate Predicted Probabilities by State and Random Assignment Group

*Note.* Rounded to nearest hundredth place. Reference category was *No*. Comparison was a proxy respondent for a White non-Hispanic male control group member of average age from Florida who was in good/excellent health compared to peers, could get out of bed without help, did not receive publicly funded paid care, and did not live rurally at baseline.

<sup>a</sup>Comparison did not need more help at baseline.

The second model had a good fit based on a nonsignificant Hosmer–Lemeshow test:  $\chi^2$  (10, n = 618) = 6.71, p = .57. A likelihood ratio test also confirmed that models one and two were significantly different:  $\gamma^2$  (13) = 106.44, p < .001. The level of predictive power for the second model was fair based on an area under the ROC curve of .74, which was improved over .55 for the first model. Mean VIF was 1.75, with the highest VIF value 3.00 for needing more help with personal care at baseline, representing a lack of multicollinearity. The second model also had a nonsignificant linear predicted value squared that showed the model was likely specified correctly (z = .03, p = .98). In addition, McFadden's adjusted  $R^2$  was .10, improved over model one (.002). The second model also reduced prediction error by 23% compared to 0% in the first. The correct classification rate stayed the same (69.42% to 69.42%) when the imbalance in sensitivity (58.20%) and specificity (76.74%) was corrected (sensitivity = 72.95\%, specificity = 67.11%) based on a probability of .39 (244/618= .39). Finally, a drop of 155.20 in BIC between models one (969.92) and two (814.72) gave very strong support for the second model.

Influential outlier screening. Screening for potentially influential outliers showed that the second model had only seven cases with standardized residuals outside of the -2.5 to 2.5 range. Fourteen cases had Cook's *D* values greater than .1, with 11 responding *Yes* to young adults' needing more assistance with personal care at follow-up. One case appeared visually outlying with a Cook's *D* value above .2, a proxy respondent for a Black female treatment group member in Arkansas who did not have unmet needs with personal care at baseline. Excluding the 14 cases with Cook's *D* values greater than .1 from the second model caused a small decrease in log odds for treatment status, from - .35 to -.42, which also lowered the alpha to the level of significance (.059 to .029). These potentially influential cases were included in the second model reported here.

Unmet needs with help around the house. Table 16 (pp. 138-139) presents the bivariate logistic regression model showing that although being in the treatment groups was associated with 11% lower odds of young adults having unmet needs with help around the house at nine-month follow-up, like preparing meals, laundry, housework, or, for participants, completing yardwork, this relationship was not significant (z = -.78, p = .44, CI = .66 - 1.19). This bivariate model was the same as the Pearson's and likelihood ratio chi-squares reported in Table 5 (pp. 87-88):  $\chi^2$  (1, n = 740) = .60, p = .44. The multivariate logistic regression model in Table 16 (pp. 138-139) also showed that young adults in the Cash and Counseling treatment groups had 12% lower odds of having unmet needs with help around the house at follow-up than control group members. However, although in the hypothesized direction, this relationship was not significant when compared to all other baseline control variable reference categories and when holding mean-centered age constant (z = -.75, p = .451, CI = .64 - 1.22):  $\chi^2$  (14, n = 706) = 67.09, p < .001.

A few control variables were significant predictors of young adults having unmet needs for help around the house (Table 16, pp. 138-139). Specifically, young adults from New Jersey had 50% greater odds of unmet needs compared to those in Florida (z = 1.97, p = .049). Needing more help around the home or community at baseline was also associated with 232% greater odds of unmet needs for help around the house at follow-up (z = 5.99, p < .001), suggesting a component to securing assistance that may have been independent from the demonstration or not met by the tested interventions. In regards to multivariate predicted probabilities by state and random assignment (Table 17, p. 140), minimal differences of only 3% were seen between treatment and control groups in each of the three demonstration states, reflective of the nonsignificant finding for treatment status. However, as shown by the significant differences in odds between New Jersey and Florida in the second model (Table 16, pp. 138-139), probabilities also differed significantly between New Jersey and Florida. Regardless of random assignment, young adults in New Jersey had the highest probabilities of unmet needs with help around the house at follow-up: 47% for those in the treatment group, and 50% for those in the control group. Young adults in the Florida treatment group had the lowest probability of unmet needs at 37%. This significant finding suggests that the Florida Cash and Counseling program was more able to meet participants' needs for assistance around the house than the corresponding New Jersey program.

Goodness of fit indexes for the second model were mixed. A nonsignificant Hosmer–Lemeshow goodness of fit test showed that the second model had a good fit:  $\chi^2$ (10, n = 706) = 5.65, p = .69. In addition, a likelihood ratio test found that the two models were significantly different:  $\chi^2$  (13) = 66.56, p < .001. The second model was also likely specified correctly based on a nonsignificant linear predicted value squared (z = -.38, p =.70). The mean VIF for the model was 1.72, with the highest VIF for needing more help with personal care at baseline (3.06), suggesting a lack of multicollinearity. Moreover, BIC dropped by 27.38 between models one (1018.92) and two (991.54), which, while still high, gave very strong support for the second model. However, the second model had a poor level of predictive power with an area under the ROC curve of .67, although improved over .51 for the first model. Additionally, McFadden's adjusted  $R^2$  was .04, slightly improved over the first model (-.003). The second model also only reduced prediction error by 8% compared to 0% in the first. Lastly, when sensitivity (43.24%) and specificity (74.63%) were balanced based on a .42 probability (296/706 = .42), the correct classification rate dropped slightly from 61.47% to 60.48%. However, sensitivity (75.34%) and specificity (49.76%) remained unbalanced.

*Influential outlier screening.* No cases had standardized residuals outside of the - 2.5 to 2.5 range in the second model. In addition, most Cook's *D* values fell below .1, with 10 between .1 and .2. Screening did not produce any causes for these outlying values. Excluding a total of 10 cases with Cook's *D* values greater than .1 from the second model resulted in small changes to the log odds, standard error, and alpha for treatment status, which stayed nonsignificant. The balanced correct classification rate also only improved slightly from 60.48% to 61.06%. These non-influential cases were included in the second model reported here.

Unmet needs with medication or routine health care at home. The first bivariate logistic regression model in Table 16 (pp. 138-139) shows support for this hypothesis, where being in the treatment groups was significantly associated with 49% lower odds of unmet needs with medication or routine health care at home compared to controls at nine-month follow-up (z = -3.84, p < .001, CI = .36 - .72). This bivariate model was the same as the likelihood ratio chi-square reported in Table 5 (pp. 87-88):  $\chi^2$  (1, n = 747) = 15.25, p < .001. The second, multivariate logistic regression model in Table 16 (pp. 138-139) provides further support for the hypothesis, where the significant finding demonstrates that compared to those in the control groups, Cash and Counseling treatment group members had 46% lower odds of unmet medication or routine health

care needs at follow-up than control group members when compared to all other baseline control variable reference categories and when holding mean-centered age constant (z = -3.30, p = .001, CI = .38 - .78):  $\chi^2$  (13, n = 736) = 86.37, p < .001.

As shown in Table 16 (pp. 138-139), many control variables for the second model also predicted unmet needs in this area. Regarding state, compared to those in Florida, Arkansas residents had 112% greater odds (z = 2.42, p = .016), and residents from New Jersey had 163% greater odds of unmet medication or routine health care needs at home (z = 4.08, p < .001). Furthermore, females had 58% greater odds than males (z = 2.52, p = .012). Race was also predictive, where compared to White young adults, young adults who were other races than White or Black or were multiracial had 99% greater odds (z = 2.92, p = .029), while those who were Black had 89% greater odds of unmet needs (z = 2.92, p = .003). Similarly, Hispanic young adults had 85% greater odds than non-Hispanics (z = 2.59, p = .01). However, young adults who responded to the interviews themselves at baseline had 55% lower odds than those with proxies (z = -3.20, p = .001), suggesting these young adults may have been more able to manage medications and routine health care themselves or personally coordinate their home health-related care during the demonstration than those with baseline proxy respondents.

Table 17 (p. 140) presents multivariate predicted probabilities by state and random assignment. Regardless of treatment group assignment, demonstration enrollees in Florida had the lowest probabilities of unmet medication or routine health care needs, followed by Arkansas, then New Jersey. Florida treatment group members had the lowest probability overall at 14%, compared to 25% and 29% in the Arkansas and New Jersey treatment groups, respectively. However, the New Jersey treatment group probability was 14% lower than the state's control group, the largest difference between random assignment groups of the three states. New Jersey control group members did have the highest probability of unmet medication or routine health care needs at 43%. These findings are reflective of the significant differences based on state and random assignment.

Table 18 (p. 147) further outlines predicted probabilities by baseline respondent type, state, and random assignment. In general, young adults who took part in baseline interviews themselves had lower probabilities of unmet medication or routine health care needs at follow-up than those with baseline proxy respondents, a finding that was significant. This was regardless of random assignment, although those assigned to the treatment groups had lower probabilities than their respective control group, reflective of the significant effect of treatment status, as was also shown in Table 17 (p. 140).

The second model was an improved fit over the first in some areas. For instance, a Hosmer–Lemeshow goodness of fit test was nonsignificant:  $\chi^2 (10, n = 736) = 3.71, p =$ .88. A significant likelihood ratio test also showed the two models were different:  $\chi^2 (12)$ = 71.29, p < .001. Mean VIF for the second model was 1.55, with the highest VIF value 2.20 for receiving publicly funded paid help at baseline, showing no evidence of multicollinearity. The linear predicted value squared was also nonsignificant, illustrating the model was likely correctly specified (z = -.62, p = .537). McFadden's adjusted  $R^2$  was .07, an improvement from model one (.01). Yet the second model only reduced prediction error by 2%, slightly above the first model (0%). Predictive power was fair with an area under the ROC curve of .72, improved from .58 in the first model. The correct classification rate dropped from 75.27% to 66.71% when sensitivity (15.59% to 67.20%) and specificity (95.45% to 66.55%) were balanced using a .25 probability level

(186/736 = .25). Although still high, the second model also had strong support based on a

drop of 7.01 in BIC between models one (845.18) and two (838.17).

#### Table 18

Unmet Needs with Medication or Routine Health Care at Home: Multivariate Predicted Probabilities by Baseline Respondent Type, State, and Random Assignment Group

	Random	Baseli	Baseline Respondent Type				
	Assignment	Pre	dicted Probability				
State	Group	Young Adult	Proxy	Difference			
Florida	Treatment	.08 (.0412)	.16 (.1220)	08			
	Control	.14 (.0720)	.26 (.2131)	12			
	Difference	06	10				
New Jersey	Treatment	.18 (.1026)	.33 (.2344)	15			
	Control	.29 (.1940)	.48 (.3759)	19			
	Difference	11	15				
Arkansas	Treatment	.15 (.0823)	.29 (.1641)	14			
	Control	.25 (.1436)	.43 (.2857)	18			
	Difference	10	14				

*Note*. Rounded to nearest hundredth place. Reference category was *No*. Comparison was a proxy respondent for a White non-Hispanic male control group member of average age from Florida who was in good/excellent health compared to peers, could get out of bed without help, did not receive publicly funded paid care, and did not live rurally at baseline.

*Influential outlier screening.* The second model had 17 cases with standardized residuals outside of the -2.5 to 2.5 range, less than 5% of the sample. Most Cook's D values were clustered under .1, although 25 cases appeared to be visually outlying, all with Cook's D values between .1 and .22. Twenty-three of these cases had *Yes* responses to the dependent variable. When the 25 cases with Cook's D values above .1 were excluded from the model, the log odds for treatment status dropped from -.61 to -.87, with a small increase in the standard error and the alpha also dropping from p = .001 to p

< .001. The balanced correct classification rate improved from 66.71% to 71.31%. The model presented here included these cases.

**Unmet needs with transportation.** The bivariate logistic regression model presented in Table 16 (pp. 138-139) illustrates the hypothesized relationship, namely that being in the Cash and Counseling treatment groups was significantly associated with 35% lower odds of unmet needs with transportation at nine-month follow-up compared to control groups (z = -2.78, p = .005, CI = .49 - .88). This bivariate model was the same as the likelihood ratio chi-square presented in Table 5 (pp. 87-88):  $\chi^2$  (1, n = 747) = 7.79, p = .005. In addition, the multivariate logistic regression model provided further support for the hypothesis (Table 16, pp. 138-139). Being in the Cash and Counseling treatment groups was significantly associated with 39% lower odds of unmet needs with transportation at follow-up than those in the control groups when compared to all other baseline control variable reference categories and when holding mean-centered age constant (z = -2.72, p = .007, CI = .43 - .87):  $\chi^2$  (14, n = 645) = 104.02, p < .001.

Additional baseline control variables that predicted unmet needs with transportation at follow-up are shown in Table 16 (pp. 138-139). Compared to young adults who were White, being another race than White or Black or being multiracial was associated with 109% greater odds of unmet transportation needs (z = 2.23, p = .026). Needing assistance with getting out of bed was associated with 85% greater odds (z =3.31, p = .001), a population that likely had high assistance with transportation needs. However, those who lived rurally had 40% lower odds of unmet needs with transportation (z = -2.54, p = .011). This finding may be due to transportation having multiple interpretations. Lastly, needing more help with transportation at baseline was associated with 286% greater odds of having unmet needs in this area at follow-up (z = 6.98, p < .001), suggesting that problems with transportation at baseline may have continued through the demonstration for some individuals.

Table 17 (p. 140) presents multivariate predicted probabilities by state and random assignment. Probabilities between respective groups were similar across the three demonstration states, reflective of the nonsignificant difference seen between states. Treatment group members in Arkansas had the lowest probability of unmet transportation needs at 29%, while control group members in New Jersey had the highest probability at 44%. In each state, treatment group members had 11% significantly lower probabilities of unmet needs with transportation than those in the control groups.

The second model had a good fit based on a nonsignificant Hosmer–Lemeshow test:  $\chi^2$  (10, n = 645) = 5.79, p = .67. In addition, a significant likelihood ratio test illustrated that models one and two were different:  $\chi^2$  (13) = 95.38, p < .001. The second model also had a fair level of predictive power with an area under the ROC curve of .73, which was improved over .55 for the first model. Multicollinearity was not found for the second model, with a mean VIF of 1.61 and the highest VIF 2.26 for needing more help with transportation at baseline. A nonsignificant linear predicted value squared showed the second model did not have a specification error (z = .77, p = .44). McFadden's adjusted  $R^2$  was .09, an improvement from model one (.004). The second model also reduced prediction error by 16% compared to 0% in the first model. The correct classification rate dropped slightly from 67.91% to 66.82% when sensitivity (45.53% to 67.89%) and specificity (81.70% to 66.17%) were balanced based on a .38 probability

level (246/645 = .38). Finally, while still high, the second model had very strong support based on a drop of 147.15 in BIC between models one (997.69) and two (850.53).

*Influential outlier screening.* The second model had just four cases with standardized residuals outside of the -2.5 to 2.5 range. Most Cook's *D* values fell below .1, with 16 cases having seemingly outlying values between .1 and .14, of which 13 had unmet needs with transportation at follow-up. Only small changes to the treatment status log odds, standard error, and alpha were seen when a model was run excluding these 16 cases, although the balanced correct classification rate increased from 66.82% to 69.16%. These non-influential cases were included in the second model reported here.

#### Health Status Rating Compared to Peers

With my fourth hypothesis, I answered the research question on whether young adult participants in the Cash and Counseling treatment groups in the CCDE had a lower likelihood of reporting their health status compared to their peers as poor or fair than those in control groups at nine-month follow-up. I did so based on previous research that found Cash and Counseling treatment group members, whether participant or proxy, were significantly less likely than control group members to report participants' health as being poor or fair compared to their peers (Brown et al., 2007). This hypothesis was tested with logistic regression.

Table 19 (p. 151) presents the logistic regression results for the two models. The bivariate model illustrated that while being in the Cash and Counseling treatment groups was associated with 12% lower odds that young adults were in poor or fair health compared to their peers at nine-month follow-up than those in the control groups, in the hypothesized direction, this effect was not significant (z = -.87, p = .384, CI = .67 - 1.16).

### Table 19

Models	в	Odds Ratio
Model 1 (Main Effect) <sup>a</sup>	Ρ	10000
Cash and Counseling treatment group member	12	.88
Change in -2LL <sup>b</sup>	-561	1.17
n	82	21
Model 2 (Main Effect & Baseline Control Variables) <sup>c</sup>		
Cash and Counseling treatment group member	08	.93
Could not get out of bed without help	.15	1.16
Female	.13	1.13
Hispanic	.03	1.03
Lived rurally	.69**	1.96
Mean-centered age	.05**	1.05
Poor/fair health compared to peers	2.31***	10.03
Publicly funded paid help	.16	1.17
Race		
Black	05	.95
Other or multiracial	.01	1.01
State		
Arkansas	.38	1.46
New Jersey	.59*	1.79
Young adult respondent	.17	1.19
Change in -2LL <sup>b</sup>	-421.	59 <sup>***</sup>
<u>n</u>	80	)9

Health Status Rating Poor/Fair Compared to Peers: Binary Logistic Regression Analyses

*Note.* Rounded to nearest hundredth place. p < .05, p < .01, p < .001. Hyphens (-) denote variables not included in a model. Reference category was *Good/Excellent*. <sup>a</sup>Comparison was a control group member.

<sup>b</sup>Least Likelihood – compared to the null model.

<sup>c</sup>Comparison was a proxy respondent for a White non-Hispanic male control group member of average age from Florida who was in good/excellent health compared to peers, could get out of bed without help, did not receive publicly funded paid care, and did not live rurally at baseline.

The bivariate model was the same as the nonsignificant Pearson's and likelihood ratio chi-squares shown in Table 5 (pp. 87-88):  $\chi^2(1, n = 821) = .76, p = .38$ . The multivariate model also did not support the hypothesis. Although in the predicted direction, where Cash and Counseling treatment group members had 7% lower odds of reporting poor or fair health compared to peers at follow-up than those in the control groups when controlling for other baseline control variable reference categories and when holding mean-centered age constant (z = ..45, p = ..652, CI = ..66 - 1..30), this relationship was not significant:  $\chi^2(13, n = 809) = 263.05, p < ..001$ .

Other baseline control variables did predict young adults' perceived health status ratings compared to peers (Table 19, p. 151). Young adults from New Jersey were 80% more likely to report poor or fair health compared to peers at follow-up than participants in Florida (z = 2.55, p = .011). Age was also a predictor, where a one year increase from the mean age (25.73) was associated with a 5% increase in likelihood (z = 2.66, p = .008). Reporting poor or fair health compared to peers at baseline also increased the odds by a factor of 10.03 (z = 13.15, p < .001), which points towards health issues beyond the direct influence of participant direction. Finally, those who lived rurally had 96% higher odds of reporting poor or fair health compared to peers (z = 3.00, p = .003), a finding that could represent less access to health care services needed to improve health in rural settings.

Regarding multivariate predicted probabilities by state and random assignment (Table 20, p. 153), little differences were seen between treatment and control groups, as expected based on the nonsignificant findings. Young adults in Florida had the lowest probabilities of poor or fair health compared to their peers, followed by Arkansas, then New Jersey, although only the difference between Florida and New Jersey was

significant in the second model.

#### Table 20

Health Status Rating Poor/Fair Compared to Peers: Multivariate Predicted
Probabilities by State and Random Assignment Group

	Random Assignment	Predicted	
State	Group	Probability	Difference
Florida	Treatment	.37 (.3143)	02
	Control	.39 (.3245)	
New Jersey	Treatment	.51 (.4162)	02
-	Control	.53 (.4363)	
Arkansas	Treatment	.46 (.3359)	02
	Control	.48 (.3561)	

*Note*. Rounded to nearest hundredth place. Reference category was *Good/Excellent*. Comparison was a proxy respondent for a White non-Hispanic male control group member of average age from Florida who was in good/excellent health compared to peers, could get out of bed without help, did not receive publicly funded paid care, and did not live rurally at baseline.

The second model had a good fit with a nonsignificant Hosmer–Lemeshow test:  $\chi^2 (10, n = 809) = 5.07, p = .75$ . In addition, a likelihood ratio test showed that the two models were significantly different:  $\chi^2 (12) = 262.54, p < .001$ . Multicollinearity was unlikely to be a problem based on a mean VIF of 1.54 for the second model, with receiving publicly funded paid help at baseline having the highest VIF at 2.20. Specification errors were also not found with a nonsignificant linear predicted value squared (z = ..05, p = .957). McFadden's adjusted  $R^2$  was .21, an improvement from the first model (-.003), and the second model reduced prediction error by 46% compared to 0% in the first. The area under the ROC curve was .81, a good level of predictive power and improved from .52 in the first model. Sensitivity (70.77%) and specificity (81.09%) were fairly balanced with a .50 probability level, giving a correct classification rate of 76.64%. Finally, the second model had very strong support based on a drop of 198.83 in BIC between models one (1135.76) and two (936.93), although both BIC values were high.

*Influential outlier* screening. When examining potentially influential outliers, 11 cases had standardized residuals outside of the -2.5 to 2.5 range in the second model, less than 5% of the sample. Graphical screening of Cook's *D* values showed that the majority clustered below .1. However, 17 cases had potentially outlying Cook's *D* values between .1 and .26. No apparent reason for these outlying values was identified from a visual review of the data. When these 17 cases were excluded from the model, little changes were seen to the log odds, standard error, or alpha for treatment status. The correct classification rate, already balanced, increased slightly from 76.64% to 77.53%. These non-influential outliers were included in the second model presented here.

Comparison between binary and multinomial logistic regression health status rating models. Table 21 (p. 155) presents multinomial logistic regression coefficients for comparison and cross validation with the binary logistic regression results. Similar to the bivariate and multivariate logistic regression models, no significant relationship was seen between treatment and control group members when comparing *fair, good,* and *excellent* health status ratings compared to peers to the reference category *poor* for either multinomial model tested. Furthermore, no significant effects were seen when reference categories were changed to *fair, good,* or *excellent* (not shown). This suggests that combining categories for logistic regression was an acceptable short-hand way to assess the significance of treatment status on young adults' health rating in this study.

### Table 21

Health Status Rating Compared to Peers by Random Assignment Group: Multinomial Logistic Regression Analyses

	Treatment Gr	oup Members
Models	β	р
Model 1 (Main effect, $n = 821$ ) <sup>a</sup>		
Fair	03	.90
Good	.07	.72
Excellent	.18	.42
Model 2 (Main effect and baseline control		
variables, $n = 809$ ) <sup>b</sup>		
Fair	.08	.74
Good	.17	.49
Excellent	.19	.52

*Note*. Rounded to nearest hundredth place.  $p^* < .05$ ,  $p^{**} < .01$ ,  $p^{***} < .001$ . Reference category was *Poor* health compared to peers at nine-month follow-up. <sup>*a*</sup>Comparison was a control group member.

<sup>b</sup>Comparison was a proxy respondent for a White non-Hispanic male control group member of average age from Florida who was in poor health compared to peers, could get out of bed without help, did not receive publicly funded paid care, and did not live rurally at baseline.

### Significant Differences in Multivariate Predicted Probabilities for Study Hypotheses

Table 22 (p. 157) presents differences in predicted probabilities for treatment and

control groups for each of the multivariate models by hypothesis. Concerning the first set

of hypotheses on community involvement, Cash and Counseling treatment group

members had slightly higher predicted probabilities than those in the control groups,

which were in the expected direction, aside from reported attendance of social or

recreational group programs at nine-month follow-up, where those in the treatment

groups had a 1% lower probability. The only significant difference was the 8% greater

probability of attending school or college as much as young adults would like in the Cash and Counseling treatment groups compared to those in the control groups. Regarding life satisfaction, even though Cash and Counseling treatment group participants who responded to baseline interviews themselves had a 15% greater probability of being very satisfied with life at follow-up than those in the control groups, which was in the expected direction, this difference was not significant. However, Cash and Counseling treatment group members had significantly higher probabilities that young adults were very satisfied for all other program satisfaction variables studied, with differences ranging from 7% to 24%. When examining unmet needs, Cash and Counseling treatment group members had lower probabilities of unmet needs with personal care and all three IADLs, again in the expected directions. However, only the 11% lower probabilities for Cash and Counseling treatment group members of unmet needs with medication or routine health care at home and with transportation were significant. Finally, the slightly lower probability of young adults in Cash and Counseling being in poor or fair health compared to their peers at follow-up was not significant.

## Table 22

	Predicted I	Probability	
	Treatment	Control	-
Hypotheses	Group	Group	Difference
Community Involvement	-	_	
Worked for pay as much as young adult would like	.16 (.1221)	.15 (.1119)	.01
Attended school or college as much as young adult would like	.35 (.2940)	.27 (.2232)	.08*
Took part in activities as much as young adult would like	.40 (.3445)	.34 (.2939)	.06
Attended social or recreational group programs at follow-up	.32 (.2737)	.32 (.2737)	.00
Satisfaction Ratings			
Very satisfied with life	.42 (.2954)	.27 (.1638)	.15
Very satisfied with times of day help	.86 (.7992)	.69 (.6177)	.17**
was received			
Very satisfied with care arrangement	.70 (.6476)		.24***
Very satisfied with help with	.70 (.6476)	.57 (.5163)	.13**
transportation			***
Very satisfied with personal care	.93 (.8996)	( )	.16 <sup>****</sup> .21 <sup>****</sup>
Very satisfied with the way paid help assisted around the house or community	.88 (.8394)	.67 (.5876)	.21
Very satisfied with getting along	.94 (.9097)	.87 (.8292)	$.07^{*}$
with paid help		(((((((((((((((((((((((((((((((((((((((	,
Unmet Needs for Assistance			
With personal care	.33 ( .2739)	.41 (.3547)	08
With help around the house	.39 (.3445)	.42 (.3748)	03
With medications or routine health	.17 (.1321)	.28 (.2333)	11**
care at home			
With transportation	.30 (.2536)	.41 (.3647)	<b>-</b> .11 <sup>**</sup>
Health Status			
Poor or fair health compared to peers Note. Rounded to nearest hundredth place	.41 (.3546)	.43 (.3749)	02
<i>Note</i> . Rounded to nearest hundredth place	ce. $p < .05; p <$	.01; p < .001.	

Differences in Predicted Probabilities between Random Assignment Groups for Multivariate Logistic Regression Models

#### **Chapter V: Discussion**

The purpose of this study was to examine the effectiveness of PD-HCBS during the transition to adulthood for young adults with long-term care disabilities to determine the effectiveness of this option during young adulthood, including whether it could help fill the post-secondary school service gap experienced by this population. Using secondary data from the CCDE randomized control trial, I examined the effects of the Cash and Counseling budget authority model of PD-HCBS compared to agency-based care as usual for young adults with disabilities aged 18 to 35 focusing on four areas identified from previous research and theory. These included community involvement and satisfaction ratings based on the CDTE (Kosciulek, 1999; Kosciulek, 2005; Kosciulek & Merz, 2001) and self-determination theories and principles (Nerney & Shumway, 1996; Ryan & Deci, 2000), and satisfaction ratings, unmet needs for assistance, and health status rating compared to peers based on previous research on Cash and Counseling programs (e.g., Brown et al., 2007; Foster et al., 2003a; Harry, Kong, et al., 2016; Harry, MacDonald, et al., 2016; Shen, Smyer, Mahoney, Loughlin, et al., 2008; Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008). All analyses were guided by the developmental life stage of young adulthood (Arnett, 2004; Côté, 2006; Erikson, 1950; Furstenberg et al., 2005; Konstam, 2015). In this chapter, I first summarize the primary findings, comparing them to previously reported CCDE findings for other subgroups and available research on young adults. Next, I discuss some of the repeatedly significant baseline control variables from the multivariate models as a way of identifying potential mediators and moderators of outcomes for young adults in PD-HCBS to inform future research. I also give a brief summary on the potentially influential outlying cases

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encountered in this study. I then discuss contributions to current theory and knowledgebuilding, present implications for social work practice and policy, and offer an examination of study limitations. I close this chapter by suggesting areas for future research on participant direction and young adulthood.

#### **Summary of Findings**

Table 23 (p. 160) presents a visual summary of study hypotheses related to the four guiding research questions on community involvement, satisfaction ratings, unmet needs for assistance, and health status rating, the expected relationships between dependent variables and the main effect of treatment status, and the bivariate and multivariate relationships identified in this study. My hypotheses on satisfaction ratings were supported by all of the bivariate and six of the seven multivariate findings; the only exception in the multivariate models was *life satisfaction*. However, my hypotheses relating to community involvement and health status ratings did not fare as well. The findings on health status rating compared to peers were in the expected direction, but not significant in either the bivariate or multivariate analysis, while the only community involvement outcomes that yielded statistically significant findings were for achieving preferred levels of taking part in recreational, cultural, religious, social, or volunteer activities at the bivariate level and attending school or college at the multivariate level. Finally, support for my hypotheses related to unmet needs for assistance were mixed. There were statistically significant findings on three of the four measures at the bivariate level, but only reductions in unmet needs for *medications or routine health care at home* and *transportation* remained significant in the multivariate models. It is worth noting that all of the findings (with the exception of greater involvement *attending social or* 

# Table 23

# Summary of Research Hypotheses and Findings

	Hypothesis	Expected	Identified Bivariate	Identified Multivariate
Hypothesis	Number	Relationship	Relationship	Relationship
Community Involvement		-	•	•
Working for pay as much as would like	$H_{1A}$	Positive	Positive – NS	Positive – NS
Attending school or college as much as would like	$H_{1B}$	Positive	Positive – NS	Positive
Taking part in activities as much as would like	$H_{1C}$	Positive	Positive	Positive – NS
Attending social or recreational group programs	$H_{1D}$	Positive	Positive – NS	Negative – NS
Satisfaction Ratings				
Very satisfied with:				
Life	$H_{2A}$	Positive	Positive	Positive – NS
Times of day care was received	$H_{2B}$	Positive	Positive	Positive
Care arrangement	$H_{2C}$	Positive	Positive	Positive
Transportation	$H_{2D}$	Positive	Positive	Positive
Personal care	$H_{2E}$	Positive	Positive	Positive
Help around the house or community	$H_{2F}$	Positive	Positive	Positive
Getting along with paid help	$H_{2G}$	Positive	Positive	Positive
Unmet Needs				
Personal care	H <sub>3A</sub>	Negative	Negative	Negative – NS
Help around the house	$H_{3B}$	Negative	Negative - NS	Negative – NS
Medications or routine health care	$H_{3C}$	Negative	Negative	Negative
Transportation	$H_{3D}$	Negative	Negative	Negative
Health Status Rating				
Poor/Fair compared to peers	$H_4$	Negative	Negative- NS	Negative- NS

*Note.* NS = Not Significant. Significant findings are bolded.

recreational group programs in the multivariate model) were in the expected direction.

### **Community Involvement**

**Paid employment.** When considering the hypothesis on young adults *working for pay as much as they would like* at nine-month follow-up, the main effect of treatment group assignment, although positive and in the expected direction, was not significant for either model tested (Table 23, p. 160). Consequently, the null hypothesis could not be rejected. However, the positive finding suggests that Cash and Counseling was at least as effective as care as usual received by control groups on young adults achieving a desired level of paid employment, which was low in general with only about one-fifth of the sample in either group working for pay as much as they would like at follow-up.

While this finding may identify a gap in paid employment opportunities for young adults with disabilities, the multivariate analysis revealed that young adults who were able to respond for themselves at baseline were significantly more likely to achieve this outcome than those with proxy baseline respondents (OR = 4.52, p < .001). In addition, young adults who had ever worked for pay at baseline were significantly more likely to be *working for pay* at a preferred level at follow-up. Aside from the quadratic effect of age on young adults achieving a desired level of paid employment, the only other significant baseline control variable in the multivariate model was state of residence, suggesting a possible difference in sample characteristics or geographic opportunities that cannot be ascertained in this secondary analysis.

Attending school or college. The bivariate model testing the main effect of being randomly assigned to a Cash and Counseling treatment group with young adults *going to school or college as much as they would like* at nine-month follow-up was not significant,

although it became significant when baseline control variables were added into the multivariate model (Table 23, p. 160). As such, being enrolled in Cash and Counseling was significantly associated with a greater likelihood of young adults going to school or college as much as they would like compared to those in the control groups (OR = 1.42, p = .048), as hypothesized. The change in significance level for treatment status suggests that baseline control variables may have accounted for or affected the relationship between being enrolled in Cash and Counseling and achieving a desired level of educational involvement for young adults in the sample. Most significant baseline control variables predicted lower odds of young adults attending school or college at a preferred level, namely mean-centered age, being from Arkansas, or being Black. The only control variable to significantly predict higher odds was for young adults who took part in baseline interviews themselves, who had 400% greater odds (p < .001) than those with proxies. This suggests that baseline respondent type may have accounted for the significant multivariate relationship between treatment status and young adults attending school or college at a preferred level. Conversely, baseline respondent type may have strengthened the relationship between treatment status and the dependent variable to a significant level. Future research could further examine this finding.

The statistically significant difference in predicted probabilities between treatment and control groups for the multivariate model supported the hypothesized relationship between young adults enrolled in Cash and Counseling having higher likelihoods of attending school or college at a preferred level. However, the difference was small at 8% and probability levels were low at 35% for treatment group members and 27% for those in the control groups (Table 22, p. 157). Also, log odds only differed by .04 between the two models (Table 6, pp. 91-92), thus limiting the clinical significance of this finding.

**Participating in activities.** The statistically significant positive bivariate finding of young adults in Cash and Counseling being more likely than control group members to be *taking part in recreational, cultural, religious, social, or volunteer activities as much as they would like* at follow-up (OR = 1.35, p = .048), although still in the hypothesized direction, disappeared when baseline control variables were added into the multivariate model (Table 23, p. 160), precluding the rejection of the null hypothesis. Regardless, the positive multivariate finding does show that Cash and Counseling was at least as good as care as usual on assisting young adults with taking part in activities at a desired level. While young adults in the study had greater probabilities of having an affirmative response to this question than for the other three measures of community involvement, predicted probabilities were still fairly low at 40% for treatment group members and 34% for those in the control groups, showing that at least 60% of the sample was not engaged in activity at a preferred level at follow-up.

The results of the multivariate analysis did indicate that the bivariate effect of treatment status on activity attendance was likely suppressed by the addition of baseline control variables, several of which portray a young adult as unable to get out of bed without help, in poor or fair health, and needing a proxy respondent that were significantly predictive of lower likelihoods of achieving desired levels of activity. This suggests that young adults in the sample who likely had more severe disability may have affected the strength of the relationship or suppressed a significant effect of enrollment in Cash and Counseling on achieving a desired level of activity attendance in the multivariate model by weakening the relationship between treatment status and taking part in activities. This finding also points toward an opportunity for future research to examine interventions that may assist self-directing young adults with more severe disability in achieving a preferred level of activity involvement. Also, other potentially influential variables included significant findings that young adults from both New Jersey and Arkansas were less likely to be taking part in activities as much as preferred than those from Florida, suggesting further geographic differences. Young adults who received publicly funded paid help at baseline were also less likely to take part in activities at a preferred level. Future research could examine these areas in more detail.

**Social or recreational group program attendance.** For the hypothesis that young adults in the Cash and Counseling program would be more likely to *attend social or recreational group programs* at nine-month follow-up, the nonsignificant bivariate relationship was positive and in the hypothesized direction (Table 23, p. 160). While the direction reversed in the multivariate model, this difference was negligible and nonsignificant (OR = .99, p = .93). As a result, the null hypothesis could not be rejected, illustrating that young adults in Cash and Counseling did not have appreciable differences in their attendance of these programs compared to those in the control groups. Only about one-third of participants in both treatment and control groups responded affirmatively, showing that most were not taking part in these sorts of programs. The significant control variables of not being able to get out of bed and lack of participation in activities in the past also suggests a group who may be at particularly high risk and for whom creative interventions could be tailored. Furthermore, having attended a social or recreational group program in the past year at baseline significantly predicted young adults *attending* 

*a social or recreational group program* at follow-up, suggesting an area for future research.

**Comparison with previous research.** The primary findings in this study can be compared to those from Arkansas in the original CCDE, the only state with data available on the three questions pertaining to achieving preferred levels of community involvement. Of note, Foster et al. (2003a) analyzed participants' limitations with employment, education, and activities, the opposite of what was done in this study, still with similar findings. Specifically, nonelderly adult respondents aged 18 to 64 in Arkansas' Cash and Counseling treatment group did not have significantly different predicted means from the control group for being limited in working for pay or going to school or college as much as participants would like (Foster et al., 2003a, Table A.9). Furthermore, the treatment group had slightly lower predicted means for being limited in taking part in activities (Foster et al., 2003a, Table A.9), although this finding was also not significant. Foster et al. (2003a) stated they did not expect Cash and Counseling "group members to fare better than control group members" (p. A.24) when the primary reason for participants' lack of activity in these areas were health problem-related, which is supported by the results of the current study. My finding on young adults in the treatment groups having slightly lower rates of social or recreational group program attendance at follow-up than those in the control groups was similar to the slightly lower, but also nonsignificant rates of social or recreational group program attendance found for non-elderly, working-age adults in the New Jersey and Arkansas treatment groups compared to the respective control groups in the original CCDE (Brown et al., 2007). As noted previously, not everyone in the CCDE treatment groups had received their budget

at follow-up (Brown et al., 2007), which may have affected community involvement outcomes. Disability severity and type may also have played a role in limiting community involvement opportunities.

Qualitative studies with self-directing young adults, their formal or informal caregivers, and other stakeholders, as well as self-directing adults provide an additional avenue for comparison. For example, recent research on the long-term experiences of young adults, as described by their familial program representatives, in one Cash and Counseling-based program that began under the CCDE did show that five of the 11 young adults in the sample were enrolled in supported day, school, or work programs, which they attended with the personal care assistance received by their personally hired workers (Harry, MacDonald, et al., 2016). Young adults were also taking part in social and recreational activities at home and in the community through assistance provided by paid workers in the program (Harry, MacDonald, et al., 2016). Moreover, the qualitative study of long-term outcomes with 17 adult participants who were ages 40 to 83 in one of the demonstration states provided additional experiential evidence of paid program workers assisting participants with community engagement in multiple ways, although not with paid employment (Harry, Kong, et al., 2016). Similarly, Harry, MacDonald, et al. (2016) found that only one young adult was working for pay in what was described by the representative as a sheltered workshop, which typically pays less than minimum wage, although this may be changing as a few states are prohibiting sub-minimum wages for people with disabilities (DePillis, 2016). One of the international qualitative studies on self-directed budgets for young adults showed additional community involvement findings. Specifically, when Robinson et al. (2012) studied the outcomes of self-directing

a budget for 29 young adults aged 20 to 36 with traumatic brain injury and physical disability in Australia, the authors found that the young adults were utilizing their personcentered budget for career and professional development, education, independencebuilding, and taking part in activities.

These qualitative studies provide preliminary evidence that the flexible use of the budget can promote community involvement. The findings in the present study also parallel those from population-based studies of young adults with disabilities transitioning to adulthood (Gray et al., 2014; Lin et al., 2015). For example, Lin et al. (2015) reported that young adults with both disability and special health care needs were significantly less likely to have achieved similar levels of community and activity involvement as their counterparts with only special health care needs. In addition, Gray et al. (2014) reported low percentages of young adults with intellectual disability living independently, working for pay, or taking part in mainstream activities with people without intellectual disability, where those with milder forms of intellectual disability had higher rates in each area. Together with the findings reported in this dissertation on community involvement, these studies suggest that more could be done to help young adults with long-term care disabilities achieve individualized social and community involvement needs.

Based on my results and the guidelines drawn from Brown and Dale (2007) of considering a significant finding in the expected direction as a favorable program effect if it followed a pattern within a theme area, my first set of hypotheses were partially supported. I did not find an overall favorable impact of Cash and Counseling on young adults' community involvement in the CCDE compared to care as usual. However, I did find a significant favorable effect of Cash and Counseling on young adults *attending social or college as much as they wanted* in the multivariate models and on *taking parting in activities as much as they wanted* in the bivariate models. Other nonsignificant outcomes were comparable with agency-based care.

My findings did show that young adults in both groups had low probabilities of achieving a desired level of involvement in the areas studied regardless of which group they were randomly assigned to. Positive effects on community involvement that were noted were small, which could mean that larger samples may have been needed to achieve significance for the main effect of treatment status. Further questions on community involvement may also have elicited more detailed findings. Theoretically, the services provided by the Cash and Counseling model, which is highly flexible and allows participants to adapt their budget to meet personal needs, could be used to ready individuals for involvement with their community, including by providing assistance with personal care grooming and transportation from young adults' homes. Young adults in Cash and Counseling may have needed more assistance or encouragement with planning how to use their budget in innovative ways to meet their personal needs for community involvement, such as how to attain goals related to employment, taking part in activities, or attending social and recreational programs. For instance, young adults interested in paid employment, taking a class, or volunteering may have been able to budget for paying a job coach or caregiver to assist them in these endeavors. Those interested in activities or social or recreational programs may have wanted to budget some of their hours to assist with attendance. Conversely, some young adults may have preferred to utilize their budget for other things than community involvement, which the choice and

control inherent without budget authority supports. Furthermore, young adults who may have had health problems that inhibited their ability to be involved with their community in the ways measured in the CCDE may have still engaged meaningfully with others. For example, they could have been engaging with family members and friends, contributing to their social network as was shown for young adults in the qualitative study of longterm experiences (Harry, MacDonald, et al., 2016). Each of these areas presents opportunities for future research.

Young adults may also have required larger budgets in order to more fully meet their desired levels of community involvement. Each young adult in the CCDE was working with a limited budget, although increases were available by petition for participants with more intensive support needs (Brown et al., 2007). This was particularly the case in Arkansas where the median monthly allowance was only \$313 for workingage adult participants according to Brown et al. (2007). At follow-up, Brown et al. reported that working-age adults in Cash and Counseling in Arkansas had received an average of 23.1 hours of paid help in the past two weeks, 39.4 hours in Florida, and 38.8 hours in New Jersey. As such, young adults in the demonstration may not have had enough money left over after purchasing needed supports to focus a portion of their budget on community involvement or other areas outside of their primary needs related to personal care. Future research could examine the effects of increasing budgets for young adults interested in budgeting for community involvement.

# **Satisfaction Ratings**

All bivariate models testing the effect of being randomly assigned to the Cash and Counseling treatment groups on the seven satisfaction rating items were significant and in

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the hypothesized directions (Table 23, p. 160). However, *life satisfaction* rating lost significance when controlling for baseline demographic and health-related variables and the baseline measure of life satisfaction. The multivariate model was quite conservative, as the baseline measure of life satisfaction had 42% missing data due to this question not being asked of proxy respondents for young adults at baseline. Together with the loss of study participants at nine-month follow-up from attrition, only 19% of young adults in the baseline sample were included in the multivariate *life satisfaction* model. This reduced sample may have suppressed the effect of Cash and Counseling on young adults' satisfaction with life by excluding responses for young adults with baseline proxy respondents. In addition, being dissatisfied with life at baseline significantly predicted a lower likelihood of young adults being very satisfied with life at follow-up (OR = .12, p < ....001), which may also have had a suppressive effect on treatment status. A quadratic effect of age on life satisfaction was also found. Together, these findings suggest that the benefit of participant direction on improving *life satisfaction* may have been mild or moderate rather than strong when factoring in baseline satisfaction, likely requiring larger samples to discern, or may have required a measurement scale rather than a single item to more fully ascertain young adults' satisfaction with life. The multivariate finding was still positive, showing that young adults in the treatment groups were more likely to be very satisfied with life at follow-up than those in the control groups (OR = 1.92, p = .08), illustrating that Cash and Counseling was at least as good as, and possibly better than, agency-based care as usual on satisfaction with life for young adult baseline selfrespondents. However, the probabilities that young adults were very satisfied with the way they were spending their life at follow-up were low, where young adults in the

treatment groups had only a 42% probability and those in the control groups a 27% probability, suggesting an area for future research and intervention.

In total, six out of the seven satisfaction ratings remained significant and in the expected directions in the multivariate models (Table 23, p. 160). Specifically, compared to the control groups, those in the Cash and Counseling treatment groups were more likely to be very satisfied with: *the times of day care was received, care arrangement, transportation, personal care, help received around the house or community,* and *how young adults got along with paid help.* The probability levels of young adults in the CCDE being very satisfied with these six satisfaction ratings tended to be quite high, with the highest probabilities for those in Cash and Counseling that ranged from 70% to 96%. Together these findings showed that Cash and Counseling had favorable effects on a wide range of satisfaction areas at follow-up that were significantly greater than for young adults in the control groups. These results offer evidence of increased satisfaction with the flexibility of the HCBS services received in Cash and Counseling over similar services offered through agency-based care.

Other baseline control variables also significantly affected satisfaction ratings. For instance, young adults who responded to baseline interviews themselves were less likely to be very satisfied with *transportation* compared to those with proxies at baseline. Young adults who were of another race than Black or White or were multiracial also had significantly lower odds of being very satisfied with the *times of day care was received* and with *how well they got along with paid help* compared to young adults who were White. In addition, young adults of Hispanic ethnicity had significantly greater likelihoods of being very satisfied with their *care arrangement* than non-Hispanics.

Furthermore, young adults who were not able to get out of bed without assistance at baseline were significantly less likely to be very satisfied with *transportation* at follow-up. Differences in *personal care* satisfaction was also seen between some states. All of these areas could be examined through future research and intervention.

An important additional finding was that being dissatisfied with tasks at baseline was significantly associated with lower odds of being very satisfied with *help around the home and community* at follow-up, and being dissatisfied with young adults' care arrangement at baseline was associated with significantly lower odds of being very satisfied with the *care arrangement* and *how young adults got along with paid help* at follow-up. These findings suggest that more could be done to assist young adults with utilizing their budget in a satisfactory manner, for instance by helping them measure their satisfaction with program aspects, such as how tasks are performed and their care arrangement, then targeting their budget on these areas. Future research could study this area in more detail.

**Comparison with previous research.** The primary findings on Cash and Counseling and satisfaction ratings reported here are supported by past research in the CCDE, continuing the pattern of many significantly higher satisfaction ratings for those in Cash and Counseling compared to control groups. For instance, 18 to 64 year-olds in Arkansas and New Jersey, and 18 to 59 year-olds in Florida, were all significantly more likely to be very satisfied with assistance received with daily tasks, help around the house or community, transportation, and their overall care arrangements than were controls by large margins (Brown et al., 2007). Brown et al. (2007) also found that treatment group members in each of the three states had significantly greater likelihoods of being very

satisfied with life and significantly lower likelihoods of being dissatisfied than those in each state's respective control group. Where nonsignificant results were found, Cash and Counseling was at least as good as care as usual. Proxy respondents for children ages 3 to 17 in the Florida treatment group also had significantly greater likelihoods of being very satisfied on all satisfaction measures studied. Furthermore, Shen, Smyer, Mahoney, Loughlin, et al. (2008) examined outcomes for a subgroup of elderly participants with mental health diagnoses in Arkansas. The authors found that, compared to controls, elderly treatment group members with mental health diagnoses had significantly higher odds of being very satisfied with the relationships they had with their caregivers, along with being significantly more satisfied with their care arrangement. When controlling for variables like baseline life satisfaction in a reduced and more conservative model, the positive relationship with life satisfaction was no longer significant, although the finding still showed that Cash and Counseling was as good as care as usual for elderly individuals with mental health diagnoses (Shen, Smyer, Mahoney, Loughlin, et al., 2008), similar to the multivariate finding on life satisfaction reported here for young adults. When examining outcomes for participants ages 18 to 64 with mental health diagnoses in New Jersey, Shen, Smyer, Mahoney, Simon-Rusinowitz, et al. (2008) found that treatment group members had significantly higher odds of being very satisfied with caregiving schedules, with the way participants were spending their life, the overall care arrangement, and how caregivers helped out around the home and community. While not significant, Shen, Smyer, Mahoney, Simon-Rusinowitz, et al. did report higher odds of participants being very satisfied with the caregiver relationship and with caregivers'

assistance with transportation, again suggesting that Cash and Counseling was better than or at least as good as care as usual for this subgroup.

In regards to the available literature on young adults and self-directed budgets, previous qualitative studies showed that young adults and their family members were generally satisfied with self-direction. For instance, the 11 familial unpaid program representatives interviewed for young adults with severe disability in one Cash and Counseling-based program all reported satisfaction with the program for the young adults they represented, even after five or more years of enrollment (Harry, MacDonald, et al., 2016). Young adults with traumatic brain injury and physical disability in Australia were also primarily satisfied with the self-directed program and their outcomes, although they did report issues with "delays in obtaining goods and services and limitations to the ways in which purchasing could occur" (Robinson et al., 2012, p. 31). Young adults in that study provided constructive suggestions for improving those areas. The findings on satisfaction with Cash and Counseling in this dissertation further support this past research by showing that young adults and their proxy respondents, primarily family members, were generally satisfied with the CCDE self-directed budget programs.

#### **Unmet Needs for Assistance**

Both bivariate and multivariate models illustrated that young adults in the Cash and Counseling treatment groups were less likely to have unmet needs for assistance than control group members receiving agency-based care at nine-month follow-up with all four unmet needs studied (Table 23, p. 160), each of which were in the expected directions. Bivariate models related to less unmet needs for *personal care, medication or routine health care at home*, and *transportation* were also significant as hypothesized. In

the multivariate models, the significant relationships seen in the bivariate models held for less unmet needs with *medication or routine health care at home* and *transportation*, suggesting a suppressive effect from baseline control variables on treatment status and unmet needs with *personal care* at follow-up. Results did suggest that young adults who were unable to get out of bed without help (OR = 2.72, p < .001) and needed more help with personal care (OR = 3.60, p < .001) at baseline experienced a significant amount of difficulty meeting their personal care needs at follow-up. These strong predictors could certainly have weakened the effect of treatment status on *personal care*, as the log odds for treatment status and having unmet needs with *personal care* only differed by .02 between models, where the bivariate log odds was -.37 (p = .016) compared to -.35 (p = .016).059) in the multivariate model. Self-directed budget models like Cash and Counseling could work with young adults with more problems with ADLs and unmet needs at baseline to more fully meet their needs for personal care assistance with their budgets, or allow for swift increases in the amount of the allowance to meet young adults' level of need. Those with more need and higher levels of disability may also require larger budgets. Moreover, caregivers for young adults, many of whom were family members in this study, may need additional supports to more effectively provide needed personal care services. Future research could examine this area in more detail.

An additional finding was that all measures showing needs for assistance at baseline were significantly associated with higher odds of young adults' having unmet needs in those areas at follow-up. This suggests a potential focus for future research and intervention. For instance, young adults may benefit from program counselors working with young adults to identify both formal and informal resources and supports capable of providing needed assistance, as well as considering ways of utilizing their budget in managing the necessary assistance required to fulfill unmet needs.

A number of baseline control variables were also associated with higher odds of unmet needs with *medication or routine health care at home*. These included young adults being from New Jersey and Arkansas, those who were female, Black, and another race than White or Black or who were multiracial, each of which suggests areas for future research and intervention. Lastly, young adults who took part in baseline interviews themselves were significantly less likely to report unmet needs with *medication or routine health care at home* compared to those who had proxy respondents, suggesting possible differences in this outcome in relation to disability severity.

In regards to other unmet needs, a few additional control variables were significant predictors in the multivariate models. Young adults who could not get out of bed and those who were of another race than White or Black or were multiracial were more likely to have unmet needs with *transportation*, while those who lived rurally were less likely to experience unmet needs in this area. This latter finding may appear counterintuitive. However, young adults living rurally may have relied on cars or other vehicles to get around. Research has shown that personal vehicles like cars are the primary means of motorized transportation in rural areas (Pucher & Renne, 2004), which lack sidewalks and often have little to no mass transit or taxi service, unlike areas with larger populations. As such, respondents who lived rurally may have been considering a specific form of transportation, namely cars and other personal vehicles, and therefore felt less unmet needs for transportation due to the widespread reliance on this sort of transportation in rural America. However, further research is needed to identify actual reasons for differences in opinions on transportation between young adults who live rurally and those who do not. In addition, differences between some states were seen on unmet needs for *help around the house* and with *medication or routine healthcare at home*. Each of these areas suggests potential targets for future intervention and research.

**Comparison with previous research.** The findings on unmet needs for assistance reported here are similar to those for the larger CCDE (Brown et al., 2007), where findings on Cash and Counseling significantly lowering the likelihood of unmet needs in the four areas studied showed some variability by subgroup and between states. For example, children ages 3 to 17 in the Florida treatment group had significantly lower unmet needs with all four areas. Adults aged 18 to 64 in the Arkansas treatment group were significantly less likely to have unmet needs with daily living (termed personal care in this dissertation), household activities, and transportation than control group members in that state, while those from that age range in the New Jersey treatment group had significantly less unmet needs with daily living, transportation, and medication or routine health care. Florida treatment group respondents aged 18 to 59 had significantly less unmet needs with daily living, household activities, and medication or routine health care. The strongest differences were for the elderly (defined as age 65 and over in Arkansas and New Jersey, and age 60 and over in Florida), where elderly treatment group respondents in New Jersey had significant large effect sizes for a reduction on all four unmet needs, those in the Arkansas treatment group had significant modest effects on less unmet needs with household activities and transportation, and those in the Florida treatment group had no significant findings on unmet needs for assistance. Other findings for adults ages 18 to 64 with mental health diagnoses in New Jersey also showed that

while the treatment group members in this subgroup had lower unmet needs for help with household activities and with medication or routine health care, only the relationship with medication or routine health care was significant (Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008). A common theme in these studies was that nonsignificant findings still showed that Cash and Counseling was at least as good as care as usual in addressing unmet needs. When taken together with the findings on unmet needs for young adults reported in this dissertation, it appears that the full benefits of the adaptability of the Cash and Counseling budget for meeting an individual's unmet needs may not been fully realized for all age groups and subgroups studied at the time of follow-up interviews. Considering that not all treatment group members had received a budget at follow-up, particularly the elderly in Florida (Brown et al., 2007), this would not be surprising. Based on the findings reported in this dissertation for young adults, additional attention could be paid by program counselors to identifying an individual's unmet needs when developing a budget, then with helping young adults identify ways to meet these needs through their budget, including by utilizing available community resources. Conversely, policies limiting the size of budgets should be examined and adequate opportunities for appeals – requesting additional assistance – should be made available.

While this study is the first to report on a control group comparison of how PD-HCBS affects unmet needs for assistance for self-directing young adults, some findings on meeting personal care needs in PD-HCBS are available from qualitative studies. According to all 11 unpaid familial program representatives interviewed for young adults with severe disability in the recent qualitative study of long-term experiences by Harry, MacDonald, et al. (2016), the Cash and Counseling-based PD-HCBS program was meeting the personal care needs of the young adults they represented, a program at least four young adults enrolled in after more traditional services failed to provide adequate care. While the sample was small, this finding may suggest that when individuals, in this case representatives for young adults, are able to be descriptive about the receipt of personal care in qualitative research, they are able to express more detailed accounts of how Cash and Counseling can assist with meeting personal care needs. The nonsignificant multivariate finding in the present study also suggests that more could have been done to meet young adults' personal care needs during the demonstration if other factors that could influence this outcome had been identified and addressed. However, the focus of the demonstration was on the effectiveness of the Cash and Counseling model. Future research could examine and design interventions for potential influences on participants' ability to fulfill personal care and other unmet needs for assistance in PD-HCBS.

As a result of my multivariate findings, my hypotheses on unmet needs for assistance being significantly lower for those in Cash and Counseling were partially supported, showing a favorable effect of the program on meeting young adult's *medication or routine health care at home* and *transportation* needs in the multivariate models, and on unmet needs with *personal care*, *medication or routine health care at home*, and *transportation* in the bivariate models. Cash and Counseling was also found to be at least as good as care as usual on reducing young adults' unmet needs for *help around the house or community*, as it was for the multivariate model on unmet needs with *personal care*. Both *personal care* and *help around the home and community* are aspects of paid caregivers' employment and are likely amenable to personalized modification. Young adults in Cash and Counseling, and their formal and informal caregivers, may need more assistance with accessing additional resources and thinking creatively about how to adapt the budget to more effectively address young adults' unmet needs in these two areas, suggesting areas for future research and intervention.

## **Health Status Ratings**

Both bivariate and multivariate models showed the predicted negative relationship, but not significant differences in health status ratings compared to their peers between young adults in the treatment and control groups at nine-month follow-up (Table 23, p. 160). Consequently, although in the expected direction, the null hypothesis could not be rejected. However, for the young adults in the sample, it appears that Cash and Counseling was at least as good as agency-based care on young adults' reported health status compared to their peers. A noteworthy finding was that young adults who were in poor or fair health compared to peers at baseline were much more likely to be in poor or fair health compared to their peers at follow-up (OR = 10.03, p < .001). This finding suggests that perceptions of health compared to peers may reflect disability and health concerns that existed since baseline. Additional baseline control variables that significantly predicted health status included being from Arkansas, mean-centered age, and living rurally, where all three were associated with higher odds of young adults being in poor or fair health compared to their peers at follow-up. These findings suggest that self-directed budgets, and future research and interventions aimed at improving the health status ratings for young adults with disabilities, could be personalized to more fully meet young adults' individualized health-related needs.

**Comparison with previous research.** Although my results were in the same direction as those in the CCDE reported by Brown et al. (2007), they did not achieve the necessary level of significance. In the CCDE, when the full sample was examined in each state at follow-up, those in the treatment groups were significantly less likely to report their health as poor or fair relative to their peers than those in the control groups irrespective of age grouping (Brown et al., 2007). However, similar to the study reported here, other research with CCDE sub-groups did find additional nonsignificant results. For instance, Shen, Smyer, Mahoney, Simon-Rusinowitz, et al. (2008) reported that adults ages 18 to 64 with mental health diagnoses in the New Jersey treatment group had 2% higher odds of reporting they were in poor or fair health compared to their peers than controls, although this finding was not significant.

### **Research Question Summary**

In summary, this study provided the following answers to my guiding research questions. Young adult participants randomly assigned to the Cash and Counseling treatment groups in the CCDE did not have overall greater likelihoods of community involvement than those in the control groups at nine-month follow-up, with the exception of *taking part in activities as much as they would like* in the bivariate models and *going to school or college as much as they would like* in the multivariate models. Young adults in Cash and Counseling did have greater likelihoods of being very satisfied with life and six areas affected by the program than those in the control groups in all bivariate models (*the times of day care was received, care arrangement, transportation, personal care, help received around the house or community*, and *how young adults got along with paid* 

*help*) in the multivariate models, *life satisfaction* was not significant at the multivariate level. In regards to the research question on unmet needs for assistance, young adults in Cash and Counseling did have lower likelihoods of unmet needs for assistance for *personal care, medication or routine health care at home*, and *transportation* in the bivariate models, although these findings held for *medication or routine health care at home* and *transportation* only in the multivariate models. Finally, young adults in the Cash and Counseling treatment groups did not have a significantly lower likelihood of reporting their *health status* as poor or fair compared to their peers than those in control groups at follow-up in either bivariate or multivariate models.

# **Additional Findings**

An examination of the multivariate analyses across outcomes revealed patterns of responses among baseline control variables that together were significant predictors of several outcomes when compared to the model reference groups. These patterns suggest possible moderators of the effect of the Cash and Counseling intervention on theory-based outcomes and identify new areas for research and theory development in the future. For example, patterns were seen for combinations of variables that served as a proxy for level of disability and, across hypotheses, higher levels of disability were negatively associated with the outcomes measured in this secondary analysis. In no case did any single control variable explain the likelihood of achieving an outcome. This new focus on patterns creates the opportunity to advance our understanding of implementation issues such as what works for whom under what conditions, create guidelines for tailoring interventions like Cash and Counseling for sub-populations, and identify what new research is needed to expand theory and identify meaningful outcomes.

A number of significant differences were seen between who the respondent was at baseline, whether the young adult participant themselves or a proxy respondent for young adults unable to take part in the interviews likely due to more severe disability. Young adults who took part in baseline interviews were significantly more likely to be involved with their community as much as they would have liked at follow-up than those with proxy respondents at baseline. Future research could examine the reason behind these differences and how outcomes may be affected. For instance, young adults who could respond for themselves may have had more options for employment, education, and activity than those with proxies. Young adults with baseline proxies might also have had more severe disability, which could negatively affect their achieving a desirable level of community involvement in these areas. Furthermore, these findings could reflect a difference in opinions between young adults and proxy respondents, who may have provided an answer that reflected their own opinions and not those of the young adults they represented. Also, similar to Squillace et al. (2001), I found no significant differences on *personal care* satisfaction ratings between young adults and proxy respondents, or on most other satisfaction ratings. I did find that while young adults who responded to baseline interviews themselves had lower likelihoods of being very satisfied with *transportation* compared to those with proxies at baseline, young adult selfrespondents did not have a significantly greater likelihood of reporting unmet needs with *transportation* at follow-up. Together, these findings lend some support to the impression that young adults who responded to baseline interviews themselves may have had differing personal preferences or aspirations regarding transportation than was reported by proxy respondents, reflected in lower satisfaction ratings, which offers an area for

future research.

The multivariate models did show that the likelihood of some outcomes differed significantly by demonstration state, particularly in the multivariate models for *working* for pay, attending school or college, and taking part in activities at a preferred level, satisfaction with personal care, unmet needs with help around the house and medication or routine health care at home, and health status compared to peers. However, even with these differences and with the exception of satisfaction with *personal care* in the multivariate models, satisfaction rates did not differ significantly between the three demonstration states. While programmatic differences existed between states, such as PD-HCBS program rules, target populations, and demographics, the significant effects of treatment status on most satisfaction ratings regardless of state may illustrate that the Cash and Counseling model was a more satisfactory model than agency-based care as usual across the three demonstration states. These findings seem to be supported by other findings on satisfaction across demonstration states from the CCDE (Brown et al., 2007) Carlson et al., 2007). However, more research is needed in this area, as the present study did not test the significance level of differences between treatment and control groups within each CCDE enrollment state due to small samples in New Jersey and Arkansas.

One baseline control variable that likely represented a high degree of disability severity, the transfer-related ADL for being unable to get out of bed without assistance in the last week at baseline, was also a significant predictor of less desirable outcomes in a number of areas. This group of young adults were less likely to be attending *social and recreational group programs* or *taking part in activities* at a preferred level at follow-up. They were also less likely to be very satisfied with *transportation*, and were more likely to have unmet needs with both *personal care* and *transportation*. These findings suggest that young adults who experience difficulty with this particular ADL may benefit from interventions that assist them with using their self-directed budget in these areas. The allowance amount budgeted may also have been too small to adequately cover the full amount of services and supports this group of young adults might have needed to more effectively assist them with mobility, such as the likely more extensive personal care assistance required compared to those young adults who were able to get out of bed on their own. Future research could examine how disability type and severity may affect the way that young adults, including when assisted by representatives, utilize their budgets for purchasing needed supports and services and how they experience outcomes, as well as how effectively programs react to participant needs through adapting the allowance amount offered to meet an individual's unique health situation.

Significant differences were also seen for race and Hispanic ethnicity across some models. Compared to young adults who were White, those who were Black were more likely to have unmet needs with *medication or routine health care at home* and were less likely to be *attending school or college* at a preferred level. Young adults who were another race than Black or White or who were multiracial were also more likely to have unmet needs with *medication or routine health care at home* and were less likely to be very satisfied with the *time of day care was received* than those who were White. Similarly, young adults who were Hispanic were more likely to have unmet needs with *medication or routine health care at home* of to those who were non-Hispanic; however, this group of young adults were more likely to be very satisfied with their *care at home* and their *care arrangement* than those who were non-Hispanic. The budget amounts received by these

groups may not have been large enough to adequately cover the services and supports young adults required, particularly for routine health care at home. Program counselors may have also needed to more effectively connect young adults with formal and informal community supports to help address their needs. These findings also suggest that socioeconomic factors and cultural considerations could play a role in outcomes. Future research could study the effects of equalizing access to services and supports across racial and ethnic groups, or how PD-HCBS could be most effective with these groups.

Finally, baseline measures of outcome variables that showed young adults as being dissatisfied and needing more help at the start of the demonstration were for the most part significantly predictive of less desirable outcomes at follow-up. The exception was the baseline measure of satisfaction with the time of day care was received, which did not have a significant effect on participant outcomes. Conversely, young adults who reported ever working for pay or attending a social or recreational group program at baseline had significantly greater likelihoods in the related areas at follow-up. Future research could focus on analyzing these areas in more detail, as well as what identifying what role PD-HCBS can play in improving outcomes for young adults with greater needs at enrollment.

In summary, baseline control variables within the multivariate models exhibited a number of patterns across hypotheses in this study. Specifically, indicators reflecting young adults' disability severity, race, ethnicity, state of residence, and baseline needs for assistance, community involvement, and levels of satisfaction all significantly affected a variety of outcomes, primarily negatively, although this was not always the case. While these results are exploratory, as related hypotheses were not tested in this study, baseline

control variables co-occurred with other variables in the models, and differences existed in sample sizes between models, the findings do present opportunities for future research and intervention. In order for programs like Cash and Counseling to have the greatest positive impact on young adults, areas such as these should to be identified and addressed, particularly when they have the potential to negatively affect participant outcomes.

### **Summary of Potentially Influential Outliers**

The multivariate logistic regression models in this study encountered a number of individuals, or cases, which may have influenced the effect of treatment status on outcomes. Screening for potentially influential outlying cases showed that influential effects did not extend to the treatment status variable for most models. While no single case affected treatment status across models, excluding potentially influential cases did affect treatment status for seven dependent variables. Specifically, influences on the significance level of treatment status were seen for *satisfaction with life* and *unmet needs* for personal care, where both became significant at the p < .05 level when excluding outlying cases. Also, the treatment status variable was dropped from the models for satisfaction with personal care and satisfaction with how participants got along with paid attendants when outlying cases were excluded from those models. Finally, excluding outlying cases in the significant multivariate models for *attending school or college as* much as young adults would like, unmet needs with medication or routine health care at home, and satisfaction with the way paid attendants helped around the house or *community* further lowered the already significant effect of treatment status compared to the models including these cases.

### **Contributions to Theory and Knowledge-Building**

In this study, the areas of knowledge-building and contributions to theory on PD-HCBS for young adults appear to be fourfold. Foremost, this study was the first to examine the effectiveness of participant direction with young adults with disabilities using data from a randomized control trial. As such, it helped to fill the knowledge gap in this area by providing evidence of the effectiveness of PD-HCBS during young adulthood for young adults with long-term care disabilities. Second, a number of additional factors that affected young adults' outcomes were identified in the multivariate logistic regression models. These preliminary findings suggest areas for future research and intervention through personalized budgets. Third, findings suggest that the CDTE may have a more nuanced application in Cash and Counseling than in vocational rehabilitation. Fourth and finally, self-determination affecting community involvement and life satisfaction may need more time to evolve in PD- HCBS or may be related to young adults' disability type and severity.

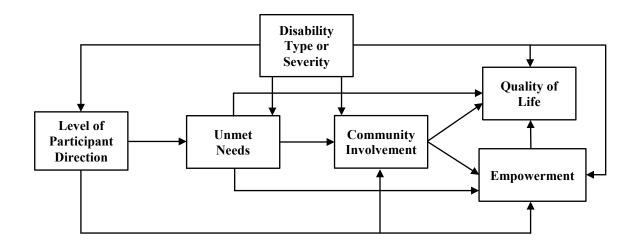
First, previous research on participant direction and young adults has been primarily qualitative with small sample sizes (Harry, MacDonald, et al., 2016; F. Mitchell, 2012, 2013, 2015; Orentlicher & Frattarola-Saulino, 2014; Robinson et al., 2012). This dissertation built on these qualitative studies and provided robust quantitative evidence of the effectiveness of the Cash and Counseling model of PD-HCBS with young adults in three U.S. states. Compared to agency-based care as usual, Cash and Counseling functioned as designed in achieving higher rates of satisfaction with key HCBS program components, reducing some important unmet needs for assistance, improving some aspects of community involvement, and in other areas where significant effects were not seen, being as good as care as usual. These findings were similar to those from the CCDE with other participant subgroups (e.g. Brown et al., 2007; Foster et al., 2003a; Shen, Smyer, Mahoney, Loughlin, et al., 2008; Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008). This study also extended the knowledge base by adding to, and in many cases complementing, previously reported experiences with PD-HCBS found for young adults in the previous qualitative studies (e.g., Harry, MacDonald, et al., 2016; Robinson et al., 2012). The positive findings reported here support this model as an option to fill the post-secondary school service gap for young adults with disabilities by suggesting this option could be offered to young adults transitioning out of secondary school, as well as in young adulthood. Findings may also motivate states and programs to more frequently offer PD-HCBS options to young adults, including with the support of social workers, as well as reduce the time young adults can spend on waitlists for waivered PD-HCBS.

Second, an opportunity exists to work on translating the positive effects reported in this dissertation into more targeted uses of self-directed budgets for young adults with varied characteristics and needs through future research and intervention. Specifically, a number of baseline control variables were seen as significant predictors of outcomes across hypotheses in the multivariate logistic regression models. For example, whether young adults or proxy respondents for young adults took part in baseline interviews, baseline measures of unmet needs and satisfaction, difficulty with the ADL getting out of bed, those that were significantly associated with lower odds of achieving some desirable outcomes, and additional variables that may have acted as moderators or mediators in the multivariate models. Each presents opportunities for future research and intervention through programs based on the Cash and Counseling model of PD-HCBS. Future research could aid in identifying opportunities for enhancing these programs for specific groups of young adults, such as helping young adults with more severe disabilities employ their budget with the help of available community resources in achieving their preferred level of community involvement and further reducing unmet needs for assistance, among other areas.

Third, the authors of the CDTE, which theorized a positive effect of consumer direction on community integration, empowerment, and quality of life (Kosciulek, 1999; Kosciulek, 2005; Kosciulek & Merz, 2001), did so by testing this theory through a consumer-directed vocational rehabilitation model where employment played a larger role than it did in the CCDE. Also, questions on participants' involvement at home and with their families were included in Kosciulek's (2005) construct of community integration, where many of these sorts of questions were not available for this study, aside from the satisfaction rating for the relationships young adults had with their paid caregivers. Furthermore, life satisfaction was measured by a single scale question in the CCDE rather than multiple questions as in the CDTE. However, it could be argued that the other satisfaction ratings in the CCDE provided additional information on satisfaction with program-related aspects of young adults' lives. In this dissertation, exploratory factor analysis did show an acceptable two-factor solution for the satisfaction rating questions. Empowerment also had a mediating effect in the CDTE, and though implicit in consumer direction, empowerment was not directly assessed in the CCDE or in the study recounted here.

Taking these differences and similarities into consideration, future theory development could consider designing and testing a modification of the CDTE for PD-

HCBS programs like Cash and Counseling. For example, theory could take into consideration the potential for different outcomes across or between disability types and severity levels experienced by young adults in PD-HCBS. More precisely, the way constructs interact within theoretical frameworks like the CDTE may differ between young adults with more or less severe disabilities, particularly around personal goals and aspirations for community integration, quality of life, and feelings of empowerment that were tested in the CDTE (Kosciulek, 1999; Kosciulek, 2005; Kosciulek & Merz, 2001). Along with disability type or severity, unmet needs may also play a role in young adults' level of community integration or involvement, their quality of life, and feelings of empowerment in relation to PD-HCBS. Future research could test a modification of the CDTE that includes measures related to unmet needs for assistance (e.g., with IADLs, ADLs, personal care) that also take into account the effects of various disability types and severities, as well as the degree to which participants rely on representatives to manage program responsibilities for them. For instance, Figure 5 (p. 192) illustrates one suggested theoretical model that may be useful for adapting the CDTE to PD-HCBS. This model includes the potential relationships between participant direction and disability type and severity on a range of outcomes, including those related to young adults' unmet needs, level community involvement, perceived quality of life, and feelings of empowerment. Future research could test this model through structural equation modeling.



*Figure 5*. Suggested theoretical framework for future testing and modification of the CDTE.

The structural model presented in Figure 5 (p. 192) could also be tested without a construct for disability type or severity by testing the model separately between groups of young people with varied disability types and severities, as well as between young adults with and without program representatives. Specific aspects of participant direction, similar to those included in the construct of consumer direction in the CDTE (Kosciulek, 1999; Kosciulek, 2005; Kosciulek & Merz, 2001), could also be identified and measured for inclusion in the construct. Doing so may allow the full model to be tested between groups of self-directing young adults and those involved with agency-based personal care services to develop a better theoretical understanding of how outcomes are comparable or dissimilar for young adults between these two forms of supports, as well as how further knowledge in this area may guide theory development.

Fourth and finally, in regards to the self-determination theories and principles of Nerney and Shumway (1996) and Ryan and Deci (2000), the hypothesized connections between self-determination and increased community involvement and life satisfaction were not seen in the multivariate models, aside from the bivariate model for *attending* activities as much as young adults would like and the multivariate model for attending school or college as much as young adults would like. The CCDE was relatively brief at nine months. More time might have been needed for a broader application of the selfdetermined components underlying self-direction in these areas. The majority of young adult participants in the CCDE, except for in Arkansas, also participated with the assistance of representatives primarily due to disability severity and may have had fewer opportunities for self-determination, which could be examined in future research. However, the high rates of satisfaction seen with all aspects of the program in the present study suggests that young adults, and their proxies, were satisfied with the selfdetermination aspects involved in self-direction compared to agency-based care as usual, such as choosing their own caregivers and times when care was received. In addition, the qualitative long-term outcome studies in one Cash and Counseling-based program provide experiential evidence of self-determination over time, as well as continued satisfaction with the program. For example, young adults' choices and preferences were supported by their program representatives and paid caregivers through the program (Harry, MacDonald, et al., 2016). For adults ages 40 to 83, all were making selfdetermined choices in their daily lives and in managing the program (Harry, Kong, et al., 2016). Respondents for both studies also reported being satisfied with the program. These findings give support to the idea that more time may be required for participants to experience the full benefits of self-determination in PD-HCBS, including giving young adults, either themselves or when assisted by representatives, more time to consider their needs and make decisions on how those needs could be met through the program with

available resources. These findings also support the value of qualitative research in learning what participants value most about the experience of self-direction. Finally, Figure 5 (p. 192) could be further modified to examine how young adults' feelings of self-determination affect outcomes in PD-HCBS. Considering the shared choice-making that has been seen between young adults with disabilities and their families (F. Mitchell, 2015; W. Mitchell, 2011), a future theoretical study on self-determination could assess the degree to which young adults are making autonomous decisions for themselves in self-directed programs. Research in this area may identify additional potential influences on young adults' ability to be self-determined, such as disability severity and whether young adults' parents and other familial caregivers who also act as representatives in the program affect young adults' self-determination.

## **Implications for Social Work Practice and Policy**

As evidenced by the spread of PD-HCBS models to all fifty U.S. states (National Resource Center for Participant-Directed Services, 2013) and internationally (Alakeson, 2010; Cowen et al., 2011; Harkes et al., 2012; Kodner, 2003; F. Mitchell, 2012, 2013, 2015; Robinson et al., 2012), more and more areas of social services will be influenced by participant-directed budgets in the years to come. Medicaid expansion under ADA will also increase the number of young adults eligible for PD-HCBS (Rudowitz & Musumeci, 2015). Social workers, who are on the front line working with individuals who may be eligible for these programs and services, will need to understand how they work for their clients and will also need to support clients who want to participate. The strong evidence of the effectiveness of the Cash and Counseling model compared to agency-based care for young adults on improving satisfaction ratings, reducing unmet

needs, and increasing areas of community involvement provided in this study could help encourage social workers, who may otherwise be reluctant to support PD-HCBS for young adults, to work with young adults interested in this option.

Social workers could help young adults think creatively about ways to utilize their budget to meet their needs, for example those related to personal care, independent living needs, or meeting their desired level of community involvement, among others. Periodic revisiting of targeted areas could help determine whether the budget is working for young adults or if it needs adjustment. Additionally, social workers could advocate for increases in participants' budgets where larger allowance could better assist young adults with meeting their personalized needs, such as for community involvement or unmet needs for assistance. A larger allowance may be particularly important for young adults with severe disability. Moreover, social workers could help connect young adults with other available resources and supports in their communities to help augment the services received through their self-directed budgets in order to more fully meet young adults' individualized needs and goals. Also, for young adults with greater likelihoods of poor outcomes and more severe disability, social workers could provide assistance to and design interventions for young adults' caregivers and representatives to help them with more fully meeting the needs of these particularly vulnerable young adults.

The positive findings in this study also suggest that PD-HCBS may be a suitable option for filling the service gap experienced by many young adults with disabilities after they transition out of pediatric care and the supports offered through IDEA (Harry, MacDonald, et al., 2016). Social work practitioners in the U.S. could work with young adults and the states or other governing bodies to develop and test new areas for PD-

HCBS budgets during the transition to adulthood, like those employed internationally that allow individualized budgets for health care, education, and social care (Cowen et al., 2011). Social workers could also advocate for changes in HCBS policy to increase access to and the spread of self-directed budgets for youth and young adults. For example, in the United States, additional supports for the transition to adulthood could be utilized outside of the auspices of IDEA, such as through self-directed budgets under Medicaid. While IDEA typically ends when students turn 22 or on the last day of their 22<sup>nd</sup> year (Arkansas Department of Education Special Education Unit, n.d.; Florida Department of Education, 2015), although some states do grant extensions (N.J.A.C. 6A:14, n.d.), this transition does not end at a specific age point for young adults with disabilities; they must still successfully navigate through multiple systems, such as health, social, economic, and community-related. The findings in this study suggest that self-directed budgets could provide effective supports during this transition. Social workers, with a person-centered and social justice focus, are prime candidates for aiding young adults with disabilities through the transition to adulthood by adding knowledge on participant-directed services to their toolkit.

# Limitations

This study was primarily limited by a reliance on secondary data in answering the guiding research questions, rather than utilizing data generated specifically for examining the transition to adulthood for young adults with disabilities in PD-HCBS. However, this limitation was for the most part mitigated by analyzing a subset of data previously collected during a randomized control trial, which provided a number of variables related to both the experience of participant direction and study research questions with the

benefit of empirical comparison between randomly assigned treatment and control groups. Also, participant diagnosis data was unavailable for analysis. Measuring participants' health status by utilizing only a one-question measure was another limitation, although other researchers have found single-item measures of self-rated health status correlate highly with multi-item measures and demonstrate good reliability and reproducibility (e.g., DeSalvo et al., 2006). Categories in the health status rating variable were combined in this study and in those previously undertaken with the CCDE (e.g. Brown et al., 2007), which may have limited the ability of this study, and past research in the CCDE, to fully distinguish differences in health status ratings compared to peers between baseline and follow-up for random assignment groups. However, examinations of nonsignificant multinomial logistic regression results for the health status rating compared to peers variable in this study addressed this limitation. Also, questions in the CCDE on community involvement (aside from attending social or recreational group programs), participant satisfaction, unmet needs for assistance, and health status rating compared to peers were subjective measures, where objective measures could have provided more conclusive detail on program effectiveness in these areas. A further limitation of this study was having to analyze treatment and control groups for the three demonstration states together due to small sample sizes in New Jersey and Arkansas. Yet controlling for state of enrollment and reporting predicted probabilities by state provided information on outcomes between the treatment and control groups in each state. This study was also limited by the reliance on proxy respondents for young adults and other participants in the original CCDE who were unable to complete both baseline and follow-up interviews themselves, although

controlling for and reporting results for baseline respondent type helped ameliorate this issue. The reduced sample size in a subgroup analysis may also have contributed to a loss of some of the benefits of a randomized control trial, such as the uniform distribution of participant characteristics between groups found in probability sampling. This issue was addressed by controlling for baseline participant characteristics in the multivariate models. Also, the findings reported in this study related to significant baseline multivariate control variables were exploratory in nature. Future research is needed to test the utility and generalizability of these initial findings. Furthermore, analyses with multiple comparisons may contribute to an increased risk of Type I errors. However, problems related to incorrectly identifying an effect as significant were reduced by utilizing some of the criteria for determining favorable program effects set forth by Brown and Dale (2007). The primary results from tested hypotheses in this study were also supported by previous CCDE research (e.g., Brown et al., 2007; Shen, Smyer, Mahoney, Loughlin, et al., 2008; Shen, Smyer, Mahoney, Simon-Rusinowitz, et al., 2008). The same cannot be said about the significant baseline control variables, which all require future evaluation and research. Finally, missing data, including from intentional skip patterns, on baseline measures and outcome variables reduced the sensitivity of the analyses.

Additional limitations comprise those also encountered in the CCDE. Please refer to Brown and Dale (2007) for an in-depth discussion of these primarily methodological limitations, which included not all participants having received a budget by follow-up, as well as "potential selection bias for some outcomes due to missing data, self-reported data, uncertain generalizability, a short follow-up period, and limited precision for estimating subgroup effects" (p. 440). As stated by Brown and Dale, internally consistent robust analyses across multiple subgroups in the CCDE showed that the methodological issues outlined by the authors did not "cast doubt on the basic findings of the evaluation" (p. 442). Indeed, the findings in this dissertation further support many of the original demonstration results reported for other age and demographic groups.

### **Implications for Future Research**

The findings from this study point towards the need for future research in four areas. First, research could examine outcomes for young adults when they are assisted with identifying goals such as their preferred levels of community involvement and how satisfied they are with their lives, as well as with thinking creatively about how their budget could be used to meet their individualized goals and needs. Second, significant differences in the likelihood of some outcomes between young adults with and without baseline proxy respondents suggests that research could identify differential outcomes in PD-HCBS for young adults related to disability type and severity and develop ways to flexibly utilize the self-directed budget to improve outcomes. Third, baseline control variables that significantly affected outcomes across the multivariate models provide opportunities for future research and intervention. Lastly, as participant direction becomes more widespread, more research will be needed examining the effectiveness of PD-HCBS during various aspects of the transition to adulthood, such as assisting young adults with disabilities before and during the service gap when supports offered through IDEA end. More detailed explanations of each of these future research areas are described in the following discussion.

First, future research could examine interventions designed to assist young adults with achieving personalized goals for community involvement and increasing quality of life with their self-directed budgets. However, young adults' aspirations for community involvement may differ dependent on disability type and severity, which future research could examine in more detail. In addition, as posited by Maslow's (1943) Hierarchy of Needs, motivation for achieving areas like self-actualization are not likely to be addressed by an individual if critical physiological and safety needs have not been sufficiently met. This suggests that young adults, including those who rely on representatives, may benefit from assistance with thinking about how to use their flexible, yet limited budget to meet their desired level of community involvement after having met more immediate needs for personal and health-related care. When meeting with participants, whether in person or over the phone, program counselors have opportunities to help connect young adults with additional community services and also keep tabs on how satisfied young adults are with the services they are receiving and with life in general. Young adults' person-centered spending plans for utilizing limited allowances through personalized budgets that are developed by young adults, and in some cases representatives, and program counselors, could attempt to address young adults' specific needs and goals in these and other areas. Research could study interventions that help program counselors assist young adults with creatively thinking about using their available budget to successfully meet their individualized needs and goals, including those related to community involvement and life satisfaction, with available community services and resources supplementing budgeted supports. Future research could also examine the effects of increasing the budget to assist young adults with pursuing a wider

range of goals for engaging with community than allowed for by allowance amounts, which are typically based around the hours required for agency-based personal care assistance. For those that are interested in this option, job coaches or other caregivers could be hired by an individual to assist with numerous areas related to community involvement and social engagement that are unique to an individual's goals and needs. Positive findings could motivate programs to increase allowance amounts for community involvement needs, especially for those with more severe disability who may require larger allowance amounts to purchase needed supports, or otherwise work with participants to help them utilize their budget in the most personalized manner in meeting young adults' needs and goals. However, this discussion must be tempered with a reminder that not all young adults may want to use their budget for being more involved in their community, which is a perfectly acceptable self-determined choice. For young adults with the most severe health problems or who may be nearing the end of their lives, community involvement may simply mean being able to spend more time with their families at this critical time. Ultimately, the personal choices that young adults make when designing their self-directed budgets should reflect their needs and goals, not necessarily those of society.

In addition, longer follow-up periods or a more detailed examination of how selfdirecting young adults' are involved with their community might allow for a deeper understanding of the ways in which young adults interact with their community and how satisfaction with life may change over time. Future research could employ measures with a broader range of questions on both community involvement and quality of life. For instance, inquiring about young adults' relationships and social connections may provide

additional information on how effectively young adults are connecting with their community in PD-HCBS. The study on long-term experiences with representatives of young adults with primarily intellectual disability did show that familial and social relationships appeared to be bolstered by enrollment in PD-HCBS (Harry, MacDonald, et al., 2016). Young adults were able to continue living with their families, where they had active roles in social groups that also comprised natural support persons, primarily in the form of relatives and family friends, some of whom were paid caregivers. Some young adults also took part in supported day, school, or work programs with assistance from paid program caregivers. Also, in addition to asking program-related satisfaction questions, future research could employ a multi-item quality of life measure developed for young adults with disabilities. If one does not exist that reflects the disability types or range reflected in the study population, a more suitable quality of life scale could be developed or adapted (Townsend-White, Pham, & Vassos, 2012). Of note, the measures of life satisfaction and other satisfaction ratings were adapted and developed in this manner for the CCDE (Foster et al., 2003a). Research could also examine the effects of community involvement on quality of life in PD-HCBS. Results may show a significant improvement in quality of life through community involvement, as is posited in the CDTE (Kosciulek, 1999; Kosciulek, 2005; Kosciulek & Merz, 2001), a finding which could provide additional rationale for supporting using self-directed budgets in meeting young adults' community involvement goals. This sort of evidence may be needed if the potential benefits of community involvement alone are not sufficient for programs to support budgeting portions of young adults' allowances in this manner for those that are interested in having that option.

Second, the difference in opinions seen between baseline young adult and proxy respondents for those with more severe disability suggests that when developing PD-HCBS budgets to meet young adults' personal aspirations and preferences, care could be taken to ensure the budget is personalized either by young adults themselves, or with dedicated caregivers for young adults who require assistance in managing program responsibilities, a group that may have differing needs and goals related to disability severity. To ensure that self-directed budgets are working for young adults during the transition to adulthood, future research could provide an in-depth examination and comparison of experiences on how the budget is utilized for the range of young adults served, from those who handle all program details themselves, to those that require a representative to make all program decisions for them, as was done in the CCDE. Disability type and severity could also be taken into consideration. However, rather than relying solely on proxy respondents for young adults with limited communication ability, interactive methods like photo voice, tablet applications, and visualization methods could be utilized in examining outcomes, as well as in-depth observation of young adults, their caregivers, and representatives working together in PD-HCBS. Innovative ways to help young adults with severe disabilities make personalized choices about how to utilize their budget could also be developed and tested. As shown in previous research (Harry, MacDonald, et al., 2016; F. Mitchell, 2012, 2015; W. Mitchell, 2011), and evidenced by the majority of proxy respondents and paid caregivers being related to young adults in the present study, many young adults with long-term disabilities are likely deeply connected with their families for support and care. This suggests that interventions designed to assist young adults with most effectively utilizing their budgets may need to be sensitive to

familial relationships at the same time as being responsive to influences on budget allocation that may be a reflection of a familial caregiver's choices that may or may not reflect those of the young adult. Joint or supported decision making with the assistance of parents has been seen with other self-directed budget programs (F. Mitchell, 2012, 2015). This suggests that when social workers, program counselors, or other program staff who provide budget counseling for participants assist young adults with creating a personcentered budget, supports could also be made available for familial caregivers. These could include respite services, as well as training or interventions on how family members could more fully meet young adults' needs for assistance and also increase young adults' independence and self-determined choices in PD-HCBS. Future research could examine the effectiveness of these sorts of approaches.

Third, this study identified a number of additional significant baseline control variables that showed patterns across hypotheses in the multivariate logistic regression models, such as state of enrollment, baseline measures of unmet needs, satisfaction, and community involvement, difficulty with the ADL getting out of bed, and race and ethnicity, many of which were significantly associated with lower odds of achieving desirable outcomes and may have influenced outcomes in the multivariate models. All present opportunities for future research and interventions through programs based on the Cash and Counseling model of PD-HCBS. For instance, baseline variables may have moderated participant outcomes by affecting the strength or changing the direction of the association between treatment status and measured outcomes (Baron & Kenny, 1986), which could be examined through the testing of interaction effects in future research. For example, treatment status could be multiplied by potential indicators of young adults'

disability severity, such as respondent type, a constructed continuous ADL score variable, single ADL measures, or disability-related measures that were significant predictors in the multivariate models presented here, to test for interaction effects between treatment status and these measures on young adults' outcomes. Some baseline variables may have also acted as mediators, in other words partially or totally accounting for the relationship between treatment status and an outcome (Baron & Kenny, 1986), the study of which could help identify targets for future intervention.

Findings related to baseline control variables affecting outcomes also support the research by Nusselder et al. (2005) on the effects of non-disease factors on disability trajectories, highlighting the importance of research and interventions that also address a range of potential influences when considering participant outcomes. For example, future research could determine if and how characteristics like race, age, and health status may affect young adults' person-centered needs, choices, and outcomes, both positively and negatively, and how program counselors could assist young adults with adapting their budgets to most effectively meet their personalized goals when also taking these factors into consideration. Future research could then examine the outcomes of young adults' adapting their budget in this manner. Young adults with more severe disability may also require larger allowances to sufficiently budget for needed supports, which future research could assess. In addition, research could examine the effects of identifying young adults' baseline levels of satisfaction and unmet needs for assistance and then how helpful it is for young adults to target these areas when young adults are developing personalized budgets, either themselves or with the assistance of representatives or program counselors. Findings may help determine if doing so better meets the

individualized needs of young adults. Furthermore, reassessments in Cash and Counseling are typically completed every six months, annually, or when changes need to be made to a spending plan. Research could test the effectiveness of coupling more frequent assessments examining how the budget is meeting a young adult's needs with flexibly tailoring the budget to address any changes in needs over time. Lastly, rather than emphasizing a deficit-focus, future research could also examine the effects of assisting young adults with taking advantage of their personal strengths as tools for meeting budget-related goals.

Fourth and finally, when targeting self-directed budgets at filling the service gap between pediatric and secondary school supports and adult services, research could identify critical junctures for intervention and all relevant stakeholders, from young adults and their caregivers to those who enact the laws that affect program funding, development, and implementation. As the ACA expands Medicaid and more states develop plans for and follow through with integration efforts based on the Olmstead decision (Olmstead v. L.C., 1999), opportunities will likely develop for incorporating participant direction with a wide range of services for young adults and others with disabilities requiring varying levels of assistance. Research will be needed to assure the effectiveness of new programs and expansions of PD-HCBS and self-directed budgets. If large-scale randomized control trials like the CCDE are not possible or are limited in geographical scope, additional forms of effectiveness studies could be considered. For instance, quasi-experimental longitudinal studies using matched pairs or propensity scoring could compare outcomes between young adults on waitlists for self-directed waivers or state plans with those already enrolled in these programs. Young adults with

disabilities, and their caregivers, could also take part in future research on PD-HCBS and self-directed budgets during the transition to adulthood. Doing so may allow for developing or adapting relevant interventions, programs, and policy solutions that are targeted at meeting their goals, such as those related to independent living, relationships, employment, education, and health and personal care. Maximizing the participation of young adults with disabilities within the research itself, their community, and the larger socioeconomic system is a practical goal that supports the basic choice and control tenets that underlie participant direction.

#### Conclusion

This study provided robust evidence of the effectiveness of the Cash and Counseling model of PD-HCBS with young adults aged 18 to 35 with long-term care disabilities and eligible for Medicaid. Compared to those randomly assigned to control groups receiving agency-based care in the CCDE, multivariate logistic regression models showed that treatment group members receiving the Cash and Counseling model of PD-HCBS had greater likelihoods of attending school or college as much as preferred, as well as being very satisfied with the times of day care was received, their care arrangements, transportation, the way paid attendants completed personal care, how paid attendants helped around the house and community, and how well young adults got along with paid help, all central aspects of HCBS. The likelihoods of unmet needs for assistance with medication or routine health care at home and transportation were also reduced for treatment group members, illustrating that Cash and Counseling was more effective at meeting unmet needs in these areas than traditional, agency-based care. While not significant in the multivariate models, bivariate logistic regression models showed that young adults in the Cash and Counseling treatment groups had significantly greater likelihoods of taking part in activities at a preferred level, being very satisfied with the way they were spending their lives, and having lower likelihoods of unmet needs with personal care compared to those in the control groups. Together, these findings suggest that the Cash and Counseling model was more effective than agency-based care on a wide array of areas studied. Where findings were not significant, results were in the expected direction and comparable with agency-based care, with the exception of young adults attending social or recreational group programs in the multivariate model, a questionable nonsignificant result.

The findings presented in this study suggest that Cash and Counseling functioned as designed and offers an important option for filling the service gap that can be experienced by young adults with long-term care disabilities after pediatric health services and secondary school supports through IDEA have ended. Social workers could support young adults taking part in PD-HCBS programs during the transition to adulthood and during young adulthood. In addition, program counselors could assist young adults with thinking creatively about meeting their needs and developing and utilizing their personalized budget in ways that maximize their achievement of personal goals, including when augmented by community supports and services. Doing so may increase young adults' ability to meet community involvement, personal care, and other identified needs during the transition to adulthood.

Areas for future research were also identified, including testing person-centered interventions that assist young adults with meeting their personalized needs and goals with participant-directed budgets. Also, a number of baseline control variables were found to predict young adults' outcomes across multivariate models, suggesting areas for future research, intervention, and theory development. For example, research could examine the effects of aiding young adults with disabilities enrolled in PD-HCBS, including when assisted by representatives, with adapting their budget and individualized goals to meet client characteristics, such as disability type or severity. Interventions that assist young adults with identifying and targeting areas that may reduce the likelihood of positive outcomes could also be developed and tested, as could those that capitalize on participant strengths. Furthermore, effectiveness studies on PD-HCBS during the service gap and other time frames during the transition to adulthood could compare outcomes between young adults already receiving self-directed budgets through a waiver program and those on program waiting lists if a randomized control trial is unfeasible. Finally, to extend the self-determination aspect of PD-HCBS, researchers and policy makers could include young adults with disabilities, and their caregivers, in future research on PD-HCBS during the transition to adulthood.

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### **Appendix A - Supplemental Tables**

Table A1

Follow-Up Dependent Variables **Recoded Values** H<sub>1</sub> Community Involvement  $H_{1A}$ : Able to go to work for pay as 0 = No, 1 = Yes, v = Participant notmuch as participant wants interested/not available, h = NA skipped B/C E6 1/R & Participant 18-75, .q = Participant don't know 0 = No, 1 = Yes, v = Participant notH<sub>1B</sub>: Able to attend school or college interested/not available, h = NA skipped as much as participant wants B/C E6 1/R & Participant 18-75, q =Participant don't know 0 = No, 1 = Yes, w. Participant not H<sub>1C</sub>: Able to take part in recreational, cultural, religious, social, or volunteer interested, .q = Participant don't know, .r = activities as much as participant wants Participant refused H<sub>1D</sub>: Attended social or recreational 0 = No, 1 = Yesgroup programs H<sub>2</sub> Satisfaction Ratings H<sub>2A</sub>: Very satisfied with life 1 =Very satisfied, 0 =Other (combined) Very Dissatisfied, Somewhat Dissatisfied, Dissatisfied, Satisfied, and Somewhat *Satisfied*), .t = Participant skipped from E13 D OR R, e = NA skipped B/C Participant coma or dead, g = NA skipped from E9 0, 7, D OR R, .u = NA skipped from E6 1 or R, .q = Participant don't know H<sub>2B</sub>: Very satisfied with times of day 1 =Very satisfied, 0 =Other (combined help is received Very Dissatisfied, Somewhat Dissatisfied, Dissatisfied, Satisfied, and Somewhat Satisfied), b = Participant NA, SKIPPED B/C D1<1, .q = Participant don't know 1 =Very satisfied, 0 =Other (combined H<sub>2C</sub>: Very satisfied with care arrangement Very Dissatisfied, Somewhat Dissatisfied, Dissatisfied, Satisfied, and Somewhat Satisfied), q = Participant don't know, x =NA, skipped no paid help in C7,8,9,11 1 =Very satisfied, 0 =Other (combined H<sub>2D</sub>: Very satisfied with transportation help Very Dissatisfied, Somewhat Dissatisfied, Dissatisfied, Satisfied, and Somewhat *Satisfied*), .q = Participant don't know. .v = Participant no attempt to get help with transport

Dependent Variables: Nine-Month Follow-Up CCDE Interviews

(continued)

Follow-Up Dependent Variables	Recoded Values
H <sub>2E</sub> : Very satisfied with personal care	1 = Very Satisfied, 0 = Other (combined Very Dissatisfied, Somewhat Dissatisfied, Dissatisfied, Satisfied, and Somewhat Satisfied), .a = Participant NA, skipped B/C all D14/15/16/17/18 NE 1, .b = Participant NA, skipped B/C D1<1
H <sub>2F</sub> : Very satisfied with paid help around the house or community	1 = Very satisfied, 0 = Other (combined Very Dissatisfied, Somewhat Dissatisfied, Dissatisfied, Satisfied, and Somewhat Satisfied), .a = Participant NA, skipped B/C ALL D20/21/22/24 NE 1, .b = Participant NA, skipped B/C D1<1 OR NOT
H <sub>2G</sub> : Very satisfied with way getting along with paid help	1 = Very satisfied, 0 = Other (combined Very Dissatisfied, Somewhat Dissatisfied, Dissatisfied, Satisfied, and Somewhat Satisfied), d. = Participant NA, skipped B/C D1 1 or not answered, .q = Participant don't know
H <sub>3</sub> Unmet Needs	
$H_{3A}$ : Needed more help with personal care	0 = No, 1 = Yes, .h = NA skipped B/C E6 1/R & Participant 18-75, .q = Participant don't know, .r Participant refused
$H_{3B}$ : Needed more help around the house	0 = No, 1 = Yes, .h = NA skipped B/C E6 1/R & Participant 18-75, .q = Participant don't know
$H_{3C}$ : Needed more help with medications or routine health care at home	0 = No, 1 = Yes, h = NA skipped B/C E6 1/R & Participant 18-75, $q = Participant$ don't know
H <sub>3D</sub> : Needed more help with transportation	0 = No, 1 = Yes, .h = NA skipped B/C E6 1/R & Participant 18-75, .q = Participant don't know
H <sub>4</sub> Health Status	
Participants' nine-month health rating compared to peers	0 = Good/Excellent, 1 = Poor/ Fair, .i = NA skipped B/O Participant died < 2 months or, .l = NA skipped B/C Participant died 2 or more, .t = Participant don't know

Table A1 Dependent Variables: Nine-Month Follow-Up CCDE Interviews (continued)

	Fac	ctor	
Dependent Variables	1	2	$h^2$
Four-item solution			
Employed for pay as much as young adults want	.526	.053	.721
Attending school or college as much as young adults want	.537	.011	.712
Taking part in activities as much as young adults want	.561	.055	.682
Participating in a social or recreational group program	.200	.112	.948
Eigenvalue	.927	.010	
Percent variance explained	23.2%	.032%	
Three-item solution			
Employed for pay as much as young adults want	.521	-	.728
Attending school or college as much as young adults want	.547	-	.701
Taking part in activities as much as young adults want	.554	-	.693
Eigenvalue	.878	-	
Percent variance explained	29.3%		

Community Involvement Dependent Variables: Varimax PAF Rotated Factor Matrix

*Note*. Rounded to nearest thousandth place. Factor loadings over .4 are bolded, the preferred minimum recommended by Polit, 2010.  $h^2$  = Item commonality, variance reproduced. Extraction method: Principal Axis Factoring with varimax orthogonal rotation. Two factors extracted.

	Factor			
Dependent Variables	1	2	3	$h^2$
Very satisfied with:				
Life	.200	.466	059	.741
Times of day paid attendants perform duties	.360	.323	.192	.729
Care arrangement	.276	.648	.074	.499
Transportation	.218	.544	044	.654
Personal care	.736	.229	.014	.406
Help around home and community	.721	.181	005	.447
Getting along with paid attendants	.625	.152	.084	.579
Eigenvalue	2.402	.497	.045	
Percent variance explained	34%	7.1%	.006%	

Satisfaction Rating Dependent Variables: Varimax PAF Rotated Factor Matrix

*Note.* Rounded to nearest thousandth place. Factor loadings over .4 are bolded, the preferred minimum recommended by Polit, 2010.  $h^2$  = Item commonality, variance reproduced. Extraction method: Principal Axis Factoring with varimax orthogonal rotation. Three factors extracted.

Dependent Variables	Factor 1	$h^2$
Unmet needs with:		
Personal care	.662	.562
Help around the house	.706	.502
Medication or routine healthcare	.552	.695
Transportation	.479	.770
Eigenvalue	1.471	
Percent variance explained	36.8%	

Unmet Needs Dependent Variables: Varimax PAF Rotated Factor Matrix

*Note.* Rounded to nearest thousandth place. Factor loadings over .4 are bolded, the preferred minimum recommended by Polit, 2010.  $h^2$  = Item commonality, variance reproduced. Extraction method: Principal Axis Factoring with varimax orthogonal rotation. One factor extracted.

Assessing Construct Validity for Dependent Variables: Varimax PAF Rotated Factor Matrix

	Factor							
Dependent Variables	1	2	3	4	5	6	7	$h^2$
Met desired level of:								
Paid employment			.599					.624
Attending school or college			.624					.586
Taking part in activities			.615					.535
Social or recreational group program								.833
attendance								
Very satisfied with:								
Life				.353				.672
Times of day paid attendants perform duties	.390					.333		.623
Care arrangement	.395			.536				.468
Transportation				.591				.547
Personal care	.775							.358
Help around home and community	.750							.416
Getting along with paid attendants	.630							.571
Unmet needs with:								
Help around house		.738						.419
Personal care		.694						.490
Medication or routine health care		.491					.301	.625
Transportation		.375		447				.591
Poor or fair health compared to peers					421			.779
Eigenvalue	3.267	1.673	.855	.447	.297	.209	.115	
Percent variance explained	20.4%	10.5%	5.3%	2.8%	1.9%	1.3%	.7%	

*Note*. Rounded to nearest thousandth place. Factor loadings over .4 are bolded, the preferred minimum recommended by Polit, 2010.  $h^2$  = Item commonality, variance reproduced. Extraction method: Principal Axis Factoring with varimax orthogonal rotation. Seven factors extracted.

# Recoded Independent Variables: Baseline CCDE Interviews

Baseline Independent Variables	Recoded Values
Age	18 - 35
Ever worked for pay	0 = No, 1 = Yes, . = missing
Health status compared to peers	0 = Good/Excellent, 1 = Poor/ Fair, .=
	missing
Hispanic ethnicity	0 = No, 1 = Yes, . = missing
Needed more help with	0 = No, 1 = Yes. = missing
home/community than received	
Needed more help with personal care	0 = No, 1 = Yes, . = missing
than received	
Needed more help with transportation	0 = No, 1 = Yes, . = missing
than received	
Race	0 = White, $1 =$ Black/African American, $3$
	= Other or multiracial, . = missing
Received paid help through Medicaid or	0 = No, 1 = Yes, . = missing
other publicly funded program in the	
previous week	
Respondent type for over half the	0 = Proxy, 1 = Participant
interview	57 1
Satisfaction with care arrangement	0 = Dissatisfied (combined <i>Very</i>
e	Dissatisfied, Somewhat Dissatisfied, and
	Dissatisfied), 1 = Satisfied (combined
	Very Satisfied, Somewhat Satisfied, and
	Satisfied), . = missing
Satisfaction with life	0 = Dissatisfied (combined Very
	Dissatisfied and Somewhat Dissatisfied,),
	1 = Satisfied (combined <i>Somewhat</i>
	Satisfied and Very Satisfied), . = missing
Satisfaction with the how workers	0 = Dissatisfied (combined Very
carried out their duties helping with	Dissatisfied, Somewhat Dissatisfied, and
personal care	Dissatisfied), 1 = Satisfied (combined
1	Very Satisfied, Somewhat Satisfied, and
	Satisfied), . = missing
Satisfaction with times of day attendant	0 = Dissatisfied (combined <i>Very</i>
worked	Dissatisfied, Somewhat Dissatisfied, and
	Dissatisfied), 1 = Satisfied (combined
	Very Satisfied, Somewhat Satisfied, and
	<i>Satisfied</i> ), . = missing
Sex	0 = Male, 1 = Female
State code	0 = Arkansas, $1 =$ Florida, $2 =$ New Jersey
Social or recreational group programs	0 = No, 1 = Yes, . = missing
last year	-,,

Second Model Regression Equations for Individual Hypotheses

### H<sub>1</sub>: Community Involvement

H<sub>1A</sub>: Y(Work for pay) =  $\beta_0$ (intercept) +  $\beta_1 X_1$ (treatment group member) +  $\beta_2 X_2$ (state)  $+\beta_3X_3(sex) + \beta_4X_4(race) + \beta_5X_5(Hispanic) + \beta_6X_6(respondent type) + \beta_7X_7(mean$ centered age) +  $\beta_8 X_8$ (squared mean-centered age) +  $\beta_9 X_9$ (health status compared to peers) +  $\beta_{10}X_{10}$  (help getting in or out of bed) +  $\beta_{11}X_{11}$  (publicly funded paid help)  $+\beta_{12}X_{12}$  (lived in rural location)  $+\beta_{13}X_{13}$  (baseline ever worked for pay) H<sub>1B</sub>: Y(Attend school or college) =  $\beta_0$ (intercept) +  $\beta_1$ X<sub>1</sub>(treatment group member) +  $\beta_2 X_2(state) + \beta_3 X_3(sex) + \beta_4 X_4(race) + \beta_5 X_5(Hispanic) + \beta_6 X_6(respondent type) +$  $\beta_7 X_7$  (mean-centered age) +  $\beta_8 X_8$  (health status compared to peers) +  $\beta_9 X_9$  (help getting in or out of bed) +  $\beta_{10}X_{10}$  (publicly funded paid help) +  $\beta_{11}X_{11}$  (living rurally) H<sub>1C</sub>: Y(Take part in activities) =  $\beta_0$ (intercept) +  $\beta_1 X_1$ (treatment group member) +  $\beta_2 X_2(state) + \beta_3 X_3(sex) + \beta_4 X_4(race) + \beta_5 X_5(Hispanic) + \beta_6 X_6(respondent type) +$  $\beta_{7}X_{7}$ (mean-centered age) +  $\beta_{8}X_{8}$ (squared mean-centered age) +  $\beta_{9}X_{9}$ (health status compared to peers) +  $\beta_{10}X_{10}$  (baseline needed help getting in or out of bed) +  $\beta_{11}X_{11}$ (publicly funded paid help) +  $\beta_{12}X_{12}$ (lived in rural location) H<sub>1D</sub>: Y(Attend social or recreational group programs) =  $\beta_0$ (intercept) +  $\beta_1 X_1$ (treatment group member) +  $\beta_2 X_2$ (state) +  $\beta_3 X_3$ (sex) +  $\beta_4 X_4$ (race) +  $\beta_5 X_5$ (Hispanic) +  $\beta_6 X_6$ (respondent type) +  $\beta_7 X_7$ (mean-centered age) +  $\beta_8 X_8$ (health

 $\beta_5 X_5(Hispanic) + \beta_6 X_6(respondent type) + \beta_7 X_7(mean-centered age) + \beta_8 X_8(health status compared to peers) + \beta_9 X_9(help getting in or out of bed) + \beta_{10} X_{10}(publicly funded paid help) + \beta_{11} X_{11}(lived in rural location) + \beta_{12} X_{12}(took part in social or recreational group programs in the past year at baseline)$ 

# H<sub>2</sub>: Program and Life Satisfaction

- $$\begin{split} &H_{2A}: Y(Participant\ satisfaction\ with\ life) = \beta_0(intercept) + \beta_1 X_1(treatment\ group \\ member) + \beta_2 X_2(state) + \beta_3 X_3(sex) + \beta_4 X_4(race) + \beta_5 X_5(Hispanic) + \\ &\beta_6 X_6(respondent\ type) + \beta_7 X_7(mean-centered\ age) + \beta_8 X_8(squared\ mean-centered\ age) + \beta_9 X_9(health\ status\ compared\ to\ peers) + \beta_{10} X_{10}(help\ getting\ in\ or\ out\ of\ bed) + \beta_{11} X_{11}(publicly\ funded\ paid\ help) + \beta_{12} X_{12}(lived\ in\ rural\ location) + \\ &\beta_{13} X_{13}(baseline\ life\ satisfaction) \end{split}$$
- H<sub>2B</sub>: Y(Satisfaction with times of day help is received) =  $\beta_0(intercept) + \beta_1 X_1(treatment group member) + \beta_2 X_2(state) + \beta_3 X_3(sex) + \beta_4 X_4(race) + \beta_5 X_5(Hispanic) + \beta_6 X_6(respondent type) + \beta_7 X_7(mean-centered age) + \beta_8 X_8(health status compared to peers) + \beta_9 X_9(help getting in or out of bed) + \beta_{10} X_{10}(publicly funded paid help) + \beta_{11} X_{11}(lived in rural location) + \beta_{12} X_{12}(baseline satisfaction with times of day help is received)$
- $\begin{array}{l} H_{2C}: Y(Satisfaction \ with \ the \ arrangement \ of \ care) = \beta_0(intercept) + \beta_1 X_1(treatment \ group \ member) + \beta_2 X_2(state) + \beta_3 X_3(sex) + \beta_4 X_4(race) + \beta_5 X_5(Hispanic) + \\ \beta_6 X_6(respondent \ type) + \beta_7 X_7(mean-centered \ age) + \beta_8 X_8(health \ status \ compared \ to \ peers) + \beta_9 X_9(help \ getting \ in \ or \ out \ of \ bed) + \beta_{10} X_{10}(publicly \ funded \ paid \ help) + \\ \beta_{11} X_{11}(lived \ in \ rural \ location) + \beta_{12} X_{12}(baseline \ satisfaction \ with \ care \ arrangement) \end{array}$

*(continued)* 

Table A7 Second Model Regression Equations for Individual Hypotheses (continued)

H<sub>2D</sub>: Y(Satisfaction of help with transportation) =  $\beta_0(intercept) + \beta_1 X_1(treatment group member) + \beta_2 X_2(state) + \beta_3 X_3(sex) + \beta_4 X_4(race) + \beta_5 X_5(Hispanic) + \beta_6 X_6(respondent type) + \beta_7 X_7(mean-centered age) + \beta_8 X_8(health status compared to peers) + \beta_9 X_9(help getting in or out of bed) + \beta_{10} X_{10}(publicly funded paid help) + \beta_{11} X_{11}(lived in rural location)$ 

H<sub>2E</sub>: Y(Satisfaction with the way paid attendants carried out personal care duties) =  $\beta_0(intercept) + \beta_1 X_1(treatment group member) + \beta_2 X_2(state) + \beta_3 X_3(sex) + \beta_4 X_4(race) + \beta_5 X_5(Hispanic) + \beta_6 X_6(respondent type) + \beta_7 X_7(mean-centered age) + \beta_8 X_8(health status compared to peers) + \beta_9 X_9(help getting in or out of bed) + \beta_{10} X_{10}(publicly funded paid help) + \beta_{11} X_{11}(lived in rural location)$ 

- H<sub>2F</sub>: Y(Satisfaction with paid help around the house or community) =  $\beta_0(intercept) + \beta_1 X_1(treatment group member) + \beta_2 X_2(state) + \beta_3 X_3(sex) + \beta_4 X_4(race) + \beta_5 X_5(Hispanic) + \beta_6 X_6(respondent type) + \beta_7 X_7(mean-centered age) + \beta_8 X_8(health status compared to peers) + \beta_9 X_9(help getting in or out of bed) + \beta_{10} X_{10}(publicly funded paid help) + \beta_{11} X_{11}(lived in rural location) + \beta_{12} X_{12}(baseline satisfaction with tasks)$
- $$\begin{split} &H_{2G}: Y(Satisfaction how young adults got along with attendant) = \beta_0(intercept) + \\ &\beta_1 X_1(treatment group member) + \beta_2 X_2(state) + \beta_3 X_3(sex) + \beta_4 X_4(race) + \\ &\beta_5 X_5(Hispanic) + \beta_6 X_6(respondent type) + \beta_7 X_7(mean-centered age) + \beta_8 X_8(health status compared to peers) + \beta_9 X_9(help getting in or out of bed) + \beta_{10} X_{10}(publicly funded paid help) + \beta_{11} X_{11}(lived in rural location) + \beta_{12} X_{12}(baseline satisfaction with care arrangement) \end{split}$$

### H<sub>3</sub>: Unmet Needs For Assistance

 $\begin{array}{l} H_{3A}: \ Y(Unmet \ needs \ for \ personal \ care) = \beta_0(intercept) + \beta_1 X_1(treatment \ group \\ member) + \beta_2 X_2(state) + \beta_3 X_3(sex) + \beta_4 X_4(race) + \beta_5 X_5(Hispanic) + \\ \beta_6 X_6(respondent \ type) + \beta_7 X_7(mean-centered \ age) + \beta_8 X_8(health \ status \ compared \\ to \ peers) + \beta_9 X_9(help \ getting \ in \ or \ out \ of \ bed) + \beta_{10} X_{10}(publicly \ funded \ paid \ help) + \\ \beta_{11} X_{11}(lived \ in \ rural \ location) + \beta_{12} X_{12}(baseline \ needed \ more \ help \ with \ personal \\ care) \end{array}$ 

 $\begin{array}{l} H_{3B}: Y(Unmet needs for help around house) = \beta_0(intercept) + \beta_1 X_1(treatment group member) + \beta_2 X_2(state) + \beta_3 X_3(sex) + \beta_4 X_4(race) + \beta_5 X_5(Hispanic) + \\ \beta_6 X_6(respondent type) + \beta_7 X_7(mean-centered age) + \beta_8 X_8(health status compared to peers) + \beta_9 X_9(help getting in or out of bed) + \beta_{10} X_{10}(publicly funded paid help) + \\ \beta_{11} X_{11}(lived in rural location) + \beta_{12} X_{12} (baseline needed more help around house/community) \end{array}$ 

H<sub>3C</sub>: Y(Unmet needs for medication or routine health care at home) =  $\beta_0(intercept) + \beta_1 X_1(treatment group member) + \beta_2 X_2(state) + \beta_3 X_3(sex) + \beta_4 X_4(race) + \beta_5 X_5(Hispanic) + \beta_6 X_6(respondent type) + \beta_7 X_7(mean-centered age) + \beta_8 X_8(health status compared to peers) + \beta_9 X_9(help getting in or out of bed) + \beta_{10} X_{10}(publicly funded paid help) + \beta_{11} X_{11}(lived in rural location)$ 

(continued)

Table A7 Second Model Regression Equations for Individual Hypotheses (continued)

H<sub>3D</sub>: Y(Unmet needs for help with transportation) =  $\beta_0(intercept) + \beta_1 X_1(treatment group member) + \beta_2 X_2(state) + \beta_3 X_3(sex) + \beta_4 X_4(race) + \beta_5 X_5(Hispanic) + \beta_6 X_6(respondent type) + \beta_7 X_7(mean-centered age) + \beta_8 X_8(health status compared to peers) + \beta_9 X_9(help getting in or out of bed) + \beta_{10} X_{10}(publicly funded paid help) + \beta_{11} X_{11}(lived in rural location) + \beta_{12} X_{12}(baseline needed more help with transportation)$ 

### H<sub>4</sub>: Nine-Month Health Rating

$$\begin{split} &Y(Poor \ or \ fair \ health \ rating \ compared \ to \ peers) = \beta_0(intercept) + \beta_1 X_1(treatment \ group \ member) + \beta_2 X_2(state) + \beta_3 X_3(sex) + \beta_4 X_4(race) + \beta_5 X_5(Hispanic) + \\ &\beta_6 X_6(respondent \ type) + \beta_7 X_7(mean-centered \ age) + \beta_8 X_8(health \ status \ compared \ to \ peers) + \beta_9 X_9(help \ getting \ in \ or \ out \ of \ bed) + \beta_{10} X_{10}(publicly \ funded \ paid \ help) + \\ &\beta_{11} X_{11}(lived \ in \ rural \ location) \end{split}$$